Exploring End-of-Life Nutrition Care for Residents of Long-Term Care: A Retrospective Chart Review

by

Jill Marie Koechl

A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Kinesiology and Health Sciences (Aging, Health and Well-Being)

Waterloo, Ontario, Canada, 2023

© Jill Marie Koechl 2023

Examining Committee Membership

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

External Examiner	Genevieve Thompson, RN, PhD Professor, College of Nursing University of Manitoba, Winnipeg, MB
Supervisor	Heather Keller, RD, PhD Schlegel Research Chair, Nutrition & Aging Professor, Kinesiology and Health Sciences University of Waterloo, Waterloo, ON
Internal Member	George Heckman, MD, MSc Schlegel Research Chair, Geriatric Medicine Associate Professor, School of Public Health Sciences University of Waterloo, Waterloo, ON
Internal-external Member	Sharon Kirkpatrick, RD, PhD Associate Professor, School of Public Health Sciences University of Waterloo, Waterloo, ON
Other Member(s)	Albert Banerjee, PhD Associate Professor, Gerontology St. Thomas University, Fredericton, NB

Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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

Statement of Contributions

I (Jill M. Koechl) am the sole author for Chapters 1, 2, 3, 4 and 9, which were written under the supervision of Dr. Heather Keller and were not written for publication.

This thesis consists, in part, of four manuscripts (Chapters 5-8) written for publication. Exceptions to sole authorship of material in this dissertation are based on the contributions of co-authors to these four manuscripts. As primary author of these four chapters, I was responsible for conceptualizing the study design, carrying out data collection and analysis, and drafting and submitting manuscripts. My co-authors provided theoretical and methodological guidance and thoughtful feedback on draft manuscripts. All co-authors have approved the manuscripts for submission in their current form, with full knowledge that they would also be included in this doctoral dissertation.

Authorship for the four manuscripts, which required substantial intellectual input including contribution to research processes and feedback on the final draft, is as follows:

Chapter 5: Morrison-Koechl, J., Heckman, G.A., Costa, A., Banerjee, A., & Keller H.H. (2023). Eating challenges leading up to death among residents of long-term care. *Manuscript in preparation for submission.*

Chapter 6: Morrison-Koechl, J., Banerjee, A., Heckman, G.A., & Keller, H.H. (2023). Factors associated with the initiation of comfort-focused nutrition care orders for long-term care residents at the end of life. *Manuscript in preparation for submission.*

Chapter 7: Morrison-Koechl, J., Liu, S.H., Banerjee, A., Heckman, G.A., & Keller, H.H. (2023). Nutrition and non-nutrition-related challenges predict time to death in long-term care residents: A retrospective chart review. *Journal of Multidisciplinary Healthcare*. Accepted August 8, 2023.

Note: This is an Accepted Manuscript version of the article, accepted for publication in the Journal of Multidisciplinary Healthcare. It is deposited under the terms of the Creative Commons Attribution-Non-Commercial License (http://creativecommons.org/licenses/by-nc/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

Chapter 8: Morrison-Koechl, J., Heckman, G.A., Banerjee, A., & Keller, H.H. (2023). Factors associated with dietitian referrals to support LTC residents advancing towards the end of life. *Manuscript in preparation for submission.*

Abstract

Introduction: Eating challenges are prevalent in long-term care (LTC) and have been associated with mortality, particularly in older adults with advanced conditions such as dementia. However, changes to eating habits and nutrition care practices to support LTC residents who experience difficulties with eating have not been described within the context of end-of-life decline. Despite a general move towards palliative approaches to care in LTC, research on the implementation of comfort-focused nutrition care practices is lacking to date and the implications of a palliative approach to nutrition care is unknown. Nutrition care is an ideal target for palliative-focused initiatives because of the deeper meaning often placed on food and mealtimes as symbolic of relationships and care and the additional emotional challenges associated with health decline and death. When poorly addressed, severe eating challenges can cause distress among residents and care partners and contribute to decreased quality of life for residents and care providers. As such, best practices to support residents with severe eating challenges moving towards the end of life are needed to maintain quality of life for residents and provide positive care experiences for care providers, but the end-of-life nutrition care experience must first be understood. Towards this end, this dissertation aims to describe longitudinal changes in various aspects of the nutrition care experience for LTC residents approaching the end of life.

Methods: Data for this study were obtained from a retrospective resident chart review of a convenience sample of deceased residents from 18 LTC homes in southern Ontario, Canada. Two sampling frames, the "Better tArgeting, Better outcomes for frail ELderly patients (BABEL)" study and a chain of homes were accessed to meet sample size requirements. The latter included random selection of decedents for chart review. Eligible participants were over the age of 65 years at death and living in residence for at least 6 months. Data were collected from electronic charts. Admission forms provided information on demographics (e.g., age at death, sex, length of admission), and resident assessments completed approximately 6 months prior to death provided functional and health characteristics (e.g., cognitive performance, health instability) and diagnoses. Nutrition-related information (e.g., nutrition interventions, eating challenges) were obtained from monthly weight records, progress notes, and care plans, narrowed to four time points at 6-, 3-, 1-month and 2 weeks prior to the date of death. The point at which the first mention of end-of-life decline occurred and the details around this event were also noted. Study 1 described the eating challenges documented at each time point: a mixed effects logistic regression model tested longitudinal within-resident differences in eating challenges, and an unconditional repeated measures latent class analysis identified patterns of change in multiple eating challenges over time. Study 2 described the nutrition care interventions used to support residents and identified resident-level and time-dependent factors associated with comfort-focused nutrition care orders using a mixed methods logistic regression analysis. Study 3 determined which nutrition- and non-nutrition-related challenges factored into the first documentation of suspected end-of-life decline from the care provider perspective and assessed the association of each factor with time to death using a Cox proportional hazards regression analysis. Study 4 described dietitian referrals documented at each of the four time points and identified time-dependent factors, including comfort-focused orders, that were associated with dietitian referrals.

Results: The sample was comprised of 164 LTC residents (mean age 88.3±7.5 years at death; 61% female) and had a high level of health challenges and functional impairments, including 79.3% with moderate/severe cognitive impairment and 58.5% who left food uneaten at most meals 6 months prior to death. *Study 1:* All but 1 resident (99.4%, n=163) exhibited one or more eating challenges in the 6 months prior to death. Likelihood of severe and complex eating challenges (e.g., poor appetite, dysphagia, refusing to eat, decreased food intake) increased in the month preceding death compared to 6 months prior. A significant increase in lethargy at mealtimes was found as early as 3 months (Odds ratio [OR] = 1.78, 95% confidence interval [CI] = [1.06, 3.00]) compared to 6 months prior to death, and increased in a stepwise fashion at 1 month (OR = 4.09 [2.47, 6.76]) and 2 weeks (OR = 8.24 [4.92, 13.78]) before death. Four patterns of eating challenges were identified with the repeated measures latent class analysis, labeled for the most prominent features defining each group over time: "refusing" (20.1%), "complex" (18.9%), "progressive" (30.5%), and "end-stage" (30.5%). *Study 2:* Restorative nutrition interventions (e.g., physical assistance, oral nutritional supplementation) to support oral nutrient intake were also common (99.4% of the sample) in the last 6 months of life, and nearly half of the sample had nutrition care plan modifications between each time point. Despite a high need for nutritional interventions, only 30.5% of the sample received a comfort-focused nutrition care order, and most often these occurred within two weeks of death. Comfort orders were more likely with health instability (OR = 4.35 [1.49, 13.76]), within two weeks of death (OR = 5.50 [1.70, 17.11]), following an end-of-life conversation (OR = 5.66 [2.83, 11.33]), with discontinued nutrition interventions (OR = 6.31 [1.75, 22.72]), with the co-occurrence of other care plan modifications (OR = 1.48 [1.10, 1.98]), and with a higher number of eating challenges (OR=1.19 [1.02, 1.38]), especially dysphagia (OR = 2.59 [1.09, 6.17]), at the preceding time point. *Study 3:* Several of the eating challenges cited above were documented by care providers to suggest suspected end-of-life decline. Of 7 eating challenges cited, only dysphagia was significantly associated with increased risk of death (HR = 2.99; 95% CI = 1.41, 6.33). *Study 4:* Dietitian referrals were common (73% of participants) in the last six months of life and were significantly associated with number of eating challenges (OR = 1.38 [1.25, 1.54]). A higher frequency of comfort-focused nutrition care orders was found when a dietitian was referred (24.7%) compared to when not referred (11.9 %) in the final month of life, though a causal association could not be established.

Conclusion: Findings demonstrate that nutrition care is an important aspect of the end-of-life experience for LTC residents and that there is potential room for growth in supporting residents with severe and complex eating challenges. Eating challenges were common and increased in prevalence with proximity to death requiring several modifications to nutrition care plans, while comfort-focused nutrition care plans were used infrequently and often late in the end-of-life trajectory. Given the common occurrence of eating challenges with proximity to death and the evidence that they are considered by care providers as informal signals of end-of-life decline in current practice, changes to eating habits (e.g., decreased food intake) may be useful targets for initiating timely comfort-focused nutrition care conversations. The involvement of dietitians at key moments when comfort-focused nutrition care may be appropriate suggests that dietitians are well-positioned to champion palliative approaches to nutrition care within the multidisciplinary LTC team. Future work should explore residents' and care providers attitudes towards comfort-focused nutrition care to develop best practices that align with their needs and preferences to support quality of life across the final months of life.

Acknowledgements

“No man is an island, entire of itself” (John Donne, 1572-1631). These words could not be truer from my perspective; I have been connected to and supported by so many people on this journey, and each person that I have encountered has immensely enriched the experience.

My deep and sincere gratitude is owed to Dr. Heather Keller. I could not have imagined that I was to end up here, on the other end of a doctoral dissertation, when I started working as a research assistant collecting data for the Making the Most of Mealtimes (M3) project in 2015. Since then, you have continually supported me and mentored me through new opportunities to develop my research skills, for which I am so grateful.

I would also like to acknowledge the contributions of Dr. George Heckman, Dr. Albert Banerjee, and Dr. Andrew Costa for your support and feedback throughout the many stages of my research development, including the bumps and redirections along the way. You have challenged me to think in new and critical ways and this is a stronger dissertation because of the expertise each of you has offered.

Thank you to Dr. Genevieve Thompson and Dr. Sharon Kirkpatrick for your willingness to review this dissertation and to serve as examiners on my committee.

I am grateful for the funding I have received to carry out this research in the form of a doctoral trainee award from the Canadian Institutes of Health Research (CIHR).

To my Nutrition and Aging lab colleagues, past and present, I am grateful for your friendship and collaboration. Thank you to Sheng Han “Sukie” Liu for volunteering to support my research through literature reviews and coding for Study 3. Your enthusiasm for the project and for learning in general has been very encouraging! Thank you to Safura Syed and Hana Dakkak for your insights and validating my work with your insider knowledge of LTC nutrition care. And a special “thank you” to Dr. Sarah Wu for all of the fun times, long chats, stats collaborations, and for all of your support as we navigated our doctoral studies together.

Thank you to Elisabeth at the UW Writing and Communication Centre for going above and beyond at the eleventh hour to help me to strengthen my writing in some sections of this dissertation.

To Dr. Rachel Laxer, whose friendship has endured since our first days as grad students in SPHHS in 2012, you have been a faithful source of encouragement throughout this process and I look forward to many adventures to come as “mom friends”.

Finally, an inadequate attempt at thanking my immediate and extended family for the many sacrifices, patience, love and care, prayers, and many meals that have allowed me to focus on my doctoral work over the past several years: Thank you to my husband, Rob, for your support and agreeing to come along with me on this journey. It’s been a wild ride with many sacrifices, joys, and sorrows, and I am so grateful for you and your patience, support, encouragement, sense of humour, and consoling shoulder through it all. Thank you to our sweet daughter, Zelie, my faithful driving buddy, and daily source of joy. You have brought a fresh perspective to my life and work and have taught me so much about slowing down and cherishing each moment. And to all of our extended family who have kept our little family afloat throughout this process: To Ania and Father George, thank you for being our family away from home, for always having the most scrumptious food, wine, coffee, chocolate, and Polish desserts for us even when we show up unannounced, for being available for babysitting on short notice, for hours of comic relief, and most especially for your spiritual support and prayers. Thank you to my parents-in-law, Bob & Bonnie, and to my sisters-in-law Sarah and Marie (and Josie, Amelia, and Felix!) for the weekly check-ins, words of encouragement, prayers, delicious meals, and for always welcoming us with open arms. I have so appreciated your availability to care for Zelie and for creating a loving, fun, and stimulating environment for her during our weekly visits. Thank you to Callum for sharing your studio space with me, and to Jason for your unrelenting pursuit of faster internet. We feel so blessed by all of you and the time that we have spent at Belwood! Last but certainly not least, I am eternally grateful to my parents, Paul and Claudette, for your unconditional love and support, and for faithfully sacrificing your time and home so that I could continue working with Zelie close by. Words cannot express how special it has been for me to spend the extended time with you each week and to watch you dote on Zelie. I am so grateful for your love and can only hope that I have inherited some of your generosity.

"*I will give thanks to the Lord with my whole heart; I will recount all of your wonderful deeds. I will be glad and exult in you; I will sing praise to your name, O Most High.*"

(Psalm 9:1-2)

Dedication

This work is dedicated to

Saints Anne and Joachim, patrons of Grandparents and the Elderly, on whose feast day I defended this dissertation

and

The long-term care residents whose final months and days of life were the subject of my study.
Eternal rest grant unto them, O Lord.

Table of Contents

List of Figures

Main Text:

Appendices:

List of Tables

Appendices:

List of Abbreviations

ABS – Aggressive Behaviour Scale

ACP – advance care plan

ADLs – activities of daily living

AGS – American Geriatric Society

AIC – Akaike Information Criteria

ANOVA – analysis of variance

BABEL – “Better tArgeting, Better outcomes for frail Elderly patients” study

BIC – Bayesian Information Criteria

BMI – body mass index

CHESS - Changes in Health, End Stage disease and Symptoms and Signs score

CHPCA – Canadian Hospice Palliative Care Association

CI – confidence interval

COPD – chronic obstructive pulmonary disease

CPS – Cognitive Performance Scale

CSA – Canadian Standards Association

CIHI – Canadian Institute for Health Information

DRS – Depression Risk Scale

FLTCA – *Fixing Long-Term Care Act*

HSO – Health Standards Organization

LTC – long-term care

MDS 2.0 – Resident Assessment Instrument Minimum Data Set 2.0

OLTCA – Ontario Long-Term Care Association

ONS – oral nutritional supplements

OR – odds ratio

PPS – palliative performance scale

PSW – personal support worker

Q1, Q3 – first quartile, third quartile

RMLCA – repeated measures latent class analysis

SD – standard deviation

VPN – virtual private network

Chapter 1

Introduction and Overview

People have gathered around food to form strong communal bonds throughout history, resulting in rich cultural and social symbolism in addition to the more primal necessity of food for survival (M. Douglas & Gross, 1981). These cultural, symbolic, and physical functions of food persist in long-term care (LTC) homes where adults with severe and complex health and functional needs receive 24-hour nursing care and personal support including meals. Among the daily activities offered within LTC homes, mealtimes serve as touch points around which the rest of the day revolves for residents, providing opportunities for social engagement, familiarity, and routine (Watkins et al., 2017) and offering nourishment to support physical health and nutritional status, thus minimizing adverse outcomes such as hospitalization, functional decline, and mortality (Dent et al., 2023). As such, mealtimes, and food intake more generally (i.e., including snacks), are an important aspect of LTC service provision and carry strong potential to impact the quality of life of residents and their care providers, for better or for worse.

Widely held symbolic understandings of food inform the dynamics between residents and care providers in the LTC dining environment, though perhaps unconsciously (Jones, 2007). One such symbol is that of caring, as an act of providing one of the most basic needs to others and particularly to the weak and vulnerable (R. Caspar, 1988). Care providers, both paid and unpaid (e.g., spouse, adult child, non-familial relation), may perceive provision of food as an act of caring; the former may associate food provision with job performance, while the latter, with their ability to care for their relative or with role reversals, as in the case of an adult child caring for an aging parent (Barrado-Martín et al., 2022; J. W. Douglas et al., 2021; Wallin et al., 2022). Furthermore, symbols abound of food as a representation of health, vitality, and social belonging (Jones, 2007; Wallin et al., 2015, 2022). Residents with poor appetite and difficulties eating cause care provider distress, and refusal to eat may be interpreted by care providers as a loss of will to live or a rejection of care on the part of the resident (Barrado-Martín et al., 2022; Fringer et al., 2020). These symbols suggest that the effects of mealtime dynamics in LTC are twofold: adequate food intake among residents can positively impact care providers' perceptions providing peace of mind and strengthened relationships (Hamburg et al., 2014), but low intake may result in feelings of distress, resentment, guilt, shame, or rejection (Barrado-Martín et al., 2022; del Río et al., 2012). Thus, supporting food intake through pleasurable dining environments and navigating eating challenges with a sensitivity towards the deeper meaning of food has the potential to uphold the quality of life of residents and care providers alike.

The importance of food for both its nutritional and psychosocial merits, rooted in person- and relationship-centered care principles, is the impetus of ongoing efforts to improve mealtimes and promote food intake in the LTC sector (Keller et al., 2022; Sloane et al., 2008; Wu, Sarah A., 2021). Appropriately so, the overarching aims of these interventions are to optimize nutrient intake to prevent or reverse malnutrition and to avoid adverse outcomes in the face of institutional, structural, and systemic deficiencies (Estabrooks et al., 2020; Keller et al., 2022; Wendland et al., 2003). With malnutrition risk at rates as high as 50% or more among LTC residents (Keller et al., 2019), many modifiable factors undoubtedly have the potential to improve or at least prevent or delay the deterioration of nutritional status among residents (Abbott et al., 2013; Keller et al., 2014; M. O'Keeffe et al., 2019; Whear et al., 2014). However, considering the complexity of conditions found among LTC residents, it may be argued that nutritional decline, though undesirable, is inevitable and an expected feature of the end-of-life experience for many residents. Indeed, malnutrition, weight loss, low body mass index (BMI), and eating difficulties are strong predictors of mortality (Dent et al., 2023; S. L. Mitchell et al., 2009; Söderström et al., 2017; Wirth, Streicher, et al., 2016). Eating challenges that are associated with the end-of-life process (i.e., "eating-related decline") require special considerations for care. Failure to recognize and address the unique psychosocial and physical needs associated with eating-related decline, for example, inappropriately using interventions aimed to enhance nutritional intake, can lead to suboptimal care and poor quality of life for residents and care providers (S. L. Mitchell et al., 2009; Volicer & Simard, 2015). As such, development of person- and relationship-centered care practices to support residents with complex and changing nutritional needs in the face of eating-related decline represents a natural extension of the existing high-quality efforts to improve nutrition care in LTC.

A growing body of literature promotes the integration of a palliative, or comfort-focused, philosophy of care for LTC residents with life-limiting illness (Canadian Institute for Health Information [CIHI], 2018; Kaasalainen et al., 2020; J. Lee et al., 2013; G. Mitchell et al., 2016; Palecek et al., 2010; Palliative Alliance, 2017; Sussman et al., 2017; Volicer & Simard, 2015). At the same time, best practices have been developed specifically for nutrition and hydration decline in residents with dementia (G. Mitchell et al., 2016; Palecek et al., 2010; Volkert, Beck, et al., 2019). However, there is little evidence that a palliative philosophy has been applied to nutrition care in

LTC, nor that comfort-focused nutrition care practices have received much attention in LTC practice. An informal survey of 28 healthcare professionals (e.g., dietitians, speech language pathologists) working directly with individuals facing end-of-life nutritional challenges in Ontario, Canada revealed that formalized policies to support end-of-life nutrition decision-making were rare and definitions of “comfort feeding” were varied and surrounded by confusion (Davenport & Yeung, 2019). Similar uncertainty or unawareness of nutrition-related aspects of palliative care is demonstrated internationally (Chen et al., 2018; J. Lee et al., 2013; Soar et al., 2021). Artificial nutrition and hydration remain a large focus of the conversation for supporting older adults with severe eating challenges at the end of life (Anantapong et al., 2020; Loofs & Haubrick, 2021; Newman et al., 2020), despite recommendations against its use when prognosis is poor (e.g., severe dementia) with a strong preference for oral options for nutritional intake (American Geriatrics Society [AGS] Ethics Committee and Clinical Practice and Models of Care Committee, 2014; Lam & Lam, 2014; Volkert, Beck, et al., 2019; Volkert et al., 2015). As such, further clarity, and development of strategies to implement comfort-focused nutrition care best practices are needed (Baillie et al., 2018; Soar et al., 2021).

In order to apply a palliative approach to nutrition care, there is a need to understand how nutrition care is currently offered in response to eating challenges experienced by residents in the last months of life. A better understanding of various aspects of nutrition-related care at the end of life of LTC residents can assist care providers in managing care expectations, decision-making, and earlier initiation of comfort-focused care conversations (Baillie et al., 2018; Wallin et al., 2022). To this end, several recent publications have focused on nutrition and hydration-related challenges and decision-making at the end of life of older adults, and particularly for those with cognitive impairment (Anantapong et al., 2020, 2021; Barrado-Martín et al., 2021, 2022; Firnhaber et al., 2020; Loofs & Haubrick, 2021; Newman et al., 2020; Soar et al., 2021). However, none have provided a quantitative description of these issues considering longitudinal changes in eating challenges in the specific context of long-term care and including residents with various conditions (i.e., not limited to dementia).

Through this dissertation, I aim to fill this gap in quantitative knowledge using originally collected data from resident charts of 164 decedents from 18 LTC homes in southern Ontario. I retrospectively extracted nutrition-related information from resident charts documented in their last six months of life, focusing on four time points (i.e., 6 months, 3 months, 1 month, and 2 weeks prior to death) to capture longitudinal differences in nutrition-related documentation with proximity to death. I also identified the point at which end-of-life decline was first suspected (i.e., reported) by care providers and qualitatively assessed these reports for signals of end-of-life decline. The dissertation contains four studies that represent various aspects of the end-of-life nutrition care experience that are relevant to understanding current practice. First, the eating challenges and patterns of eating decline with proximity to death identified in study 1 illustrate the need for tailored end-of-life nutrition care practices. Second, the nutrition care interventions prescribed in the resident care plans leading up to death as well as the factors associated with comfort-focused nutrition care orders described in study 2 illustrate the complexity of managing nutrition care for LTC residents at the end of life. Third, the nutrition-related factors identified as signals of end-of-life decline from the care provider perspective in study 3 suggest a potential opportunity for initiating earlier comfort-focused conversations. Lastly, the patterns of dietitian referrals leading up to death are highlighted in study 4 to suggest the particular role of dietitians in championing comfort-focused nutrition care practices in LTC. Taken all together, the findings from these studies provide a fundamental description of end-of-life nutrition care experiences of residents and care providers.

Overall, my aim in this dissertation is to advance our understanding of the intersection between nutrition care and end-of-life decline among residents of LTC, representing an important step towards effective implementation of palliative (i.e., comfort-focused) end-of-life nutrition care in LTC. Throughout the dissertation, I use culture change and a social model of care as a conceptual framework to discuss the potential application of my quantitative findings to improve the quality of nutrition care and palliative care more broadly in LTC. Specifically, the culture change movement represents an evolution of care practices to meet resident needs while fostering personal and interprofessional relationships between the people who live and work in these homes. I discuss how improvements in end-of-life nutrition care could be used to address at least four of the six culture change principles identified by Koren and colleagues (Koren, 2010), including resident direction, fostering of close relationships between residents and care providers, staff empowerment, and collaborative decision-making.[1] By and large, this dissertation represents a relatively small, but hopefully compelling, contribution to the culture change movement as a whole.

---

[1] The remaining two principles of culture change are homelike atmosphere and quality improvement processes (Koren, 2010)

The document is a manuscript-based thesis, in which following this introductory chapter, Chapter 2 provides a literature review and context for the overall study. Chapter 3 features the research questions that guided each of the four separate but related studies found in the subsequent chapters. Chapter 4 describes the chart review methodology and specific methods that were used to collect data for each of the studies for publication written in manuscript format found in Chapters 5, 6, 7, and 8. Finally, Chapter 9 contains a general discussion of overarching themes and findings with acknowledgment of the limitations of the study, an integration of current literature, and recommendations for future directions including practical implications and suggested future research in this area. By the end of these nine chapters and an array of appendices for further optional reading, my hope is that the reader will be convinced of the value of investing time and resources into enhancing palliative-focused nutrition care practices for residents nearing the end-of-life in LTC.

Chapter 2

Literature Review and Study Rationale

2.1 Introduction

Before delving into this description of specific aspects of nutrition care provided to long-term care (LTC) residents at the end of life, some context will be helpful. Specifically, the reader will benefit from a basic understanding of the complexity of care in the LTC environment. This chapter will describe the typical profile of LTC residents and the interprofessional nature of care, while highlighting the systems and structures within which daily care occurs along with some of the associated benefits and challenges. A brief discussion of the predominant philosophies guiding LTC practice and the ongoing culture change movement will serve as a conceptual framework for the research and will situate the reader to the timeliness of the topic. A description of the current literature on nutritional challenges faced by residents and the interventions that are commonly offered to address these challenges will emphasize the importance of integrating comfort-focused approaches to nutrition care. Certainly, any one of these topics could supply its own full dissertation, so the information provided in this chapter will serve as a general overview and not a comprehensive review of the literature. Given that the research was completed in Ontario, Canada, literature available from this and the broader Canadian context is presented where possible but many of the concepts are globally relevant. While the knowledge presented in this literature review may be commonplace to certain readers, the chapter will also serve to situate the reader to my perspective as the author, which has undoubtedly influenced the way in which all aspects of the research have unfolded.

2.2 Long-Term Care (LTC) in Context

LTC refers to residential facilities that accommodate adults, the majority of whom are over the age of 75, who require 24-hour nursing and personal care, supervision, and assistance with activities of daily living as a result of complex health-related, functional, and cognitive impairments (Ontario Long Term Care Association [OLTCA], 2019). These facilities are also given other names, such as nursing homes, continuing care facilities, residential care homes, and skilled nursing facilities, to name a few. The individuals who access LTC (i.e., “residents”) comprise some of the most frail and vulnerable members of our society, and the services offered extend across all aspects of their lives, supporting their healthcare, physical, recreational, social, emotional, and spiritual needs. As such, LTC represents an immensely complex and intense set of services that must balance both medical and personal needs of its residents.

Several layers of organization determine the operations of LTC homes across Canada, which numbers 2076 LTC homes nationally and 627 (30%) in Ontario (CIHI, 2021b, 2021c). At the national level, LTC operations may be guided by two national standards, the Health Standards Organization (HSO) *National Long-Term Care Services Standard* (CAN/HSO 21001:2023) and the Canadian Standards Association (CSA) *Standards for Safer Long-Term Care Homes* (CSA Z8004:22), both newly released in 2023, that address various aspects of the care and physical environment of LTC homes. At the provincial level, legislation is in place to regulate the organization, administration, and operations, and services provided in licensed LTC homes; in Ontario, this legislation is found under the *Fixing Long-Term Care Act, 2021* (S.O. 2021, c. 39, Sched. 1). The LTC homes in Ontario have a range of funding models, including private (i.e., for-profit and nonprofit), public, and charitable institutions, and various organizational structures (e.g., single home, chain). These financial and organizational factors affect the priorities and structure of operations within each home (Hsu et al., 2016; Lindmark et al., 2023; OLTCA, 2019; You et al., 2016). Ultimately, while there are some consistencies across all LTC homes, there is considerable variation found within the LTC sector in the way that the overarching requirements for care are fulfilled. The day-to-day care is largely dependent on the unique culture of each home and the people that live and work in them.

2.2.1 Description of the Complex Needs of LTC Residents

Although adults over the age of 18 years are eligible for admission to LTC, the sector predominantly serves the older adult population; the average age of all residents admitted to Ontario homes was 83 years in 2019 (CIHI, 2020). The most recent data show that there are approximately 76,000 LTC spaces filled to capacity in Ontario, with an additional 40,000 older adults on the waitlist; these numbers are projected to increase in the coming decade (OLTCA, 2023). Given the high demand and long wait times, residents are being admitted later in the trajectory of their conditions and with higher needs, even compared to 10 years ago. For example, as of 2023, 80% of individuals require assistance with activities of daily living on admission, which is up from 67% in 2011, representing an overall increase in residents with high care needs (OLTCA, 2023). Likewise, the current rate of 76% of individuals with moderate to severe cognitive impairment on admission has increased by 25% since 2011 (OLTCA, 2023), and an estimated 90% or more of all residents have some level of cognitive impairment (OLTCA, 2019). As a result, the majority of LTC residents are frail and require extensive help performing activities of daily living, such as support at mealtimes (OLTCA, 2019).

As is suggested by these statistics, individuals are typically admitted to LTC because of physical or cognitive limitations that necessitate more care than is available through home care or assisted living. Life-limiting conditions can be physical or cognitive and are often a combination of both, with approximately 75% of residents having at least three comorbidities (OLTCA, 2023). A wide range of conditions are found within the LTC population. Some of the more common conditions include cardiovascular disorders (74%), dementia (67%), arthritis (45%), diabetes (28%), and gastrointestinal diseases (26%) (OLTCA, 2019).[2] Regardless of specific prevalence, the variation in conditions found among LTC residents suggests that care providers are responsible for managing a whole host of varying conditions with different needs and trajectories.

2.2.2 The Interdisciplinary Nature of Care Provision in LTC

Care in LTC is provided by an interdisciplinary team of paid nursing, dietary, therapeutic, recreational, and housekeeping personnel and supported by unpaid caregivers and substitute decision-makers in the form of family, friends and public guardians that are all responsible for supporting the resident to varying degrees (Estabrooks et al., 2020).[3] This model of care has been developed to support the various health and personal needs of residents, but also poses some challenges for coordinating care and ensuring that all needs are met efficiently and effectively. Clear, effective, and respectful communication between and within teams, family/friend caregivers, and residents, and across professions are essential for positive home, caregiver, and resident outcomes, particularly as resident needs increase at the end of life (Banerjee & Rewegan, 2017; Ward & Rogan, 2021). However, challenges with communication within and between the interprofessional care team abound (Banerjee & Rewegan, 2017; Busari et al., 2017; Cranley et al., 2020; Farrell et al., 2022; Harper et al., 2021; Heckman et al., 2021; Madden et al., 2017; Puurveen et al., 2018; Towsley et al., 2015). Poor communication and engagement of professional expertise, such as highlighted in one case report

---

[2] Prevalence estimates based on 2019 data have likely increased since the time of reporting (OLTCA, 2023).

[3] A note on terminology: these various roles appear under a variety of terms in the LTC literature. For this dissertation, I use the term “care provider” generally to refer to any person, paid or unpaid, who takes part in the personal or health care of residents. When necessary for interpretation, I use more specific terminology, for example, “family caregiver” (indicating family/friends) , “direct care worker” (indicating paid staff who have direct day-to-day care interactions with residents), “personal support worker” (indicating unregulated staff), or “LTC staff/team members” (indicating all persons that provide care under the services of the LTC home).

recounting a missed opportunity for referral to a dietitian for nutrition-related challenges (College of Dietitians of Ontario, 2021), can be detrimental to residents' well-being.

Another facet of communication that challenges the quality of care provided to residents and the well-being of caregivers is the hierarchical structure of staffing and an imbalance in decision-making responsibility and time spent with residents. In 2018, LTC residents in Ontario received a daily average of 3.73 hours of direct care from paid staff (Long-Term Care Staffing Study Advisory Group, 2020).[4] An estimated 62% of this direct care is attributed to unregulated staff, such as personal support workers (PSWs), who provide daily care including mealtime support, personal hygiene, dressing, and washroom assistance (Long-Term Care Staffing Study Advisory Group, 2020). Given this role, PSWs are most likely to encounter the day-to-day needs of residents and often feel passionately about providing excellent care to residents (McCleary et al., 2018), yet have very little involvement in care decision-making (Cranley et al., 2022). PSWs, who are at high risk for oppressive working conditions as a largely female and immigrant demographic positioned at the bottom of the organizational hierarchy (Banerjee et al., 2008; Browne & Braun, 2008), also feel that their input is not valued within the broader interprofessional LTC care team (Banerjee et al., 2015; Farrell et al., 2022). Such factors may prevent relevant information from being communicated through the appropriate channels, particularly given the poor working conditions (e.g., overworked, poor support, working shorthanded, low resources) that PSWs face on a daily basis in LTC (Long-Term Care Staffing Study Advisory Group, 2020). Alternatively, registered nurses and registered practical nurses, who account for 28% of direct care hours, oversee care management and delivery (Long-Term Care Staffing Study Advisory Group, 2020) while relying on information from PSWs (e.g., reported eating challenges) to coordinate care (e.g., initiate dietitian referrals) (Beynon et al., 2021, 2022).

As demonstrated, effective communication between nurses and PSWs is invaluable for timely involvement of allied health professionals, such as dietitians, physiotherapists, and social workers, when specific needs arise. Collectively, allied health professionals and programming support account for 10% of direct care hours and dietitians comprise 2% of this group (Long-Term Care Staffing Study Advisory Group, 2020). In LTC, dietitians offer specialist nutrition-focused services according

---

[4] The target for average direct care hours per resident is aimed to increase to 4 hours per day by 2025 according to new regulations (*Fixing Long-Term Care Act,* S.O. 2021, c. 39, Sched. 1, s. 8(2)).

to allocated clinical time per resident; in Ontario, they are typically allocated 30 minutes per resident per month for oversight of food intake, nutritional status, and management of eating challenges (O. Reg. 246/22, s. 80 (2)). As a result of this small amount of time dedicated to direct care, dietitian responsibilities are limited and largely emphasize interprofessional teamwork to support residents who are experiencing eating challenges and nutrition risk (Bartrim et al., 2023; Wassink & Chapman, 2010). Consequently, interprofessional coordination through effective communication channels, such as charting in daily progress notes and referral processes, ensure that information is shared efficiently and that the right people, including unpaid caregivers, are involved in the care of residents as needed.

Unpaid caregivers, in a broad sense, are family or non-family relations that remain involved in the care of the resident, particularly with tasks involving advocacy, monitoring and management of conditions, and assistance at meals, especially as end of life nears (Gaugler, 2005; S. W. Williams et al., 2012). Given the active role that these individuals often play in the management of residents' care, as well as the knowledge of the residents' personal and family history, unpaid caregivers have great potential to contribute to the overall quality of life and well-being of residents (Zimmerman et al., 2013). However, challenges with the dynamics of the care network and broader sociopolitical environment in LTC can affect their level of involvement (Puurveen et al., 2018). As a result, the potential value of these and other team members to support the quality of life of residents remains yet to be optimized (Armstrong et al., 2023).

2.2.3 LTC Homes as Places for Living and Dying

LTC homes are emphasized as supportive environments for living, but the reality is that they are also places for dying given the complex and advanced conditions of residents. Indeed, the majority of LTC residents live out their final days in residence (Menec et al., 2009) including approximately 25% who die within one year of admission (Tanuseputro et al., 2017). Furthermore, increasing proportions of residents are aged 85+ years and have high care needs on admission (OLTCA, 2023), with high vulnerability to communicable diseases (Estabrooks et al., 2020). Such trends point to the inevitable responsibility of LTC facilities to provide residents with care leading up to death; the decreasing average length of stay and high turnover of residents suggests that this responsibility is becoming more prominent in many regions (Hoben et al., 2019). Unfortunately, however, care team members and families are resistant to acknowledging this reality for a variety of reasons (Cable-Williams & Wilson, 2017) and larger cultural, structural, and organizational factors are slow to adapt to the intensified demands placed on care teams to provide supportive relationship-centered[5] care to residents nearing the end of life (Banerjee & Rewegan, 2017). As a result, unmet needs, real or perceived, are reported by residents, their families, and frontline care providers as residents' death approaches (Banerjee & Rewegan, 2017; Durepos et al., 2017; Sussman et al., 2017). Given a growing awareness of the disconnect between resident needs and LTC services, the sector is in the midst of a philosophical shift to better align with this growing need (see Section 2.3). Continued efforts to embrace the reality of LTC as a place for living *and* dying – and what this means for all aspects of daily life in LTC (e.g., nutrition care) – is crucial to the well-being of both caregivers and residents moving forward.

The acknowledgment of death in LTC is important for several reasons. On a practical level, a general awareness of impending death could allow for more timely identification of decline and a transition in goals of care (Cable-Williams & Wilson, 2014, 2017). Earlier transitions to end-of-life oriented goals of care have the potential to significantly reduce burdensome interventions, improve quality of life, and decrease costs associated with accessing acute care services (CIHI, 2018; Eisenmann et al., 2020; Kaasalainen, Sussman, Durepos, et al., 2019; S. L. Mitchell et al., 2009; Qureshi et al., 2019). Arguably more important are the potential psychosocial benefits of a "death-friendly" culture within the LTC environment. The meaning derived from developing relationships and providing good end-of-life care to residents can be empowering for both direct care partners and family members. Direct care partners express a willingness to develop skills in end-of-life care, realizing the gravity of the dying experience, and fostering relationships with the residents is acknowledged as an important aspect of this care (Bükki et al., 2016). The death of a resident has the potential to affirm direct care partners and develop confidence if they are well-prepared, as summed up in the following quote by a nursing assistant:

> It is an honor to be the person taking care of a dying resident. Not only do you become closer with the patient's family, but you also learn a lot about the past. Also it is about the only time a [clinical

---

[5] Although Banerjee and Rewegan (2017) use the term "relational", I have chosen to use "relationship-centered" here to distinguish between the two aspects incorporated into their definition of relational care (pp. 400-401) and my use of the two terms throughout this dissertation. In this dissertation, I use "relationship-centered" to imply interpersonal care dynamics, consistent with Banerjee and Rewegan's first application of the term, and "relational" to imply the broader structural, organizational, political, and cultural contexts that affect the ability of persons to engage in relationship-centered care. See section 2.3.1 for further clarification, including a model presented by Keller and colleagues (2022) that presents a hierarchical understanding of these terms.

> nursing assistant] feels appreciated and noticed. The families appreciate what we do! (Cagle et al., 2017, p. 200)

These positive feelings and acknowledgment of the importance of the dying experience for residents and their families, as well as the sense of purpose that is obtained from providing good end-of-life care builds confidence and compels care providers to advocate for the needs of the resident (Wiersma et al., 2019). Furthermore, the confidence gained by doing so contributes to better, more personalized care for the residents, and higher well-being and more satisfaction for LTC staff and family caregivers alike (Cagle et al., 2017).

Alternatively, as a unique environment where work and life are intertwined and personal relationships naturally form between the residents and care team, continual death and sense of loss make staff vulnerable to distress and burnout, exacerbated by poor working conditions and lack of resources (Banerjee & Rewegan, 2017; Long-Term Care Staffing Study Advisory Group, 2020; Marcella & Kelley, 2015; McCleary et al., 2018; Molloy & Phelan, 2022; Pott et al., 2020). Improvements to the cultural acceptance of death as a part of life in LTC, and appropriate organizational shifts in policies and procedures, has the potential to reduce caregiver distress and retain LTC staff (Marcella & Kelley, 2015; Pott et al., 2020), ultimately supporting better quality of life for residents and care providers.

2.3 Shifting of Care Philosophies: Past, Present, and Future

This dissertation will be approached from a culture change perspective, which is founded on a social model of care that recognizes the need for transformation to create a dignified environment for the people who live and work in LTC. An historical look at the development of the LTC system in Canada reveals something of the underlying philosophies and attitudes that are entrenched in its origins, against which the culture change movement has been working for over two decades (Rahman & Schnelle, 2008). Stigma surrounding institutionalization dates back to the 19th century in Canada when destitute older adults with no family to care for them were housed in prisons and workhouses, collectively grouped with criminals and the "undeserving poor" in meager living conditions that stripped them of their personhood (Emodi, 1977). The quality of care for residents of LTC has come a long way since the workhouses of the early 20th century as a result of government intervention to institutionalize care specific to older adults in 1973 (Forbes et al., 2013), with the subsequent development of person-centered, relationship-centred, and relational care concepts (section 2.3.1), and concerted efforts to shift from a medical model to a more holistic social model of care (section 2.3.2). However, there is still much work to be done, especially considering the recognized need for a further shift in care philosophies to support LTC residents across the spectrum of living and dying.

Despite the promising cultural shifts that have been unfolding, and continue to unfold, in LTC over the last two decades, the vestiges of stigmatizing attitudes towards LTC residents and the people who provide their daily care remain both in actuality and in the public perception and are in need of continual reflection and transformation (Castillo et al., 2022; Hector, 2022; G. J. Mitchell et al., 2013). Lack of government resources, limited budgets, and staff shortages in LTC indicate that this sector is still undervalued in society as a whole, and all too often, care providers are subjected to poor working conditions and residents receive sub-optimal care as a result (Estabrooks et al., 2020). Most recently, long-standing challenges found within the sector (e.g., understaffing, quality of life and human rights issues for residents and staff) were exposed as a result of the disproportionate impact of the COVID-19 pandemic on LTC residents (Estabrooks et al., 2020; *Ontario's Long-Term Care COVID-19 Commission, Final Report*, 2021). As part of a larger and long-overdue effort to address these shortcomings, Ontario's *Fixing Long-Term Care Act, 2021* (*FLTCA*, S.O. 2021, c. 39, Sched. 1) and its associated Phase 1 regulations (O. Reg. 246/22) replaced the former *Long-Term Care Homes Act, 2007* (O. Reg 79/10). This newest iteration of regulatory practice guidelines indicates a more formal commitment from a policy perspective to provide dignified, holistic care for residents, particularly with the addition of a regulation that requires the integration of a palliative care philosophy into LTC practices (section 2.3.3). Although rudimentary in its current form, this change represents a new frontier in LTC that calls for innovative ways of thinking and caring for residents.

2.3.1 The Progression of Person-Centered, Relationship-Centered, and Relational Care Theories

The provision of high quality, dignified care for residents is reliant on a recognition of the interpersonal dynamics within the LTC setting, the understanding of which has evolved over the last 50 years with the development of "person-centered", "relationship-centered", and "relational" care principles. This progression began with the concept of patient-centered care in the 1960s, which challenged the focus of modern medicine on treatment of illness to instead recognize the entire patient and their surrounding context (Balint, 1969); notably, the emphasis was still on the identity of the person as a patient. Decades later, the concept of person-centered care arose in consideration of individuals living with dementia, acknowledging that personhood is independent of cognitive status and care providers have the responsibility to bestow LTC residents with their personhood through respect and trustworthy actions (Kitwood, 1997). Where the person-centered model of care falls short, however, is in considering that personhood is not confined to the care recipient: care providers are also persons by their nature of participating in the care relationship (McCormack, 2001; Nolan et al., 2004). As such, relationship-centered care moves beyond previous models of care to recognize the importance of the relationship dynamics within the entire care network (Beach et al., 2006; Nolan et al., 2004). Feminist relational care theory broadens the understanding of relationship-centered care, acknowledging that relationships are influenced by various social, economic, and political factors that can either stimulate or discourage growth and development (Banerjee & Rewegan, 2017; Koggel et al., 2022). A conceptual model, provided by Keller and colleagues (Keller et al., 2022), is useful to understand how these three principles can be applied to nutrition care interactions. Their model shows that the ability to meet the individual needs of residents (i.e., person-centered care) is embedded within the context of meaningful relationships between residents, staff, and families (i.e., relationship-centered care). Likewise, the sustainment of such relationships further relies on the surrounding structures and systems that are 'relational' to enable and reinforce the pursuit of the shared goal of meeting residents' physical and psychosocial needs. These layered dynamics, which intensify at the end of life for LTC residents and their care providers (Banerjee & Rewegan, 2017), are important to consider when seeking to understand various aspects of the care experience.

2.3.2 From Medical to Social Model of Care

As person- and relationship-centered care paradigms have increasingly taken hold in the healthcare psyche over the past half-century, the LTC sector has seen a major shift in the model of care resulting from the larger culture change movement (Rahman & Schnelle, 2008). Historically, the medical model of care predominated LTC practices. Under this model, the aims of daily care interactions focused on managing the illness or specific disabilities of residents. The culture change movement has shifted the field towards a social model aiming to support all dimensions of residents' – and increasingly, care providers' – needs, with emphasis on a "homelike" physical environment, interpersonal relationships as the basis of care, staff empowerment, and supportive leadership (Armstrong et al., 2019). Efforts to transform LTC towards a social model of care have shown promise in improving residents' and care providers' quality of life and quality of care (Duan et al., 2022). However, a comprehensive shift in culture is difficult to achieve on a larger scale, even running completely opposite to the current organizational structures of many LTC homes, and thus requires an immense amount of time, energy, and resources, all of which are in short supply in the sector as a whole (Zimmerman et al., 2014). Instead, culture change efforts are slow and subtle, with piecemeal efforts to apply underlying theories and practices to the existing structures and systems within the context of individual and groups of care homes (Armstrong et al., 2019).

Such a slow transformation in LTC culture means that care is currently provided amidst a tension between the institutional and the "homelike". On the one hand, a social model of care emphasizes the holistic needs of residents, valuing relationships and quality of life. On the other hand, the nature of LTC as a congregate setting accommodating many residents with complex needs necessitates a certain level of monitoring and precautionary measures that seem counterproductive to the social model of care. Standardized protocols (e.g., charting and documentation) and mandates (e.g., quarantining for infection prevention) aim to protect both residents and care providers through professionalism, transparency, risk mitigation, and management or prioritization where resources are limited, but these occur at some cost to resident and staff well-being, autonomy, quality of life, and quality of care (Banerjee & Armstrong, 2015; Iyamu et al., 2022; Jefferies et al., 2010; Kontos et al., 2010, 2011). From a nutrition care standpoint, time-consuming regulated tasks such as documenting food intake detract from relationship-centered mealtime practices on a daily basis and create unnatural task-focused dining environments, ultimately contributing to sub-optimal care for residents and frustration for care providers (Banerjee & Armstrong, 2015; J. W. Douglas et al., 2021; Liu et al., 2022; Lowndes et al., 2015). Furthermore, mandatory adherence to prescribed care plans, such as texture modifications to mitigate risk associated with swallowing difficulties, can be overly restrictive and can detract from shared decision-making and lack of consideration for a person's values and potentially fluctuating needs (S. T. O'Keeffe et al., 2023). Certainly, optimizing food intake and safety are important goals, but emphasis on the documentation instead of on the people who are involved in the meal represents a misplacement of power (Banerjee & Armstrong, 2015). Ongoing efforts to shift systems and structures so that the regulations are at the service of people, and not the other way around, are needed to achieve real and lasting culture change in LTC.

2.3.3 Towards Palliative Care as a Philosophy and Goal of Care

An emerging concept in the culture change movement is the definition and integration of a palliative philosophy of care into the purview of LTC services as a result of a growing appreciation for the need to support care providers in caring for residents with complex and advanced end-of-life needs (Banerjee & Rewegan, 2017; Kaasalainen et al., 2020; Molloy & Phelan, 2022; Öhlén et al., 2017; Schwartz et al., 2019; Sussman et al., 2017; Volicer & Simard, 2015). To be clear, palliative care is not synonymous with end-of-life care though they often overlap; as a holistic comfort-focused philosophy of care, palliative care is well-suited to support the needs of residents who are declining towards the end of life (Schwartz et al., 2019; Sussman et al., 2017). A confusion between palliative and end-of-life care contributes to a hesitancy among care providers to initiate palliative care practices, particularly due to the uncertainty of prognosis, fear or unwillingness to accept death, or a perception of admitting failure, among other reasons (Cable-Williams & Wilson, 2014, 2017; Hawley, 2017; Löfmark et al., 2007; Reid et al., 2011; Unroe et al., 2015). As such, a clear differentiation of the two concepts is useful: palliative care refers to a **philosophy** emphasizing a holistic comfort-focused approach to care; whereas end-of-life care refers to the **timing**[6] of care, generally defined as advanced stages of disease and declining towards death. End-of-life care fits into the broader concept of palliative care in that care goals shift almost exclusively to comfort-focused symptom management as decline towards death becomes apparent (Kelley, 2015). However, a palliative approach to care is appropriate and even recommended for life-limiting conditions well before a residents' decline towards the end of life is obvious (Sawatzky et al., 2016). Advocacy for applying a palliative approach to care as early as admission of residents to LTC (e.g., Kaasalainen et al., 2016; Kelley, 2015; Palliative Alliance, 2017) has contributed to the addition of the new legislation requiring integration of a palliative philosophy for all Ontario LTC homes (*FLTCA,* S. O. 2021, c. 39, s. 12; O. Reg. 246/22, s. 61).

On an organizational level, the palliative philosophy of care is complementary to the restorative philosophy, which has been the guiding principle in LTC and remains a key component of the current regulations (*FLTCA,* S. O. 2021, c. 39, s. 13; O. Reg. 246/22, s. 62). A restorative philosophy seeks to maintain or improve function and maximize independence of residents in order to slow physical and functional decline, operating under the assumption that the underlying condition can be reversed or at

---

[6] The definition of the end-of-life period varies significantly in the literature, ranging from a year or two at the onset of significant life-limiting conditions (Morley, 2011), to weeks or days when the resident is actively dying (e.g., Sussman et al., 2017; Toscani et al., 2019). Consensus suggests an operational definition of 'end of life' as having 6 months or less to live (Hui et al., 2014). The definition of the end-of-life care period has clinical implications regarding the approaches and goals of care.

least slowed (Resnick et al., 2009). In contrast, the palliative philosophy focuses on upholding comfort and quality of life while supporting the physical, emotional, psychological, social, spiritual, and practical needs of the residents and family caregivers, recognizing that the underlying conditions cannot be reversed (Canadian Hospice Palliative Care Association [CHPCA], 2013). Given the diverse needs of residents in LTC, incorporation of both philosophies is necessary to optimize the care and well-being of all residents and their care providers.

On an individual level, goals of care shift from restorative to palliative based on the changing needs of the resident as they experience health and functional decline. While these two approaches have different aims (i.e., function versus quality of life), they are not mutually exclusive. Rather, the transition from one to the other is a process that occurs on a continuum over time, with palliative goals of care becoming more dominant as a person approaches death (Ferris et al., 2007; Hawley, 2017). Palliative-focused interventions are flexible and can include active treatment, prevention, and management of current and future issues while promoting meaning in the day-to-day care experience of the patient and their caregivers (CHPCA, 2013). Furthermore, various aspects of a resident's life may warrant the initiation of palliative-focused goals of care at different points in the end-of-life trajectory as demonstrated by the concept of "total pain", which includes physical, psychological, social, and spiritual suffering (Mehta & Chan, 2008; Pinho-Reis et al., 2022). Despite this understanding, the shift from restorative to palliative care goals is typically delayed until the last days and weeks of life for LTC residents when death is imminent, and narrowly focuses on the physical suffering associated with end-of-life decline (Cable-Williams & Wilson, 2017; Hawley, 2014; Sussman et al., 2017; Wallin et al., 2022). As such, there is an urgent need for a paradigm shift to allow earlier initiation of palliative care goals in response to residents' holistic needs and not their prognosis (Reid et al., 2011).

Residents, family caregivers, and LTC staff have many unmet needs in the end-of-life care process including lack of clear guidelines on how and when to provide comfort-focused palliative care to residents (Banerjee & Rewegan, 2017; Durepos et al., 2017; Sussman et al., 2017), nor on what palliative care entails. Furthermore, at the end of life the trajectory toward death can vary between residents, leaving uncertainty around care goals (Banerjee & Rewegan, 2017; Lynn, 2005). As a result, initiation of palliative end-of-life care is often delayed up to the last days of life or not at all (Cable-Williams & Wilson, 2014; Löfmark et al., 2007; Morley, 2011; Sussman et al., 2017; Toscani et al., 2019). For example, in 2015, only 1 in 20 residents who died in LTC had a record of receiving any deliberate palliative care practices, compared to 20-30% of older adults who died in other care environments (CIHI, 2018). Though end-of-life care of some form is provided to almost all residents who die in the home, most LTC homes do not have the capacity, skills, or resources to provide focused palliative care, and end-of-life care is often reduced to addressing the basic physical needs (e.g., pain management) of residents (CIHI, 2018; Cloutier et al., 2021). This gap in care represents a potential missed opportunity for better management of LTC resources. When in place and administered early, palliative end-of-life care is associated with better quality of care, reduced care-associated costs, and fewer unnecessary hospitalizations (Qureshi et al., 2019; Ranganathan et al., 2013; S. Smith et al., 2014; Stokols, 1992). As such, proper protocol and training for LTC team members as well as awareness among family caregivers on how to incorporate palliative care practices to all aspects of care in LTC are of utmost importance for the provision of high quality, cost-effective end-of-life care.

2.4 Nutrition as a Focal Point for Palliative-Focused Care Initiatives

From a culture change perspective, dining and meals have been focal points in the shift towards a social model of care (Keller et al., 2022), but efforts to date have been rooted in the restorative philosophy of care while palliative approaches to nutrition care in LTC remain largely undefined. As a central part of daily life in LTC, mealtimes are recognized as an ideal opportunity to fulfill both nutritional and social needs of residents using person-centered and relationship-centered care practices (M. Douglas, 1972; Reimer & Keller, 2009; Watkins et al., 2017). These qualities of the mealtime are well-aligned with a social model of care. Indeed, consistent with a social model of care, interventions including those targeting dignified care practices (Wu et al., 2018), physical qualities of the dining environment (Chaudhury et al., 2013), and provision of appealing (Merino et al., 2021; Pu et al., 2021) and nutrient-dense foods (Romaniw et al., 2020) aim to provide a positive dining experience for residents. However, these and similar practices adopt a restorative philosophy, which is reflected in the underlying motivation to optimize residents' nutritional intake and nutritional status and thus to avoid functional and physical decline (Agarwal et al., 2016; Keller et al., 2022). Although optimizing nutritional intake is important, this may become an unrealistic and even burdensome goal for residents who are experiencing complex and advanced eating challenges (e.g., refusal to eat, severe dysphagia, lack of food recognition) (S. L. Mitchell et al., 2009; Sloane et al., 2008), representing a potential misalignment of care goals and residents' needs. In such cases, a palliative approach to nutrition care that promotes eating for comfort and quality of life instead of for optimizing nutritional intake may be more beneficial as demonstrated in theory (Palecek et al., 2010) and in other settings (Orrevall, 2015; Soar et al., 2023; Sommerville et al., 2019). Yet, palliative approaches to nutrition care have not been widely applied in LTC practice to date (Davenport & Yeung, 2019). To understand how a palliative approach to nutrition care may be systematically implemented within the context of LTC, there is a need to first describe the nutrition care experiences of LTC residents in the final months of life when a palliative approach may be most beneficial, which is the aim of this dissertation. Therefore, the following sections review current nutrition care practice in LTC to orient the reader more fully to the dissertation aims.

2.4.1 Description of the Nutrition-Related Needs of LTC Residents

The complex health-related, functional, and cognitive impairments that are common within the LTC population (see section 2.2.1) make residents susceptible to a variety of eating-related challenges that can contribute to poor nutritional intake, malnutrition risk, and further decline (Volkert, Kiesswetter, et al., 2019). Descriptions of each of these aspects of the nutrition-related needs of LTC residents are provided in the following sections.

2.4.1.1 Eating Challenges

The paragraphs in this section provide a high-level summary of the eating challenges that are most prevalent among LTC residents and that are most likely to affect food intake requiring individualized care plans. Residents experience a variety of physical and cognitive challenges that hinder food intake. Physical challenges can be due to age-related (e.g., sensory loss) or disease-related (e.g., Parkinson’s, diabetes) processes (Sloane et al., 2008), while cognitive challenges are indirectly associated with food intake through impairment of mental, social, and physical processes that challenge participation in meals (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017). Given these physical and cognitive difficulties, a variety of eating challenges can occur, including disrupted appetite, selective eating and sensory changes, loss of motor skills, dysphagia, refusal to eat, and lack of recognition of food, which may be subtle at first, but progress in severity and complexity over time (Keller, 2016; Sloane et al., 2008). While these and other unlisted eating challenges are complex in origin and clinical presentation, it is helpful to categorize them into broader groupings for the sake of discussion. For this dissertation, the categories will be pragmatic to conceptualize the implications of each type of eating challenge on food intake and interactions with care providers, as well as the care plan interventions that may be most used to address them. The broader categories include gastrointestinal issues, self-feeding difficulties, social or behavioural challenges, signs of general decline, and oral challenges. These will be described in the following paragraphs.

Gastrointestinal disorders come in a variety of clinical symptoms and can impact food intake and quality of life. Physiologic and pathologic changes that can occur with age lead to higher prevalence of several gastrointestinal disorders resulting in clinical symptoms such as nausea, emesis (i.e., vomiting), loose stool (i.e., diarrhea), and constipation (Dumic et al, 2019), as well as gas pain and discomfort. These disorders can cause a variety of challenges that reduce appetite, effective absorption and metabolism of nutrients, and overall enjoyment of food (Dumic et al., 2019), and potential avoidance of specific foods or fluids. Most common among these symptoms is constipation, which can affect as many as 55 to 75% of long-term care residents, the majority of whom are prescribed stool softeners or other laxatives (Keller, 1993; Phillips et al., 2001; Tariq, 2007). Paradoxically, constipation can also be marked by presence of loose stool, if soft or liquid stool bypasses impacted stool (Dumic et al., 2019). Loose stool occurs for a variety of reasons including gastrointestinal infections, irritable bowel syndrome, over-prescription of laxatives, medication side effects, and enteral nutrition (Bennett & Greenough, 1993; Dumic et al., 2019; Morley & Steinberg, 2009). Occurrence of loose stool in LTC is difficult to determine, with one study reporting a prevalence of 60% among residents obtained by convenience sampling (Archbald-Pannone et al., 2010), and another reporting incidence of acute gastroenteritis ranging from 6.7 to 32.4 cases per 100 patient years (Sims et al., 1995). Chronic or acute nausea and emesis most commonly occur as a side effect of medication or as a result of infections but can also arise from a broad range of other disorders (Dumic et al., 2019; Hasler & Chey, 2003) including pain. The prevalence of all-cause nausea and emesis in LTC is unknown, but disease-specific (e.g., norovirus) prevalence is high (e.g., ~75% of infected residents in one study) making infection outbreaks especially detrimental to the LTC population (Adams et al., 2020; Hughes et al., 2021). Altogether, whether acute or chronic, gastrointestinal issues can greatly affect residents' well-being, quality of life, nutritional status, and mortality and require tailored care to manage the effects of such challenges.

Self-feeding difficulties experienced by LTC residents include cognitive and physical difficulties that challenge mealtime activities, necessitating direct physical support or verbal prompting to eat by care providers. In Ontario, 86% of residents need extensive assistance with activities of daily living

(ADLs) due to loss of physical and cognitive function and increasing dependence on care providers to support their personal care including eating (OLTCA, 2019). Specific to eating dependence, dining room observations during mealtimes show that 25-30% of Canadian LTC residents require physical assistance with eating, half of which require total assistance (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Keller, Edward, et al., 2006). Reasons for requiring physical assistance or verbal cueing are varied and include both cognitive and physical challenges such as difficulties with: initiating eating, attention, energy and alertness, handling utensils, obtaining an appropriate amount of food with utensils, food spillage, and food recognition (Edahiro et al., 2012; Sloane et al., 2008). These challenges require varying degrees of mealtime prompting and assistance that tend to increase with condition severity (Edahiro et al., 2012). Attentive physical and verbal (i.e., prompting) assistance with meals that matches each residents' level of need are effective ways to support intake and maintain mealtime independence where possible (Batchelor-Murphy et al., 2017; Sloane et al., 2008). As well as supporting food intake, care providers, including family and volunteers, who provide mealtime assistance to residents can also attend to the social qualities of the dining environment to support positive mealtime experiences and mitigate the negative effects of social or behavioural challenges experienced by residents (Wu et al., 2018; Wu, Morrison-Koechl, Slaughter, et al., 2020). As such, physical and verbal supports for residents with self-feeding difficulties are important occasions for incorporating relationship-centered care practices with the potential to improve the quality of life of both residents and care providers.

Social or behavioural challenges including distractibility/wayfaring, frustration, socially unconventional behaviours, and eating inedible items are affected by the quality of the social and physical dining environment and thus require thoughtful relationship-centered care practices to mitigate the negative impact on food intake (Keller, Gibbs-Ward, et al., 2006; J. Y. Lee et al., 2021; Slaughter et al., 2011; Slaughter & Hayduk, 2012). Hectic, busy dining environments can be overwhelming and distracting for residents (Hung, 2008), which may contribute to poorer food intake. Residents who experience eating challenges eat less in highly social environments compared to low social environments, possibly because of distraction and inability to focus on the mealtime activities (Slaughter et al., 2020). Furthermore, noise and distractions in the dining environment can trigger stress, anxiety, and frustration leading to a higher rate of responsive expressions during mealtimes (Bergland et al., 2015; Goddaer & Abraham, 1994; Whear et al., 2014). Certainly, responsive expressions (i.e., agitation or other neuropsychiatric symptoms) are common in persons with cognitive impairment, with some studies reporting prevalence as high as 96% (Anatchkova et al., 2019). Responsive expressions can lead to refusal of care (Backhouse et al., 2023), including at mealtime and particularly when care practices are task-focused (J. Y. Lee et al., 2021). Alternatively, supportive, person-centered dining practices can promote food intake among LTC residents by orienting residents to the mealtime and offering social stimulation where appropriate, while also adjusting care practices according to residents' expressed needs such as offering a quiet dining environment if preferred (Chaudhury et al., 2013; J. Y. Lee et al., 2021). Consequently, the effects of social and/or behavioural challenges on food intake among LTC residents seem to be modifiable with appropriate person- and relationship-centered care practices that support optimal intake.

Alternatively, signs of general decline that affect the food intake of LTC residents including poor appetite, lethargy at mealtimes, and food refusal hinder the residents' ability to meet daily recommended nutritional intake and may be less amenable to restorative interventions. Age-related factors that affect appetite and hunger regulation are captured by a condition known as anorexia of aging (Morley & Silver, 1988), which is estimated to affect approximately 31% of LTC residents (Malafarina et al., 2013). Factors affecting appetite among LTC residents can be physiological (e.g., sensory loss, changes in hormone regulation, digestive issues), psychosocial (e.g., isolation, depression, apathy), or medical (e.g., side effect of medication, disease-related) (Malafarina et al., 2013). Any one of these symptoms can also produce fatigue or tiredness (i.e., lethargy), either directly or by affecting night-time sleep quality (Ye & Richards, 2018), that causes residents to sleep through meals, to prefer to remain in bed rather than attend the dining room, or to fall asleep during meal service. Such symptoms of fatigue are often associated with social withdrawal indicative of the early stages of end-of-life decline (Åvik Persson et al., 2018). Food refusal (e.g., turning head away when assisted, refusing to come to meals) can also be related to poor appetite and additionally may be a sign of social withdrawal and loss of desire to live, indicative of early end-of-life decline (Åvik Persson et al., 2018; Fringer et al., 2020). From a care perspective, consensus suggests that these general signs of decline (i.e., poor appetite, lethargy at meals, and food refusal) that lead to poor food intake, can be managed by addressing the underlying reasons for the challenges and offering nutritional supplements if desired, but otherwise residents' autonomy must be respected and their expressed cues of readiness to eat should determine their level of intake (Fringer et al., 2020; Malafarina et al., 2013; Palecek et al., 2010; Palese et al., 2019; Pilgrim et al., 2015). Comfort-focused goals of nutrition care may be appropriate for residents who show general signs of decline that affect food intake because of their low capacity to meet nutritional recommendations and likely trajectory towards end-of-life decline.

Likewise, oral challenges that affect food intake (i.e., swallowing difficulties/dysphagia, holding food in the mouth, dental or chewing issues) that risk going undetected until their effect on food intake is severe may be appropriate for palliative-focused care strategies as a result of such late detection and impact on food intake (Artiles et al., 2021; Julkunen et al., 2021; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Palecek et al., 2010; Wirth, Streicher, et al., 2016). Oral health affects eating habits in LTC residents; missing or broken teeth, poor saliva quality, or ill-fitting or uncomfortable dentures can contribute to low food intake, poor diet quality, and malnutrition (Kazemi et al., 2011; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017). Yet, the majority of residents do not receive regular dental care (Matthews et al., 2012) and oral health in LTC is seen as a low priority among dentists (Tang et al., 2019), indicating that these issues remain unresolved in many residents. As a result, an estimated half (46-49%) of residents in Canadian LTC have dental issues that likely affect food intake (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Keller, Gibbs-Ward, et al., 2006), and nine percent have dental issues (e.g., broken teeth, infection, decay) that require urgent treatment (Yoon et al., 2018). Similarly, dysphagia (i.e., swallowing difficulty) may go unrecognized because of inconsistent screening and poorly defined roles for detection and management across the interprofessional care team (Artiles et al., 2021; Wirth, Dziewas, et al., 2016). Dysphagia, which can also manifest as pocketing food in the mouth, can result from neurological conditions such as dementia, Parkinson's disease, or stroke, certain medications, or as part of natural age-related decline (Rofes et al., 2011). An exact estimate of prevalence of clinical dysphagia among LTC residents is elusive because of inconsistent or imprecise methods of diagnosis but ranges from 7 to 40% (Namasivayam & Steele, 2015). In a study of non-palliative LTC residents across Canada, 45% exhibited symptoms that would indicate swallowing difficulties including coughing or choking at meals, requiring thickened fluids, or failing a swallowing test (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017). Collectively, oral challenges that affect food intake are managed with modification to food textures (e.g., minced, pureed) and additional nutrition through oral supplements (Wirth, Dziewas, et al., 2016). Comfort-focused nutrition care orders may also be considered for these residents who have oral challenges due to their impaired ability to meet nutritional requirements and/or a preference to maintain a regular texture diet despite clinical counter-indication, or when strategies such as modified textures fail to promote intake or to mitigate risk (Palecek et al., 2010; Soar et al., 2021).

In summary, residents of LTC experience a variety of complex and cumulative eating challenges that contribute to poor food intake and require various forms of intervention. As highlighted, the nutrition and eating challenges that are most relevant to the LTC population include digestive and gastrointestinal issues (Dumic et al., 2019), functional impairments that require physical and verbal assistance (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017), cognitive factors (Agarwal et al., 2016), environmental and psychosocial factors (Slaughter & Hayduk, 2012), poor appetite (Malafarina et al., 2013), dysphagia (Namasivayam & Steele, 2015), and oral health and dental issues (Kazemi et al., 2011; Yoon et al., 2018). Furthermore, accumulation of multiple challenges contributes to decreased nutritional intake, with one study finding that residents ate 63 kilocalories and 3 grams of protein less daily per one-point increase in severity of eating challenges using a valid observational scale and adjusting for other key covariates (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017). However, supportive nutrition care practices, such as physical assistance, oral nutritional supplements (ONS), and modified textures, among others, have the potential to improve oral intake and nutritional status when used appropriately (Borders et al., 2020; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Palese et al., 2020). As such, individualized care practices that are responsive to individual needs are an important factor in promoting intake and mitigating nutrition risk.

2.4.1.2 Nutrition Care Plan Interventions

Nutrition care practices in LTC, guided by home-level policies and processes, are aimed towards managing and addressing eating challenges, but a key element to optimizing food intake in the face of eating challenges is identifying residents' needs. A variety of nutrition interventions are available to address eating challenges experienced by LTC residents through formalized care plans. These practices include therapeutic diets (Wu, Morrison-Koechl, Lengyel, et al., 2020), modified texture diets (Agarwal et al., 2016), ONS (Johnson et al., 2009), adaptive aids (Frissoni et al., 1998), physical and verbal assistance (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017), and adjustments to the dining environment (Chaudhury et al., 2013; Ducak et al., 2015; Sloane et al., 2008).[7] Certainly, all of these strategies have the potential to optimize food intake in LTC residents, but their effectiveness relies on a series of steps, including screening, nutrition assessment, development of an individualized multidisciplinary care plan, and monitoring (Keller et al., 2022). Evidence suggests that identification of need through screening and nutrition assessment is suboptimal, leaving some residents with unmet needs. For example, residents who require occasional, but not total, physical assistance with meals have lower intake when compared to both residents who receive maximal assistance and those who do not need any support with eating (Batchelor-Murphy et al., 2017; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017), suggesting a "middle group" of residents whose need for supportive practices are not met. However, as in this example, the challenge is to identify the residents' needs early and to intervene with appropriate and individualized care practices. Early identification and intervention of nutritional challenges is hindered by inconsistent nutrition care policies and practices across LTC homes and low quality or total lack of evidence for best practices specific to the LTC environment (Johnson et al., 2018; Keller et al., 2022; Koh et al., 2022). Furthermore, the processes that are in place to identify the nutritional needs of residents are challenging in practice because of several barriers including time, knowledge, capacity, and lack of clear responsibilities and procedures among LTC team members (Johnson et al., 2018). In particular, dietitians play a crucial role in supporting the nutritional needs of residents, but as contracted health care providers with limited time allotment they are increasingly unable to meet their professional obligations because of residents' growing complexity of needs and shorter average length of stay (Dietitians of Canada Ontario Long Term Care Action Group, 2016). Due to these increasing demands on their time, dietitians working in Ontario LTC homes report incomplete tasks such as follow-ups for residents at high nutrition risk (Dietitians of Canada Ontario Long Term Care Action Group, 2016). As a result, residents who would benefit from interventions to mitigate the risk of malnutrition may be missed or identified late (Johnson et al., 2018; Van Bokhorst-de Van Der Schueren et al., 2014; Villalon et al., 2011). Indeed, there is still much work to be done to optimize nutritional support for residents (Keller et al., 2022). However, even with optimal nutrition care the potential for nutrition interventions to improve nutritional status once severe challenges occur is limited (Abbott et al., 2013; Beck et al., 2016; Borders et al., 2020; Bunn et al., 2016; Cate et al., 2020). Given the complexities of nutrition care and the difficulties in identifying and managing

---

[7] See Appendix A, Section A.1 for further description and prevalence of these practices.

residents' nutritional needs, the likely result of eating challenges is sustained poor food intake, which when experienced over time increases the susceptibility of LTC residents to nutrition risk and malnutrition.

2.4.1.3 Nutrition Risk and Malnutrition

Malnutrition, specifically undernutrition, results from persistent poor nutritional intake and other physiological factors (e.g., inflammation) that perpetuate physical deterioration and subsequent negative outcomes among LTC residents (Dent et al., 2023). Cognitive impairment in older adults is associated with malnutrition risk across a variety of populations and samples (Agarwal et al., 2013, 2016; Hai et al., 2017; Sanders et al., 2016; Sgrò et al., 2014). Risk factors of malnutrition among LTC residents are complex and difficult to define given the unique challenges experienced by each resident (Agarwal et al., 2013). However, inadequate food intake is considered to be the primary cause of malnutrition among LTC residents (Agarwal et al., 2016; Evans, 2005; Nijs et al., 2009). Eating challenges that prevent adequate food intake are pervasive among residents of LTC, resulting from various physical, cognitive, psychosocial, and environmental factors (Evans, 2005; Sloane et al., 2008). Likewise, the inability to meet nutritional needs is common in LTC; depending on the method of assessment, up to 60% of residents are at risk or malnourished (Evans, 2005; Keller et al., 2019). Poor nutritional status is highly associated with other complications including sarcopenia and frailty (Jeejeebhoy, 2012; Sieber, 2019; Vandewoude et al., 2019), which contribute to functional impairment (Kiesswetter et al., 2013), susceptibility to illness and infection (Agarwal et al., 2016; Jeejeebhoy, 2012), and compromised skin integrity and pressure injuries (Agarwal et al., 2016; Mahmoodpoor et al., 2018; Neloska et al., 2016). Furthermore, functional and physical deterioration that arise as a result of malnutrition reduce the ability for residents to meet nutritional requirements and, as a result, malnutrition risk increases in severity over time (Agarwal et al., 2013). Downstream negative outcomes associated with malnutrition and related complications contribute to increased health care costs, poor quality of life, and increased mortality (Agarwal et al., 2016; Dent et al., 2023; Söderström et al., 2017; Visser et al., 2017; Wirth, Streicher, et al., 2016). Addressing eating challenges that are modifiable using the aforementioned care strategies can help to mitigate the risk of malnutrition (M. O'Keeffe et al., 2019), but the potential to improve the nutritional status of LTC residents who have already experienced nutritional decline is limited given their vulnerability and susceptibility to further complications (Evans, 2005).

2.4.1.4 Eating-Related Decline and Mortality

Once LTC residents experience a significant decline in nutritional status, the associated complications (e.g., weakness, fatigue, susceptibility to infection, functional impairment) contribute to a decreased ability to meet nutritional needs, further compounding their risk of poor nutritional status and representing a cycle of decline. For the purpose of this dissertation, I will refer to this [theoretical] cycle in general as "eating-related decline". When residents experience an increased number and severity of eating challenges with progression of underlying conditions, as in the case of eating-related decline, there is limited potential for nutrition care interventions to positively impact nutritional status and mitigate risk of malnutrition (Beck et al., 2016; Evans, 2005). As such, eating challenges may be a result of the end-of-life process and trajectory. This is suggested by evidence that shows that nutrition care interventions are often associated with worse nutritional status (e.g., Carrier et al., 2019; Pezzana et al., 2015). Although not a causal association, these findings suggest that individuals who receive interventions often have the highest need. Furthermore, intervention studies have failed to show the potential of nutritional interventions to reverse functional decline once it has occurred in older adults (Beck et al., 2016). In such cases when residents do not experience improvements to food intake or nutritional status in response to nutritional interventions to manage eating challenges, subsequent deterioration is inevitable and end-of-life decline should be anticipated (Evans, 2005). Indeed, difficulties with eating are an expected complication of underlying conditions, such as dementia, and often signal the approach of death (S. L. Mitchell et al., 2009; Njegovan et al., 2001). As such, once all modifiable factors are addressed, eating-related decline in LTC residents in advanced stages of illness may be properly understood to signify that they are on a trajectory towards the end of life.

The association between eating-related decline (i.e., eating challenges and malnutrition) and mortality is well-established, but the trajectory towards death amidst these conditions is less clear and likely depends on many personal and environmental factors. Risk of mortality is a common outcome of interest among studies of eating challenges in older adults, and thus independent associations have been identified with many of the eating challenges described previously. For example, a study of Ontario LTC administrative data demonstrates increased risk of 31-day mortality with several eating and nutrition-related factors including higher dependence on activities of daily living (relative risk [RR] = 1.52), insufficient fluids (RR = 1.85), weight loss (RR = 1.75), dehydration (RR = 1.43), and vomiting (RR = 1.21) (Brink & Kelley, 2015). Likewise, dysphagia is significantly associated with

1.44 times higher odds of 6-month mortality among LTC residents, even when adjusting for other important predictors including weight loss and BMI (Wirth et al., 2018). Anorexia of aging is associated with an elevated risk as high as 2.9 times greater after 11-months of follow-up compared to individuals without anorexia of aging (Malafarina et al., 2013). Social withdrawal, which likely affects mealtime involvement, is associated with 1.4 times higher risk of death in a 5-year follow-up study using administrative data from one LTC home (Kiely et al., 2000). Concerning gastrointestinal symptoms, both diarrhea and constipation have been identified as risk factors for death; incident dehydration being the major concern for diarrhea (Morley & Steinberg, 2009), and both constipation and laxative use as significant predictors of death in a sample of American veterans (Sumida et al., 2019). While these independent associations have been found, evidence suggests that nutrition-related factors may be additive and progressive in contributing to risk of death. For example, one study of Italian home care clients indicated that the risk of death was higher in individuals with anorexia of aging who also had weight loss when compared to individuals with anorexia of aging without weight loss and compared to individuals with neither anorexia of aging nor weight loss (Landi et al., 2012). Furthermore, weight loss and low body mass index (BMI) are both independently associated with mortality but have a stronger effect when occurring together, suggesting that nutritional vulnerability compounds to increase the risk of death (Wirth, Streicher, et al., 2016). Finally, a Swedish study of hospitalized older adults shows that malnutrition is a strong predictor of death regardless of the underlying cause of death (Söderström et al., 2017). However, in this same study the risk of 5-year mortality due to malnutrition was higher for some conditions (e.g., mental and neurological disorders) than others (e.g., neoplasms), suggesting that malnutrition itself is not a good predictor of time or trajectory to death. Rather, multifactorial risk factors of malnutrition, including physical, social, psychological, and environmental factors that impede or promote food intake as well as the unique health status of residents (Dent et al., 2023; Donini et al., 2020; Keller et al., 2019; Wendland et al., 2003) likely contribute to variable trajectories towards end of life. Therefore, although end-of-life decline can be expected, the specific trajectory towards death is likely unpredictable and requires a flexible approach to nutrition care to manage the continual and changing needs of residents.

2.4.2 Approaches to End-of-Life Nutrition Care for LTC Residents

The link between eating-related decline and mortality has implications for nutrition care practices for LTC residents, including a potential need to shift from restorative to palliative goals of care. Given that current nutrition care practices are guided by a restorative philosophy of care, the care practices and decision-making for residents with severe and complex eating challenges take on a trial-and-error approach while aiming to improve oral intake and maintain nutritional status (Anantapong et al., 2020; Barrado-Martín et al., 2022). For example, nutrition interventions such as physical assistance at mealtimes, ONS, or texture modification may be initiated and then subsequently modified in the care plan in an attempt to enhance a resident's food intake, and in some cases artificial nutrition is considered by substitute decision-makers (e.g., family members) as an option to maintain nutritional status, despite consensus recommending against it (American Geriatrics Society [AGS] Ethics Committee and Clinical Practice and Models of Care Committee, 2014; Anantapong et al., 2020; Chou et al., 2020; Ijaopo & Ijaopo, 2019; Lam & Lam, 2014; Lynch, 2016; S. L. Mitchell et al., 2016; Rousseau, 2018).[8] However, restorative goals of care may be inappropriate for managing eating-related decline, particularly given the limited potential to improve the nutritional and functional status of residents (Evans, 2005) and numerous adjustments to the nutrition care plan expends a significant amount of dietitians' already limited time (Dietitians of Canada Ontario Long Term Care Action Group, 2016). Furthermore, these care practices may be considered burdensome or undesirable to residents and may increase care providers' distress when the goals of care are unrealistic or do not match the needs of the resident (Barrado-Martín et al., 2022; S. L. Mitchell et al., 2009; Palecek et al., 2010; Wallin et al., 2022). Instead, goals of nutrition care grounded in a palliative philosophy that emphasize comfort and quality of life may better align with residents' needs (Palecek et al., 2010). However, to date, specific care plan orders to address end-of-life eating decline, especially dysphagia, using a comfort-focused (i.e., palliative) approach have been proposed (Palecek et al., 2010; Soar et al., 2021) but not well-defined in practice (Davenport & Yeung, 2019). Furthermore, the effective implementation of comfort-focused practices is likely contingent on the acceptance of a palliative philosophy to nutrition care in LTC, which has not yet been developed. As such, there is a need to review and understand current comfort-focused care practices and to develop an overarching palliative philosophy concerning LTC nutrition care to improve integration of these practices into the scope of LTC services.

---

[8] Professional consensus recommends against the use of artificial nutrition to address eating challenges in persons with advanced dementia (AGS, 2014; Lam & Lam, 2014) in favour of gentle handfeeding. While this is an important discussion in the broader end-of-life nutrition care discussion, it is beyond the main scope of this dissertation. As such, the discourse surrounding artificial nutrition can be found in Appendix A, Section A.2 .

The current understanding of formalized comfort-focused nutrition care practices is limited. To be sure, any care practice that is applied with the goal of enhancing the resident's comfort or quality of life could be understood to be "comfort-focused". For example, care decisions that support a "food first" approach, as opposed to using less-appealing nutritional supplements or invasive artificial nutrition, are certainly made with the resident's comfort in mind (Agarwal et al., 2016; AGS, 2014; Arcand, 2015; Chou et al., 2020; Lam & Lam, 2014; Simmons et al., 2003; Sloane et al., 2008; Volkert, Beck, et al., 2019). Furthermore, interventions that emphasize the provision of favourite foods and choice in meals and that promote dignified person-centered care practices while serving and assisting residents during meals are designed to enhance the quality of life of residents through positive mealtime interactions (J. Y. Lee et al., 2021; Liu et al., 2022; Wu et al., 2018). Nevertheless, explicit care orders that specify palliative goals of care are important to ensure that nutrition care practices are fully oriented towards the comfort and quality of life of the resident, allowing care providers to adopt this mindset when providing nutrition care to the resident. To this end, specific care plan orders, namely "comfort feeding only", which may appear under other labels such as "risk feeding", "feeding as tolerated", "diet as tolerated", "oral intake for taste/pleasure", "eating and drinking with acknowledged risk", and other variations have been developed with varying implications across care providers (Davenport & Yeung, 2019; Palecek et al., 2010; Soar et al., 2021). Such orders aim to formalize responsive nutrition care based on the expressed needs and preferences of the individual in the moment, for example when the resident displays readiness to eat and only if it is not distressing to the resident (i.e., palliative aim) rather than according to pre-determined nutritional requirements and mealtime protocols (i.e., restorative aim) (Palecek et al., 2010). For this dissertation, "comfort-focused nutrition orders" will be used as a collective term for any formalized initiative to adjust residents' nutrition care with the goal of comfort, as opposed to the goal of improving, maintaining, or preventing nutritional decline consistent with restorative care interventions. Generally, comfort-focused nutrition orders aim to alleviate the concerns of care providers by acknowledging that the primary goal is comfort, while continued weight loss and overall decline are expected (Palecek et al., 2010). Despite these options, there is little research to describe the feasibility, acceptability, or effectiveness of these care practices to address eating challenges as residents near the end of life; the implementation of such palliative/comfort-focused approaches to nutrition care in LTC remains to be seen.

2.5 Summary and Study Rationale

The LTC sector is undergoing continual transformation to adapt to residents' changing needs stemming from an increased appreciation for dignified care practices using person- and relationship-centered care approaches. Significant advancements have been made to improve the quality of care while moving towards a social model of care, but until recently, LTC care practices, which are largely guided by a restorative philosophy, have fallen short of incorporating palliative (i.e., comfort-oriented) principles to support residents as they near the end of their life. The most recent shift within the LTC purview is the integration of a palliative approach to care in response to the increasingly complex and advanced needs of residents who will typically live out their final days in residence. Given this shift, and especially motivated by recent legislation requiring the integration of a palliative philosophy of care, there is an urgent need to develop palliative-minded initiatives to support residents in all aspects of their lives. One such aspect of care in LTC that may benefit from a palliative approach is nutrition care.

Nutrition care is an important target for further exploration in the context of palliative-focused initiatives for several reasons. First, nutrition care processes that address eating challenges and malnutrition among LTC residents are difficult to navigate because of various factors including fluctuating symptoms, uncertain trajectory towards death, and unclear goals of care. Given these complexities, residents may have unmet needs around comfort and quality of life as they relate to food and nutrition. Second, nutrition care practices can become distressing to care providers when the goals of care do not meet the residents' needs or desires (Barrado-Martín et al., 2022; Keller, Edward, et al., 2006; Wallin et al., 2022; Ying, 2015). Most of the interventions for eating challenges are fundamentally aimed towards maintaining or improving nutritional status, which is an unrealistic goal in advanced stages of disease particularly when eating challenges have already compromised the resident's nutritional status. As such, attentive relationship-centered palliative care practices have the potential to enhance both residents' and care providers' quality of life but have not yet been well-developed and are scarcely applied in practice. To this end, palliative-focused nutrition care practices are needed to support residents with eating-related decline.

This dissertation is a response to a broader call to develop a palliative approach to care in LTC homes through a description of the nutrition care needs of residents as they approach the end of life when a palliative approach to care is most likely to be beneficial. Food and nutrition are a prime target for developing specific palliative care practices and guidelines because of the prevalence of eating challenges as LTC residents near the end of life, as well as the underlying social and relational importance of food and mealtimes. However, current practices and experiences surrounding nutrition care at the end of life for LTC residents and care providers have not been quantified longitudinally, so the need or opportunities for integrating a palliative philosophy and comfort-focused care practices to nutrition care in LTC is currently unknown. This dissertation aims to fill this gap in knowledge through a description of nutrition-related factors (e.g., examination of eating challenges, care practices, identification of nutrition-related decline, and dietitian referrals) in residents' last six months of life. A retrospective chart review will be performed to describe the intersection of nutrition care and end-of-life decline among LTC residents.

Chapter 3

Research Questions and Study Objectives

To better understand the current state of nutrition care at end of life for LTC residents, the dissertation will be guided by two main objectives:

1) Describe the nutrition-related experiences (e.g., eating challenges, nutrition care practices) of LTC residents in the last six months of life and the resident-level factors that are associated with these experiences; and
2) Develop a better understanding of how a palliative philosophy of care may be applied to nutrition-related experiences in the context of end-of-life decline based on nutrition-related signals of decline and dietitian involvement.

3.1 Study 1 – Description of End-of-Life Eating Challenges

3.1.1 Objective

The objectives of study 1 are to describe the longitudinal changes in prevalence of individual eating challenges, and patterns of decline across multiple eating challenges, with proximity to death.

3.1.2 Research Questions and Hypotheses

RQ1-1 What is the prevalence of individual eating challenges documented at four time points (i.e., 6 months, 3 months, 1 month and 2 weeks prior to death)[9] in the last six months of life of residents living in LTC?

Hypothesis: *Several eating challenges will increase in prevalence across the time points with increased prevalence just before death.*

RQ1-2 What are the within-person odds of experiencing individual eating challenges with proximity to death, adjusting for sampling frame?

Hypothesis: *The odds of experiencing various eating challenges will be higher at later time points compared to 6 months prior to death.*

---

[9] These will be referred to as the ‘time points’ throughout the research questions without further reference to the specific timing.

RQ1-3 Do multiple eating challenges (e.g., refusal to eat, lethargy at mealtimes, frustration, distractibility, self-feeding difficulties, swallowing difficulty) cluster together in distinct patterns? What resident characteristics are associated with these trajectory patterns?

Hypothesis: *Resident characteristics (e.g., cognitive performance, health instability) measured at 6 months prior to death will be significantly different between the identified trajectories of eating decline.*

3.2 Study 2 – Description of End-of-Life Nutrition Care Practices

3.2.1 Objective

The objective of study 2 is to describe the initiation and modification of nutrition interventions recorded in the formalized care plans at the four time points, with a particular focus on the prevalence and predictive factors of comfort-focused nutrition orders.

3.2.2 Research Questions and Hypotheses

RQ2-1 What is the prevalence of formalized nutrition care interventions documented in LTC residents' care plans at the four time points leading up to death?

Hypothesis: *Restorative interventions that provide increased nutritional and physical support for residents (e.g., oral nutritional supplements, physical assistance) will increase in prevalence towards death.*

RQ2-2 What are the within-person odds of receiving a comfort-focused nutrition care order at the three time points leading up to death compared to 6 months prior to death?

Hypothesis: *The odds of receiving a comfort-focused nutrition care order will be higher at later time points compared to 6 months prior to death.*

RQ2-3 What resident-level and time-varying factors are associated with receiving a formalized comfort-focused nutrition care order?

Hypotheses: *An accumulation of eating challenges (i.e., number of eating challenges), and dysphagia specifically will be associated with receiving a comfort-focused care order.*

The number of restorative care plan interventions in place at the same time point will be negatively associated with comfort-focused nutrition care orders, signifying a transition towards palliative-focused care goals.

3.3 Study 3 – Nutrition-Related Factors as Signals of End-of-Life Decline

3.3.1 Objective

The objective of study 3 is to identify the point at which care providers consider that the resident may be approaching the end of life, the nutrition-related factors that contribute to this consideration, and the timing to death once the "end-of-life phase" has been identified.

3.3.2 Research Questions

RQ3-1 What events lead up to the documentation of the "end-of-life" phase? (e.g., who? what concerns?)

Hypothesis: *Nutrition-related challenges (e.g., decreased intake, weight loss) will be routinely considered to indicate end-of-life decline among care providers.*

RQ3-2 What is the typical time frame for indication of the "end-of-life phase" prior to death? Do nutrition-related reasons for suspecting end-of-life decline predict the time to death?

Hypotheses: *Given the reluctance among LTC care providers to acknowledge death, identification of end-of-life decline is likely to occur late in the end-of-life trajectory (i.e., in the final weeks).*

Decreased food intake and weight loss will be associated with a longer time to death while dysphagia will be associated with a shorter time to death.

3.4 Study 4 – Dietitian Referrals at the End of Life

3.4.1 Objective

The objective of study 4 is to describe dietitian referrals and the association of these referrals with comfort-focused care practices in the last six months of life.

3.4.2 Research questions

RQ4-1 What proportion of residents had a dietitian referral at the four time points in the last six months of life and what was the average length of time between referral and follow-up?

Hypotheses: *Given an anticipated increase in eating challenges towards death, prevalence of dietitian referrals will increase with proximity to death.*

Given the anticipated increase in severity of eating-related challenges with proximity to death, the length of time between dietitian referral and first follow-up will to be shorter at later time points.

RQ4-2 What resident-level and time-varying factors are associated with dietitian referral?

Hypothesis: *Dietitian referrals will be more likely when a higher number of eating challenges are reported, and when severe eating challenges (e.g., dysphagia, dehydration) are documented.*

RQ4-3 Are dietitian referrals associated with initiation of a comfort-focused nutrition care order in the last month of life?

Hypothesis: *Dietitian referrals will be associated with a higher prevalence of comfort-focused nutrition care orders in the last month of life.*

Chapter 4

Retrospective Chart Review Methodology and Methods

A retrospective chart review of documented information from the last six months of life of LTC residents was used to answer the research questions for this dissertation and will be described in detail in this chapter. First, a background of the retrospective chart review methodology is provided followed by a discussion of the applicability of this methodology to the research questions. The chapter also provides a description of the specific methods used to acquire the data for the studies found in Chapters 5-8 and highlights the limitations of the methodology and our methods and the ways in which these were addressed.

4.1 Overview of the Retrospective Chart Review

The retrospective chart review methodology is used to convert clinical chart information into useable data for research purposes. Retrospective chart reviews, also known as chart audits or medical record reviews, among other labels, have been applied in a variety of healthcare settings. Health care services, including LTC, collect information on various aspect of patients' or residents' health, functional ability, and well-being as a regular part of daily operations. Though they are collected for clinical purposes, medical records (e.g., patient charts, progress notes, physicians' orders, lab results) have the potential to contribute to both qualitative and quantitative research. However, charted records often appear in formats that are difficult to access and require substantial manipulation and abstraction before they can be used for research purposes. As such, retrospective chart reviews focus on quantifying medical chart data into observational data for use in more complex statistical analyses (Banks, 1998; Gearing et al., 2006; Worster & Haines, 2004). The methodology as a whole has been described as "theoretically straightforward but operationally difficult" (Allison et al., 2000, p. 17) and requires flexibility but also rigour to ensure that high quality data is produced (Gilbert et al., 1996). The medical record review as a formal methodology is not well-recognized, though widely applied across several fields (Worster & Haines, 2004), likely in part because of the seeming simplicity of extracting information from medical charts to use for research purposes. As a result, the methods in many chart review studies are poorly defined and contain deficiencies in validity and reliability (Gilbert et al., 1996; Wickson-Griffiths et al., 2014). Despite these challenges, a well-designed chart review can be an efficient and effective way to answer a variety of research questions when other methods of data collection are impractical or impossible (Vassar & Matthew, 2013).

4.2 Application of the Retrospective Chart Review to the Current Study

The retrospective chart review methodology is well-suited to answer the research questions that I have posed in this dissertation and has been strengthened by intentional study design processes that have addressed several issues underlying this methodology. LTC resident charts, which contain information found in admission records, standardized assessments, care plans, daily progress notes, and physician's orders, and other health and personal records, are rich sources of data with demonstrated potential for conducting research in palliative and end-of-life care practices specifically (G. N. Thompson et al., 2018; Wickson-Griffiths et al., 2014). The benefits of a retrospective chart review include efficiency, flexibility, and ability to access information and answer research questions on vulnerable populations that might be otherwise inaccessible, indicating it to be a valuable research method. The retrospective nature of data collection allowed for selection of a relatively robust sample of participants based on specific criteria (i.e., deceased, ≥65 years of age, admitted for ≥6 months) and to capture longitudinal changes in charted information (e.g., eating challenges, nutrition care practices). It also allowed for efficient data collection across multiple LTC homes, providing a richer description of nutrition-related experiences of residents nearing the end of life. Furthermore, this methodology overcame several challenges with performing research in the LTC setting, including obtaining informed consent from residents and their substitute decision makers, requiring time and attention from overburdened care providers, and collecting data on a vulnerable population at a particularly sensitive time of life for residents and their loved ones. For these and other reasons, the retrospective chart review has been highlighted as a potentially useful approach to assess end-of-life processes in LTC, provided that the limitations of the methodology are addressed within the study design (Wickson-Griffiths et al., 2014).

4.3 Methods for Data Extraction

The methods for our retrospective chart review were guided by three core elements that were pieced together from several sources (Allison et al., 2000; Banks, 1998; Gearing et al., 2006; Worster & Haines, 2004). These elements included a literature review and clinical scan, refinement of a standardized data abstraction form, and full data extraction with a consistency check for reliability of coding over time (Table 4.1). The following sections describe the methods used to obtain data for use in this dissertation and conclude with a discussion addressing the limitations of the retrospective chart review methodology in our context of studying nutrition care for LTC residents in the last six months of life.

Table 4.1

Overview of the process and elements of the nutrition care data abstraction form development

Phase	Purpose
1) Literature review, clinical input, creation and expert review	• Situate the objectives within existing literature • Obtain insight from relevant stakeholders/clinicians familiar with the field on items of relevance • Establish, reinforce, confirm research objectives • Identify relevant items to collect, and field-specific terminology for coding consistency • Create draft data abstraction form • Create preliminary definitions for items, where required • Clinicians review the draft form and consider if items reflect the research objectives
2) Refinement of the data abstraction form	• Apply the preliminary data abstraction form and definitions to a small number of charts (n=10) • Modify research questions according to available information, if required • Test feasibility of collecting specified items • Format abstraction form according to organization of charted information • Identify challenges, charting inconsistencies, discrepancies, ambiguity of items etc. • Refine items and definitions as required • At the end of this phase, the data abstraction form should be in its (nearly) finalized form for use in the study
3) Full data abstraction and consistency check for reliability of coding over time	• Extract data from the resident charts while monitoring the functionality and consistency of the data collection process (n=150) • Further refine item definitions and update codebook when new terms, discrepancies etc. are uncovered • Determine intra-rater reliability (a single rater was responsible for all chart reviews in this case) after three blocks of data collection; five randomly selected after every 50 charts to ensure consistency over time (n=15) • Identify “problem” variables

4.3.1 Phase 1 – Literature Review and Clinical Scan

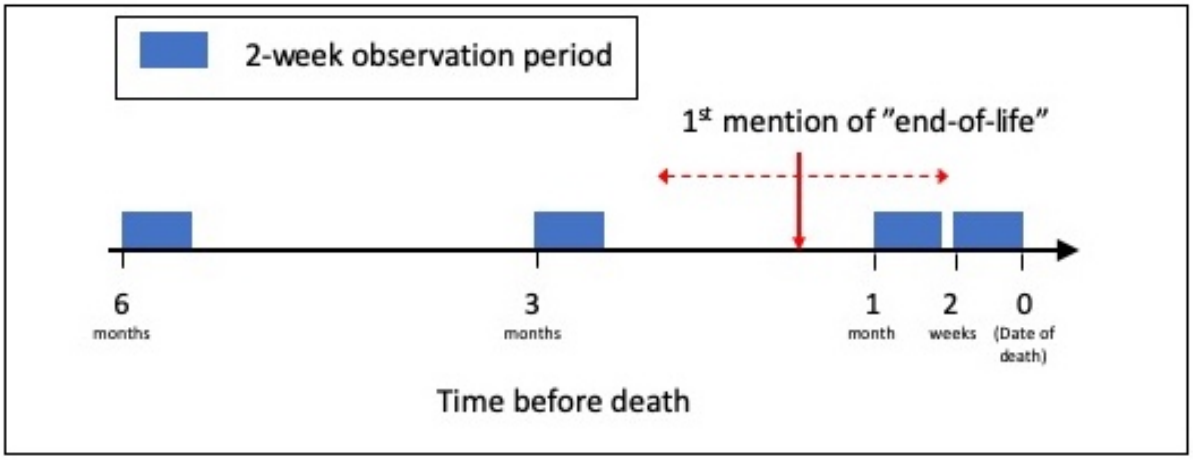
We first identified relevant items for inclusion on the data abstraction form based on a literature review, previous personal experience in the LTC dining environment, and conferences and interviews with key informants from the participating LTC homes. A crude initial data abstraction form was developed based on existing literature and informed by my personal experiences collecting data on the Making the Most of Mealtimes (M3) project, which included more than 1000 hours of observations of the food service and mealtime experience in eight Ontario LTC homes (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Brown, et al., 2017; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017) and guided by the expertise of Prof. Heather Keller, who is an internationally recognized expert in geriatric nutrition. The original form included a list of care interventions and practices, eating challenges, and other relevant information (e.g., weight records) that we expected to find documented in the last six months of life of LTC residents, while also acknowledging that the specific format of the variables for intended collection would largely depend on the information communicated in the resident charts. The draft data abstraction form containing all of the items of interest was reviewed by 10 LTC personnel from five of the participating homes, including two dietitians, a dietetic intern, two food service workers, and five LTC administrative staff who were all familiar with providing and documenting nutrition care for LTC residents. These individuals were provided with a summary of the study objectives and an initial draft of the data abstraction form and were asked to confirm that the data planned for extraction would address the research objectives (i.e., to describe the end-of-life nutrition care experience of LTC residents) and that collection of these data from the resident charts was feasible. The feedback received from the LTC personnel was generally positive and confirmed that the information we were seeking was regularly recorded in the resident charts. The next phase of the data extraction was to test this initial list of items of interest on a small sample of resident charts.

4.3.2 Phase 2 – Refinement of the Data Abstraction Form

The contents and location of information within the resident charts dictated the refinement of the data abstraction form. The initial data abstraction form was tested on 10 resident charts and adjustments were made to the formatting and content according to chart set-up and contents. All of the participating homes used the same cloud-based health records software, PointClickCare© (Mississauga, ON, 2020), for documenting their resident charts so although language and communication style differed, the data extraction was uniform across the homes. Upon initial review of several resident charts, there was an overwhelming amount of information documented on eating habits and mealtime events, such that the data abstraction as originally planned was infeasible. As a result, data were extracted from four two-week observation periods leading up to death (i.e., 6-, 3-, 1-month, and 2 weeks prior to death) (Figure 4.1). This was done to narrow the vast amount of information on nutrition and mealtime challenges recorded in the resident charts, and to address the aims of our research questions that pertained to longitudinal changes in eating challenges and nutrition care leading up to death. The data abstraction form was formatted using REDCap Software (Harris et al., 2009, 2019) and all data were recorded electronically to improve the efficiency of the data collection and mitigate potential errors in transcribing from paper to electronic records (Allison et al., 2000). A balance of variables aiming for comprehensiveness but simplicity is recommended so as not to make the data abstraction burdensome and thus increasing the risk of errors and lengthening completion time (Allison et al., 2000). Extraction of nutrition care and eating challenge items was simplified such that each item was checked "yes (1)" if it appeared in the respective care plans or progress notes at the specified time point and the default was "no (0)" if the checkbox was not checked. The structure of the data abstraction form in relation to the electronic charts was another important consideration of this phase. Intentional organization of the form can minimize data collection errors because it eliminates the need to search for data elements within the chart to enter into the abstraction form (Allison et al., 2000). This process was facilitated by the fact that all participating homes used the same software for charting. A codebook was also developed to track and define all variables and to provide a list of synonyms and clarifications for each variable, which was referenced whenever there were discrepancies (Appendix B). Additions to the codebook were ongoing through the study when decisions had to be made around unclear wording or new terminology.

Figure 4.1

The timeline for data collection within the resident chart reviews



Note. Nutrition care plans in place at each of the time points of interest (i.e., 6-, 3-, 1-month and 2 weeks prior to death) were extracted. Progress notes were reviewed for the two-week observation periods following each of the time points, as indicated by the blue blocks. The date of the first mention of “end-of-life” or related acknowledgment of decline (e.g., “palliative”, “terminal”, “EOL”, “nearing the end”, “deterioration”, “comfort measures”) was noted and was expected to be variable between residents, as indicted by the red dashed bi-directional arrow.

4.3.3 Phase 3 – Data Abstraction and Consistency Check for Coding Reliability

Phase 3 of the data collection process involved extraction of the data from all resident charts while ensuring consistency of data collection over time, largely completed by myself as the sole data abstractor. Consistency testing was completed in stages, after every 50 resident charts reviewed. After 50 chart reviews, 10% (n=5) of the charts were randomly selected for a second review based on previous recommendations (Gearing et al., 2006; Worster & Haines, 2004). Discrepancies between the two extractions were examined in detail to clarify the inconsistencies and to refine the item definitions in the codebook. The same process was repeated three times, working in 50-chart blocks (i.e., re-reviewed charts were randomly selected from within the most recent block); the third block, after 150 chart reviews, demonstrated good consistency in extraction and further checking in the total sample of 176 records was deemed unnecessary by the research team. Through this process, I identified five problematic items with a high degree of disagreement and lack of clarity of item definition. In these cases, a more thorough check was necessary where I reviewed the specific items in all prior charts. In the instances where the item was indicated “yes”, the accuracy of the response was confirmed in the resident chart; “no” responses were assumed to be accurate because this suggested that the item was not mentioned in the chart. In one instance, a significant problem with the way care plans and eating challenge history was recorded led to a restructuring of the question and the first two blocks of charts (n=100) charts were re-evaluated for that item.

Intra-rater reliability was assessed based on agreement within the re-reviewed charts after every 50 charts reviewed and tracked for improvement over time. There were 293 items on the data abstraction form for comparison, and an additional five items reflecting eating challenge history were tested in the last block. Text responses were not included in the reliability analysis but were compared for consistency across the two chart reviews and showed general similarities in responses. The proportion of items that had complete agreement across the five re-reviewed charts in each 50-chart block (“total item agreement”) was assessed. That is, if only four of the five charts agreed on an item, this item was not in agreement. Total item agreement was assessed by section of the data abstraction form (e.g., care plans, eating challenges etc.) as well as overall across all items (Table 4.2). “Overall chart agreement” which was agreement per chart (# agreed / total items) averaged across the five charts was also calculated. We expected to see improvement in agreement from one block to the next with greater experience in extraction and refinement of the codebook. The total item agreement increased from 73% after the first 50 charts, to 86% after the last 50 charts. Overall chart agreement was 93% in the first block up to 97% in the last block.

Table 4.2

Total item and overall chart agreement of each of the test blocks

Section from the data abstraction form	n	Block 1 (after 50 charts)	Block 2 (after 100 charts)	Block 3 (after 150 charts)
Weight/nutritional status records	19	1.0	1.0	1.0
Care plans	27 x 4[a,b]	0.88	0.88	0.88
Eating challenge history	5[c]	--	--	0.4
Eating challenges (progress notes)	22 x 4[a]	0.64	0.72	0.88
Actions taken (progress notes)	12 x 4[a]	0.52	0.65	0.67
Palliative care practices	20	0.60	0.95	0.90
Misc. Dates	11	0.64	0.73	0.91
Total item agreement[d]	293[c]	0.73	0.80	0.86
Overall chart agreement[e]	5	0.93	0.95	0.97

[a] Number of items was multiplied by 4 because these items were collected four times, once per longitudinal wave corresponding to 6 months, 3 months, 1 month, and 2 weeks prior to death.
[b] One item “no change to care plan” was omitted from the first time point (i.e., only collected 3 times), accounting for one less item in the total number of items.
[c] Items in the “eating challenge history” section were added in the last block of 50 charts so were only reviewed in the last block, making the total number of items 298 in that block.
[d] Proportion of items that had complete agreement across the 5 re-reviewed charts within each block.
[e] Proportion of agreement per chart (# agreed / total items) averaged across the 5 charts within each block.

4.4 Addressing the Limitations of the Methodology

As the primary author, I was the sole data abstractor with direct access to the resident charts, which presents benefits and limitations for the overall research process, data quality, and results interpretation. The dominant reasons for choosing to have a single data abstractor were because of limited time and personnel resources to train a second abstractor and duplicate the data abstraction, as well as to reduce the number of research personnel with access to the resident charts. Having a single data abstractor may detract from the validity and reliability of the extracted data because it relied solely on my perspective without a second opinion or test of interrater reliability to confirm agreement with other trained researchers. However, several factors were considered to mitigate this challenge. My previous experience in the LTC environment and extensive observations of various eating challenges and nutrition care practices provided background for interpreting the progress notes and care plans (Wickson-Griffiths et al., 2014). Furthermore, while no other researchers had access to the resident charts, I discussed interpretations of specific language and discrepancies as they came up throughout the data extraction process during regular meetings with Prof. Keller and other colleagues in the Nutrition & Aging lab, including other experts in LTC dietetics. Although not all extracted data were confirmed at these meetings, the discussions around challenging chart entries offered some monitoring of my performance as the abstractor (Gilbert et al., 1996). Being the sole data abstractor who also designed the research study and refined the data abstraction form undoubtedly introduced challenges for data reliability, including a biased interpretation (Allison et al., 2000). However, this could also be considered a defining feature in that our interpretation of the findings was informed by the contextual understanding gained from my previous experiences and the process of performing the chart review. Furthermore, the general objective from the outset of the study was to describe the nutrition care experiences of residents leading up to death, but our specific research questions were not well-defined at the beginning of the data abstraction. As such, I approached the data extraction with curiosity and did not have preconceived notions about what information would be uncovered or about anticipated patterns in the data. Also, I was intentional about regularly revisiting the coding rules and definitions recorded in the codebook because of the acknowledged issues with having only one data abstractor (Worster & Haines, 2004). The intra-rater reliability checks ensured that the data collection remained consistent over time. These considerations were intended to mitigate the limitations of having only one data abstractor.

Concerns with the quality of clinical documentation in general have led to contention around the value of the retrospective chart review methodology, with one major concern being the risk of poor data quality. Clinical nursing documentation is known to be filled with errors, inaccuracies, and omissions (Gilbert et al., 1996; Jefferies et al., 2010; N. Wang et al., 2011). In the LTC setting, the hierarchical organization of the staff, interprofessional dynamics, and communication problems between direct care providers who provide most of the daily care to residents and nursing supervisors who are largely responsible for documentation may further hinder relevant information from being recorded in the progress notes (Banerjee et al., 2015; Beynon et al., 2022; Farrell et al., 2022; Madden et al., 2017). Since the retrospective chart review relies on the information contained in these documents, these challenges can call into question the validity of the data. However, the quality of charted information can vary between fields and specific types of information based on established nursing practices (N. Wang et al., 2011). For example, psychosocial, cultural, and spiritual aspects of patient care are particularly deficient in nursing documentation whereas biomedical observations are more robust (N. Wang et al., 2011). In the case of our data collection, nutrition-related observations (e.g., eating challenges at mealtimes) may cover a range of these aspects of the resident experience but the more tangible behaviours and mealtime difficulties were arguably more likely to have been documented. This seemed to be the case from my experience of extracting data for this dissertation; as noted previously, documentation to describe mealtime/food-related behaviours and events of residents was quite common in the resident charts, indicating that documentation deficiencies are less of a concern in this aspect of LTC. However, the accuracy and completeness of charting must still be questioned. To address this potential limitation in accuracy and completeness of the nutrition-related information obtained from the resident charts for the purposes of this dissertation, our interpretations of the study findings were framed within the context of the chart review. For example, eating challenges were qualified with words such as "documented" or "noteworthy". Additionally, a portion of our data collection relied on formalized documentation (i.e., care plans, dietitian referrals) thus informing the clinical focus of the research questions and limiting the potential for discrepancies for how we interpreted what was charted. As such, while challenges around the quality of nursing documentation exist, studies using retrospective chart review methodology, in particular this current study, can still make a valuable contribution where specific attention is paid to careful interpretation of the study findings and where the limitations are acknowledged and mitigated when possible.

Chapter 5

Study 1: Eating Challenges Leading up to Death Among Residents of Long-Term Care

5.1 Overview

Introduction: Eating challenges are common among long-term care (LTC) residents and are associated with advanced disease stages and mortality. Characterising these challenges may help to guide end-of-life care. This study describes patterns of eating challenges in residents' last six months of life and associated resident characteristics.

Methods: Electronic chart data of deceased residents (admitted >6 months; 65+ years old) from 18 LTC homes across southern Ontario, Canada provided information on resident characteristics (e.g., cognitive performance); eating challenges were extracted from progress notes during two-week periods at 6-, 3-, 1-month, and 2 weeks prior to death. A repeated measures latent class analysis identified unique classes based on response probabilities of refusal to eat, distractibility, frustration, self-feeding difficulties, swallowing difficulties, and lethargy. Bivariate (chi-square, ANOVA) and logistic regression analyses tested associated resident characteristics with four identified patterns.

Results: Among 164 decedents (61.0% female; mean age=88.3±7.5 years), eating challenges increased in prevalence across the four time points. Four patterns were identified: "refusing" (20.1%), "complex" (18.9%), "progressive" (30.5%), and "end-stage" (30.5%). Shorter length of admission (odds ratio [OR]=0.98, 95% confidence interval [CI]=0.96, 0.99), less severe cognitive impairment (OR=0.15, CI=0.04, 0.62], aphasia (OR=10.92, CI=3.08, 38.73), and cancer (OR=3.96, CI=1.15, 13.65) were associated with "complex" challenges. Leaving food uneaten at baseline was associated with lower odds (OR=0.23, CI=0.09, 0.60) of "progressive" challenges, and higher odds of "refusing" (OR=3.85, CI=1.20, 12.35).

Conclusion: The identified patterns could prompt a more holistic approach to nutrition care for LTC residents, recognizing that an accumulation of eating challenges may warrant comfort-focused care.

Keywords: end-of-life, nutrition care, longitudinal analysis

5.2 Introduction

Residents living in long-term care (LTC) experience a variety of eating challenges of increasing severity in advanced stages of disease (Keller, 2016; S. L. Mitchell et al., 2009; Rawal & Yadav, 2015). While there is some debate around terminology (Jung et al., 2021), eating challenges are defined here as any observable factors experienced by the resident that may hinder nutritional intake, such as difficulty with self-feeding, loss of appetite, refusing to eat, distractibility, low physical energy, digestive issues, and dysphagia. Eating challenges are particularly prevalent among residents with cognitive impairment, which affects 86.2% of all LTC residents in Ontario, Canada (CIHI, 2021a). They have also been associated with other diseases and conditions common among LTC residents (Hopkinson & Corner, 2006; Luca et al., 2014; Malafarina et al., 2013; Munshi et al., 2016; Sørensen et al., 2020). Longitudinal and prognostic attributes of eating challenges have been identified, including their concurrence with different stages of dementia progression (Kai et al., 2015; Keller, 2016), accumulation in a predictable pattern among persons with dementia (Watson, 1994), and association with end-stage disease and mortality (Malafarina et al., 2013; Sakamoto et al., 2018; Sørensen et al., 2020). Eating ability is cited as one of the last functions to decline before death in advanced dementia (S. L. Mitchell et al., 2009). Although these studies have elucidated that eating challenges change over time and that they are associated with end-stage disease, it is not known how they change or if the changes are impacted by resident characteristics.

Identification of longitudinal patterns of eating challenges among residents may have clinical implications in acknowledging proximity to death. Current nutrition care practices in LTC are largely reactive to significant, often late, changes in resident status (e.g., weight change, swallowing difficulties, skin breakdown, major health change) (Johnson et al., 2018) and emphasize restorative goals (Evans, 2005; Volicer & Simard, 2015). In advanced stages of dementia and other chronic diseases typical of LTC, such goals of care become unrealistic, and aggressive interventions can increase the risk of discomfort, undesirable side effects, or serious medical consequences (Volicer & Simard, 2015). For this reason, palliative (i.e., comfort-focused) goals aimed at maximizing quality of life become more dominant in the later stages of disease when terminal decline is evident (Evans, 2005; Hawley, 2014; Kelley, 2015; Volicer & Simard, 2015). Recognition that eating challenges may indicate a progression towards end-of-life among LTC residents could support care providers to incorporate holistic, comfort-focused care goals.

The aim of this analysis is to describe longitudinal changes in eating challenges recorded in the last six months of life of LTC residents. Specifically, our objectives are: 1) to describe the eating challenges that occur; 2) to identify potential patterns of trajectory of eating challenges leading up to death; and 3) to investigate associations between eating challenge patterns and resident characteristics such as cognitive impairment and disease diagnoses. We hypothesize that eating challenges emerge in predictable patterns in the final six months of life, and that these patterns are associated with resident characteristics (e.g., cognitive impairment, responsive behaviours) and clinical indicators (e.g., existing mealtime challenges, diagnoses). The findings are meant to highlight the importance of eating challenges to the care experience as LTC residents journey towards death, without claiming they have prognostic value in predicting death.

5.3 Materials & Methods

5.3.1 Sample Populations

Participants were deceased residents (December 2018 – March 2020) selected from 18 LTC homes in southern Ontario, Canada from two sampling frames: the Better Targeting, Better Outcomes for Frail Elderly Patients (BABEL; ClinicalTrials.gov Identifier: NCT03649191) study (Garland et al., 2022) and a for-profit chain of LTC homes. Two sampling frames were used to ensure an adequate sample size and increased sample diversity.

BABEL was a prospective advance care planning intervention study; the intervention was not specific to eating challenges. Eligibility required that residents were over 65 years of age and at high risk of death in the next 6-12 months as indicated by: Changes in Health, End Stage disease and Symptoms and Signs (CHESS) score ≥3, current cancer, congestive heart failure, or leaving >25% of their food uneaten. Participants from nine Ontario homes were included in the current study upon death. Recruitment began in September 2018 with the first deaths recorded in December 2018; participants who died after March 11, 2020 were excluded given the drastic impact of the COVID-19 pandemic on the LTC sector.

The second sampling frame was a chain of for-profit LTC homes located across southern Ontario. Nine homes from the chain were selected through a combination of random sequence generator and purposive selection to ensure representation of a variety of geographic regions. Ten decedents from each home were randomly chosen for inclusion in the current study to promote diversity.

5.3.2 Sample Selection

Residents were eligible for inclusion in this analysis if they were admitted to the LTC home for at least six months based on our decision *a priori* that this was an acceptable length of time to pattern the trajectory of eating challenges before death and existing definitions of the "end-of-life" period (Hui et al., 2014). Informed consent for the BABEL study was attained for 303 residents in the Ontario homes, and 86 (28.4%) of these had died within the specified period. Of this sample, 79 lived in the home for at least 6 months. Eighty-five residents (94% of those randomly selected) from the home chain sample were over the age of 65 years and had lived in the home for at least 6 months. The final sample included 164 individuals, which was adequate to identify general patterns of eating challenge trajectory using *a priori* theory and a limited number of eating challenges (Nylund-Gibson & Choi, 2018).

5.3.3 Data Collection

Data were collected through retrospective chart reviews using medical record review methodology (Allison et al., 2000; Gearing et al., 2006). Resident characteristics, health, and functional status were obtained from the resident charts. Eating challenges were collected using a form rigorously created by the researchers to facilitate extensive manual extraction of information from daily progress notes (Chapter 4). The progress notes included all charted notes such as free text, orders, referrals, and forms reported by nursing staff, physicians, dietitians, therapeutic, or other support services. Four 2-week long excerpts of progress notes at 6 months, 3 months, 1 month, and 2 weeks prior to death were designated for extraction of eating challenge data; eating challenges reported within each time period were noted (yes/no). All data were collected by JMK excepting the BABEL demographic and Resident Assessment Instrument Minimum Data Set 2.0 (MDS 2.0) data, which were collected by the BABEL study coordinator. Data collection consistency was checked through duplicate extraction by JMK for 5 randomly selected charts per 50 charts reviewed. Points of disagreement were used to refine the definitions in the data extraction form.

5.3.3.1 Eating Challenges

Eighteen eating challenges and 3 outcomes were included on the data extraction form based on previous literature, personal experience, professional consensus, and the chart review process. These eating challenges included: poor appetite; lethargy or low physical energy at mealtimes; refusal to eat or attend at least one meal resulting in a missed meal; swallowing difficulties or dysphagia; holding food in mouth; dental or chewing issues; requiring verbal or physical prompting; cognitive difficulties that challenge self-feeding; physical difficulties with self-feeding; distractibility including loss of focus, poor concentration, or wandering during mealtime; frustration or expressive behaviours, sometimes referred to as aggression, during meals; socially unconventional behaviour such as eating a tablemate's food or eating breakfast in the middle of the night; eating inedible items (e.g., napkins); short-term (i.e, ≤3 days within a week, non-recurrent) emesis; long-term (i.e., >3 days within a week and/or recurrent across multiple weeks) emesis; short- and long-term diarrhea/loose stools according to the same parameters; and constipation defined as ≥3 or more days without a bowel movement.

5.3.3.2 Outcomes of Eating Challenges

Decreased food intake, decreased fluid intake, and skin breakdown reported in the progress notes were conceptualized as downstream outcomes of the noted eating challenges. Decreased food intake was defined as eating less food than usual as noted by care staff, going a full day without eating, or uncharacteristically missing one or more meals on at least 3 consecutive days. Decreased fluid intake was indicated if care staff reported poor fluid intake, signs of dehydration, or otherwise suggested that the resident was not drinking offered fluids. Skin breakdown was defined as any documentation of compromised skin beyond rashes, redness, or what could be explained by a fall or other injury.

5.3.3.3 Demographics

Resident demographics, including age at death, sex, and months of admission in the LTC home, were obtained from the electronic admission record.

5.3.3.4 Functional and Health Characteristics

Baseline resident characteristics were obtained from the MDS 2.0, a standardized assessment of several clinical and functional characteristics of LTC residents (CIHI, 2021a; Carpenter & Hirdes, 2013). Ontario LTC standards require that the MDS 2.0 is reported by trained nursing staff for each resident on admission and quarterly (CIHI, 2021a). These data were obtained from the most recent assessment at the time of recruitment for BABEL participants and approximately 6 months prior to death for home chain participants. MDS 2.0 items extracted for the current study were: leaves >25% of food uneaten at most meals (yes/no); Cognitive Performance Scale (CPS, max. 6; moderate/severe [≥3] vs. no/mild [<3] impairment) (Morris et al., 1994); health instability (CHESS, max. 5; moderate/high [≥3] vs. no/low [<3] instability) (Hirdes et al., 2003); Activities of Daily Living Self

Performance Hierarchy Scale (ADL, max. 6; extensive/total [≥3] vs. no/limited [<3] dependence) (Morris et al., 1999); Depression Risk Scale (DRS, max. 14; potential/actual [≥3] vs. no/low [<3] depression) (Burrows et al., 2000); Aggressive Behaviour Scale (ABS, max. 12; any responsive behaviours [≥1] vs. none [0]) (Perlman & Hirdes, 2008); and the Pain Scale (daily vs. less than daily pain) (Fries et al., 2001). Medical diagnoses were also obtained from the MDS 2.0.

5.3.4 Data Analysis

Residents' eating challenges were described and compared across the four time points leading up to death using mixed effects logistic regression, which allowed for testing within-resident odds of each eating challenge over time compared to baseline and adjusting for sampling frame. Inferences about meaningful associations were based on 95% confidence levels, corresponding with a *p*-value less than 0.05. An unconditional repeated measures latent class analysis (RMLCA), which classifies patterns of change in categorical variables over time (L. M. Collins & Lanza, 2010), was performed to identify patterns in the trajectory of eating challenges experienced by residents in the last 6 months of life. RMLCA is a person-centred analytic approach that groups persons based on having similar response probabilities to multiple factors (e.g., eating challenges), as opposed to a variable-centred approach that assesses independent associations between factors (Mangoni & Woodman, 2019; Muthén & Muthén, 2000). This methodology is useful in the current context since eating challenges likely cluster together; although members of the same group may not have identical challenges, identification of clinically relevant patterns may allow for tailored approaches to care within these groups (Mangoni & Woodman, 2019).

The eating challenges analyzed in the RMLCA were based on theory, including: frustration; self-feeding challenges, which was a composite of verbal/physical prompting required, cognitive difficulties, and physical difficulties; distractibility; swallowing difficulties; and refusal to eat (Keller, 2016). Lethargy and poor appetite were tested in subsequent RMLCA models because of their prevalence in the observations and potential clinical importance in identifying decline towards death.

Various versions (5-, 6-, 7- items; 1 to 8 classes) of the RMLCA were tested and the best model was selected considering both the fit statistics and the practical interpretability of the identified classes (Muthén & Muthén, 2000; Nylund et al., 2007). Lower values of the fit statistics (e.g., Akaike Information Criteria [AIC], Bayesian Information Criteria [BIC]) indicated better model fit so were favoured for model selection (Weller et al., 2020). *Post hoc* average latent class posterior probability and entropy confirmed the model classifications; values closer to 1.0 and no less than 0.80 were deemed acceptable (Muthén & Muthén, 2000; M. C. Wang et al., 2017; Weller et al., 2020). A multi-group RMLCA, which allowed for item means and class probabilities to vary by sampling frame, was also tested to check for consistency in class definitions between BABEL and home chain participants.

Associations between resident characteristics and eating challenge class membership were determined with chi-square and analysis of variance (ANOVA) tests. *P*-values less than 0.05 were considered to represent statistically significant associations. Multivariable logistic regression analyses identified significant predictors of class membership while adjusting for relevant variables (e.g., age, sex, cognitive performance, diagnoses) selected based on *a priori* hypotheses and significant associations identified in the bivariate analyses. The classes were analyzed individually (i.e., class membership vs. not) to identify characteristics that were unique to each class. Patterns in the three outcomes (i.e., decreased food/fluid intake, skin breakdown) across the four time points were also presented visually, but not statistically, for each class. Data analyses were performed using SAS® 9.4 statistical software (SAS Institute Inc., Cary, NC; 2016).

5.3.5 Ethics

Ethics approval for data collection, including access to resident charts was obtained through the University of Waterloo as an amendment to the BABEL study (ORE#31782) and a separate protocol for the home chain sample (ORE#40789).

5.4 Results

Of the 164 decedents included in our sample, the majority were female (61.0%, n=100), and the average age at death was 88.3±7.5 years (Table 5.1). Residents were admitted for a median of 33 (1st quartile, 3rd quartile: 19, 50.5) months. On average, the MDS 2.0 assessments were collected 256±131 days prior to death for BABEL participants and 206±34 days for home chain participants (non-significant difference). The two samples differed on several characteristics (Table 5.1), and on prevalence of several eating challenges documented in the last six months of life (Table 5.2). These differences were not unexpected given the contrasting eligibility criteria.

Table 5.1

Description of the total sample and comparison of participants from the two sampling frames

	Full Sample (n=164)	**Home Chain (n=85)**	**BABEL (n=79)**
	% (n)[a]	**% (n)[a]**	**% (n)[a]**
Resident Demographics			
Age at death, years, Mean±SD	88.3±7.5	87.6±7.4	89.0±7.5)
Sex, female	61.0 (100)	58.8 (50)	63.3 (50)
Length of admission, months, Median [Q1, Q3]	33 [19, 50.5]	**37 [24, 57]**	**28 [16, 45]**
MDS 2.0 Scores[b]			
Leaves >25% of food uneaten at most meals	58.5 (96)	**48.2 (41)**	**69.6 (55)**
Cognitive impairment, moderate/severe (CPS ≥3)	79.3 (130)	81.2 (69)	77.2 (61)
Health Instability, moderate/high (CHESS≥3)	13.4 (22)	**5.9 (5)**	**21.5 (17)**
Significant loss of independence (ADL≥3)	89.0 (146)	**95.3 (81)**	**82.3 (65)**
Depression risk (DRS≥3)	47.0 (77)	47.1 (40)	46.8 (37)
Exhibits responsive behaviours (ABS≥1)	54.9 (90)	54.1 (46)	55.7 (44)
Pain Scale, daily	4.9 (8)	5.9 (5)	3.8 (3)
Diagnoses[b]			
Cancer	18.3 (30)	17.6 (15)	19.0 (15)
Diabetes mellitus	24.4 (40)	24.7 (21)	24.0 (19)
Hypothyroidism	23.8 (39)	23.5 (20)	24.0 (19)
Cardiovascular disorders	79.3 (130)	77.6 (66)	81.0 (64)
Congestive heart failure	16.5 (27)	**7.1 (6)**	**26.6 (21)**
Arthritis	47.0 (77)	**37.6 (32)**	**57.0 (45)**
Osteoporosis	26.2 (43)	24.7 (21)	27.8 (22)
Alzheimer's	15.2 (25)	15.3 (13)	15.2 (12)
Non-Alzheimer's dementia	62.2 (102)	58.8 (50)	65.8 (52)
Aphasia	20.7 (34)	**8.2 (7)**	**34.2 (27)**
Stroke/Cerebrovascular accident	23.8 (39)	23.5 (20)	24.0 (19)
Parkinson's	9.8 (16)	9.4 (8)	10.1 (8)
Seizure disorder	6.7 (11)	9.4 (8)	3.8 (3)
Anxiety disorder	14.6 (24)	**7.1 (6)**	**22.8 (18)**
Depression	32.3 (53)	25.9 (22)	39.2 (31)
Asthma	4.3 (7)	2.4 (2)	6.3 (5)
COPD/emphysema	17.1 (28)	16.5 (14)	17.7 (14)
Sensory condition (e.g., vision impairment)	26.8 (44)	28.2 (24)	25.3 (20)
Renal condition	9.2 (15)	5.9 (5)	12.7 (10)

Note. Abbreviations: ABS, Aggressive Behaviour Scale (max. 12); ADL, Activities of Daily Living Self Performance Hierarchy Scale (max. 6); BABEL, Better Targeting, Better Outcomes for Frail Elderly Patients study; CHESS, Changes in Health, End-stage Disease and Signs and Symptoms (max. 5); COPD, chronic obstructive pulmonary disease; CPS, Cognitive Performance Scale (max. 6); DRS, Depression Risk Scale (max. 14); MDS 2.0, InterRAI Minimum Dataset 2.0.

[a] Descriptives are % (n) unless otherwise specified.

[b] MDS assessment obtained on average 256±131 days (BABEL) and 206±34 days (home chain) prior to death. Bolded values are statistically significant, $p<0.05$.

Table 5.2

Description of documented eating challenges among long-term care residents in the last 6 months of life (n=164)

Eating challenge	**Time point prior to death**					**Sampling frame**	
	6 months	**3 months**	**1 month**	**2 weeks**		**BABEL[a]**	
	Referent ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**Time point *p*-value**	**OR [95% CI]**	**Sample *p*-value**
None noted	1.00 *(19.5)*	1.04 [0.60, 1.80] *(20.1)*	0.54 [0.29, 1.00] *(11.6)*	**0.10 [0.04, 0.30]** *(2.4)*	**<0.0001**	**0.59 [0.37, 0.95]**	**0.0297**
Signs of general decline							
Poor appetite	1.00 *(5.5)*	2.12 [0.92, 4.90] *(11.0)*	**4.68 [2.16, 10.13]** *(21.3)*	**4.34 [2.00, 9.44]** *(20.1)*	**0.0002**	1.18 [0.76, 1.84]	0.4663
Lethargy at mealtimes	1.00 *(19.5)*	**1.78 [1.06, 3.00]** *(29.9)*	**4.09 [2.47, 6.76]** *(48.8)*	**8.24 [4.92, 13.78]** *(65.2)*	**<0.0001**	**2.08 [1.48, 2.93]**	**<0.0001**
Refusal to eat	1.00 *(28.7)*	1.19 [0.74, 1.91] *(32.3)*	**2.11 [1.33, 3.35]** *(45.7)*	**5.43 [3.37, 8.74]** *(68.3)*	**<0.0001**	**1.42 [1.02, 1.97]**	**0.0359**
Oral challenges							
Swallowing difficulties	1.00 *(6.7)*	1.20 [0.52, 2.76] *(7.9)*	**3.24 [1.56, 6.72]** *(18.9)*	**15.73 [7.91, 31.27]** *(53.0)*	**<0.0001**	1.08 [0.71, 1.64]	0.7370
Holding food in mouth	1.00 *(1.2)*	4.15 [0.86, 19.95] *(4.9)*	**5.82 [1.26, 26.81]** *(6.7)*	**27.01 [6.38, 114.27]** *(25.0)*	**<0.0001**	1.10 [0.63, 1.91]	0.7495]
Dental or chewing issues	1.00 *(6.1)*	1.22 [0.51, 2.92] *(7.3)*	**2.65 [1.22, 5.78]** *(14.6)*	**2.65 [1.22, 5.78]** *(14.6)*	**0.0160**	1.61 [0.97, 2.68]	0.0664
Self-feeding difficulties							
Prompting required	1.00 *(2.4)*	2.61 [0.80, 8.56] *(6.1)*	**4.67 [1.53, 14.31]** *(10.4)*	**3.76 [1.20, 11.76]** *(8.5)*	**0.0457**	**2.07 [1.09, 3.91]**	**0.0259**
Cognitive difficulties	1.00 *(10.4)*	0.80 [0.38, 1.72] *(8.5)*	0.55 [0.24, 1.27] *(6.1)*	0.80 [0.38, 1.71] *(8.5)*	0.5784	**3.87 [2.03, 7.38]**	**<0.0001**
Physical difficulties	1.00 *(4.9)*	0.61 [0.20, 1.93] *(3.0)*	1.27 [0.48, 3.31] *(6.1)*	1.27 [0.48, 3.31] *(6.1)*	0.5604	1.21 [0.64, 2.66]	0.4549

Eating challenge	**Time point prior to death**					**Sampling frame**	
	6 months	**3 months**	**1 month**	**2 weeks**		**BABEL[a]**	
	Referent ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**Time point *p*-value**	**OR [95% CI]**	**Sample *p*-value**
Social/behavioural challenges							
Distractibility	1.00 *(5.5)*	1.12 [0.44, 2.84] *(6.1)*	1.99 [0.86, 4.63] *(10.4)*	1.61 [0.67, 3.84] *(8.5)*	0.3281	1.18 [0.66, 2.12]	0.5731
Frustration	1.00 *(11.6)*	1.00 [0.50, 2.00] *(11.6)*	1.12 [0.57, 2.21] *(12.8)*	1.00 [0.50, 2.00] *(11.6)*	0.9812	**3.11 [1.85, 5.25]**	**<0.0001**
Socially unconventional behaviour	1.00 *(4.9)*	1.40 [0.55, 3.60] *(6.7)*	1.00 [0.36, 2.74] *(4.9)*	1.40 [0.55, 3.60] *(6.7)*	0.8034	1.08 [0.56, 2.09]	0.8168
Eating inedibles[b]	1.00 *(1.2)*	--- *0.0*	--- *1.8*	--- *0.0*	---	---	---
Gastrointestinal issues							
Emesis - short term	1.00 *(6.7)*	0.81 [0.32, 2.01] *(5.5)*	1.50 [0.64, 3.36] *(9.8)*	**3.65 [1.77, 7.51]** *(20.7)*	**<0.0001**	1.33 [0.80, 2.21]	0.2739
Emesis - long-term	1.00 *(1.2)*	1.00 [0.14, 7.30] *(1.2)*	0.50 [0.04, 5.62] *(0.6)*	2.04 [0.36, 11.52] *(2.4)*	0.5819	3.85 [0.79, 18.86]	0.0961
Diarrhea - short term	1.00 *(14.0)*	0.85 [0.45, 1.63] *(12.2)*	0.90 [0.47, 1.71] *(12.8)*	1.49 [0.82, 2.69] *(19.5)*	0.2305	0.70 [0.45, 1.09]	0.1111
Diarrhea - long term	1.00 *(0.6)*	2.01 [0.18, 22.58] *(1.2)*	5.12 [0.59, 44.65] *(3.0)*	3.04 [0.31, 29.72] *(1.8)*	0.4176	0.89 [0.27, 2.99]	0.8558
Constipation	1.00 *(47.0)*	0.80 [0.51, 1.24] *(41.5)*	0.78 [0.50, 1.21] *(40.8)*	0.93 [0.60, 1.44] *(45.1)*	0.6310	**1.75 [1.28, 2.39]**	**0.0005**
Downstream outcomes							
Decreased food intake	1.00 *(25.6)*	1.55 [0.96, 2.50] *(34.8)*	**2.46 [1.54, 3.93]** *(45.7)*	**14.91 [8.64, 25.73]** *(83.5)*	**<0.0001**	1.32 [0.94, 1.87]	0.1114

Eating challenge	**Time point prior to death**					**Sampling frame**	
	6 months	**3 months**	**1 month**	**2 weeks**		**BABEL**[a]	
	Referent ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**OR [95% CI]** ***(%)***	**Time point *p*-value**	**OR [95% CI]**	**Sample *p*-value**
Decreased fluid intake	1.00 *(14.0)*	1.15 [0.63, 2.13] *(15.8)*	**2.05 [1.16, 3.61]** *(25.0)*	**13.29 [7.64, 23.12]** *(68.3)*	**<0.0001**	1.24 [0.84, 1.81]	0.2747
Skin breakdown	1.00 *(16.5)*	0.96 [0.53, 1.73] *(15.8)*	1.43 [0.82, 2.49] *(22.0)*	**2.36 [1.39, 4.01]** *(31.7)*	**0.0018**	1.08 [0.74, 1.58]	0.6907

Note. Values are within-subject odds (OR) of experiencing each eating challenge at 3 months, 1 month and 2 weeks compared to 6 months prior to death and by sampling frame based on generalized linear mixed effects modeling with repeated measures. Italicized values appearing in parentheses are the proportion (%) of residents with the documented eating challenge at each time point

Abbreviations: BABEL, Better Targeting, Better Outcomes for Frail Elderly Patients study; CI, confidence interval; OR, odds ratio.

[a] Compared to home chain.[10]

[b] Model did not converge due to low number of events.

Bolded values are statistically significant, $p<0.05$.

---

[10] See Appendix C, Figure C.1 for a visual comparison of the eating challenges that were significantly different between the two sampling frames in the mixed effects logistic regression analysis.

All but one resident (99.4%, n=163) exhibited one or more eating challenges in the 6 months prior to death. The most reported eating challenges were refusal to eat (83.5% of residents), lethargy at mealtimes (79.9%), and swallowing difficulties (63.4%). Compared to 6 months prior to death, odds of poor appetite, lethargy, refusal to eat, swallowing difficulties, holding food in mouth, dental issues, and requiring prompting all increased in the final month of life, with the highest odds of most of these challenges occurring in the final two weeks of life (Table 5.2). Odds of lethargy were significantly higher than baseline as early as 3 months prior to death (OR= 1.76, 95% CI = [1.05, 2.94]), and increased in a stepwise fashion at 1 month (OR= 3.93, 95% CI = [2.40, 6.45]), and 2 weeks (OR= 7.74, 95% CI = [4.68, 12.83]) prior to death as compared to baseline. Decreased food and fluid intake, and skin breakdown all increased in probability within the final month of life compared to 6 months prior to death. Within 2 weeks of death decreased food intake was 14.74 (95% CI = [8.56, 25.39]) times more likely, decreased fluid intake was 13.20 (95% CI = [7.60, 22.94]) times more likely, and skin breakdown was 2.36 (95% CI = [1.39, 4.00]) times more likely to be reported than at 6 months prior to death.

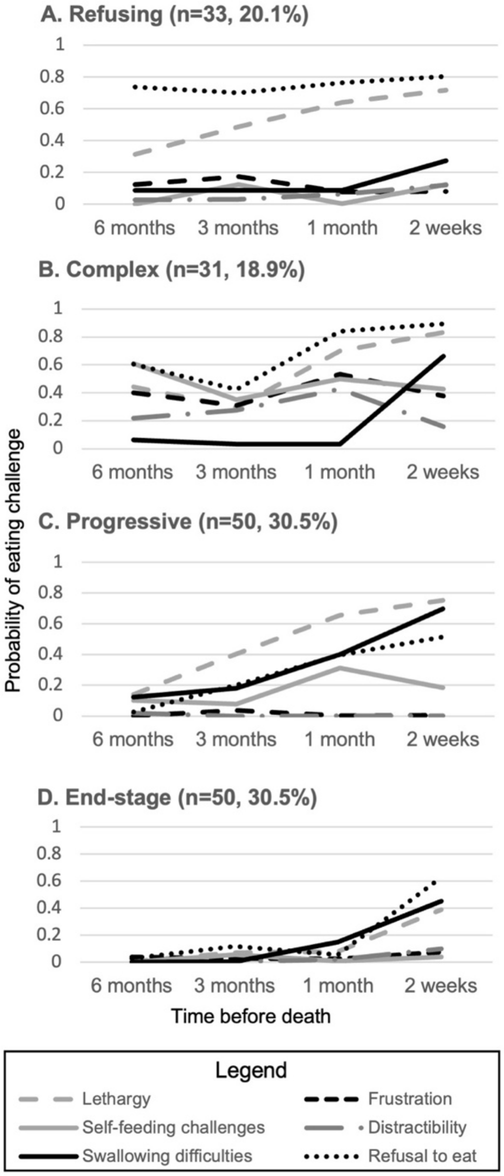
The RMLCA modeling change over time for 5 eating challenges selected based on theory (Keller, 2016), initially identified optimal model fit with 2-4 classes, according to the lowest BIC, AIC, ABIC, and CAIC values (Appendix C, Table C.1). Practical interpretation of the models suggested that four classes best summarized the patterns of decline. The subsequent addition of lethargy did not substantially change the class profiles but was retained to support description of the classes. Poor appetite did not make a meaningful contribution across the classes and was excluded. The final RMLCA model highlights 4 distinct patterns of trajectory based on 6 eating challenges. The diagnostic statistics indicated that the model accurately predicted individual class membership (average latent class posterior probability=0.93) and represented the classes well (entropy=0.84) (Weller et al., 2020). Similar patterns were produced by the multi-group RMLCA, which allowed response probabilities to vary across the two sampling frames (Appendix C, section C.2), though the class descriptions were more distinct, especially for the BABEL group, when the entire sample was analyzed together.

Figure 5.1 provides a visual description of the four patterns of eating challenges: “refusing” (20.1%, n=33); “complex” (18.9%, n=31); “end-stage” (30.5%, n=50); and “progressive” (30.5%, n=50). “Refusing” was defined by high probability of refusal to eat and increasing probability of lethargy approaching death. The “complex” group were defined by moderate to high probability of several eating challenges across time points. “Progressive” challenges were indicated by a gradual increase in probability of eating challenges except for frustration and distractibility. “End-stage” challenges were defined by relatively low probability of any eating challenges until the two weeks leading up to death when refusal, lethargy, and swallowing difficulties increased. Prevalence of decreased food intake, dehydration, and skin breakdown across the 4 time points varied by class membership (Figure 5.2).

The classes did not differ in age, sex, or length of admission as indicated by bivariate analyses, but a significantly higher proportion of “complex” challenges came from the BABEL sample compared to the home chain sample (Appendix C, Table C.2). When adjusted for resident demographics and relevant covariates of interest, those with “complex” challenges demonstrated the most difference in baseline characteristics compared to the other classes (Table 5.3). Length of admission (odds ratio [OR] = 0.98, 95% confidence interval [CI] = 0.96, 0.99), and moderate/severe cognitive impairment (OR = 0.15, 95% CI = 0.04, 0.62) were associated with lower odds of being in this group, while aphasia (OR = 10.92, 95% CI = 3.08, 38.73), and cancer diagnoses (OR = 3.96, 95% CI = 1.15, 13.65) were associated with higher odds. Also of note, leaving >25% of food on the plate according to the baseline MDS 2.0 assessment was associated with lower odds of being categorized as having “progressive” challenges (OR = 0.23, 95% CI = 0.09, 0.60) and higher odds of being in the “refusing” group (OR = 3.85, 95% CI = 1.20, 12.35) when compared to members of all other classes (Table 5.3).

Figure 5.1

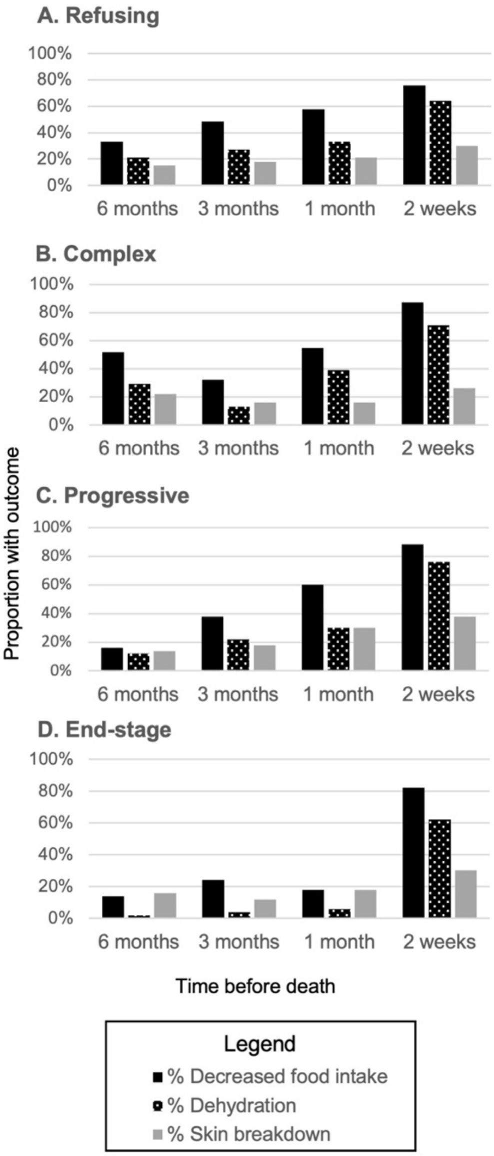
Four classes identified in the repeated measures latent class analysis (n=164)



Note. These classes are based on the probabilities (y-axis) of experiencing 6 eating challenges, represented by each data line, at 6 months, 3 months, 1 month, and 2 weeks prior to death (x-axis). The classes were labeled: A. "Refusing", n=33 (20.1%); B. "Complex", n=31 (18.9%); C. "Progressive", n=50 (30.5%); and D. "End-stage", n=50 (30.5%). The post hoc diagnostic statistics, average latent class posterior probability=0.93 and entropy=0.84, indicated good model fit.

Figure 5.2

The prevalence of decreased food intake, dehydration, and skin breakdown at the four time points prior to death by trajectory of decline (n=164).



Note. Prevalence differed across the four time points (6 months, 3 months, 1 month, and 2 weeks prior to death) and between the four classes identified by repeated measures latent class analysis, A. “Refusing”, B. “Complex, C. “Progressive”, D. “End-stage”. These differences were not assessed statistically; the graphs are for data visualization purposes only.

Table 5.3

Multivariable logistic regression analysis identifying characteristics uniquely associated with each of the eating challenge classes compared to the rest of the residents (n=164)

	Eating challenge class			
	Refusing **OR [95% CI]**	**Complex** **OR [95% CI]**	**Progressive** **OR [95% CI]**	**End-stage** **OR [95% CI]**
Age at death, years	0.98 [0.92, 1.05]	1.04 [0.95, 1.12]	0.98 [0.93, 1.04]	1.01 [0.96, 1.07]
Sex, male	2.05 [0.79, 5.36]	0.70 [0.21, 2.34]	0.91 [0.39, 2.15]	0.70 [0.30, 1.67]
Length of admission, months	1.01 [0.99, 1.02]	**0.98 [0.96, 0.99]**	0.99 [0.98, 1.01]	1.01 [0.99, 1.02]
Cognitive impairment, moderate/severe	0.59 [0.20, 1.72]	**0.15 [0.04, 0.62]**	1.96 [0.73, 5.28]	1.83 [0.72, 4.69]
Leaves 25% food on plate	**3.85 [1.20, 12.35]**	3.05 [0.78, 11.97]	**0.23 [0.09, 0.60]**	1.26 [0.49, 3.25]
Health Instability	0.73 [0.45, 1.19]	1.58 [0.96, 2.57]	1.28 [0.86, 1.90]	0.63 [0.39, 1.03]
Exhibits responsive behaviours	1.92 [0.78, 4.78]	2.37 [0.67, 8.34]	0.63 [0.28, 1.40]	0.61 [0.28, 1.31]
Aphasia	0.69 [0.21, 2.25]	**10.92 [3.08, 38.73]**	0.61 [0.22, 1.70]	0.44 [0.15, 1.34]
Anxiety	0.38 [0.08, 1.88]	1.26 [0.36, 4.38]	1.26 [0.42, 3.81]	0.98 [0.30, 3.20]
Cancer	1.87 [0.69, 5.09]	**3.96 [1.15, 13.65]**	0.50 [0.19, 1.37]	0.54 [0.19, 1.50]

Note. Odds and 95% confidence intervals (OR [95% CI]) of being in the specified class compared to not being in that class (i.e., membership in any other group) based on multivariable logistic regression analyses controlling for all relevant factors identified by *a priori* theory and bivariate analyses (Appendix C, Table C.2). Bolded values are statistically significant, $p<0.05$

5.5 Discussion

This investigation describes the odds of eating challenges experienced by residents of LTC in the final six months of life and identifies four unique patterns of trajectory as residents approach death. It expands on previous cross-sectional research among LTC residents to describe how the prevalence of individual eating challenges fluctuates over time with proximity to death and how eating challenges cluster together. While eating challenges and mortality have been linked previously (S. L. Mitchell et al., 2009; Sakamoto et al., 2018), this is the first, to our knowledge, to use the RMLCA method to classify distinct patterns of eating challenges (i.e., "refusing", "progressive", "end-stage", and "complex") leading up to death. These patterns were generally consistent across the two sampling frames, which had different eligibility criteria, although proportions with each eating pattern varied. This comparison strengthens our findings suggesting that the patterns are not simply an artefact of charting practices that can vary by home. The patterns identified in the investigation are intended to generate further exploration and discussion of expectations around eating challenges and goals of nutrition care as residents decline towards death.

The novelty of defining four general patterns of eating challenges in the final months of life could have important clinical implications for anticipating potential trajectory towards end-of-life and creating realistic goals of care including, but not limited to, comfort-focused goals. For example, residents who experience a variety of challenges including responsive behaviours at mealtimes (i.e., "complex"), may be expected to require long-term management of fluctuating challenges leading up to death. Alternatively, a sudden increase in lethargy, refusal to eat, and/or swallowing difficulties without previous history of eating challenges (i.e., "end-stage") may signal that death is imminent, warranting emphasis on end-of-life comfort care. Awareness of these patterns could also trigger clinicians to develop more tailored approaches to nutrition care, including investigation of potentially reversible causes of eating decline (e.g., appetite-altering medications, mental health concerns, dining environment) and anticipation of need. For example, the defining features of the "refusing" group, including persistent refusal of food, increasing lethargy, low food intake, and a history of leaving food uneaten, suggest that the persistent refusal of food contributes to a subtle decline that may go under-addressed until consequent issues (e.g., lethargy, decreased food intake, significant weight change) are noted. Likewise, the risk factors associated with "complex" challenges denote a subset of residents with health and functional impairments that could lead to unmet needs and loss of independence at mealtimes and who may benefit from targeted interventions that support eating independence and individual preferences when the ability to verbally communicate is compromised. Further investigation of the nuances of these patterns, including the effects of care interventions, is needed.

The trajectory of eating challenges was hypothesized to be associated with various health and functional factors. For example, previous research has suggested that specific eating challenges are associated with stages of dementia, being more or less prevalent with moderate or severe cognitive impairment (Kai et al., 2015; Keller, 2016). Our findings are consistent with this nuanced interpretation, indicating that eating challenges become more prevalent as time (and presumably disease state) progress, while fluctuating in probability with proximity to death. However, the logistic regression analysis found few resident characteristics predictive of the identified trajectories (Table 5.3). Prior cross-sectional research also found no association between medical diagnoses and food intake among LTC residents (Barkema et al., 2019). Instead, eating challenges are likely influenced by a constellation of factors including health and functional issues, personality, dining environment, institutional policies, and available supports (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Mann et al., 2019; Morrison-Koechl et al., 2021; Slaughter et al., 2020). While our findings identify general patterns of decline, they cannot be used for prognostic purposes based on specific disease profiles. Care providers should approach eating challenges holistically, acknowledging that disturbances to mealtime participation and food intake can result from a variety of issues, some of which may indicate terminal decline.

This novel perspective of end-of-life eating challenges is intended to broaden the discussion to consider a holistic, palliative approach to nutrition care incorporating both restorative and comfort-focused care goals when eating challenges appear among LTC residents. Mealtimes present daily opportunities to observe changes in residents' eating status and offer an appropriate focal point for implementing palliative care practices. Strategies such as comfort feeding, where residents are offered the foods they desire at times when they are most receptive to eating as opposed to at scheduled mealtimes, and finding other ways to connect with residents when eating is not possible or desired support a holistic approach to health and well-being in the final months of life (Morrison et al., 2019; Palecek et al., 2010). A better understanding of how eating challenges progress towards end-of-life will empower care providers to implement these strategies when appropriate.

5.5.1 Limitations

The medical chart review methodology is an efficient way to collect longitudinal data on LTC residents and provides insights into a vulnerable population but is limited in that it relies on information recorded by care providers for clinical purposes and may not provide a complete account of eating challenges. Clinical chart information has been shown to have deficiencies in specific types of information, such as psychological and social aspects of care (N. Wang et al., 2011). Furthermore, the accuracy of the data relies on effective communication especially between direct care workers who are most responsible for the daily care of residents and nurses who are responsible for recording daily progress notes in the resident charts. An imbalance of power and hierarchical dynamics between these two groups may result in suboptimal communication in some LTC settings (Banerjee et al., 2015; Beynon et al., 2022; Farrell et al., 2022; Madden et al., 2017) and so may have affected the quality of the information accessed for data extraction. As a result, important information may have been missed. Another limitation of the chart review methodology used was that eating challenges were extracted manually in contrast to automated reporting, increasing the potential for errors; however, reliability testing of data collection promoted consistency over time. Given the vast amount of information available in charts, data collection was limited to two-week observations periods, which may have led to missed eating challenges if they occurred between observations. Reporting styles also varied across LTC homes, potentially producing misleading results.

A wide range was found in the number of days before death that baseline MDS 2.0 data were collected between the two sampling frames. While the difference (50 days on average) was not statistically significant, it may have had clinical significance. A more consistent time frame, and ideally multiple waves of resident characteristics corresponding to the waves of eating challenge observations would have allowed for better comparison of the characteristics of the identified patterns. The sample size was relatively small for RMLCA, so statistical power to define "rare" patterns may have been inadequate (Nylund-Gibson & Choi, 2018); to mitigate this challenge a limited number of eating challenges was modeled. We cannot conclude that these trajectories are unique to the dying process because we did not have a surviving control group for comparison, but the increased probability of these challenges towards death suggests that such a control group could be elusive. The study may have benefited from an observation period longer than six months, as previous work suggests that eating challenges are predictive of two-year mortality (Sakamoto et al., 2018).

5.6 Conclusion

Our findings demonstrate that many eating challenges increase in prevalence and probability with proximity to death and that these challenges present in patterns. Specifically, four patterns were identified, including refusing to eat, experiencing complex fluctuating challenges, exhibiting a progressive increase in challenges, and having a low probability of any eating challenges until the end stages of life. These patterns require further exploration to understand their clinical implications. Care providers in LTC are encouraged to consider eating challenges from a broader perspective, observing longitudinal patterns among residents as demonstrated in this study, to better understand trajectories towards death, to rule out remediable issues, and to support earlier introduction of comfort-focused goals of care.

Chapter 6

Study 2: Factors Associated with the Initiation of Comfort-Focused Nutrition Care Orders for Long-Term Care Residents at the End of Life

6.1 Overview

Background: Comfort-focused nutrition orders are recommended to manage severe eating challenges among long-term care (LTC) residents nearing the end of life, though little is known about their current use. This investigation aims to describe current practices and to identify resident-level and time-dependent factors associated with comfort-focused nutrition orders in this context.

Methods: Data were retrospectively extracted from resident charts of decedents (≥65 years at death, admitted ≥6 months) in 18 LTC homes from two sampling frames across southern Ontario, Canada. Observations occurred at 6- (baseline), 3-, 1-month, and 2 weeks prior to death. Extracted data included: functional measures (e.g., cognitive performance, health instability) at baseline; formalized restorative and comfort-focused nutrition care interventions at each time point; and eating challenges reported in the progress notes in the two weeks following each time point. Logistic regression and time-varying logistic regression models determined resident-level (e.g., functional characteristics) and time-dependent factors (e.g., eating challenges) associated with receiving a comfort-focused nutrition order.

Results: Less than one third (30.5%; n = 50) of 164 participants (61.0% female; mean age = 88.3±7.5 years) received a comfort-focused nutrition order, whereas most (99%) received at least one restorative nutrition intervention to support oral food intake. Discontinuation of a nutrition intervention was rare (8.5%). Comfort orders were more likely with health instability (OR [95% CI] = 4.35 [1.49, 13.76]), within two weeks of death (OR = 5.50 [1.70, 17.11]), when an end-of-life conversation had occurred since the previous time point (OR = 5.66 [2.83, 11.33]), with discontinued nutrition interventions (OR = 6.31 [1.75, 22.72]), with a co-occurrence of other care plan modifications (OR = 1.48 [1.10, 1.98]), and with a greater number of eating challenges (OR = 1.19 [1.02, 1.38]), especially dysphagia (OR = 2.59 [1.09, 6.17]), at the preceding time point.

Conclusions: Comfort-focused nutrition orders were used in less than one third of decedents and most often initiated in the end stages of life, possibly representing missed opportunities to support quality of life for this vulnerable population. An increase in eating challenges, including new dysphagia, may signal a need for proactive end-of-life conversations involving comfort nutrition care options.

Keywords: Patient Comfort, Palliative Care, Retrospective Studies, Long-Term Care, Dietary Services

6.2 Introduction

Canadian long-term care (LTC) homes, or nursing homes, provide 24-hour care for frail older adults, many of whom will die in residence (Menec et al., 2009; Ng et al., 2020). Management of nutrition and hydration at the end of life for LTC residents, and particularly those with advanced cognitive impairment, is the focus of a growing body of evidence (Anantapong et al., 2020, 2021; Barrado-Martín et al., 2021, 2022; Firnhaber et al., 2020; Loofs & Haubrick, 2021; Newman et al., 2020; Soar et al., 2021). This is an important facet of care in LTC, given the deeper meaning of nourishment as a form of care and the potential for emotional distress among care providers and residents when food and fluid provision is poorly managed (del Río et al., 2012). Despite its importance and the high prevalence and complexity of eating challenges in advanced stages of disease and with proximity to death (Chapter 5), clear consensus on how nutrition and hydration should be managed in these circumstances is lacking (Keller, 2016; Newman et al., 2020). Artificial nutrition and hydration are generally not recommended for individuals with advanced dementia (AGS, 2014; Lam & Lam, 2014) yet remain a focus of discussion (Anantapong et al., 2020; Loofs & Haubrick, 2021; Newman et al., 2020). Exploration of strategies to meet the social and physical needs associated with food and mealtimes for LTC residents nearing the end of life is needed (Morrison et al., 2019; Palecek et al., 2010; Soar et al., 2021).

To this end, best practices should emphasize oral intake when possible and desired by the resident, but these practices have not been well-developed to date. Strategies such as verbal encouragement and gentle hand feeding have been recommended (Liu et al., 2022; Palecek et al., 2010; Palese et al., 2018). Moreover, palliative (i.e., comfort-focused) approaches such as “Comfort Feeding Only” orders and “Eating and Drinking with Acknowledged Risk” that value quality of life over the nutritional function of food are appropriate for the LTC sector (Palecek et al., 2010; Soar et al., 2021). Yet, guidance on when and how these strategies should be introduced is lacking. Difficulties applying such approaches include poor recognition of when residents are nearing the end of life and uncertainty around optimal timing for transition to palliative care goals, family and caregiver dynamics, the complexity and wide range of eating challenges experienced by residents, and lack of strong evidence pointing to effective interventions or gold standard practices (Anantapong et al., 2020; Barrado-Martín et al., 2022; Bunn et al., 2016; Clarke et al., 2018; Hill et al., 2018). A better understanding of current practice, and particularly the application of formalized comfort-focused nutrition care goals, as they relate to eating challenges in the final months of life will help to navigate future directions for managing nutrition care as residents progress towards the end of life.

This study aims to describe the formalized nutrition care provided to LTC residents in the last six months of life through a retrospective chart review. In particular, the study (1) describes the specific nutrition-related interventions initiated or modified at four discrete time points leading up to death, and (2) identifies resident-level and time-dependent factors that predict the implementation of comfort-focused nutrition orders before death.

6.3 Methods

6.3.1 Sample Population

A sample size calculation performed at the outset of the study indicated that between 97 and 171 subjects were required to determine the prevalence of an (unspecified) outcome within a margin of error between 7.5% and 10% with 95% confidence, based on the most conservative outcome prevalence estimate of 50%, which is recommended when the outcome is unknown (Dhand & Khatkar, 2014). We started with a single sampling frame, the "Better tArgeting, Better outcomes for frail ELderly patients (BABEL)" study (Garland et al., 2022), but ultimately had to access a second sampling frame, a for-profit chain of LTC homes situated in southern Ontario, Canada, in order to obtain an adequate sample size. These two sampling frames were accessed based on convenience and to understand the care practices offered across a variety of homes. The two samples were notably different in their eligibility criteria and in their characteristics as a result, but merging the two samples was justified given that the aim of our study is to provide a general description of the nutrition care practices that are offered and focuses on within-resident factors that are predictive of these factors.

Briefly, the BABEL study trialed an intervention in LTC homes acquired through voluntary participation. The intervention consisted of structured advance care planning (ACP) discussions with

LTC residents and their substitute decision makers, where some homes received the intervention and others acted as controls providing usual care (ClinicalTrials.gov Identifier: NCT03649191) (Garland et al., 2022). The BABEL intervention did not specifically pertain to food or nutrition but focused on preferences for care at the end of life, such as hospitalization or antibiotic use. Despite inclusion of LTC homes in three Canadian provinces, only the nine (4 intervention, 5 control homes) from Ontario were used in the current study, given the restrictions against accessing BABEL data across provincial borders for a secondary study. Residents were eligible for participation if they were over the age of 65 years and at increased risk of mortality according to the following criteria: moderate to severe health instability per a Changes in Health, End Stage disease and Symptoms and Signs (CHESS) score ≥3, current cancer, congestive heart failure, or leaving >25% of their food uneaten. Upon death, recruited participants for whom consent to participate had been received were included in the current study; BABEL recruitment began in September 2018 and the first deaths were recorded in December 2018. Decedents after March 11, 2020 were not included in the current study given the considerable impact of the COVID-19 pandemic on care provided in the LTC sector. Less than 80 participants from BABEL were found to be eligible for this secondary data analysis, necessitating the second sample.

The second sampling frame was an Ontario-based chain of 19 LTC homes; nine of these homes were randomly selected for participant recruitment. Ten decedents with death date between December 1, 2018 and March 11, 2020 (to match the BABEL study time frame) were randomly selected from each of these nine homes for inclusion in the study.

6.3.2 Study Sample

Eligibility criteria for the current sample were: ≥65 years of age; and admitted to the home ≥6 months to adequately capture the changes in nutrition care interventions leading up to death. Of 303 BABEL participants, 86 (28.4%) had died within the specified period and 79 of these (91.9%) had been admitted to their respective home for at least 6 months. Of 90 randomly selected home chain residents, 85 (94.4%) were over the age of 65 years and had lived in the home for at least 6 months, totaling 164 participants for the current study.

6.3.3 Data Collection

Data were obtained from retrospective chart reviews using medical record review methodology (Allison et al., 2000; Gearing et al., 2006). Information on nutrition care practices and eating challenges experienced in the last 6 months of life were extracted from the formalized care plans and daily progress notes of resident charts using a data extraction form developed by the authors (JMK & HK; Chapter 4). The resident charts were accessed electronically with remote access using a virtual private network (VPN) and data were recorded directly into REDCap Software, a secure web platform for building and managing online databases (Harris et al., 2009, 2019). The data extraction was completed by one coder (JMK) and demonstrated acceptable intra-rater reliability (percent agreement = 0.73-0.86) based on a full re-extraction of 15 charts, with five charts randomly selected for re-extraction after every 50 completed charts. The extraction form listed nutrition care interventions and eating challenges commonly experienced by LTC residents, which were identified through literature review, professional consensus, and personal experience. To capture the changes in nutrition care interventions with proximity to death, care plan data were collected at four discrete time points at 6-, 3-, 1-month and 2 weeks prior to the date of death. Eating challenges reported in the progress notes in the two weeks following each of these time points were extracted.

6.3.3.1 Nutrition Care Interventions

The formalized care plans at each of the four time points were reviewed for indication (yes/no) of initiation or modification of eight common restorative nutrition interventions of interest and initiation of artificial nutrition, including during hospitalization (Table 6.1). We also noted comfort-focused nutrition orders, which were liberally defined as any indication of food provision according to the resident's desire or readiness to eat for the purpose of comfort, regardless of wording of the order. Examples of documented comfort-focused nutrition care orders included: "provide food/fluid as desired and tolerated by the resident", "continue to offer food and fluids as tolerated", "palliative goals for nutrition", "provide food and fluid for comfort, if desired, and when [the resident] is alert and able to swallow safely" (Palecek et al., 2010). Comfort-focused nutrition orders also included modifications to nutrition care plans according to personal preference with acknowledged risk (e.g., pureed texture recommended but regular texture given as per request) (Soar et al., 2021). Comfort-focused nutrition orders and restorative interventions were not mutually exclusive but were differentiated by the implied end goals. Whereas restorative interventions were aimed at meeting nutritional requirements and prevention of malnutrition, comfort-focused nutrition care orders were explicitly concerned with the resident's comfort or preference. This differentiation is important from a practical standpoint because, although restorative interventions may be used to support resident comfort, orders that explicitly prioritize residents' comfort and quality of life over the nutritional function of food represent an important shift in mindset for care providers (Barrado-Martín et al., 2022; Niedert & American Dietetic Association, 2005).

Table 6.1

List of aspects of nutrition care extracted from the resident charts

Aspect of nutrition care experience	**Items extracted**	
Nutrition care interventions [a]		
Restorative (i.e., aimed to support oral intake)	• Physical assistance • Encouragement (verbal or other prompting) • Oral nutritional supplement (ONS) • Texture modification	• Adaptive aid • Therapeutic diet prescription • Protocol to increase fluid intake • Hypodermoclysis
Extraordinary	• Artificial nutrition (including in hospital)	
Comfort-focused	• Comfort-focused nutrition orders, e.g., “provide food/fluid as desired and tolerated by the resident”, “palliative goals for nutrition”	
Eating challenges	• Decreased food intake • Decreased fluid intake • Demonstrated need for verbal or physical prompting • Distractibility • Lethargy • Poor appetite • Refusal to eat • Cognitive difficulties	• Physical difficulties • Frustration • Socially inappropriate behaviour • Dysphagia / Swallowing difficulties • Chewing issues • Holding food in mouth • Eating inedible items (e.g., napkin)
Malnutrition-related complication	• Pressure injury	

Note. Presence (yes/no) of each item was extracted from four time point (i.e., 6 months, 3 months, 1 month, and 2 weeks) prior to death. Nutrition care interventions, with the exception of artificial nutrition, were extracted from the care plans on each of the specified dates. Artificial nutrition, eating challenges and complications were observed in the two weeks of progress notes following each date.

[a] Nutrition care interventions are grouped according to intended aim. Restorative care practices are aimed to meeting nutritional requirements to prevent malnutrition and retain the resident’s function. Alternatively, comfort-focused nutrition care orders are explicitly concerned with the resident’s comfort or preference with quality of life as the end goal. Artificial nutrition is seen as an extraordinary intervention because it is not recommended for older adults with life-limiting conditions like dementia (AGS, 2014; Lam & Lam, 2014).

Discontinuation of interventions, defined as complete removal from the care plan as opposed to modifications of existing orders, was also noted. This action by care providers could imply a potential relaxing of diet restrictions consistent with the aim to improve residents’ quality of life (Niedert & American Dietetic Association, 2005). The resident care plan in place on the date six months prior to the date of death was considered baseline. At each of the subsequent time points, newly initiated, modified, or discontinued nutrition interventions were recorded.

6.3.3.2 Eating Challenges

The daily progress notes reported by members of the care team during the two weeks following each of the time points at 6-, 3- and 1-month and 2 weeks prior to death were reviewed for reports of eating challenges. A list of 15 specific challenges (Table 6.1), which were broadly defined as any difficulties that affected residents’ mealtime experience and/or food and fluid intake, were recorded and summed for an overall eating challenges score (max. 15) at each time point. This summed score provided a proxy measurement for severity of mealtime difficulties experienced by each participant.

6.3.3.3 Palliative/End-of-Life Conversation Documented

A key word search of all progress notes (i.e., not limited to the four time points) were also performed to identify suspected end-of-life decline or a re-orientation of goals of care towards a comfort-focused approach. The ‘control-F’ function was used to identify specific and related words pertaining to suspected end-of-life decline, including “end-of-life”, “terminal”, “palliative”, “comfort”, “decline”, and “deteriorate”, among others. The full process for identifying end-of-life decline is described elsewhere (Chapter 7; Appendix D). These notes did not necessarily focus on food and nutrition and could be initiated by any care provider at any time, even before 6 months prior to death. The earliest date of such documentation, if any, was recorded and the number of days prior to death was calculated.

6.3.3.4 Resident characteristics

Demographic information (age at death, sex, length of admission) were collected from the resident admission forms. Resident characteristics were obtained from the standardized Resident Assessment Instrument Minimum Data Set 2.0 (MDS 2.0), which assesses clinical and functional characteristics of LTC residents and is collected by trained staff quarterly for each resident in LTC homes across Ontario (CIHI, 2021a; Carpenter & Hirdes, 2013). For BABEL participants, the most recent MDS 2.0 assessment recorded prior to recruitment was used to obtain these data; for home chain participants, the assessment approximately six months prior to death was used. The MDS 2.0 items used in the current analysis included: leaving >25% of food uneaten at most meals (yes vs. no); moderate/severe cognitive impairment (Cognitive Performance Scale [CPS] ≥3 vs. <3)(Morris et al., 1994); moderate/high health instability (CHESS ≥3 vs. <3)(Hirdes et al., 2003); extensive/total dependence on the Activities of Daily Living Self Performance Hierarchy Scale (ADL ≥3 vs. <3)(Morris et al., 1999); probable depression (Depression Risk Scale [DRS] ≥3 vs. <3)(Burrows et al., 2000); any responsive behaviors (Aggressive Behavior Scale [ABS] ≥1 vs. 0)(Perlman & Hirdes, 2008); and daily vs. less than daily pain (Fries et al., 2001). Diagnoses were also obtained from the MDS 2.0 assessment.

Body weight, which is typically reported monthly for most LTC residents, was collected for the last six months; if there was more than one weight record for any given month, the measurements closest to one-month intervals were recorded. Missing weight values were not imputed.

6.3.4 Data Analysis

All data analysis were performed using SAS® Studio v3.6 (Enterprise Edition; SAS Institute Inc., Cary, NC, 2017) and inferences of statistical significance were made based on *p*-values less than 0.05. Resident demographics and baseline characteristics were described, as were the proportion and frequency of individual nutrition interventions and number of eating challenges reported at each time point. Mean (standard deviation [SD]) number of additions/changes per resident at each time point and the cumulative incidence of each intervention were described.

6.3.4.1 Logistic Regression to Identify Resident-Level Predictors of Comfort-Focused Nutrition Orders

Predictors of any comfort-focused nutrition order during the six months before death were identified using bivariate (chi-square, t-test) and logistic regression analyses. Resident characteristics (e.g., age, cognitive performance), diagnoses, eating challenges, number of interventions in place at baseline, and number of changes to the care plan after baseline were compared between those who did and did not receive a comfort-focused nutrition order. Purposeful selection of the final adjusted logistic regression model considered parsimony, key variables of interest such as eating challenges and care interventions, and sample size limitations (Peduzzi et al., 1996; Zhang, 2016). The model was also adjusted for the sampling frame to account for potential differences (e.g., recruitment, organizational structure). The final model fit was established using the Hosmer-Lemeshow goodness-of-fit statistic; a non-significant p-value ($p>0.05$) was considered adequate for indicating good model fit.

6.3.4.2 Time-Varying Logistic Regression to Identify Time-Dependent Predictors of Comfort-Focused Nutrition Orders

Logistic random effects regression modeling was used to identify time-specific factors associated with receiving a comfort-focused nutrition order, with time point (i.e., 6 months, 3 months, 1 month, 2 weeks prior to death) as a random effect and resident as the subject (Li et al., 2011). Fixed effects of interest included: sampling frame; time point; number of restorative interventions initiated or modified at the same time point; documentation of an end-of-life/palliative conversation since previous time point; significant weight loss of ≥5% compared to the previous month; total number of eating challenges, and specific eating challenges including dysphagia, refusal to eat, and lethargy experienced at the previous time point. Pressure injury, a downstream complication of poor nutritional status, observed at the previous time point was also tested.

Several models were tested to maximize sample size while accounting for missing and unavailable data. Model 1 included variables that were available for the full sample at all four time points, while Models 2-4 excluded time point 1 since data prior to time point 1 were not collected for weight loss and eating challenges. Model 2 tested weight loss separately because of missing data that further reduced the sample size. Model 3 and 4 tested total number and individual eating challenges at the previous time point.

6.3.5 Ethics

This study was approved by the Office of Research Ethics at the University of Waterloo as an amendment to the BABEL study (ORE#31782) and a separate protocol for the home chain sample (ORE#40789). Some participating LTC homes also provided approval as per individual policies.

6.4 Results

The study sample consisted of 164 decedents who were over the age of 65 years at death and had been admitted to the LTC home for at least six months (median = 33 months, quartiles 1 & 3 = [19, 50.5]) (Table 6.2). Almost two-thirds (61.0%) of participants were female and the average age was 88.3 ± 7.5 years.

Table 6.2

Description of the total sample and bivariate predictors of ever receiving a comfort-focused nutrition order (n = 164)

		Comfort-focused nutrition order initiated	
	Total sample n=164	**No (n=114)**	**Yes (n=50)**
	% (n)[a]	**% (n)[a]**	**% (n)[a]**
Resident Demographics			
Sampling frame, BABEL (vs. home chain)	48.2 (79)	51.8 (59)	40.0 (20)
Age at death, years, Mean±SD	88.3 ± 7.5	88.3 ± 7.7	88.3 ± 7.1
Sex, female	61.0 (100)	62.3 (71)	58.0 (29)
Length of admission, months, Median [Q1, Q3]	33 [19, 50.5]	31.5 [19, 50]	35 [20, 55]
MDS 2.0 Scores			
Leaves >25% of food uneaten at most meals	58.5 (96)	57.0 (65)	62.0 (31)
Cognitive impairment, moderate/severe (CPS ≥3)	79.3 (130)	80.7 (92)	76.0 (38)
Health Instability, moderate/high (CHESS≥3)	13.4 (22)	**9.6 (11)**	**22.0 (11)**
Significant loss of independence (ADL≥3)	89.0 (146)	88.6 (101)	90.0 (45)
Depression risk (DRS≥3)	47.0 (77)	49.1 (56)	42.0 (21)
Exhibits responsive behaviours (ABS≥1)	54.9 (90)	55.3 (63)	54.0 (27)
Pain Scale, daily	4.8 (8)	3.5 (4)	8.0 (4)
Diagnoses			
Cancer	18.3 (30)	15.8 (18)	24.0 (12)
Diabetes	24.4 (40)	23.7 (27)	26.0 (13)
Cardiovascular disease	79.3 (130)	80.7 (92)	76.0 (38)
Congestive heart failure	16.5 (27)	19.3 (22)	10.0 (5)
Alzheimer's disease	15.2 (25)	15.8 (18)	14.0 (7)
Non-Alzheimer's dementia	62.2 (102)	63.2 (72)	60.0 (30)
Stroke	23.8 (39)	20.2 (23)	32.0 (16)
Eating Challenges			
Total eating challenges, mean±SD	10.6 ± 5.4	**10.0 ± 5.5**	**11.9 ± 5.1**
Restorative Nutrition Interventions			
Total number at baseline, mean±SD	2.9 ± 1.2	2.9 ± 1.2	2.9 ± 1.2
Number of additions/changes after baseline, mean±SD	1.9 ± 1.7	**1.7 ± 1.5**	**2.5 ± 2.0**
Discontinued, yes[c]	8.5 (14)	**4.4 (5)**	**18.0 (9)**

Note. Abbreviations: ABS, Aggressive Behaviour Scale (max. 12); ADL, Activities of Daily Living Self Performance Hierarchy Scale (max. 6); BABEL, Better Targeting, Better Outcomes for Frail Elderly Patients study; CHESS, Changes in Health, End-stage Disease and Signs and Symptoms (max. 5); CPS, Cognitive Performance Scale (max. 6); DRS, Depression Risk Scale (max. 14); MDS 2.0, InterRAI Minimum Dataset 2.0; [Q1, Q3], 1st and 3rd quartile; SD, standard deviation; vs, versus.

[a] Descriptives are % (n) unless otherwise specified.

[b] MDS scores recorded on average 256 ±131 days (BABEL) and 206±34 days (home chain) prior to death.

[c] Discontinued interventions include modified texture, diet prescription, or oral nutritional supplement and were noted as discontinued within the 6 months prior to death.

Bolded values are statistically significant, $p < 0.05$.

Nearly all (98.2%) of the participants had at least one of the eight (mean = 3±1.2) restorative nutrition interventions in their care plan at baseline, 6 months prior to death (Table 6.3). The most common interventions initiated during any point in the six months prior to death were physical eating assistance (85.4%), encouragement (75.6%), oral nutritional supplement (ONS; 73.2%), and texture modification (71.3%). Nineteen (11.6%) participants received temporary artificial hydration through hypodermoclysis within the last month of life. Four participants received tube-feeding within the last six months of life, all initiated during an acute admission to hospital, and discontinued prior to (n = 3), or shortly after (n = 1), return to the LTC home. One participant did not have any restorative nutrition interventions initiated within the 6 months prior to death; this resident had a comfort-focused nutrition order in place at baseline.

Discontinuation of nutrition interventions was a relatively rare event, totaling 14 interventions that were completely removed from residents' care plans (Table 6.2). Of these 14 discontinuations, the majority were attributed to ONS, which was discontinued at various time points for 12 (10%) of the 120 individuals who ever received ONS (Table 6.3). The other two discontinuations were a therapeutic diet prescription that was discontinued for one resident between six and three months prior to death, while a texture modification was removed for one resident within two weeks of death.

Comfort-focused nutrition orders were specified for a total of 50 (30.5%) residents, with almost two-thirds (n = 32; 64%) initiated within two weeks of death (Table 6.3). These were spread disproportionately across the 18 participating homes, ranging from 0% in two homes (one from each sampling frame) up to 70% of decedents in another home. Bivariate analyses indicated that individuals who received comfort-focused nutrition orders had more reported eating challenges, nutrition care plan modifications and discontinuations, and health instability (Table 6.2). In the logistic regression analysis adjusting for resident-level factors (Table 6.4), comfort-focused nutrition orders were less likely among the BABEL sample (OR = 0.36 [0.16, 0.82]), and more likely with moderate/high health instability (OR = 4.53, 95% CI = [1.49, 13.76]) and discontinued nutrition interventions (OR = 6.31 [1.75, 22.72]). Cognitive performance was not associated with comfort-focused nutrition orders. Influence diagnostics (i.e., Pearson residuals, dfbetas) confirmed no major outliers or highly influential observations and satisfactory model fit was established with a Hosmer-Lemeshow goodness-of-fit test ($\chi^2 = 9.52$; df = 8; p = 0.30).

Table 6.3

Prevalence of initiated or modified nutrition interventions and reported eating challenges at each time point in the last six months of life of LTC residents (n=164)

	Time prior to death				
	6 months	**3 months**	**1 month**	**2 weeks**	**Cumulative Incidence**
Care Plan Orders Added/Altered					
Comfort-focused, % (n)					
Offer food as desired/for comfort or preference	4.9 (8)	3.0 (5)	4.9 (8)	19.5 (32)	30.5 (50)
Restorative, % (n)					
Physical eating assistance	73.8 (121)	11.0 (18)	12.8 (21)	12.2 (20)	85.4 (140)
Encouragement	73.8 (121)	6.7 (11)	4.9 (8)	1.8 (3)	75.6 (124)
ONS	51.8 (85)	20.7 (34)	22.0 (36)	18.3 (30)	73.2 (120)
ONS discontinued	0.0 (0)	3.7 (6)	0.6 (1)	3.0 (5)	7.3 (12)
Texture modification	47.0 (77)	16.5 (27)	15.2 (25)	19.5 (32)	71.3 (117)
Adaptive aid	25.0 (41)	6.1 (10)	3.0 (5)	2.4 (4)	32.3 (53)
Therapeutic diet prescription	11.0 (18)	1.8 (3)	0.0 (0)	0.0 (0)	12.2 (20)
Protocol to increase fluid intake	7.9 (13)	3.0 (5)	1.2 (2)	2.4 (4)	14.6 (24)
Hypodermoclysis	1.2 (2)	0.0 (0)	1.2 (2)	10.4 (17)	11.6 (19)
Any addition/change [a]	98.2 (3)	45.1 (74)	41.5 (68)	43.3 (71)	99.4 (163)
Total changes, [a] mean ± SD	3 ± 1.2	0.6 ± 0.88	0.6 ± 0.88	0.7 ± 0.92	5 ± 2.0
Eating Challenge Score, mean ± SD	1.5 ± 1.9	1.8 ± 2.0	2.8 ± 2.3	4.5 ± 2.2	10.6 ± 5.4 [b]

Note. Nutrition interventions were extracted from the resident care plans on the specified dates. All interventions in place at the six-month time point ("baseline") were noted, as were modifications/additions that were recorded in the care plans at subsequent time points. Individual eating challenges were extracted from the residents' progress notes documented in the two weeks following each time point and the number of eating challenges was summed at each time point (max. 15) and across the four time points (max. 60).
Abbreviations: ONS, oral nutritional supplement; SD, standard deviation

[a] Changes to restorative interventions; could be new order initiated or alterations to existing orders (e.g., adjustment to ONS prescription) but not withdrawn intervention.

[b] Total number of eating challenges recorded across the four time points.

Table 6.4

Resident-level predictors of ever receiving a comfort-focused nutrition order (n=164)

	OR [95% CI]
Demographic variables	
Sampling frame, BABEL (vs. home chain)	**0.36 [0.16, 0.82]**
Health/Functional status	
Moderate/severe cognitive impairment [a]	0.43 [0.17, 1.10]
Health instability, moderate/high [b]	**4.53 [1.49, 13.76]**
Eating challenges	
Total number of eating challenges, last six months	1.05 [0.96, 1.13]
Nutrition Care plans	
Number of additions/alterations after baseline	1.26 [1.00, 1.58]
Discontinued interventions [c]	**6.31 [1.75, 22.72]**

Note. Final adjusted logistic regression modeling odds and 95% confidence interval (OR [95% CI]) of receiving a comfort-focused nutrition order at any time point. Hosmer-Lemeshow goodness of fit statistics indicate acceptable fit: $\chi^2 = 9.52$; df = 8; $p = 0.30$.
Abbreviations: BABEL, Better tArgeting, Better outcomes for frail ELderly patients study.
[a] Cognitive Performance Scale (CPS) score ≥3.
[b] Changes in Health, End-stage Disease and Signs and Symptoms (CHESS) score ≥3.
[c] Discontinued interventions were oral nutritional supplement (n=12), modified texture diet (n = 1), and therapeutic diet (n = 1).
Bolded values were statistically significant, $p<0.05$.

The time-varying logistic regression model including all four time points (Table 6.5; Model 1) demonstrated that comfort-focused nutrition orders were more likely in the last two weeks of life compared to six months prior to death (OR = 5.50 [1.70, 17.77]), with a higher number of care plan modifications at the same time point (OR = 1.48 [1.10, 1.98]), and an end-of-life conversation recorded since the previous time point (OR = 5.66 [2.83, 11.33]). These associations persisted to varying degrees across all models. Severe weight loss in the preceding month was not a significant predictor of a comfort-focused nutrition order (Model 2). Number of eating challenges documented at the previous time point, representing unmanaged or increasing difficulties with eating, was associated with increased odds of a comfort-focused nutrition order (OR = 1.19 [1.02, 1.38]) (Model 3); dysphagia was the only specific eating challenge with a significant association (OR = 2.59 [1.09, 6.17]) (Model 4). Sampling frame was not consistently significant across the models suggesting that this association may be confounded by other factors.

Table 6.5

Time-dependent factors associated with receiving a comfort-focused nutrition order

Variables	**Model 1 (n=656)** **OR [95% CI]**	**Model 2 (n=442)** **OR [95% CI]**	**Model 3 (n=492)** **OR [95% CI]**	**Model 4 (n=492)** **OR [95% CI]**
Sampling frame, BABEL vs. home chain	0.62 [0.33, 1.18]	0.60 [0.28, 1.27]	**0.46 [0.22, 0.96]**	0.50 [0.24, 1.05]
Time point [a]				
2 vs. ref	1.58 [0.40, 6.25]	---	---	---
3 vs. ref	2.18 [0.61, 7.76]	1.76 [0.49, 6.33]	1.28 [0.39, 4.19]	1.36 [0.41, 4.46]
4 vs. ref	**5.50 [1.70, 17.77]**	**5.38 [1.64, 17.62]**	**3.62 [1.23, 10.67]**	**3.61 [1.21, 10.79]**
Number of care plan modifications at same time point	**1.48 [1.10, 1.98]**	**1.65 [1.17, 2.33]**	**1.45 [1.02, 2.06]**	**1.53 [1.09, 2.16]**
End-of-life conversation occurred since last time point	**5.66 [2.83, 11.33]**	**2.74 [1.20, 6.25]**	**3.27 [1.54, 6.92]**	**3.73 [1.72, 8.05]**
≥5% weight loss in previous month [b]	---	1.49 [0.59, 3.78]	---	---
Eating challenges at previous time point				
Number of challenges documented			**1.19 [1.02, 1.38]**	---
Dysphagia				**2.59 [1.09, 6.17]**
Refusal to eat				1.98 [0.89, 4.41]
Low energy				0.90 [0.39, 2.08]
Pressure injury				0.72 [0.29, 1.76]

Note. Adjusted time-varying logistic regression modeling odds and 95% confidence interval (OR [95% CI]) of receiving a comfort-focused nutrition order. Model 1: full sample with all four time points and no missing data; Model 2-4: data from time point 1 (i.e., baseline at 6 months prior to death) was not included in the model because weight loss and eating challenges were not collected prior to this time point.

[a] Time point 1 = 6 months prior to death; time point 2 = 3 months prior to death; time point 3 = 1 month prior to death; time point 4 = 2 weeks prior to death; ref = referent category, which was time point 1 for Model 1, and time point 2 for Models 2-4, since these models excluded data from time point 1.

[b] n = 442 with weight loss data; this variable was excluded from Models 1, 3, and 4 to retain larger sample size. Bolded values are statistically significant, $p < 0.05$.

6.5 Discussion

This retrospective chart review provides a description of nutrition care practices used to support LTC residents in the last six months of life. Our results showed that comfort-focused nutrition orders were used infrequently despite a high proportion who experienced eating challenges and required restorative nutrition interventions; of 164 deceased residents, 98% of whom were already receiving at least one restorative nutrition intervention six months prior to death, less than one third went on to receive a formalized comfort-focused nutrition order. These orders were often initiated within two weeks of death despite earlier indication of health instability, eating challenges and functional decline, and were disproportionally distributed among the 18 homes in the two sampling frames. Seemingly, comfort-focused nutrition orders appear to be used reactively in current practice and are likely dependent on care provider experience with discussing these orders with family and residents, reinforcing previous findings that transitions to comfort-focused goals of care in LTC are full of uncertainty and often occur late in the end-of-life trajectory (Bunn et al., 2016; Hill et al., 2018). These findings highlight a potential opportunity for quality improvement in nutrition care offered to frail LTC residents nearing the end of life that requires further exploration.

Comfort nutrition care emphasizes quality of life over the nutritional value of food, recognizing that nutrient intake becomes less relevant amidst end-of-life decline (Palecek et al., 2010). We defined ‘comfort-focused nutrition orders’ broadly for our data collection. Yet, incidence was still low and varied significantly across the homes and sampling frames, indicating that institutional factors (e.g., home culture, educational opportunities) are likely an important consideration in the application of formal comfort nutrition orders in practice. Although the incidence of formalized orders documented within the care plans varied widely in our sample, we cannot conclude that LTC homes were not engaged in comfort-focused nutrition care practices. Modifications to restorative interventions were made for nearly half of residents at each time point leading up to death, suggesting that the nutrition care decision-making process is heavily-context dependent and requires a ‘trial and error’ approach (Anantapong et al., 2020; Barrado-Martín et al., 2022). Furthermore, likelihood of receiving a comfort-focused nutrition order was greater with more care plan modifications and with discontinued interventions. Such renegotiation and withdrawal of care orders may imply individualization of care plans consistent with a palliative philosophy of care even in the absence of, or prior to, a formalized order (Dorner & Friedrich, 2018; Niedert & American Dietetic Association, 2005). The question remains whether there is an additional benefit to formalizing comfort-focused nutrition care. If so, residents with health instability and complex nutritional needs who require several care plan modifications could be considered candidates for earlier initiation of formal comfort-focused nutrition orders.

At the resident level, our findings highlight several factors that may affect the decision to initiate comfort-focused nutrition care. The strongest predictors of a formalized order were those that indicated poor prognosis (i.e., CHESS≥3, prior end-of-life conversation, initiation within two weeks of death). This is consistent with previous findings that showed that palliative care goals are typically pursued following an acknowledged clinical awareness that a resident is nearing the end of life – usually within days or hours of death – despite an earlier general awareness of their impending death, potentially due to uncertainty within the LTC community about the acceptability of death (Cable-Williams & Wilson, 2014). The emphasis on comfort nutrition orders to address dysphagia specifically (Palecek et al., 2010; Soar et al., 2021), which often occurs late in the end-of-life trajectory, may further contribute to the limited and delayed initiation of comfort nutrition care orders. However, these orders may have a wider application, such as in the context of advanced directives or if a resident refuses to eat (Relias Media, 2014). Further investigation is needed to understand the reasons why comfort-focused nutrition care goals are delayed until the very end of life, and the potential for earlier initiation of these care goals to support the quality of life for residents with diverse challenges in LTC.

Health instability, which was significantly associated with eventual initiation of a comfort-focused nutrition care order, is an important focal point for future research on timely initiation of comfort-focused conversations in LTC. Comfort-focused nutrition orders may be well-suited to address health instability because they allow flexibility to respond to the resident’s fluctuating needs using various interventions (e.g., ONS, texture modification) while minimizing the need for many care plan modifications. The CHESS score, which contains several items on nutritional status (e.g., weight loss, decreased food/fluid intake), has been shown as a robust predictor of resident outcomes, including mortality (Hirdes et al., 2003, 2019; N. Williams et al., 2022), and provides a clinical measure to alleviate care partners’ concerns around premature initiation of comfort-focused care goals (Anantapong et al., 2020; Clarke et al., 2018; Hill et al., 2018). Prospective studies should explore the use of CHESS and other indicators of health instability to trigger comfort care conversations and dietitian support to plan for potential and anticipated eating challenges.

6.5.1 Limitations

A limitation of the study was that the care practices were based on charted information and formalized care, which may not have captured all strategies that were used to provide comfort and quality of life to the resident. For example, providing favourite foods is a common way for family members and staff to provide comfort for residents (Firnhaber et al., 2020), but this would not have been captured in the formalized care plan. Our data collection was strengthened by having only one extractor for collection with an intra-rater reliability check, yet errors could have been made recording events. We chose to limit extraction to a two-week period around each time point, which may have resulted in misclassification (e.g., missed eating challenges). Furthermore, reliance on information documented in the progress notes may have resulted in under-representation of eating challenges because of known challenges with communication and information flow between direct care providers and the nursing staff responsible for charting (Banerjee et al., 2015; Beynon et al., 2022; Farrell et al., 2022; Madden et al., 2017; N. Wang et al., 2011). It is likely that some eating challenges were not reported. The decision to collect eating challenges as dichotomous variables as well as to sum these as a proxy for severity of eating challenges results in a simplistic analysis that may not fully represent the nuances of the factors associated with comfort-focused nutrition care. Differing recruitment methods for the sampling frames could have confounded the results, although this was mitigated by adjusting for the sampling frame in all models. Future studies should investigate end-of-life nutrition care practices in a more representative sample. The various ownership, profit statuses and organizational structures of the participating homes may have affected the comfort-focused practices in place in each home, but our data collection did not account for these differences. Finally, our sample size limited the number of factors that could be considered in regression analyses.

6.5.2 Conclusions

Nutrition care management in the last six months of LTC residents' life is complex, requiring accommodation of their changing needs. Comfort-focused nutrition orders, which allow for flexible nutrition care, have great potential to uphold quality of life when eating becomes challenging and less desirable for residents. However, our findings suggest that formalized comfort-focused nutrition orders are used inconsistently and initiated close to the occurrence of death. We contend that these and similar palliative-minded nutrition care strategies could be implemented more frequently and earlier in the end-of-life journey considering the increasing eating challenges and health instability noted. Future studies exploring opportunities for timely introduction of comfort care conversations and formalized comfort nutrition care options are needed.

Chapter 7

Study 3: Nutrition and non-nutrition-related challenges predict time to death in long-term care residents: A retrospective chart review

This is an Accepted Manuscript version of the following article, accepted for publication in the Journal of Multidisciplinary Healthcare.

Morrison-Koechl, J., Liu, S. H., Banerjee, A., Heckman, G., & Keller, H. (2023). Nutrition and non-nutrition-related challenges predict time to death in long-term care residents: A retrospective chart review. *Journal of Multidisciplinary Healthcare*, accepted for publication on August 8, 2023.

It is deposited under the terms of the Creative Commons Attribution-Non Commercial License (http://creativecommons.org/licenses/by-nc/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

7.1 Overview

Purpose: Signals of end-of-life decline observed in daily habits, such as mealtime participation, are important for moving towards comfort-focused goals of care in the final months of life of long-term care (LTC) residents. It is unclear how eating issues observed in real-time in LTC homes are used as indicators of suspected end of life. The study quantifies nutrition and key non-nutrition related signals (e.g. general decline, unstable vitals) documented to describe end-of-life decline and the subsequent time to death.

Patients and methods: A retrospective chart review identified the first documented conversation where end-of-life decline was considered by members of the care team (e.g., nurses, physicians, dietitian, family member) for 76 randomly selected decedents from 9 LTC homes in southwestern Ontario, Canada. Time (days) to death was calculated. A directed content analysis of the free text description of the suspected end-of-life decline was used to categorize signals. Cox proportional hazards regression analysis tested the risk of mortality associated with each categorized signal.

Results: Time to death of residents (mean age = 88±7 years; 60% female) from the first documentation of potential end-of-life decline ranged from 0 days to over 2 years prior to death (median = 27.5 days). Seven nutrition-related and 18 non-nutrition related signals were identified. Dysphagia (HR = 2.99; 95% CI = 1.41, 6.33), cognitive decline (HR = 0.40; 95% CI = 0.20, 0.77),

delirium (HR = 13.23; 95% CI = 1.57, 111.69), and cancer (HR = 0.18; 95% CI = 0.07, 0.48) were associated with time to death.

Conclusion: This study provides insight into the signals used by care providers in LTC to suspect that residents are declining towards the end of life and identifies four signals that were associated with time to death. When identified by care providers as indicators of end-of-life decline, swallowing difficulty and delirium predicted a shorter time to death, while cancer and cognitive decline predicted a longer time to death. Recognition of nutrition and non-nutrition related signals may be leveraged to systematically introduce timely comfort care conversations.

Keywords: time to death, dysphagia, delirium, LTC

7.2 Introduction

Residents of long-term care (LTC) in Canada represent some of the oldest and frailest members of society, with many complex health, cognitive, and functional impairments that increase the risk of mortality. The LTC population is characterized by a high level of cognitive impairment affecting at least 90% of residents (OLTCA, 2019), and approximately 75% of residents have three or more comorbidities, including cardiovascular disorders and diabetes among other conditions (OLTCA, 2023). Multimorbidity contributes to an increased risk of functional decline which, combined with age-associated sarcopenia and frailty, leads to increased vulnerability to complications such as pain, delirium, weakness, and dysphagia (i.e., swallowing difficulty) (Yang et al., 2022; Yarnall et al., 2017). Given the high prevalence of frailty in the LTC population, with estimates ranging up to 75% of residents internationally (Kojima, 2015; Milte et al., 2022), these complications are also common among residents of LTC. Evidence suggests that LTC residents experience a high prevalence of dysphagia and swallowing difficulties, with estimates ranging from 7% to 40% according to one systematic review (Namasivayam & Steele, 2015). Further compounding these vulnerabilities, cognitive impairment, multimorbidity, frailty, and their associated challenges hinder adequate food intake and increase the risk of malnutrition (Borkent et al., 2023; Komici et al., 2022; Namasivayam & Steele, 2015), which is estimated to affect over half of LTC residents (Keller et al., 2019) and contributes to an increased risk of mortality (Söderström et al., 2017).

As a result of such complex physical and functional challenges, many residents live their final months and days of life in the LTC home (Menec et al., 2009; Ng et al., 2020). An estimated 25% of residents in Ontario LTC homes die within one year of admission (Tanuseputro et al., 2017) and approximately 20% of admitted residents are discharged due to death each year, according to publicly reported Canadian data (CIHI, 2021a). Given the high rate of mortality, the demand for palliative (i.e., comfort-focused) approaches to care in LTC is growing (Cloutier et al., 2021; Eisenmann et al., 2020; Kaasalainen et al., 2016). Such approaches become increasingly important as residents experience changes in health, function, and cognitive status that increase the complexity of care needs and severity of their conditions. Yet, very few decedents in Canadian LTC homes receive specialist palliative care (CIHI, 2018; Xiong et al., 2019). Integrated palliative approaches to care, though undergoing rapid development in the Canadian LTC landscape, are still limited by many challenges (Cloutier et al., 2021).

Early initiation of comfort care practices has been demonstrated to decrease burdensome interventions and improve quality of life of persons living with dementia and other life-limiting conditions, and to decrease costs associated with accessing acute care services (CIHI, 2018; Eisenmann et al., 2020; Qureshi et al., 2019). Imminent or obvious end-of-life decline is not a prerequisite for initiating comfort approaches to care. However, commonly cited barriers to implementing early comfort-focused care, such as complexity of symptoms, unclear prognosis, and variable condition-related trajectories towards end-of-life (Barclay et al., 2014; Brandt, 2005; Hill et al., 2018; Stuart, 1999; The National Hospice Organization, 1996; van der Steen et al., 2014) indicate that care providers look for signs of decline before initiating these goals of care conversations. While previous theory suggests that end-of-life trajectories differ by diagnostic category (i.e., cancer, organ failure, and frailty/dementia) (Lunney, 2003; Murray et al., 2005), these categories have not been useful in distinguishing end-of-life decline among older adults living in residential and LTC facilities (Barclay et al., 2014; Boyd et al., 2019) likely due to the complexity of health conditions and functional changes found among residents in these settings. As such, alternative opportunities for recognizing the need for comfort-focused goals of care are needed.

Signals of end-of-life decline that are observable in daily habits and routines of LTC residents have been identified and regarded as fundamental to initiating high-quality palliative end-of-life care (Åvik Persson et al., 2018; Bern-Klug, 2006; Brandt, 2005; Gonella et al., 2021). A Swedish study of multidisciplinary healthcare professionals working in LTC found that early signals were subtle, and although not immediately obvious, could be identified with some reflection from care staff (Åvik Persson et al., 2018). Another study had Dutch nursing home physicians list signs and symptoms that would indicate a life expectancy of six weeks or less; little/no fluid and food intake, generalized weakness, and respiratory problems were most commonly reported as the top symptoms (Brandt, 2005). Categorization of observed and recorded signs and symptoms that lead to suspected end-of-life decline, from a care provider perspective, has not been done to confirm these findings. The timing of such signals in relation to death may also inform strategies for initiating earlier comfort-focused care conversations.

Eating challenges are common in LTC residents and become more prominent in many residents in the final months of life (Chapter 5). Most prognostic tools used to indicate risk of 6-month mortality include at least one item such as malnutrition, weight loss, and/or reduced food intake (Brown et al., 2013; Eisenmann et al., 2020), highlighting the relevance of eating challenges as a signal of terminal decline. In addition to the use of prognostic tools, daily observations of residents' changing habits and behaviors surrounding food and fluid may be useful to initiate conversations and to support the decision to transition towards end-of-life care goals. Decreased food/fluid intake, refusal to eat, and dysphagia have been cited by health care providers to signal terminal decline in practice (Åvik Persson et al., 2018; Brandt, 2005; Gonella et al., 2021), yet it is not known if these challenges predict time to death. Studies of signals of end-of-life decline have been qualitative (Åvik Persson et al., 2018; Bern-Klug, 2006; Gonella et al., 2021) or do not consider timing to death after the signs are recognized (Brandt, 2005). It is unclear how eating issues observed in real-time in LTC homes, from the viewpoint of the care provider, are used as indicators of suspected end of life.

This study is descriptive and aims to better understand the transition to end-of-life care goals for LTC residents from a multidisciplinary perspective with a particular focus on nutrition-related signals. To meet these objectives, a retrospective chart review was used to identify the point at which care providers first documented potential end-of-life decline and the factors surrounding this event (Allison et al., 2000; Gearing et al., 2006). A retrospective chart review is advantageous for this purpose because it allowed for efficient collection of data on deceased residents and an unbiased account of the care providers' perspective of the important signals which led them to consider that the resident was experiencing end-of-life decline. The study is led by two objectives: 1) to describe the nutrition-related and other (i.e., non-nutrition) challenges that led care providers to suspect the end-of-life phase was starting for residents; and 2) to investigate whether any of the identified challenges, when flagged to indicate potential end-of-life decline, consistently predicted a shorter or longer time to death.

7.3 Material and Methods

This investigation is one part of a larger study designed to describe eating-related challenges and nutrition care practices within the context of the end-of-life experience of long-term care (LTC) residents.

7.3.1 Study Sample

The sample was comprised of deceased residents from LTC homes affiliated with a single for-profit chain in southern Ontario, Canada. Participants were selected after death so there was no researcher influence on the anticipation of end-of-life decline. Of 19 homes in the chain, nine were randomly selected for participant recruitment. Residents were eligible for inclusion if they had been admitted to one of these nine homes for at least six months to ensure adequate health record history, and had a death date falling between December 1, 2018 and March 11, 2020. These dates ensured availability of electronic records, which were implemented chain-wide in the year prior, and excluded deaths that occurred after the World Health Organization (WHO) declaration of the COVID-19 pandemic on March 11, 2020 given the significant impact of the emergency order on the care provided in the LTC sector. Ten residents from each home were randomly selected using a random number generator. Residents under the age of 65 years (n = 5) were removed retroactively, so the sample consisted of 85 residents who were over the age of 65 and had been admitted to their respective home for at least six months. Individuals who did not have a change of status indicative of end-of-life decline documented in their progress notes prior to death (n = 9) were excluded from the study. Thus, the final sample consisted of 76 participants.

7.3.2 Data Collection

Data for the study were collected by a single researcher (JMK) through a retrospective chart review using medical record review methodology (Allison et al., 2000; Gearing et al., 2006) (Chapter 4). The resident charts were documented electronically in PointClickCare© (Mississauga, ON, 2020), a cloud-based health records software, and accessed remotely using a virtual private network (VPN). Data on nutrition-related eating challenges and care interventions, focusing on the last 6 months of life, were extracted from the participants' clinical progress notes, assessments, and care plans by a single researcher using a data extraction form with detailed definitions for each item. Extracted data were recorded electronically using REDCap Software, a secure web platform for building and managing online databases (Harris et al., 2009, 2019). Only the first author (JMK) had access to the resident charts for data extraction and all data were de-identified by name and LTC home upon extraction to protect resident privacy. Deidentified datasets and associated documents were stored on an encrypted, password-protected network drive hosted by the University of Waterloo in accordance with data protection regulations. Ethics approval for the study was obtained from the Office of Research Ethics at the University of Waterloo (ORE#40789) and subjected to an additional approval process according to institutional policies within the LTC home chain.

Resident characteristics for sample description were obtained from the resident admission forms, progress notes, and the standardized Resident Assessment Instrument Minimum Data Set 2.0 (MDS 2.0), a standardized instrument that assesses the health and functional status of residents, reported quarterly by trained staff in LTC homes across Ontario (CIHI, 2021a; Carpenter & Hirdes, 2013). To align with the goals of the larger study, the MDS 2.0 assessment recorded approximately six months prior to death was extracted. Extracted items included: diagnoses; leaving >25% of food uneaten at most meals (yes vs. no); moderate/severe cognitive impairment (Cognitive Performance Scale [CPS] ≥3 vs. <3)(Morris et al., 1994); moderate/high health instability (CHESS ≥3 vs. <3)(Hirdes et al., 2003); extensive/total dependence on Activities of Daily Living Self Performance Hierarchy Scale (ADL ≥3 vs. <3)(Morris et al., 1999); probable depression (Depression Risk Scale [DRS] ≥3 vs. <3)(Burrows et al., 2000); any responsive behaviors (Aggressive Behavior Scale [ABS] ≥1 vs. 0)(Perlman & Hirdes, 2008); and daily vs. less than daily pain (Fries et al., 2001). One item indicating existing swallowing problems was also extracted from the MDS 2.0 assessment recorded approximately six months prior to death. The residents' progress notes from the final month of life were scanned for swallowing difficulty reported by the LTC care team.

The event of interest was the point at which the care providers reported a 'change in status' that signaled suspected end-of-life decline, including a guarded prognosis, transition to comfort-focused care, or direct anticipation of death. This event was identified primarily by a keyword search, described in further detail below. Since the aim of this study was to retrospectively understand the resident nutrition and non-nutrition challenges that led the care team to suspect an end-of-life decline, the search was first limited to progress notes documented in the six months prior to death. If a change in status event was not obvious in the last six months of the resident's life, or if the care goals expressed in the progress notes within six months of death suggested that the change in status had already occurred (e.g., comfort-focused care goals were already established), earlier progress notes (i.e., prior to six months before death) were reviewed to identify the point at which a significant change in status was first noted, if at all. Change in status was identified by first reviewing the progress notes informally to get a sense of the resident's trajectory towards death. This initial chart scan was followed by a keyword search of the charted progress notes. Search terms included "end-of-life", "terminal", "deteriorate", "comfort", and derivatives and synonyms of these words (e.g., "end of life" and "EOL" were also searched), to identify the earliest mention of the change in residents' status. A description of the process to identify the change of status, including the list of search terms, can be found in Appendix D (Table D.1).

The date of the change in status reported by health care providers was noted. Contextual details around the documented change in status were extracted as a free text description, preserving the original wording of the progress notes as much as possible. Details of interest included the role of the person who initiated the conversation (e.g., nursing staff, physician, family member), the reasons for flagging the change in status, and the context around the conversation (e.g., arising from a planned care conference, recent hospitalization). Progress notes in the days leading up to the change in status reporting were summarized where necessary to gain more context, for example, if the progress note referred to an event occurring on a previous day. The date of initiation of formalized palliative/end-of-life orders (i.e., ordered by physician or entered into the care plan) were also noted for descriptive purposes.

Intra-rater reliability of the entire data extraction (293 items), including the date of first mention of a change in status, was done in duplicate for 15 randomly selected resident charts (~10% of the total sample for the larger study, n=164) (Chapter 4). Agreement on the change of status date was found for 13 (87%) of the 15 charts, indicating an acceptable level of reliability. One of the disagreements referred to the same event but was one day off. In the other case of disagreement, two different dates were recorded in the variable field, but both dates with similar text descriptions were noted both times the chart was reviewed.

7.3.3 Dependent Variable

The outcome of interest was "time to death", measured as the number of days from the date on which the change in status was reported in the resident's progress notes to the date of death.

7.3.4 Independent Variables

The independent variables of interest were the signs and symptoms ('signals') reported at the same time as the health care provider reported the change in the resident's status. A directed content analysis, consisting of three steps, was performed to convert the free text description of the change in status progress note into quantitative data points (Hsieh & Shannon, 2005). First, authors (JMK and HK) developed preliminary codes for these signals based on *a priori* knowledge, existing literature, and a brief scan of the contents of the documented texts. JMK and SL then independently coded the progress note extracts using the preliminary list of signals. Once all resident extracts had been independently coded, JMK and SL compared their codes for each resident, discussed discrepancies, and refined the definition of each code until a consensus was reached for all resident files. HK reviewed the final list of codes and definitions for appropriateness. The final list of codes included seven nutrition-related and 18 non-nutrition signals (Appendix D, Table D.2).

7.3.5 Analysis

Chi-square, Fisher's exact, t-tests, and Mann-Whitney U tests were used to compare the demographic (i.e., age, sex, length of admission, hospital death) and functional characteristics (i.e., MDS 2.0 scores, diagnoses, history of swallowing problems, swallowing difficulty reported in the final month of life) between included and excluded individuals. Statistical significance was inferred where *p*-values were less than 0.05. Descriptive statistics of the change-in-status event, including the frequency of each signal and other contextual details, were provided. The distribution of the time to death following the change in status in this sample was highly right-skewed, so in addition to mean time to death, survival time was described using quartile estimates (i.e., the number of days at which 25%, 50%, and 75% of residents were expected to have died) and 95% confidence intervals using a log-log transformation. Formalized end-of-life orders were also described, similarly including mean number of days to death and quartile estimates of survival time.

Bivariate tests of equality (i.e., log-rank test) compared the homogeneity of survival curves (i.e., Kaplan-Meier estimate) for each signal (Goel et al., 2010). Cox proportional hazards regression analysis with backwards elimination removing all variables that had a p-value >0.05 identified which signals were associated with time to death. Model fit statistics (-2LogL, AIC, and BIC) were compared during model-building to identify the final model; lower values for each of these three scores indicated better model fit, so were preferred.

7.4 Results

The study sample consisted of LTC decedents who had a documented change in status that suggested end-of-life decline (n = 76) while those without a documented change in status were excluded (n = 9) (Table 7.1). Participants had a mean age of 88 ± 7 years at the time of death, were 60% female, had been admitted to the LTC home for a median of 37 [Q1, Q3: 24, 59] months. A high proportion of participants (83%) had moderate/severe cognitive impairment. Nearly half (49%) of participants had a history of leaving food uneaten and more than one fifth (22%) had a history of swallowing problems according to the MDS 2.0 assessment completed approximately 6 months prior to death. The sample had a high level of complex comorbidities, including cancer (20%), diabetes (25%), hypothyroid disorder (22%), cardiovascular disorders (78%), arthritis (37%), and stroke (25%). Multimorbidity was highly prevalent in this sample, with 88.2% (n=67) participants having three or more diagnoses. In the final month of life, 59% of residents exhibited signs of swallowing difficulty as reported by LTC care providers in the progress notes. The sample demographics were not significantly different from the excluded group, except for the proportion who died in the hospital (9% of included vs. 56% of excluded; $p<0.001$), proportion who exhibited responsive behaviors (58% of included vs. 22% of excluded; $p=0.04$), and report of swallowing difficulty in the final month of life (59% included vs. 11% excluded; p=0.01).

The time to death following the documented change in status was highly variable, ranging from zero days to over two years, and skewed 53% of conversations documented within the last month of life (Table 7.2). The change in status was documented within the context of a planned care conference for nearly 20% (n = 15) of participants. These participants had a longer time to death (median = 84 days) as compared to individuals for whom the change in status was noted based on routine care (median = 21 days), though this difference was not statistically significant ($p = 0.25$). Nursing staff (41%) were the most common group to first document the change in status of residents. The dietitian first flagged a change in status in 7% of participants. In 15% of cases, family members initiated the end-of-life discussions by raising concerns about the health of the resident or opting out of life-prolonging treatments such as dialysis. A formalized palliative/end-of-life order was initiated for 80% of participants, the majority of which occurred in the last two weeks of life.

Table 7.1

Description of the sample characteristics and comparison between residents who met the inclusion criteria requiring documentation of an end-of-life discussion prior to death (n=76) compared to excluded residents (n=9) who did not have an end-of-life discussion documented prior to death

	Included (n=76)	**Excluded (n=9)**	***p*-value** [a]
Resident Demographics			
Age at death, years, Mean±SD	87.9 ± 7.3	84.8 ± 8.2	0.23
Sex, female, % (n)	60.5 (46)	44.4 (4)	0.35
Length of admission, months, Median [Q1, Q3]	37 [24, 59]	37 [23, 45]	0.40
Died in hospital, % (n)	**9.2 (7)**	**55.6 (5)**	**0.0002**
MDS 2.0 Scores, % (n)			
Leaves >25% of food uneaten at most meals	48.7 (37)	44.4 (4)	0.81
Cognitive impairment, moderate/severe (CPS≥3)	82.9 (63)	66.7 (6)	0.24
Health Instability, moderate/high (CHESS≥3)	6.6 (5)	0.0 (0)	0.43
Significant loss of independence (ADL≥3)	94.7 (72)	100.0 (9)	0.48
Depression risk (DRS≥3)	50.0 (38)	22.2 (2)	0.11
Exhibits responsive behaviors (ABS≥1)	**57.9 (44)**	**22.2 (2)**	**0.04**
Pain, yes (Pain Scale≥1)	21.0 (16)	33.3 (3)	0.40
Swallowing difficulties			
History of swallowing problems, 6 months prior to death	22.4 (17)	11.1 (1)	0.68
Swallowing difficulty, final month of life	**59.2 (21)**	**11.1 (1)**	**0.01**
Diagnoses			
Cancer	19.7 (15)	0 (0)	0.16
Diabetes	25.0 (19)	22.2 (2)	1.00
Hypothyroid	22.4 (17)	33.3 (3)	0.43
Cardiovascular disorders	77.6 (59)	77.8 (7)	1.00
Congestive heart failure	5.3 (4)	22.2 (2)	0.12
Arthritis	36.8 (28)	44.4 (4)	0.72
Stroke	25.0 (19)	11.1 (1)	0.68
Parkinson’s	9.2 (7)	11.1 (1)	1.00
Chronic obstructive pulmonary disorder	15.8 (12)	22.2 (2)	0.64
Renal condition	5.3 (4)	11.1 (1)	0.44

Note. Long-term care (LTC) residents included in the final sample had a change in status that led to an end-of-life discussion documented in their progress notes (n=76); excluded individuals were those who did not have a significant change in status noted prior to death (n=9).

Abbreviations: ABS, Aggressive Behavior Scale; ADL, Activities of Daily Living Self Performance Hierarchy Scale; CHESS, Changes in Health, End Stage Disease and Signs and Symptoms Scale; CPS, Cognitive Performance Scale; DRS, Depression Risk Scale; MDS 2.0, Resident Assessment Instrument Minimum Data Set 2.0; Q1, 1st quartile; Q3, 3rd quartile; SD, standard deviation.

[a] Bivariate comparison between included and excluded within each sample; chi-square test for categorical variables, t-test for normally distributed continuous variables (i.e., age), and Mann-Whitney for non-parametric variables (i.e., length of admission).

Bolded values indicate statistically significant difference, $p<0.05$.

Table 7.2

Description of the first reporting of a possible end-of-life decline (n=76)

	Descriptive
Time to death after first reporting of decline	
Number of days	
Mean ± SD	88.8 ± 143.3
Range	0 – 871
Quartile estimates [95% CI] [a]	
25%	6 [2, 13]
50%	27.5 [14, 71]
75%	105.5 [83, 163]
Distribution, % (n)	
0-14 days	39.5 (30)
15-30 days	13.2 (10)
31-90 days	19.7 (15)
91-180 days	13.2 (10)
180-365 days	9.2 (7)
>365 days	5.3 (4)
Factors surrounding first reporting of decline	
Reported at planned care conference, % (n)	19.7 (15)
Reported following recent hospitalization, % (n)	13.2 (10)
Role that identified decline, % (n)	
Physician/Nurse practitioner	29.0 (22)
Nursing team	40.8 (31)
Family member	14.5 (11)
Dietitian	6.6 (5)
Hospital team	6.6 (5)
Resident	1.3 (1)
Other	1.3 (1)
Formalized end-of-life orders	
Initiated following the change in status, yes, % (n)	80.3 (61)
Time to death after formal order, days, Mean ± SD	36.6 ± 97.2
Quartile estimates, days [95% CI] [a]	
25%	2 [1, 2]
50%	4 [2, 6]
75%	13 [7, 31]

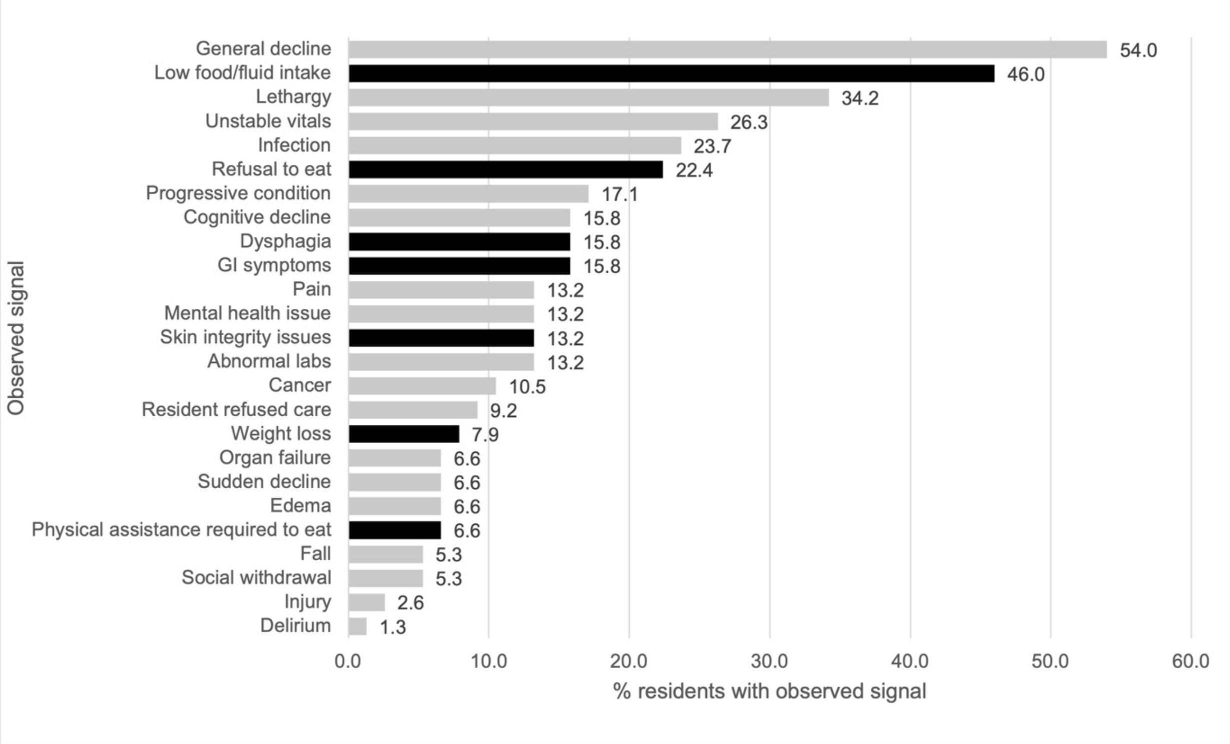
[a] Quartile estimates indicate number of days at which 25%, 50%, and 75% of residents are expected to have died. 95% confidence intervals were calculated by log-log transformation.

Twenty-five signals of end-of-life decline were coded from the contextual details of the documented change in status. The most common nutrition-related signal supporting the consideration of end-of-life decline was low food/fluid intake (46%) (Figure 7.1). Swallowing difficulty was cited as a reason for suspecting end-of-life decline for 12 individuals (13% of the sample). Of these 12 individuals, 50% had an indication of swallowing problems at least 6 months prior to death.

Furthermore, these 12 individuals accounted for slightly more than one quarter (27%) of the 45 residents who had swallowing difficulty reported in their progress notes in the final month of life. The most common non-nutrition signal was general (i.e., non-specific) decline in health (54%) (Figure 7.1). Three quarters of residents had at least one nutrition-related challenge cited, and multiple signs/symptoms were commonly cited to signal a change in status (Appendix D, Table D.3). Bivariate survival curves were significantly different for cognitive decline, cancer, and delirium although it must be noted that only one individual was flagged with delirium as an indicator of end-of-life decline in this sample (Table 7.3).

Figure 7.1

Frequency of signs and symptoms signalling change in status leading to end-of-life decline among deceased long-term care (LTC) residents (n=76).



Note. Black bars represent nutrition-related signals and grey bars represent non-nutrition related signals.

Table 7.3

Bivariate comparison of survival when each signal was observed versus not observed (n=76)

Signal	Signal observed		Signal not observed		*Median difference, days*	p-value
	n	**Median survival (95% CI)**	**n**	**Median survival (95% CI)**		
Nutrition-related signs						
Low food/fluid intake	35	21 [7, 71]	41	31 [14, 86]	*-10*	0.94
Swallowing difficulty	12	6.5 [1, 19]	64	37 [21, 84]	*-30.5*	0.15
Resident refusal to eat	17	31 [1, 86]	59	25 [13, 83]	*6*	0.51
GI symptoms	12	5.5 [1, 296]	64	33.5 [19, 83]	*-28*	0.80
Poor wound healing	10	33.5 [5, 116]	66	24 [13, 71]	*9.5*	0.78
Physical assistance with eating required	5	65 [6, --]	71	25 [13, 72]	*40*	0.84
Weight loss	6	94 [6, --]	70	24 [13, 55]	*70*	0.28
Non-nutrition signs						
Abnormal labs	10	53.5 [1, 88]	66	27.5 [13, 65]	*26*	0.33
Edema	5	89 [--, --]	71	26 [14, 65]	*63*	0.92
Lethargy	26	25.5 [6, 83]	50	27.5 [13, 84]	*-2*	0.89
General decline	41	26 [9, 65]	35	31 [13, 88]	*-5*	0.51
Cognitive decline	**12**	**125 [14, 322]**	**64**	**21 [9, 36]**	***104***	**0.02**
Delirium	**1**	**1 [--, --]**	**75**	**29 [14, 71]**	***-28***	**0.002**
Mental health issue	10	23 [1, 88]	66	30.5 [13, 72]	*-7.5*	0.66
Pain	10	32.5 [1, 84]	66	25.5 [14, 72]	*7*	0.26
Social withdrawal	4	38 [6, --]	72	27.5 [14, 71]	*10.5*	0.92
Resident refusal of treatment	7	21 [1, 322]	69	29 [13, 71]	*-8*	0.26
Infection	18	22 [5, 65]	58	33 [14, 84]	*-11*	0.25
Fall	4	13 [3, --]	72	29.5 [14, 71]	*-16.5*	0.38
Injury	2	43.5 [3, --]	74	27.5 [14, 71]	*16*	0.51
Unstable vitals	20	10.5 [2, 89]	56	33 [19, 83]	*-22.5*	0.57
Cancer	**8**	**92 [8, 409]**	**68**	**24 [13, 65]**	***68***	**0.05**
Progressive condition	13	88 [8, 152]	63	21 [13, 36]	*67*	0.51
Organ failure	5	88 [5, --]	71	25 [13, 65]	*63*	0.54
Sudden decline	5	1 [0, --]	71	29 [14, 71]	*-28*	0.73

Note. Bivariate comparison of homogeneity of survival curves when each signal was observed versus not observed was assessed by log-rank test of equality of the Kaplan-Meier survival estimates using the chi-square statistic. Where confidence intervals are represented by a double dash (--), estimates were not available due to low frequency.
Bolded values indicate statistically significant difference, $p<0.05$.

The final Cox proportional hazards model with removal of nonsignificant signals is provided in Table 7.4Table 7.4. Only one nutrition-related signal was retained; swallowing difficulty documented at the time of decline was a significant predictor of time to death. Individuals for whom swallowing difficulty was cited as a reason for considering end-of-life decline were more likely to die sooner (hazard ratio [HR] = 2.99, 95% confidence interval [CI] = 1.41, 6.33) compared to those for whom swallowing difficulty was not cited, when adjusting for other significant signals. Cognitive decline and new or existing cancer diagnosis, when cited as reasons for the change in status, were associated with a longer time to death (HR < 1). Delirium was associated with shorter time to death; the model fit (-2LogL and AIC) was improved when delirium was included in the model despite only having one participant with this signal. The total number of nutrition-related signals and total signals overall were tested in the model, but neither was significantly associated with time to death.

Table 7.4

Cox proportional hazards regression analysis to test the associations between observed signals and mortality (n=76)

Observed signal	**Hazard Ratio (95% CI)**	***p*-value**
Nutrition-related signs		
Swallowing difficulty	2.99 (1.41, 6.33)	0.004
Non-nutrition signs		
Cognitive decline	0.40 (0.20, 0.77)	0.006
Delirium	13.23 (1.57, 111.69)	0.02
Cancer	0.18 (0.07, 0.48)	0.0006

Notes: Final model was identified using backwards elimination; all values in the final model are statistically significant, $p<0.05$. Model fit statistics (-2 Log L, AIC, and BIC) were also assessed such that lower values were preferred.

7.5 Discussion

This retrospective study of deceased LTC resident charts identified both nutrition- and non-nutrition-related signs and symptoms reported by care providers to indicate potential end-of-life decline. The identified signals are consistent with other qualitative studies (Åvik Persson et al., 2018; Bern-Klug, 2006) and make a novel contribution by quantifying the prevalence and time to death of these signals in a random sample of LTC participants from a home chain in Ontario, Canada. These findings contribute to a better understanding of the changes in residents' health and routines that indicate to care providers in current practice that a transition in goals of care may be necessary. The study stimulates discussion around how these signals could serve as targets for initiating comfort-focused end-of-life conversations.

The findings of this study suggest that prognostication of LTC residents is difficult and a change in approach for managing end-of-life decline that does not rely on anticipated timelines is needed. Typical of the broader LTC population, a high proportion of the participants in this sample had significant cognitive impairment, loss of independence, and multiple diagnoses representing a highly frail population with complex health and functional needs. Given the complexity of this population, it is not surprising that a variety of signals were noted by care providers to indicate that residents were nearing death, but that very few of these signals were associated with time to death. General decline was the most often cited reason for indicating end-of-life decline, consistent with a previous study that highlighted how care providers in LTC had difficulty specifying early signs of decline but described it as residents "going into a bubble", citing subtle changes in daily routines as non-specific indicators that residents were moving toward the end of life (Åvik Persson et al., 2018). Low food/fluid intake was also noted for nearly 50% of residents as a signal of end-of-life decline indicating that care providers acknowledge decreased intake as a sign of decline, consistent with other studies (Åvik Persson et al., 2018; Brandt, 2005). Realistically, a number of factors including residents' signs and symptoms and care providers' knowledge and attitudes affect the decision to initiate end-of-life care conversations and are highly context dependent (Åvik Persson et al., 2018; J. Lee et al., 2013). The signs and symptoms identified in this study may be used as markers to indicate the need for goals of care conversations within the specific context of individual residents.

Regarding timing to death, though some signals were identified to be associated with shorter or longer time to death, findings indicate that these factors are also context dependent. The longer time between the initial documentation of potential end-of-life decline and death when cancer and cognitive impairment were noted is potentially explained by the known association between these chronic and life-limiting conditions and mortality (Jørgensen et al., 2012; Sachs et al., 2011), which may have increased the acceptability of earlier initiation of end-of-life care conversations. However, only 16% of the sample had accelerated cognitive decline documented as a signal of end-of-life decline, whereas 83% presented with moderate or severe cognitive impairment at 6 months prior to death indicating that changes in cognition are not consistently used as an indicator of end-of-life decline for LTC residents. Likewise, cancer was identified as a signal of end-of-life decline in 10% of cases but 20% had a diagnosis of cancer in the sample. It is more likely that complications, concerns, or provider-specific perspectives associated with these conditions prompted earlier end-of-life conversations. Alternatively, swallowing difficulty and delirium, when noted as a signal of end-of-life decline, were associated with a shorter time to death. As highlighted previously, adversities such as dysphagia and delirium are complications of multimorbidity and resulting frailty (Yang et al., 2022; Yarnall et al., 2017), and are both independently associated with mortality (Komici et al., 2022; Wirth et al., 2018). As such, both of these conditions may be rightly viewed as late signals of end-of-life decline in LTC residents because they are indicators of severe cognitive and physical dysregulation or impairment in an already frail and vulnerable population. However, this interpretation is limited in the current study because of a lack of context. For example, whereas 16% of residents were noted to have swallowing difficulty as a signal of end-of-life decline, nearly 60% of the total sample displayed signs of impaired swallowing in the last month of life. It could be that some residents had sudden onset of swallowing difficulty or their symptoms were more severe when noted to indicate end-of-life decline. Further context is needed to determine how care providers attribute various signals as indicators of end-of-life decline among LTC residents.

The initial conversations prompted by change of status of LTC residents most often occurred within three months of death with timing skewed towards the date of death. Identification of the change of status relied on multiple signs and symptoms and was context-dependent, reinforcing previously noted challenges with identifying the appropriate timing of comfort-focused care initiation in response to end-of-life decline among older adults with complex needs (Hill et al., 2018; Murray et al., 2005). Regular assessments of resident's health and changing needs with the support of established prognostic tools are important for adjusting goals of care and anticipating end-of-life decline, as evidenced by the longer (albeit, statistically non-significant) time to death found when the change in status was noted in the context of a planned care conference. However, the majority (80%) of documented conversations arose from concerns based on daily observations (i.e., between scheduled assessments), pointing to the importance of recognizing when resident changes may be indicative of end-of-life decline, rooted in continuity of care and a familiarity with their usual habits and routines (Gonella et al., 2021).

Mealtimes present multiple daily opportunities for observing residents' habits around eating and social participation and offer an accessible focal point for introducing comfort-focused care conversations when decline is observed. Indeed, eating challenges were a common consideration in identifying significant change in status of LTC residents, several of which (e.g., low food/fluid intake, refusal to eat, swallowing difficulty, weight loss) are commonly associated with mortality (Åvik Persson et al., 2018; Brandt, 2005; Fringer et al., 2020; S. L. Mitchell et al., 2009; Wirth et al., 2018). However, with the exception of swallowing difficulty, none were associated with a specific point in the end-of-life trajectory from the perspective of care providers. Non-nutritional signs were also identified. Although some of these were medical considerations (e.g., unstable vitals, abnormal labs, specific diagnoses), others such as general decline, lethargy, mental health issues (e.g., anxiety, restlessness), and social withdrawal are readily observable through interactions in the dining room and other points of contact with residents over the course of the day. Observed changes to residents' eating patterns and other social routines may prompt the introduction of comfort-focused care conversations, regardless of timing to death, and are recommended as novel targets for future exploration.

Most of the identified signs and symptoms were not significantly associated with timing to death. Instead, they were identified by care providers across the trajectory of decline, lending to the interpretation of dying in LTC as a process of many and sometimes fluctuating signs and symptoms that can span several months preceding death (Åvik Persson et al., 2018; Murray et al., 2005). This finding may allow some emphasis to shift away from "early" identification of end-of-life decline and alleviate concerns around "unclear prognoses" because variable trajectories allow for flexibility in initiating comfort-focused conversations over the course of complex and life-limiting conditions. Alternatively, the suggested goal may be to have "timely" conversations geared towards maintaining quality of life, where the timing is patient-centered, opportune, context-dependent, and reflective of the holistic needs of the resident and their substitute decision makers as needs arise (Dhedhi et al., 2014). The factors identified by care providers in this study may be considered as potential triggers for timely initiation of comfort-focused end-of-life conversations, regardless of the suspected prognosis. Pursuit of such opportunities for questioning possible end-of-life decline is worthwhile because, if not addressed, can lead to missed opportunities for having end-of-life conversations (Towsley et al., 2015) and for initiating comfort-focused care (Gonella et al., 2021). Indeed, conversations about the end of life with and between residents and care providers in nursing homes have been shown to improve comfort-focused care (Gonella et al., 2019). Care providers in the LTC setting are encouraged to reflect on when and if certain triggers (e.g., low food intake, weight loss, general health instability or decline) might be opportune focal points for timely discussions on comfort-focused goals of care.

7.5.1 Limitations

Our study was strengthened by a rigorous and in-depth data collection on a randomly selected sample of deceased long-term care residents. However, accessing all of the homes from one chain limited the generalizability of the findings since end-of-life care conversations are likely driven at least in part by home culture, educational resources, and specific initiatives that may have been common to all of the homes. Our sample size was relatively small, so the statistical power for identifying true associations was limited. We decided not to test interacting effects between signals (e.g., weight loss and cancer) given these sample size limitations and lack of clear hypotheses for specific interactions, but, by not doing so, may have missed significant and clinically meaningful findings.

The original data extraction from the resident charts was performed by a single rater. While there were intra-rater reliability checks to ensure consistency over time and detailed definitions of each item were recorded for transparency, the data collection may have been influenced by personal biases of the data extractor. Furthermore, we may have missed important contextual details that were not documented in the residents' progress notes, such as informal conversations and personal communications between family and team members. Relevant information may not have been recorded in the progress notes because of problems with communication and information flow between LTC team members (Banerjee et al., 2015; Beynon et al., 2022; Farrell et al., 2022; Madden et al., 2017) and so may have contributed to incomplete or inaccurate data for this study. Since this study was not the main focus of the larger study that drove the data extraction, we did not collect data on formal measures of end-of-life decline, such as the palliative performance scale (PPS) or CHESS in relation to the timing of these end-of-life conversations so were not able to assess the role of these prognostic indicators, despite their undoubted importance in end-of-life decision making (Hirdes et al., 2003; N. Williams et al., 2022).

Directed content analysis is useful in condensing qualitative data (e.g., free text from resident charts) into discrete units for quantitative analysis. However, coding based on existing literature introduces bias towards confirming previously identified signs and symptoms where a new contextual interpretation may be warranted (Hsieh & Shannon, 2005). Also, creating operational definitions for some of the codes was challenging because of the wide variety of documented information observed in the resident charts and loss of nuance with condensing the text into discrete units, which could potentially have led to misclassification (Hsieh & Shannon, 2005).

7.6 Conclusion

Given the high rate of mortality among LTC residents, initiating end-of-life discussions and transitioning to comfort-focused care goals are important aspects of the care experience for residents and their family caregivers. However, the study findings reveal that the timing of these conversations is variable, often late in the end-of-life trajectory, and context dependent from the perspective of care providers. Our novel study findings identify the reasons given by care providers for suspecting end-of-life decline in current practice and draw attention to these signs and symptoms as focal points for revisiting goals of care. Awareness of such signs and symptoms, supported by educational initiatives to conduct more timely end-of-life conversations have the potential to improve the quality of life and care outcomes for both residents and care providers (Gonella et al., 2019, 2021). The authors contend that recognition of changes in residents' eating habits and routines highlighted in this study in particular (e.g., decreased food intake, refusal to eat) that are already observed and associated with end-of-life from the care provider perspective can be transformed into opportunities for introducing timely palliative-minded goals of care regardless of prognosis. Future work should explore ways to systematically incorporate comfort care conversations in response to these changes, facilitated by resources such as conversation guides, to support and maintain quality of life in the final months of life of LTC residents and the people who care for them.

Chapter 8

Study 4: Factors associated with dietitian referrals to support LTC residents advancing towards the end of life

8.1 Overview

Background: Dietitians are central members of the multidisciplinary long-term care (LTC) healthcare team. The aim of this study was to understand factors leading to dietitian involvement near the end of life in LTC.

Methods: Retrospective chart reviews for 164 deceased residents (mean age=88.3±7.3; 61% female) in 18 LTC homes in Ontario, Canada identified dietitian referrals and documented eating challenges recorded over 2-week periods at four time points (i.e., 6 months, 3 months, 1 month, and 2 weeks) prior to death. Nutrition care plans at the beginning of these time points were also noted. Logistic mixed effects regression models identified time-varying predictors of dietitian referrals. Bivariate tests identified associations between nutrition orders and dietitian referrals that occurred in the last month of life.

Results: Nearly three quarters (73%) of participants had at least one dietitian referral across the four observations. Referrals increased significantly with proximity to death, but this association was confounded by the corresponding increase in number of eating challenges (OR=1.42, 95% CI=1.30, 1.55). Comfort-focused nutrition care orders were significantly more common when a dietitian was referred (25%) compared to when a dietitian was not referred (12%) in the final month of life (p=0.04).

Conclusions: Our findings suggest that dietitians are involved in end of life and comfort-focused nutrition care initiatives. This presents a significant opportunity for dietitians to upskill and champion palliative approaches to nutrition care within the multidisciplinary LTC team.

8.2 Introduction

Dietitians play an important role in supporting and managing malnutrition among older adults (Fleurke et al., 2020) and particularly in long-term care (LTC) homes where as many as half of residents are at risk of malnutrition or malnourished (Keller et al., 2019). LTC residents are at high risk of malnutrition, and specifically undernutrition, because of many factors that challenge food intake, digestion, and metabolism (Dent et al., 2023; Martone et al., 2013; Pilgrim et al., 2015). These include underlying diagnoses (e.g., dementia, cancer, stroke) and associated challenges, such as cognitive or physical impairments, mental health conditions, loss of interest in life, and low appetite or lack of desire to eat (Fávaro-Moreira et al., 2016). Management of such complex and severe challenges is especially important given the negative effect of poor nutritional status on the quality of life of older adults (Rasheed & Woods, 2013), and the potential added detriment to psychosocial well-being of residents and their care partners because of the deeper symbolic and cultural meaning of food and mealtimes (Dodd, 2017; M. Douglas & Gross, 1981; Wallin et al., 2015). Dietitians are well-positioned to develop individualized nutrition care plans that support the quality of life of LTC residents with specific and complex nutritional needs (Dodd, 2017; Dorner & Friedrich, 2018; Pinto et al., 2016).

LTC homes are increasingly recognized as places for palliative (i.e., comfort-focused) approaches to care that emphasize quality of life given the vulnerability and high prevalence of life-limiting conditions found among residents (Cloutier et al., 2021; Eisenmann et al., 2020; Kaasalainen et al., 2016). Regardless of specific diagnoses, older adults who are malnourished are often frail and many experience complex challenges (e.g., sarcopenia, functional decline, loss of appetite) that directly or indirectly contribute to end-of-life decline and increased risk of mortality (Martone et al., 2013; Söderström et al., 2017). In a study of end-of-life trajectory of nursing home residents living with dementia, eating problems including weight loss, swallowing/chewing problems, suspected dehydration, refusal to eat or drink, and persistently low intake, were observed in 86% of residents and significantly predicted six-month mortality (S. L. Mitchell et al., 2009). It follows, then, that dietitians' expertise can make a valuable contribution to palliative and end-of-life care experiences for LTC residents and their care providers (Pinto et al., 2016).

This study is part of a larger study intended to understand the nutrition care experience for LTC residents in the last six months of life, which has already established that eating challenges increase in severity and complexity with proximity to death (Chapter 5). Dietitian involvement for new or worsening eating challenges among residents is often contingent on referrals from a multidisciplinary team of care providers, most often nursing staff (Fleurke et al., 2020; Keller et al., 2021). However, the circumstances around such referrals (e.g., frequency, reasons for referral, resulting interventions) as they relate to end-of-life decline of residents in current practice is unclear. The first aim of this investigation is to describe the prevalence of dietitian referrals over the six months prior to death, and the specific resident-level and time-dependent factors, including eating challenges, that are associated with dietitian referrals in this sample. We also aim to assess differences in frequency of specific nutrition interventions (e.g., modified texture diets, comfort nutrition orders) used to support residents when dietitians are referred compared to when they are not referred within the final month of life. A better understanding of the frequency of formalized referrals for LTC residents progressing towards death, the associated resident factors, and resulting interventions, could help to inform nursing practices around referrals and skill development for dietitians to support residents in their final months of life.

8.3 Methods

8.3.1 Sample Selection

At the outset of the larger study, a sample size calculation was performed, which ultimately required accessing two sampling frames to reach the desired number of participants. Given the generally descriptive nature of the larger study with unspecified outcomes and therefore unknown outcome prevalence, the sample size calculation was based on a conservative prevalence estimate of 50 percent. For an outcome prevalence of 50% with a 7.5% margin of error and 95% confidence, a sample size of 171 was required; 97 individuals were required for a 10% margin of error (Dhand & Khatkar, 2014). These estimates guided the final sample size.

The initial sample for this study was obtained from the “Better tArgeting, Better outcomes for frail ELderly patients” (BABEL; ClinicalTrials.gov Identifier: NCT03649191) study (Garland et al., 2022), which was a prospective advance care planning intervention study; the intervention did not specify dietitian involvement in the advance care planning process. A convenience sample of nine LTC homes from Ontario, in addition to 20 homes from two other Canadian provinces, participated in the study. Only the Ontario homes could be included in this current study because of restrictions on sharing data for a secondary study across provincial borders. Four of these homes were intervention homes, where recruited participants received the BABEL intervention (i.e., ~60-minute structured advance care planning discussion with resident and substitute decision makers). Participants from the five control homes underwent their usual advance care planning processes. Eligibility for inclusion in the BABEL study required that residents were over 65 years of age and at high risk of death in the next 6-12 months as indicated by: Changes in Health, End Stage disease and Symptoms and Signs (CHESS) score ≥3 (i.e., moderate/severe health instability), current cancer, congestive heart failure, or leaving >25% of their food uneaten. Informed consent by the resident or a substitute decision maker were also required. A total of 303 residents in Ontario were recruited into the BABEL study from September 2018 to August 2020.

Data collection for the current study occurred concurrently with the BABEL recruitment; BABEL participants were enrolled into the current study on a rolling basis upon death. The first deaths were recorded in December 2018; participants who died after March 11, 2020 were excluded given the drastic impact of the COVID-19 pandemic on the LTC sector. A total of 86 (28.4%) BABEL participants died within these time limits and so were eligible for inclusion in the current study.

Partway through the process it became clear that the BABEL sample would not be sufficient to meet the sample size requirements, so a second sampling frame, a for-profit chain of LTC homes located across southern Ontario, was accessed. Nine of a total 19 homes from the chain were randomly selected for participant recruitment to mirror the BABEL sample. We identified all decedents from the nine randomly selected homes with a death date between December 1, 2018 and March 11, 2020; residents who were admitted to the home for less than 6 months were subsequently excluded to ensure adequate documentation of health and care history. A total of 432 decedents were eligible for inclusion; 10 individuals were randomly selected from each home using a random number generator for a sample of 90 participants from the home chain.

For consistency across the two sampling frames, residents were eligible for inclusion in this analysis if they were admitted to the LTC home for at least six months and were over the age of 65 years at the time of death. Of 86 BABEL participants, 79 (91.9%) lived in the home for at least six months prior to death. Of 90 home chain participants, 85 (94.4%) were over the age of 65. The final sample included 164 individuals, which was adequate to describe general patterns of dietitian referrals at end-of-life based on our earlier sample size calculations.

8.3.2 Ethics

Ethics approval for the study was obtained from the Office of Research Ethics at the University of Waterloo as an amendment to the BABEL study (ORE#31782) and a separate protocol for the home chain sample (ORE#40789). The study protocol was subjected to additional approval processes according to home/chain-specific institutional policies.

8.3.3 Data Collection

Data were collected through retrospective chart reviews, which were accessed remotely on a virtual private network (VPN), using medical record review methodology and manual extraction of data (Allison et al., 2000; Gearing et al., 2006). Extracted data were recorded electronically using REDCap Software, a secure web platform for building and managing online databases (Harris et al., 2009, 2019). The process for data collection was rigorously developed by the researchers (Chapter 4). All data were collected by JMK excepting the BABEL demographic and descriptive data (i.e., health/functional assessment), which were collected by the BABEL study coordinator. Consistency of data collection was checked through duplicate extraction by JMK for five randomly selected charts after every 50 new charts were reviewed. Points of disagreement were used to refine the definitions in the data extraction form.

8.3.3.1 Resident Characteristics

Resident characteristics, health, and functional status were obtained from the resident admission forms and the standardized Resident Assessment Instrument Minimum Data Set 2.0 (MDS 2.0), reported quarterly by trained staff in LTC homes across Ontario (CIHI, 2021a; Carpenter & Hirdes, 2013). Age at the time of death, sex, and length of admission were obtained from the admission forms. The MDS 2.0 assessment recorded at the time of recruitment for BABEL participants or approximately six months prior to death for home chain participants was extracted. Body mass index (BMI) was calculated from the weight record documented on the date closest to six months prior to death and the height recorded in the MDS 2.0 assessment.

Other extracted MDS 2.0 items included: leaving >25% of food uneaten at most meals (yes vs. no); moderate/severe cognitive impairment (Cognitive Performance Scale [CPS] ≥3 vs. <3)(Morris et al., 1994); moderate/high health instability (CHESS ≥3 vs. <3)(Hirdes et al., 2003); extensive/total dependence on Activities of Daily Living Self Performance Hierarchy Scale (ADL ≥3 vs. <3)(Morris et al., 1999); probable depression (Depression Risk Scale [DRS] ≥3 vs. <3)(Burrows et al., 2000); any responsive behaviours (Aggressive Behaviour Scale [ABS] ≥1 vs. 0)(Perlman & Hirdes, 2008); and daily vs. less than daily pain (Fries et al., 2001). Diagnoses were also extracted from the MDS 2.0 assessment.

8.3.3.2 Nutrition Care Information

Relevant information surrounding nutrition care occurring in the last 6 months of life, including dietitian referrals, eating challenges, and nutrition care interventions, were of interest for extraction from the resident charts. Given the breadth of information documented in LTC resident charts, it was necessary to reduce the amount of data collected by focusing on four time points (i.e., 6 months, 3 months, 1 month, and 2 weeks prior to death); this also allowed us to capture longitudinal changes with proximity to death. The formalized care plans in place on the date of these four time points were documented and changes or modifications to restorative nutrition care interventions (e.g., physical assistance, oral nutritional supplements [ONS]) from the previous time point were noted. Comfort-focused nutrition care orders, which were defined as any order that specified that the resident's comfort was the primary focus of food and fluid provision, were also extracted. Dietitian referrals initiated by care staff and reported eating challenges (e.g., dysphagia, lethargy at mealtimes, decreased food intake) were extracted from the progress notes entered in the two weeks following each time point. The progress notes included all charted notes such as free text, orders, referrals, and forms reported by nursing staff, physicians, dietitians, or other allied health professionals.

Monthly weight records were extracted for each of the six months leading up to the death of the resident. Significant weight loss (i.e., ≥5%) since the previous month was calculated for the 3-month, 1-month, and 2-week time points, but could not be calculated for the 6-month time point because we did not have the prior weight record. Since the weight measurements were collected by LTC staff, the timing of the weight records did not necessarily align with our time points, so these measures were approximate. For example, the weight loss calculation for the 2-week time point was determined from the last weight recorded prior to death, and the 1-month was based on the second last weight record.

8.3.4 Data Analysis

8.3.4.1 Outcome of Interest

The outcome of interest in this study was dietitian referrals. Occurrence of at least one new referral within the two-week observation period at each time point was noted. A "new" referral included the documented referral by care staff and the first response by the dietitian, regardless of whether the resident had been referred for the same issue previously. The referral did not have to be completed (i.e., initiated and first dietitian follow-up) within the two-week observation, but either initiation or follow-up had to occur within the observation period to be counted. We did not count dietitian notes, such as in the case where an ongoing issue was being monitored following a previous referral or nutritional assessment. We did not account for multiple new referrals within the same observation period; the outcome variable was dichotomous (i.e., at least one dietitian referral vs. none) for each time point. In addition to the time-dependent outcome (i.e., dietitian referral at each of the four time points) we also summed the dietitian referrals across the time points as a proxy for frequency of dietitian involvement in the last six months of life, with scores ranging from 0 to 4.

8.3.4.2 Predictor Variables

The association between all resident characteristics, including demographics, MDS 2.0 scores, and diagnoses, with the frequency of dietitian referrals in the last six months of life were considered. Time-dependent predictor variables included individual eating challenges (yes/no), total number of eating challenges recorded, individual care plan interventions including comfort-focused nutrition care orders (yes/no), total number of restorative interventions added or modified at each time point, and significant weight loss of ≥5% from the previous month.

8.3.4.3 Analysis

All data analysis were performed using SAS® Studio v3.6 (Enterprise Edition; SAS Institute Inc., Cary, NC, 2017) and inferences regarding statistical significance were based on *p*-values less than 0.05. A description of resident demographics and characteristics (mean [standard deviation], median [Q1, Q3], % [frequency]) were provided. Bivariate analyses between each characteristic and the frequency of dietitian referrals across the four time points were performed using multinomial logistic regression with cumulative probit function and profile-likelihood confidence intervals. Time-dependent descriptives, including proportion of residents with a dietitian referral, mean number of days to first follow-up, eating challenges, nutrition care interventions, comfort nutrition care orders, and proportion with significant weight loss in the previous month were provided.

Mixed effects logistic regression analyses, with time point as a random effect and resident as the subject, were performed to test the associations between the time-dependent nutrition factors with dietitian referral (Li et al., 2011). Models were tested in a stepwise fashion, adding one variable at a time. Given that the number of eating challenges was significantly associated with dietitian referrals, a follow-up mixed effects logistic regression model that included all individual eating challenges of interest adjusting for time as a random effect identified which specific eating challenges were most strongly associated with dietitian referrals.

The number of nutrition-related interventions in place at the beginning of each time point was also significantly associated with dietitian referrals, but the interpretation of this association was limited because the interventions were recorded in the care plan prior to the dietitian referrals noted at each time point. As such, follow-up analyses focused on the last month of life, where dietitian referrals and care plan changes were recorded concurrently. Chi-square or Fisher's exact tests were used to compare dietitian referrals in the last month of life (i.e., noted at either the 1-month or 2-week time points; yes/no) with changes noted in the care plans within two weeks of death to assess differences in initiated/modified interventions when a dietitian referral took place to support nutrition-related challenges compared to when a dietitian referral did not take place.

8.4 Results

Of the sample of 164 deceased LTC residents, 61% were female. Mean age at death was 88 ± 8 years, and residents had a median length of admission of 33 [Q1, Q3: 19, 50.5] months (Table 8.1). According to the MDS 2.0 assessment recorded approximately six months prior to death, the sample had a high level of cognitive impairment (80%), high dependence for activities of daily living (89%), and nearly 60% left food uneaten at most meals. Nearly three quarters (73%) of the sample had at least one dietitian referral across the four time points; one third (34%) had one referral and 5% had a referral at each time point (Table 8.1). Exhibiting responsive behaviours ($\beta = 0.22$ [95% CI = 0.05-0.38]) and having a cancer diagnosis ($\beta = 0.24$ [95% CI = 0.03, 0.44]) were associated with a higher frequency of dietitian referrals (Table 8.1).

Proportion of residents with a dietitian referral increased from 25% at six months and three months prior to death, to 45% at two weeks prior to death (Table 8.2). The time to the dietitian's first follow-up from the initial referral was 3.9 ± 3.8 days on average, which did not vary significantly across the four time points. Proportion of residents with at least one reported eating challenge increased incrementally as well from 57% of residents at six months prior to death, to 95% having eating challenges within the last two weeks of life. Except for comfort nutrition care orders, which increased from approximately 4% to 19% of residents in the last two weeks of life, the number of care plan additions/modifications was consistent across the three time points leading up to death following the 6-month time point.

Table 8.1

Description of the total sample and bivariate associations with dietitian referrals (n = 164)

	Descriptive	**β (95% CI)**
Frequency of referrals across the 4 time points, % (n)		
0	27.4 (45)	--
1	34.2 (56)	--
2	23.2 (38)	--
3	10.4 (17)	--
4	4.9 (8)	--
Resident Demographics		
Sampling frame, BABEL (vs. home chain), % (n)	48.2 (79)	-0.01 (-0.17, 0.15)
Age at death, years, Mean ± SD	88.3 ± 7.5	-0.01 (-0.03, 0.01)
Sex, female, % (n)	61.0 (100)	-0.05 (-0.22, 0.11)
Length of admission, months, Median [Q1, Q3]	33 [19, 50.5]	-0.004 (-0.01, 0.0002
BMI, 6 months prior to death, Median [Q1, Q3] [a]	23.4 [21.0, 27.2]	-0.002 (-0.03, 0.03)
MDS 2.0 Scores, % (n) [b]		
Leaves >25% of food uneaten at most meals	58.5 (96)	-0.10 (-0.26, 0.07)
Cognitive impairment, moderate/severe (CPS ≥3)	79.3 (130)	0.08 (-0.12, 0.28)
Health Instability, moderate/high (CHESS≥3)	13.4 (22)	0.12 (-0.12, 0.36)
Significant loss of independence (ADL≥3)	89.0 (146)	-0.05 (-0.30, 0.21)
Depression risk (DRS≥3)	47.0 (77)	0.14 (-0.02, 0.31)
Exhibits responsive behaviours (ABS≥1)	54.9 (90)	**0.22 (0.05, 0.38)**
Pain Scale, daily	4.8 (8)	-0.10 (-0.49, 0.28)
Diagnoses, % (n)		
All-cause dementia	72.6 (119)	-0.07 (-0.25, 0.11)
Cancer	18.3 (30)	**0.24 (0.03, 0.44)**
Diabetes	24.4 (40)	0.13 (-0.06, 0.32)
Hypothyroidism	23.8 (39)	-0.10 (-0.29, 0.09)
Cardiovascular disease	79.3 (130)	0.03 (-0.17, 0.23)
Congestive heart failure	16.5 (27)	0.02 (-0.19, 0.24)
Stroke	23.8 (39)	0.05 (-0.14, 0.24)
Anxiety	14.6 (24)	0.08 (-0.14, 0.31)
Depression	32.3 (53)	0.07 (-0.10, 0.25)
Renal disorder	9.2 (15)	-0.06 (-0.35, 0.21)

Note. The bivariate association with frequency of dietitian referrals was based on multinomial logistic regression with cumulative probit function and profile-likelihood confidence intervals. Bolded values are significant, p<0.05. Positive parameter (β) estimates indicate higher likelihood of frequent dietitian referrals, whereas negative parameter estimates indicate lower likelihood.

Abbreviations: ABS, Aggressive Behaviour Scale (max. 12); ADL, Activities of Daily Living Self Performance Hierarchy Scale (max. 6); BABEL, Better Targeting, Better Outcomes for Frail Elderly Patients study; CHESS, Changes in Health, End-stage Disease and Signs and Symptoms (max. 5); CPS, Cognitive Performance Scale (max. 6); DRS, Depression Risk Scale (max. 14); MDS 2.0, InterRAI Minimum Dataset 2.0.

[a] n=160, four individuals missing data on BMI.

[b] MDS scores recorded on average 256 ±131 days (BABEL) and 206±34 days (home chain) prior to death.

Table 8.2

Description of dietitian involvement and nutrition-related factors (n=164)

	Time point				
	6 months	**3 months**	**1 month**	**2 weeks**	**Cumulative**
Dietitian referrals					
≥1 Dietitian referral, % (n)	25.0 (41)	25.0 (41)	36.0 (59)	45.1 (74)	72.6 (119)
Time to first follow up, days, mean ± SD[a]	4.3 ± 4.0	3.9 ± 4.3	4.5 ± 4.1	3.0 ± 2.8 [b]	3.9 ± 3.8 [c]
Eating challenges					
≥1 eating challenges reported, % (n)	56.7 (93)	64.0 (105)	77.4 (127)	94.5 (155)	98.8 (162)
Number of eating challenges reported, mean ± SD (range)	1.5 ± 1.9 (0-12)	1.8 ± 2.0 (0-11)	2.8 ± 2.3 (0-11)	4.5 ± 2.2 (0-10)	10.6 ± 5.4 (0-24)
Weight loss					
Weight loss of ≥5% compared to the previous month, % (n)	Data unavailable [d]	10.2 (16)	9.6 (14)	19.4 (27)	n/a
Care plans					
≥1 nutrition intervention initiated/ modified, % (n)	98.2 (161)	45.7 (75)	42.1 (69)	43.3 (71)	99.4 (163)
Number of nutrition interventions initiated/ modified, mean ± SD	3 ± 1.2	0.6 ± 0.88	0.6 ± 0.88	0.7 ± 0.92	5 ± 2.0
Comfort nutrition order initiated, % (n)	4.9 (8)	3.0 (5)	4.9 (8)	19.5 (32)	30.5 (50)

[a] Time between first referral and dietitian follow-up at each time point; some residents had more than one referral/follow-up within the two-week observation period.
[b] n=72; two individuals died before the dietitian followed up.
[c] n=213 total referrals reported.
[d] Change from previous month could not be calculated because weight data were only collected up to 6 months prior to death.

The time-varying logistic regression analysis indicated that the odds of dietitian referral were higher with proximity to death, but this association was no longer significant when also adjusting for the number of eating challenges observed (Table 8.3). The number of eating challenges was significantly associated with higher odds of dietitian referral (OR = 1.42 [95% CI = 1.30, 1.55]), an association that was relatively stable when controlling for other factors, including proximity to death, number of interventions added or modified since the previous time point, and significant weight loss in the last month.

Table 8.3

Mixed effects logistic regression models identifying time-dependent factors associated with dietitian referrals

Fixed effects	**Model 1** **OR (95% CI)**	**Model 2** **OR (95% CI)**	**Model 3** **OR (95% CI)**	**Model 4** **OR (95% CI)**	**Model 5** **OR (95% CI)**	**Model 6** **OR (95% CI)**
Time point						
2 vs 1	1.00 (0.60, 1.65)	0.86 (0.50, 1.46)	**2.27** **(1.18, 4.38)**	1.46 (0.72, 2.94)	--	--
3 vs 1	**1.69** **(1.04, 2.72)**	1.07 (0.64, 1.81)	**3.95** **(2.05, 7.61)**	1.89 (0.92, 3.89)	**1.78** **(1.08, 2.92)** [a]	1.36 (0.79, 2.33) [a]
4 vs 1	**2.47** **(1.54, 3.95)**	0.90 (0.52, 1.58)	**5.69** **(2.98, 10.87)**	1.62 (0.76, 3.43)	**2.28** **(1.38, 3.75)** [a]	1.08 (0.60, 1.96) [a]
Number of eating challenges		**1.42** **(1.30, 1.55)**		**1.40** **(1.28, 1.53)**		**1.38** **(1.25, 1.54)**
Number of new/altered nutrition interventions since previous time point			**1.42** **(1.20, 1.70)**	**1.25** **(1.03, 1.51)**		**1.45** **(1.13, 1.85)**
Weight loss, >5% previous month					1.11 (0.62, 2.01)	0.81 (0.42, 1.56)

Note. Each column represents a mixed effects logistic regression model with dietitian referral as the outcome, time point as a random effect, and resident as the subject. Models were tested in a stepwise fashion, represented by each column from left to right. Values appearing in each column are the fixed effects odds ratios (OR) and 95% confidence intervals (CI) corresponding to each variable. Model 1-4: n=656, based on complete observations for 164 residents at 4 time points; Model 5 and 6: n=442, based on weight loss data unavailable at time point 1 and missing for 50 observations across time points 2-4.

[a] Weight loss history was not available prior to the first time point, so time point 1 was excluded from these models; time point 2 was the referent category.

Bolded values are statistically significant, $p < 0.05$.

The follow-up logistic regression analysis including 17 individual eating challenges in one model identified six eating challenges that were associated with higher odds of having a dietitian referral (Table 8.4). These included: dysphagia (OR = 1.84 [95% CI = 1.09, 3.11]), decreased food intake (OR = 1.72 [95% CI = 1.04, 2.83]), dehydration (OR = 3.08 [95% CI = 1.87, 5.05]), poor appetite (OR = 1.76 [95% CI = 1.02, 3.04]), dental issues (OR = 2.12 [95% CI = 1.12, 4.03]), and pocketing food in the mouth (OR = 3.13 [95% CI = 1.50, 6.56]). Exhibiting socially unconventional behaviour, for example, eating a tablemate's food or eating meals in the middle of the night, was associated with lower odds of dietitian referral (OR = 0.36 [95% CI = 0.13, 0.95]). Focusing on the last month of life, modifications to the care plan were more likely when a dietitian referral had taken place (Table 8.5). Increase in physical assistance, new (but not altered) modified texture diet and ONS prescriptions, and comfort-focused nutrition care orders were significantly more likely when a dietitian referral was documented during this time frame compared to when no dietitian referral was documented.

Table 8.4

Eating challenges associated with dietitian referrals (n=656)

	Fully adjusted model	
	Odds ratios (95% CI)	***p-value***
Time point		
2 vs 1	0.78 (0.44, 1.36)	0.06
3 vs 1	0.89 (0.50, 1.57)	
4 vs 1	0.42 (0.21, 0.84)	
Unhealable wound	1.38 (0.88, 2.17)	0.16
Dysphagia	**1.84 (1.09, 3.11)**	**0.02**
Refusal to eat	0.95 (0.58, 1.55)	0.83
Lethargy	1.25 (0.78, 2.00)	0.36
Decreased food intake	**1.72 (1.04, 2.83)**	**0.03**
Dehydration	**3.08 (1.87, 5.05)**	**<0.0001**
Poor appetite	**1.76 (1.02, 3.04)**	**0.04**
Poor concentration	1.12 (0.52, 2.40)	0.78
Prompting to eat required	1.37 (0.61, 3.08)	0.44
Cognitive difficulties	1.08 (0.52, 2.25)	0.82
Physical difficulties	0.91 (0.38, 2.16)	0.83
Frustration	1.05 (0.57, 1.93)	0.88
Socially unconventional behaviours	**0.36 (0.13, 0.95)**	**0.04**
Dental issues	**2.12 (1.12, 4.03)**	**0.02**
Holding food in mouth	**3.13 (1.50, 6.56)**	**0.002**
Eating inedibles	0.34 (0.03, 4.15)	0.40

Note. Mixed effects logistic regression model with dietitian referral as the outcome, time point as a random effect, and resident as the subject. All eating challenges were included in one model to identify most relevant predictors of dietitian referral. Bolded values are significantly associated with dietitian referrals, $p<0.05$.

Table 8.5

Comparison of care plan changes in residents' last month of life with dietitian referral (n=164)

	Dietitian referral		
	Yes (n=97)	**No (n=67)**	***p-value***
Care plan intervention, % (n)			
Any change	**65.0 (63)**	**29.8 (20)**	**<0.001**
Physical assistance	**17.5 (17)**	**4.5 (3)**	**0.01**
Encouragement/verbal prompting	3.1 (3)	0.0 (0)	0.15
Adaptive aids	3.1 (3)	1.5 (1)	0.51
Modified texture diet (MTD)	**17.5 (17)**	**1.5 (1)**	**0.001**
Alteration to MTD	10.3 (10)	6.0 (4)	0.33
Initiation of oral nutritional supplement (ONS)	**12.4 (12)**	**1.5 (1)**	**0.01**
Alteration of ONS	13.4 (13)	7.5 (5)	0.23
Fluid protocol	4.1 (4)	0.0 (0)	0.09
Hypodermoclysis	12.4 (12)	7.5 (5)	0.31
Adjusted according to preference	2.1 (2)	4.5 (3)	0.38
Comfort nutrition care order	**24.7 (24)**	**11.9 (8)**	**0.04**

Note. Bivariate comparison of care plan changes made in the last two weeks of life when a dietitian referral was documented concurrently compared to when a referral was not documented in the last month of life of residents, based on χ^2 or Fisher's exact tests.

8.5 Discussion

This investigation identifies resident-level factors that are associated with dietitian referrals in the last six months of life among LTC residents in Ontario, Canada. Dietitian referrals increased in prevalence with proximity to death, ranging from one quarter of residents having a referral at 6 months prior to death to nearly half in the last two weeks of life. This association was driven by the increase in both total and specific (e.g., dysphagia) eating challenges experienced by residents with proximity to death, as opposed to the timing itself. Furthermore, dietitian involvement in the final month of life was associated with increased physical assistance with eating, and initiation of modified texture diets, ONS, and comfort-focused nutrition care orders. This study contributes to a better understanding of dietitian involvement as residents progress towards death and highlights the important role of dietitians in supporting palliative-minded goals of care when residents experience severe and complex eating challenges.

Dietetic practice involves the assessment and treatment of nutrition-related disorders (College of Dietitians of Ontario, 2018). Unsurprisingly, therefore, LTC nursing staff sought out dietitian expertise via referral to support residents with eating difficulties that compromised intake or suggested nutritional inadequacy. The associated eating challenges (e.g., dysphagia, poor appetite, dental issues) were varied with many potential underlying causes including specific diagnoses (e.g., cancer), physical or cognitive impairment, poor oral health, and psychological factors. Ideally, dietitians work within multidisciplinary teams to address these issues, but may need to develop additional competencies to meet the needs of residents because of a scarcity of other qualified health professions such as speech language pathologists and dentists in many LTC settings (College of Dietitians of Ontario, 2018; Keller et al., 2021; Tang et al., 2019). Considering the results of a comprehensive study of Canadian LTC residents, which estimated prevalence of dysphagia risk in nearly 60% of residents, poor oral health that likely affected food intake in almost half of residents, and poorly fitting dentures in nearly one third of residents (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017), dietitians are invaluable despite limited funding allocation for their services (Dietitians of Canada Ontario Long Term Care Action Group, 2016). Policies to improve dietitian time and involvement in the care of older adults living in LTC are needed (Dietitians of Canada Ontario Long Term Care Action Group, 2016; K. M. Smith et al., 2019).

Several of the identified eating challenges are associated with mortality (S. L. Mitchell et al., 2009), indicating that while dietitians are not referred specifically for end-of-life counselling, they are often present during the end-of-life process as a result of possessing specialist knowledge to address issues that increase in prevalence with proximity to death. This points to the important roles of dietitians in managing severe eating challenges specific to the older adult/LTC population (Pinto et al., 2016), as well as facilitating end-of-life conversations when appropriate (Dodd, 2017). Comfort nutrition care orders were more likely when the dietitian was involved in the care of the resident by referral in the final month of life. Although our data did not allow establishment of a causal association between dietitian referral and comfort nutrition orders, the positive association suggests that dietitians are involved at times when comfort-focused nutrition orders are necessary. This presents a significant opportunity for dietitians to upskill and champion palliative approaches to nutrition care within the multidisciplinary LTC team (Pinto et al., 2016; Sheffer-Hilel et al., 2022).

8.5.1 Limitations

Our study was strengthened by a robust sample of 164 residents from several LTC homes and a detailed chart review to describe the longitudinal changes in dietitian referrals with proximity to death. However, our method of acquiring this large study sample (i.e., accessing two different sampling frames) limits the conclusions that can be drawn from these findings, particularly given that the recruitment methods were different (e.g.., BABEL participants were biased towards having eating challenges based on recruitment criteria), making our findings potentially non-generalizable to the greater LTC population. Furthermore, although the BABEL intervention did not include specific information on nutrition or dietitian involvement, we cannot be certain that the BABEL intervention did not bias the care providers towards dietitian referrals. These limitations are outweighed by the novel contribution and understanding that our results provide for considering dietitian involvement in the final months of life of LTC residents, acknowledging that this is not representative of all LTC residents.

Dietitian referral patterns are likely impacted by home-level factors (Fleurke et al., 2020), which were not considered in this study. We obtained data from LTC homes with varying size and structure, which capture a variety of potential institutional influences, but we were not able to assess these because of the low representation from each home and lack of meaningful home-level data. Institutional policies and practices around dietitian engagement and potential effects on the quality of nutrition care, especially as residents approach the end of life, is recommended for future study.

We extracted charted data that were documented in a clinical setting and not for research purposes, weakening the rigour of the data collection. However, the LTC homes from which we extracted data had standardized care plans and referral systems built into their charting processes, improving the likelihood that all nutrition interventions and referrals were captured. This is less likely for the eating challenges that were collected from the daily progress notes, relying on thorough reporting by the LTC care team. This may have been problematic given known deficiencies in nursing documentation across care settings (N. Wang et al., 2011) and suboptimal communication and information flow between direct care providers and the nursing staff responsible for reporting the daily progress notes (Banerjee et al., 2015; Beynon et al., 2022; Farrell et al., 2022; Madden et al., 2017). Our choice to limit the data collection to progress notes spanning two weeks at four discrete time points allowed a longitudinal analysis of changes in prevalence of dietitian referrals but by doing so, we missed referrals that occurred outside of the prescribed data collection time periods. Our choice to use dichotomous (yes/no) variables to simplify the data collection only allowed for a rudimentary assessment of dietitian referrals; other factors (e.g., number of referrals, reason for referral) would have contributed valuable insights. Furthermore, continuity of dietitian support over time and non-referral points of contact (e.g., routine assessments) were not considered and should be explored in future studies.

8.5.2 Conclusion

According to this descriptive analysis, dietitian referrals in LTC homes are driven by the imminent needs of individual residents, and particularly eating challenges associated with life-limiting conditions. Furthermore, dietitian involvement is associated with initiation of comfort-focused care practices in the final month of life. Dietitians are well-situated to support the quality of life of residents and their care partners as they navigate severe and complex eating challenges leading up to death. Future work should focus on equipping dietitians with the tools (e.g., training, resources, funding) necessary to champion multidisciplinary efforts aimed at improving comfort-focused nutrition care for LTC residents in the final months of life.

Chapter 9

General Discussion

The four studies presented in this dissertation offer a unique contribution quantifying the longitudinal changes in various aspects of nutrition care for LTC residents in the final six months of life. In particular, the studies identified: changes in several staff-documented eating challenges with proximity to death; the prevalence of nutrition care plan modifications leading up to death and factors associated with comfort-focused nutrition orders; nutrition-related challenges that were informally used by care providers as indicators of potential end-of-life decline; and the prevalence and factors associated with dietitian referrals in the final six months of life of residents. The following sections summarize these findings in light of the original research questions and hypotheses, discuss the limitations and strengths of the studies, apply the findings and their implications to the broader culture change movement, and suggest directions for future studies to advance a palliative approach to nutrition care for LTC residents experiencing eating-related decline towards the end of life.

9.1 Summary and Elaboration of Findings

Study 1 demonstrated, as hypothesized, that eating challenges increased in prevalence with proximity to death. The repeated measures latent class analysis also identified distinct patterns of eating challenge trajectory. However, very few resident characteristics were associated with the trajectories identified, and the consistency across the two sampling frames was questionable, suggesting that these trajectories as identified are not valid without further investigation.

Study 2 showed that the number of eating challenges, and dysphagia in particular, were positively associated with comfort-focused nutrition care orders. However, contrary to another hypothesis, restorative care plan modifications were also positively associated with comfort-focused nutrition orders, which occurred late in the end-of-life trajectory (i.e., last two weeks of life), suggesting that a palliative approach to nutrition care is not well-integrated into LTC practice.

Study 3 demonstrated that nutrition-related challenges were routinely considered to indicate to care providers that residents were experiencing end-of-life decline. Notably, low food/fluid intake contributed to suspected end-of-life decline in nearly half of residents in the sample and refusal to eat was indicated in nearly one quarter of residents. However, of the nutrition-related challenges cited, only dysphagia predicted a shorter time to death, and none predicted a longer time to death.

Finally, study 4 found that dietitian referrals increased in prevalence with proximity to death, but the increase was confounded by the number of eating challenges. Furthermore, the average time between dietitian referrals and dietitians' first follow-up (~4 days) remained consistent across the time points, suggesting that dietitian practices do not change in response to suspected urgency in relation to end-of-life decline as hypothesized. However, consistent with another hypothesis, a positive association was found between dietitian referrals and comfort-focused nutrition care orders in the last month of life of residents.

Taken all together, the findings from these studies highlight the relevance of considering a palliative approach to nutrition care and point to targets for further exploration and development of initiatives to support LTC residents with eating-related decline. A potential need for better integration of a palliative approach to nutrition care was suggested by the combined findings of Studies 1 and 2. These studies showed that the prevalence of eating challenges with proximity to death was high, yet the frequency of comfort-focused nutrition care orders was relatively low and initiated late in the end-of-life trajectory suggesting that there may be room for growth in this aspect of nutrition care. Although the prevalence of comfort-focused nutrition orders seemed low, the nutrition-related signals identified as indicators of suspected end-of-life decline in Study 3 demonstrate that care providers may already consider eating challenges within the broader context of end-of-life decline. This finding suggests that the concept of a palliative approach to nutrition care for residents experiencing eating-related decline may be welcomed among care providers. However, to date, it is unclear why comfort-focused nutrition orders are currently not well implemented. The acceptability of comfort-focused nutrition care orders and strategies to introduce them within the care team should be the focus of further study. Promisingly, the increase in dietitian referrals when residents experienced severe eating challenges and the association with comfort-focused nutrition care orders in the last month of life suggest that dietitians may be well-positioned to champion a palliative approach to nutrition care for LTC residents with eating-related decline. Admittedly, these findings are descriptive and the conclusions that can be drawn from these findings are limited by a lack of a non-deceased comparator group as well as sampling flaws, which will be discussed in the next section. Nevertheless, the study findings are a unique contribution to the field, as prior descriptive and predictive analyses are absent in this area. Thus, this research may be used to encourage the development of a palliative approach to nutrition care to support quality of life for LTC residents and their care providers.

9.2 Study Limitations and Strengths

Although unconventional, I have chosen to lead with an acknowledgment of the limitations of the studies found within this dissertation to establish a foundation for the rest of the discussion. By presenting the limitations first, I will be able to ruminate on the implications of these findings, satisfied that I have made my assumptions known. A full and honest disclosure of the limitations of this study will provide context and ensure that the findings are neither overemphasized by diminishing the study weaknesses, nor diminished by overemphasizing the findings without understanding the limitations, thus provoking skepticism on the part of the reader. Despite definite shortcomings, the findings reveal that there is value in advancing the conversation toward an integration of a palliative philosophy within the scope of nutrition care services in LTC. However, these shortcomings must be acknowledged first to ensure that the findings are interpreted appropriately. The study methods had several strengths as well, which in addition to the limitations, I will highlight throughout.

The most prominent limitation of the studies is the merging of the two sampling frames, despite having different recruitment methods and inclusion criteria, representing a sampling flaw that affects interpretation of the findings.[11] We originally intended to include participants from the BABEL sample only, which consisted of residents originally selected for a cluster randomized control trial based on specific eligibility criteria (Garland et al., 2022). However, as it became clear that this sample would not provide a sufficient sample size, we needed to supplement with a second sample (i.e., the home chain) but the BABEL recruitment method was not replicated. Instead, the home chain sample, which was obtained out of convenience, consisted of randomly selected decedents from nine randomly selected homes within the chain. As a result, the sampling frames were incongruent leading to the potential that eating challenges and nutrition issues would be overidentified in the BABEL sample. Specifically, BABEL participants were selected based on a high likelihood of death in the 12 months following entry into the study; one of the selection criteria was reduced food intake based on the Resident Assessment Instrument Minimum Dataset (MDS 2.0) item "Leaves >25% of food uneaten at most meals", which represented 69.6% of BABEL participants compared to 48.2% of home chain participants ($p < 0.05$). As a result, this sampling bias likely contributed to an inflated

---

[11] Study 3 is exempt from this limitation because the BABEL sample was excluded based on concerns that the recruitment for the original study may have directly biased the findings.

estimation of eating-related challenges within the overall study findings. However, the general conclusion that eating challenges are common within the last six months of life of LTC residents is still appropriate, considering that only one individual, who was from the home chain sample, had no indication of eating challenges across the four observation periods. The observations also provide insight into the specific challenges that were experienced by residents, even if the proportions are inflated. Furthermore, we controlled for the effect of the sampling frame where possible (e.g., as a covariate in regression analyses) and focused on within-person comparisons (e.g., odds of specific eating challenges, comfort-focused nutrition orders, dietitian referrals) over time such that conclusions drawn from the findings do not rely on the representativeness of the sample for the most part, but rather emphasize individual-level factors associated with eating challenges and other aspects of nutrition care. Indeed, the findings are useful as an initial understanding of end-of-life nutrition care among residents of LTC and to generate discussion, but prevalence estimates should be interpreted with caution and more rigorous data collection would be needed to establish representativeness.

The decision to merge the two sampling frames was justified in order to obtain a large enough sample size to provide adequate power for statistical analyses, including multivariable modelling, which is a strength of this study. A robust sample of 164 LTC residents was included in these studies, larger than any prior descriptive studies on end-of-life nutrition care specific to oral intake (i.e., not artificial nutrition) (Anantapong et al., 2020) and including residents with various conditions and not just those living with dementia (S. L. Mitchell et al., 2009). Furthermore, given that this was the first study of its kind, there was uncertainty about what information we would find regarding eating challenges and nutrition care within the resident charts, so including BABEL participants ensured that we would obtain some participants with an indication of eating challenges; the fact that all but one resident in the combined sample exhibited at least one eating challenge was a surprising and noteworthy finding in and of itself. Furthermore, we justified merging the two sampling frames in the original proposal because the quantitative data collection from the resident charts was intended to serve as a springboard for a follow-up qualitative study to provide depth and context to the findings. However, time constraints necessitated that the qualitative phase was left out of this dissertation so the quantitative findings are left to stand alone, limiting the conclusions that can be drawn.

Despite these sample limitations, the studies presented in this dissertation provide novel and valuable insights into the intersection of nutrition care and end-of-life decline of a large sample of residents from across several Ontario LTC homes. Remarkably, though charting and communication styles differed across the LTC homes, common reports of eating challenges and nutrition care plans were observed, demonstrating the ubiquity of these factors for LTC residents and the relevance of attending to end-of-life nutrition care in this demographic.

The extensive resident chart reviews using rigorous data extraction methodology allowed us to obtain unique insights into this vulnerable time in the residents' life, thus representing a strength of the study. However, the chart reviews also introduced limitations in that the quality of the data collection relied on the quality and completeness of the charted information. This may be problematic for two reasons. First, chart data is documented for clinical and not research purposes and is prone to errors, inaccuracies, and deficiencies in specific types of information such as psychological and social aspects of care (N. Wang et al., 2011). Second, challenges are known to exist around the communication processes and information flow between direct care providers and the interprofessional care team including nurses in supervisory and charting roles (Banerjee et al., 2015; Farrell et al., 2022; Madden et al., 2017). As such, relevant information may not have been communicated or recorded because of the complex dynamics within the organizational hierarchy. As a result of suboptimal charting, the data obtained for this dissertation may have been narrow in scope and only represented the information that was most significant from a clinical perspective, potentially leading to classification errors. On the other hand, the use of these clinically reported data offers insight into the most relevant resident experiences from the perspective of the care providers. For example, the documented eating challenges may be interpreted as new or unmanaged challenges that the direct care staff considered necessary to report or that was corroborated by observations by the nursing staff. Furthermore, classification errors were limited by the fact that data were kept relatively general through dichotomization, allowing for a wide margin of error. For example, as long as an eating challenge (e.g., swallowing difficulty) was noted at least once within the two weeks of progress notes selected for observation, it was counted in our data collection. Although this simplification of chart information limited the potential conclusions that could be drawn from the data, it otherwise allowed for a meaningful basic description of the longitudinal changes in different aspects of the nutrition care experience of LTC residents in the final months of life.

Another limitation of the studies was that the accuracy of the data relied on my own interpretation and discipline as the sole data extractor. To lessen the potential effects of my own biases on the data collection and thereby to improve the quality of the data, we took measures to improve the validity (unmeasured) and reliability of the data. First, the original data codes and any questions or decisions were developed and confirmed in close consultation with the senior author (HK), who is an internationally recognized expert in the field of geriatric nutrition care with extensive research focused on LTC specifically (e.g., Keller et al., 2014, 2022; Romaniw et al., 2020; Wu et al., 2018). Over the course of data collection, consistency was enhanced through thorough record-keeping, including development of a data dictionary to which I referred when I encountered uncertainty, and intra-rater reliability checks after every 50 charts reviewed (see Chapter 4 for a description of the process). Despite these steps, my own biases and understanding of the charted information likely affected the data collection and must be acknowledged as a limitation of this research.

Finally, the data analysis was limited in that we were not able to assess the effects of several home-level and resident-level factors that likely affect end-of-life nutrition care and eating-related decline in LTC residents. Home-level factors that may affect end-of-life nutrition care include palliative care training programs, presence of specifically skilled or passionate care providers acting as champions, policies and procedures that support high quality end-of-life and/or nutrition care practices, and individual home culture, among other factors. Indeed, there is significant variation in culture and care practices even between homes within a single chain that likely affect these care processes (anonymous, personal communication, April 13, 2023),[12] indicating that factors across homes with different organizational and funding structures is likely even more varied. Such variation was demonstrated in the initiation of comfort-focused nutrition care orders in our sample, with within-home prevalence ranging from 0% to 70% of residents across the 18 LTC homes. Many factors may have contributed to this wide variation, but we were unable to statistically analyze the home-level effects. Likewise, although we had data on individual eating challenges and care practices across the four time points, the data on resident-level characteristics were limited to one wave of MDS 2.0 measures collected at approximately 6 months prior to death. As such, we were not able to test resident-level factors that may have affected the residents' trajectory towards death, such as functional and health-related decline. Nor were we able to test if the trajectories identified in Study 1 were unique to the end-of-life experience given the lack of a living comparator group. Data were collected on deceased LTC residents only but an equivalent data collection on residents who did not die would have allowed for further conclusions to be drawn on the trajectory of eating challenges and

---

[12] The source of this personal communication is anonymous because the data agreement with the home chain required general anonymity.

also on the potentially modifying effects of nutrition care practices on this trajectory with respect to Study 1. Certainly, evidence suggests that some determinants of malnutrition, and thus presumably nutrition-related decline, are modifiable (M. O'Keeffe et al., 2019). However, we were not able to test the potentially modifiable effects of nutrition care practices on eating-related decline because all of our participants died. Instead, a focus on within-person changes provided some opportunity to draw conclusions about the end-of-life period, since comparisons between earlier and later time points revealed increased odds of various aspects of nutrition care, including eating challenges and comfort-focused nutrition care orders, with proximity to death. Further studies are required to tease out the resident- and home-level characteristics that affect the end-of-life nutrition care experience and specific trajectory towards death. Nonetheless, the primary objective of this dissertation to describe the end-of-life nutrition care experience of LTC residents was accomplished and provides a foundation on which to base further studies in this field while keeping in mind the cited limitations.

Altogether, there were limitations in the sample, data collection, and analysis that must be accounted for when interpreting the results but the strengths, including the sample size, extensive data collection, and novel research area exemplify the value of the study. The most important limitations to consider are that the prevalence of various aspects of nutrition care may be inflated by the biased sample, data collection was limited to a single rater's interpretation of the data, and the lack of data on contextual home- and resident-level factors or a living comparator group limit the conclusions that can be drawn specific to eating challenges that may be more prevalent at the end-of-life. However, the findings have merit despite these challenges in that the sample was relatively large considering the in-depth chart review that was performed, the simplified data collection mitigated potential uncertainty surrounding individual data points, and within-person comparisons allowed for conclusions to be drawn about longitudinal changes in residents' nutrition care needs. Furthermore, I have had informal correspondence with dietitians and other LTC providers in various roles that have substantiated my general findings and conclusions from a practical standpoint. As such, though careful interpretation of the results is warranted, the general conclusions can facilitate a robust discussion around the benefit to integrating a palliative approach to nutrition care for LTC residents.

9.3 (More Than) Hard to Swallow: A Variety of Challenges Contribute to Eating-Related Decline

The findings presented in this dissertation, especially the high prevalence of eating challenges and unique trajectories of eating-related decline, demonstrate that nutrition care at the end of life of LTC residents requires further study and development of palliative-minded best practices to support residents and care providers. A high prevalence of eating challenges was noted within the last six months of life in our sample of 164 LTC residents over the age of 65 and admitted to the LTC home for at least six months; the odds of experiencing a complex eating challenge increased significantly in the last month of life. Eating deficiencies and poor nutritional status among LTC residents are well-documented in the literature (Bell et al., 2013; Donini et al., 2020; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Keller et al., 2019; Sloane et al., 2008), and eating challenges have been noted among care providers as a common sign of impending death (Åvik Persson et al., 2018; Brandt, 2005; Cable-Williams & Wilson, 2014; Fringer et al., 2020; Gonella et al., 2021; Wallin et al., 2015). Yet, little work has focused on how to manage these eating challenges with comfort-focused oral intake in the context of end-of-life decline, and especially for individuals with cognitive impairment who make up a large portion of the LTC population (Anantapong et al., 2020; Barrado-Martín et al., 2022; Palecek et al., 2010). Furthermore, the four trajectories identified in study 1 suggest that eating challenges may occur in combination and different patterns of eating-related decline require tailored nutrition care approaches. As such, the most important contributions of this dissertation are to highlight this gap in nutrition care, to suggest that flexible, tailored nutrition care is required to support residents nearing the end of life, and to promote further research and development of person-/relationship-centered practices to support residents experiencing eating-related decline and their care providers.

Eating-related decline can manifest in many ways for residents nearing the end of life. In our sample, residents experienced higher odds of poor appetite, refusal to eat, swallowing difficulties, pocketing food in their mouth, dental/chewing issues, and need for verbal prompting to eat, which all contributed to decreased food and fluid intake, in the last month of life compared to six months prior to death. Increased odds of lethargy at mealtimes as indicated by, for example, the resident remaining in bed, being too tired to eat, or falling asleep during dinner service was found even earlier. Compared to the six-month time point, residents were 1.78 times as likely to experience lethargy at mealtimes three months prior to death, and these odds increased to four-fold at one month prior to death and eight-fold within two weeks of death, affecting approximately two thirds or the sample. Refusal to eat was also highly prevalent in the sample, observed in 28.7% of the sample at six months prior to death and increasing to 68.3% of the sample in the last two weeks of life, representing a more than five-times higher odds of refusing to eat as residents approached the end of life. Certainly, many of these eating challenges may contribute to distress among care providers and difficulties navigating care decisions (Anantapong et al., 2020; Barrado-Martín et al., 2022; Firnhaber et al., 2020; Wallin et al., 2022). Best practices to support residents with these eating challenges are needed.

Such diverse challenges call for a variety of strategies to address the physical, emotional, and psychosocial needs of residents and their family caregivers (Barrado-Martín et al., 2022). However, existing strategies to manage terminal eating challenges are largely focused on swallowing-related difficulties (Berkman et al., 2019; Fong et al., 2020; Palecek et al., 2010; Soar et al., 2021; Sommerville et al., 2019). This was consistent with our results, which showed that swallowing difficulty was the only eating challenge directly associated with a comfort-focused nutrition order. Swallowing difficulty, when identified as a sign of suspected end of life decline among care providers, was also associated with a shorter time to death (HR=2.99, 95% CI=[1.41, 6.33]) than individuals for whom swallowing difficulties were not noted as a sign of decline in our adjusted Cox regression analysis. As such, the association between swallowing difficulties and comfort-focused nutrition orders likely contributes to late initiation of these orders. Broadening the concept of comfort-focused nutrition care to address a variety of eating challenges beyond swallowing difficulties could potentially lead to earlier initiation and improved support for residents with eating-related decline.

9.4 A Proposed New Menu Option: Adding Palliative-Focused Nutrition Care to the Services Offered in LTC

The study results suggest that there is a need to broaden the understanding, awareness, and application of comfort-focused nutrition care options for residents nearing the end-of-life in LTC. To date, “Comfort Feeding Only” and similar “Eating and Drinking with Acknowledged Risk” orders have been proposed to support older adults with eating and swallowing difficulties as a formalized alternative to artificial nutrition (i.e., tube-feeding) that involves gentle hand-feeding, responsiveness to residents’ cues of readiness to eat, and other forms of attentive care, including mouth care, when food intake is not appropriate or desired by the resident (Palecek et al., 2010; Soar et al., 2021;

Sommerville et al., 2019). These strategies have demonstrated positive outcomes in in-patient settings, including fewer days being nil by mouth, fewer readmissions, and lower proportion of adverse events such as aspiration pneumonia (Soar et al., 2021; Sommerville et al., 2019). However, our results indicate that comfort-focused nutrition orders, broadly defined to indicate any formalized instruction to provide nutrition according to the resident's preference, desire, or tolerance to eat, were initiated for only 30% of LTC residents, and most often in the last two weeks of life.[13] Our findings suggest that comfort-focused nutrition care orders may not be used to their full potential in current practice. Certainly, a more rigorous assessment of unmet needs surrounding end-of-life nutrition care would be required to substantiate this claim. Yet, "comfort care" in relation to nutrition for LTC residents is poorly defined in current practice and hindered by a lack of clear policies for providing care for residents with eating-related decline aimed to support quality of life, implying that there is definite room for improvement in this area (Davenport & Yeung, 2019). As such, clearer definition, development of best practices, ongoing quality improvement efforts, and evaluation of outcomes regarding comfort-focused nutrition care rooted in a palliative philosophy of care are needed.

Early end-of-life care conversations, supported by advance care planning principles that incorporate clear communication of likely health trajectories, are important to prepare residents and their families for easier transitions to comfort care goals (Harasym et al., 2020; Heckman et al., 2021). Unexpected complications or difficulties, such as refusal to eat, swallowing difficulties, or other changes in eating habits, can turn into crises situations that contribute to caregiver distress; ideally, such challenges would be anticipated and discussed ahead of time to minimize the negative impact on residents and their care providers (Heckman et al., 2021; S. Thompson & Oliver, 2008). Our findings provide evidence that eating challenges are common among LTC residents. Even among the randomly selected home chain sample, all but one decedent experienced at least one eating challenge over the course of the four observations leading up to death. As such, it would be appropriate to provide information on the high probability of eating challenges as a component of advance care planning conversations and to present comfort-focused nutrition care as an option. Furthermore, findings from our repeated measures latent class analysis provide a nuanced understanding of eating challenges experienced by LTC residents in the last six months of life: some

---

[13] Interestingly, this timing is consistent with a systematic review of international studies, which found that the duration of palliative care across healthcare settings is much shorter (i.e., average 6 days for non-cancer patients) than the recommended 3-4 months prior to death for maximal benefit (Jordan et al., 2020).

participants had no eating challenges until the last two weeks, while others experienced predominantly refusal to eat, a progressive increase in challenges, or fluctuation in a variety of complex challenges across the time points. Although the validity of these specific patterns has not been established and generalizability is unknown, the main lesson to be drawn from this analysis is that eating challenges, though pervasive, do not affect residents equally. Instead, these patterns exemplify different scenarios that could be used to promote early comfort-focused nutrition care conversations with residents and family caregivers prior to the onset of eating difficulties. Altogether, the findings suggest that the anticipation of eating challenges as a likely outcome for LTC residents is an important component of a palliative approach to nutrition care.

In addition to anticipating eating challenges towards the end of life, the findings of this dissertation suggest that eating challenges may be used as a trigger to initiate comfort-focused nutrition care conversations between and among LTC residents and care providers. Formalized tools such as the Palliative Performance Scale (PPS) or the Changes in Health, End-Stage Disease, Signs and Symptoms (CHESS) are recommended as standardized measures of progressive decline for prognostication and decision support (Anderson et al., 1996; Hirdes et al., 2003; N. Williams et al., 2022).[14] However, identification of eating challenges (e.g., refusal to eat, being too tired to eat) as potential signs of decline may be useful to initiate more informal conversations related to comfort-focused goals of care and timely support between formal assessments. In the palliative care literature, eating deficiencies are considered to indicate a transitional stage between life and death (Wallin et al., 2015, 2022). Similarly, care providers in LTC describe decreased appetite as one component of residents “going into a bubble” as an early sign of death (Åvik Persson et al., 2018) and associate disinterest in food/fluid or reduced intake with end-of-life decline (Cable-Williams & Wilson, 2014). Direct care providers (e.g., PSWs), who spend the most time interacting with residents during meals and are most familiar with subtle changes in residents’ behaviours and routines (e.g., eating habits), are well-positioned to broach the topic of comfort-focused nutrition care practices with family caregivers during informal interactions (Cable-Williams & Wilson, 2014; McCleary et al., 2018; G. N. Thompson & McClement, 2019). In doing so, they may be able to attend to the holistic needs of residents and their care providers (Lopez & Amella, 2011). Educational initiatives that acknowledge

---

[14] Notably, both the PPS and the CHESS tools include one or more item on food intake and/or nutritional status.

eating-related decline as a potential sign that residents' goals of care may need to be reassessed, including guidance on how to facilitate sensitive conversations, are needed.

Comfort-focused care conversations must be followed up with evidence-based, practical solutions directed towards a palliative approach to nutrition care that allows decision-making to be fully informed. Nutrition care for LTC residents, and particularly residents in the advanced stages of dementia, requires flexibility to respond to their fluctuating needs (Anantapong et al., 2020; Barrado-Martín et al., 2022). However, overly medicalized care plans can limit care to a prescribed set of actions that restrict direct care providers from responding to residents immediate cues with person-centered approaches (Alam & Drakos, 2022; Armstrong et al., 2023; Kontos et al., 2010). This can lead to negative mealtime care practices such as coercion (Palese et al., 2019) or force-feeding (Baillie et al., 2018; del Río et al., 2012), and care provider distress in day-to-day decision making when the nutrition goals of care do not match resident needs (Anantapong et al., 2020). Furthermore, multiple nutrition care plan modifications may be required to address residents' changing needs before switching to a comfort approach, as found in our results. Comfort-focused nutrition care orders offer a potential solution to minimize the flurry of activity and documentation currently used to address residents' changing needs towards the end of life by allowing flexible, responsive care according to expressed need, desire, or preference regardless of the interventions used to achieve the goal of comfort. Providing food for enjoyment, social interaction, and quality of life should be emphasized, particularly given that eating-related decline frequently comes with other functional and social challenges in the LTC population (Morrison-Koechl et al., 2021; Pinho-Reis et al., 2022).

A shift in focus of nutrition care practices towards a palliative approach can be challenging for various reasons and requires clear communication of the benefits and risks involved to ensure that decision makers are well-informed. Certainly, care providers have reported a difficulty in transitioning from "actively doing" consistent with restorative care goals towards attending to the broader existential and emotional concerns upon which palliative goals are centered, stating a hesitancy to have tricky conversations with family members (del Río et al., 2012; Wallin et al., 2022) but also reporting the meaningfulness of having such conversations (G. N. Thompson & McClement, 2019). Certainly, clear communication of care options and the implications of different care decisions are an important part of high-quality end-of-life nutrition care. Without adequate information, family decision-makers may opt for burdensome care practices in an effort to preserve life, support comfort, and continue to fight against decline despite a lack of evidence to support these suppositions for individuals with terminal conditions (del Río et al., 2012; S. L. Mitchell et al., 2009). Alternatively, evidence suggests that comfort can be maintained and hunger and thirst adequately managed with attentive care and minimal food and fluid intake in the terminal stages of life, yet this is poorly acknowledged by care providers (McCann et al., 1994; Pasman et al., 2005; Winter, 2000). On the other hand, although relaxed approaches to nutrition care are associated with better quality of life, such approaches do carry an element of risk (e.g., aspiration, exacerbation of existing health conditions) so these should be communicated to and understood by all decision makers and care providers so that consent is fully informed (Soar et al., 2021). Considering all of these factors, there is a need to expand the evidence base for implementing comfort nutrition orders in the context of various conditions to inform the shared decision-making process between the resident when possible, family members, and the LTC care team. Further studies are required to understand the nuances of implementing comfort-focused nutrition care options for LTC residents.

9.5 A Place at the Table for Everyone: Honing in on Interdisciplinary Responsibilities in Nutrition Care at the End of Life

Interdisciplinarity is essential in all aspects of care, including nutritional and palliative care, to promote optimal experiences for LTC residents (Armstrong et al., 2023; Borders et al., 2020; Kaasalainen et al., 2020; S. Thompson & Oliver, 2008). The unique contributions of each role within the LTC staff as well as family caregivers, and the ways in which these roles complement each other, should be emphasized and optimized when addressing eating-related decline and promoting the implementation of comfort-focused nutrition care orders. Although each role (e.g., nurse, food service, recreation, spiritual care) is important in this effort, two roles in particular, dietitians and PSWs, may be considered as pivotal in these care processes in LTC so their involvement is highlighted in the following paragraphs.[15]

Dietitians have great potential to advance the integration of a palliative approach to care because of their expertise in the management of nutrition-related challenges and attentiveness to the holistic needs of older adults related to food and psychosocial well-being (Dorner & Friedrich, 2018; Pinto et

---

[15] Speech language pathologists (SLPs) have also been identified as critical to implementing comfort feeding for older adults with dysphagia (Berkman et al., 2019; Fong et al., 2020). However, given the limited availability of SLPs in LTC, and the intended broader implications of comfort-focused nutrition care beyond dysphagia I have chosen to exclude them from this discussion. Regardless, SLP expertise, when available, should be considered invaluable to a palliative approach to nutrition care for LTC residents.

al., 2016). Specialist knowledge is recommended to understand how food and nutrition affect all aspects of the concept of "total pain", including physical, psychological, social, and spiritual suffering, and how various interventions could be implemented to address these challenges (Pinho-Reis et al., 2022). Certainly, the findings within this dissertation indicated that dietitian expertise was sought by the LTC staff when residents experienced severe and complex eating challenges that presumably contribute to existential suffering. Yet, dietitian involvement in the broader palliative care movement is poor to date (Harasym et al., 2021; Kaasalainen, Sussman, McCleary, et al., 2019; Pinto et al., 2016; Sawatzky et al., 2017) and thus emphasis on the importance of attending to the palliative nutritional needs of residents is left to a few dietitian advocates with little support or educational resources (Dodd, 2017; Pinto et al., 2016). This represents an opportunity for dietitians to take a more proactive role in incorporating comfort-focused nutrition care innovations into current LTC practice, particularly given that they have been identified as strong candidates as informal champions on interprofessional LTC teams (Sheffer-Hilel et al., 2022). Tasks that are already built into the dietitians' responsibilities, such as assessment, monitoring, developing nutritional care plans, and communicating with and educating the LTC staff (e.g., nursing, PSWs, dietary) and family members about food and nutritional needs, provide several occasions to introduce comfort-focused concepts and practices (Pinto et al., 2016). Efforts should be put towards educational initiatives in palliative nutrition and in leadership training to provide dietitians with the skills to effect change within the LTC environment in this regard (Pinto et al., 2016; Sheffer-Hilel et al., 2022).

Direct care providers are essential in implementing comfort-focused nutrition care because they are largely responsible for daily care and have a high degree of familiarity with residents. However, evidence indicates that they have little autonomy to carry out tasks according to their own assessment of residents' expressed needs (Kontos et al., 2010). Additionally, they are rarely involved in the decision-making process for nutrition care (Anantapong et al., 2020; Cranley et al., 2022) or in palliative care conferences (Durepos et al., 2018) even though they are in an important position to identify and raise concerns regarding changes in the residents' conditions (Anantapong et al., 2020; G. N. Thompson & McClement, 2019). These factors can severely hinder health care providers from engaging in person-centered palliative care practices despite a willingness to do so (McCleary et al., 2018; Unroe et al., 2015), and contribute to feelings of frustration and job dissatisfaction (J. W. Douglas et al., 2021; Squires et al., 2015). A comfort-focused approach to nutrition care necessarily involves direct care partners as active members of the interdisciplinary team in advocating, assessing, planning, decision-making, and implementing attentive and responsive care practices (Kaasalainen et al., 2014). Certainly, a shift in mindset, leadership commitment, and staffing policies are needed to effectively involve and empower unregulated care providers in transforming end-of-life nutrition care for LTC residents.

9.6 Food for Thought: The Potential Contribution of a Palliative Approach to Nutrition Care to the Broader Culture Change Movement

The development of a palliative approach to nutrition care, representing a change in dynamics surrounding food and nutrition for residents with severe and complex eating challenges towards the end of life, has the potential to positively contribute to culture change in LTC. Indeed, for most LTC homes the culture change movement is characterized by small shifts in care practices and innovations that lead to improved quality of life for the people who live and work there (Armstrong et al., 2019). Specifically, four of six components of culture change, including *resident direction*, f*ostering of close relationships between residents and care providers*, *staff empowerment*, and *collaborative decision-making* (Koren, 2010) may theoretically be impacted by the implementation of comfort-focused nutrition care orders. The incorporation of a palliative philosophy into the menu of nutrition care options offered to residents and their family caregivers would help to further shift towards a social model of care that is amenable to supporting the holistic needs of residents at the end of life while empowering LTC staff.

The potential positive effects of a comfort-focused nutrition care order on changing the culture may be multifactorial and, at least in theory, result from a ripple effect spreading outward from *resident-direction*. Resident-directedness is a pillar of social models of care and a key feature of comfort-focused nutrition care, which is motivated by the goal to meet the resident's expressed need and desire for food to promote quality of life with little regard for nutritional requirements (Palecek et al., 2010). Orienting care towards the resident in the context of a comfort-focused nutrition order implies that LTC staff would receive cues for food provision directly from the resident and not from a prescribed care plan. In turn, this would allow and even encourage care providers to add personal touches based on familiarity with the resident's history, and likes and dislikes, which would bring meaning to care interactions from the perspective of care providers and families alike (Kontos et al., 2010; Lopez & Amella, 2011; G. N. Thompson & McClement, 2019; Wallin et al., 2015). An excellent demonstration of this is described by a registered nurse in the following quote concerning a resident in her care:

> She loved Pepsi. So her, on her deathbed we wet the toothette with Pepsi, you know, just so, here you go, your last kick at the can kind of thing, right. And her family cried that we even thought to do something like that. (G. N. Thompson & McClement, 2019, p. 6 of 13)

Indeed, encouragement of such personal touches as a job responsibility is an ideal way to *foster close relationships between the resident and care providers*, another component of culture change. LTC staff report an increased ability to provide comfort and compassionate care as a result of time spent caring for and developing close relationships with residents with dementia (McCleary et al., 2018). Given the social qualities of food and fluid at and outside of mealtimes, food provision presents regular opportunities for care providers to develop relationships and become familiar with residents and their family members when present (M. Douglas & Gross, 1981; Ducak et al., 2015; Reimer & Keller, 2009; Watkins et al., 2017; Wu et al., 2021). Familiarization with residents, alongside education and training to recognize eating-related decline and to conduct informal comfort-focused care discussions can further contribute to *staff empowerment*, particularly for direct care partners who are susceptible to a lack of autonomy and low access to residents' charted information in their work (Alam & Drakos, 2022; Kontos et al., 2010). Evidence suggests that staff empowerment and leadership opportunities for direct care providers contribute to better quality of life for residents (Duan et al., 2022), increased job satisfaction (Squires et al., 2015), and staff retention in LTC (Berridge et al., 2020). In turn, staff retention could further contribute to high quality end-of-life care because of an increased familiarity with residents developed through consistency over time (McCleary et al., 2018). Finally, the confidence gained from comfort care training opportunities and increased workplace autonomy as well as the expectation of active involvement in the residents' nutrition care could naturally lead to opportunities for *collaborative decision-making* between care providers and family members, giving opportunity and input for decision-making to the care providers who work most closely with residents. Given the necessary shift in responsibility to provide responsive care to residents, direct care providers would be considered important contributors to the decision-making process around comfort-focused nutrition care, in collaboration with the interprofessional LTC team, family members, and residents.

To achieve this ideal of a palliative approach to nutrition care to support LTC residents with eating challenges towards the end of life, several barriers must be acknowledged and overcome. Referring back to the model presented by Keller and colleagues, relationship-centered care dynamics between care provider and recipient are contingent on being situated within a supportive cultural and institutional context (Keller et al., 2022). In the current LTC culture, the implementation of a palliative approach to nutrition care is limited by several barriers. For one, the aversion to acknowledging death as a reality in LTC hinders the implementation of any palliative-focused initiatives (Cable-Williams & Wilson, 2017). Although there are several emerging efforts to implement a palliative approach to care in LTC in Canada and internationally (Cloutier et al., 2021; Collingridge Moore et al., 2020; Froggatt et al., 2020; Iida et al., 2022; Kaasalainen et al., 2014, 2016; Palliative Alliance, 2017), the lack of inclusion of nutrition care in these efforts to date suggests that further development is needed. Furthermore, the social and symbolic meaning of food may act as an additional deterrent to implementing comfort-focused nutrition care; such a care option and its implications must be communicated thoughtfully so as to promote the benefits of following the residents' cues for readiness to eat and allay potential fears of 'giving up' on the resident, 'doing nothing', or causing them to 'starve to death' (Palecek et al., 2010; Wallin et al., 2022; Ying, 2015). Until LTC care providers and family members become comfortable with having conversations about end-of-life issues, this barrier will persist (Harasym et al., 2020). Another barrier to implementing a palliative approach to nutrition care is that the existing processes for conducting comfort-focused conversations, such as advance care planning, are inconsistent and problematic across LTC homes (Choi et al., 2020). Furthermore, goals of care discussions typically occur too late in the end-of-life care trajectory to confer a maximal benefit (Cable-Williams & Wilson, 2017; Hawley, 2014; Sussman et al., 2017). Opportunities for initiating these conversations require further study. Finally, the current staffing issues in LTC, defined by overextended care responsibilities, high turnover, burnout, and oppressive working conditions continue to be a major challenge to culture change efforts (Alam & Drakos, 2022; Banerjee et al., 2015; Long-Term Care Staffing Study Advisory Group, 2020). As with many other initiatives in LTC, adequate compensation for staff is essential to empower them to perform their tasks and remain in place to develop strong relationships within the interprofessional LTC team and with residents and their family members (Alam & Drakos, 2022; Barken et al., 2018; Long-Term Care Staffing Study Advisory Group, 2020). Despite these barriers, small changes to develop the concept of a palliative approach to nutrition care and practical implementation of comfort-focused nutrition care orders may help to progress towards more holistic care to meet the needs of LTC residents with eating-related decline and improve the morale and care dynamics from a care provider perspective.

9.7 Let Them Eat Cake! Future Directions in Research and Practice

This dissertation has quantified longitudinal changes in various aspects of nutrition care for LTC residents nearing the end of life and highlights the need for further development of research and practice in this area. From a research perspective, several approaches may be taken to clarify, confirm, and expand upon the studies found in this dissertation. As a follow-up to this current study, a qualitative exploration of the dynamics around eating-related decline should be conducted to gain depth of understanding of the context in which nutrition care decisions are made for residents nearing the end-of-life. Perspectives from multiple stakeholders, including the dietitian, nursing staff, direct care providers, family members, and residents where possible, should be obtained to understand the experience of eating challenges among residents as it relates to end-of-life decline. Furthermore, qualitative interviews or focus groups could clarify the actual need for comfort-focused nutrition care orders, as well as the perceived barriers and facilitators to adopting a palliative approach to nutrition care. The attitudes and perceptions of dietitians, as potential champions of comfort-focused nutrition care in LTC, should be given particular attention. Findings from such a study could inform further intervention development and implementation.

Given the limitations of this dissertation, further studies are needed to confirm the conclusions. Replication of these findings in a more generalizable, unbiased sample with standardized data points would be beneficial. The Canadian Institute for Health Information (CIHI) Integrated interRAI Reporting System — Long Term Care Facilities (IRRS-LTCF)[16] data holdings, which features quarterly interRAI assessments of a large pan-Canadian sample of LTC residents offers a potential source of data for similar description of the trajectory of eating decline with proximity to death (CIHI, 2023). Although not all eating challenges that were observed in this dissertation are captured in the IRRS-LTCF, the assessment contains several nutrition-related items (e.g., swallowing, chewing problems, digestive issues, low food intake) that could be tracked across time, as well as a variety of functional (e.g., ADL related to eating), health (e.g., CHESS) and psychosocial measures (e.g.,

---

[16] Formerly the Continuing Care Reporting System (CCRS)

participation in social life of LTC home) that could reveal additional patterns of decline relevant to understanding the end-of-life care needs of residents. A similar analysis of physical symptoms at the end of life of patients with cancer receiving home care demonstrates proof of concept (Seow et al., 2021). Others (Robinson et al., 2021; Webber et al., 2022) have proposed the use of administrative interRAI data to support palliative and end-of-life care initiatives in LTC suggesting that there is potential to assess nutrition-related palliative care needs as well.

Although the retrospective chart review methodology is advantageous to efficiently obtain descriptive data on a large number of residents at a vulnerable time of life (i.e., approaching death), it is limited in scope and depth of information. As such, different quantitative methods of data collection may be used to gain a more nuanced understanding of eating-related decline and nutrition care practices experienced by residents at the end of life. For example, direct observations within the context of a prospective cohort study of residents prior to the onset of eating-related decline, though more resource-intensive, could provide insight into incident eating challenges and trajectory towards the end of life with more frequent observations (i.e., not limited to quarterly interRAI assessments). Concurrent collection of standardized assessments such as the CHESS score and clinical measures of nutritional status (e.g. mini nutritional assessment [MNA-SF]) (Kaiser et al., 2009) could help to better understand the use of prognostic indicators in relation to eating challenges across the trajectory of decline and to identify opportunities to introduce comfort-focused nutrition care conversations using multiple practice indicators. Additionally, such a study could assess the impact of various care practices on this trajectory, which is an aspect of end-of-life nutrition care that requires further exploration. Mitchell and colleagues (2006, 2009) provide a successful example of a prospective cohort study designed to address gaps in knowledge in end-of-life care for LTC residents with dementia.

Studies that compare eating-related challenges and outcomes of LTC decedents to non-decedents in consideration of existing restorative interventions are needed to clarify the potential for care practices to modify the trajectory of decline. In our study, we were not able to assess the quality or appropriateness of specific care interventions, yet evidence suggests that attentive mealtime assistance and oral nutritional supplementation have the potential to improve intake and nutritional status in some LTC residents (Batchelor-Murphy et al., 2019; Borders et al., 2020). We were not able to assess the potential impact of nutritional care interventions, which may have been particularly relevant to the trajectories identified in Study 1. For example, residents in the “complex” group, defined by an increased probability of several eating challenges across the four time points, experienced a slight decrease in probability of refusal to eat, self-feeding challenges, lethargy, and expression of frustration three months prior to death, which all increased in probability again in the last month of life; it is unclear whether this decrease was in response to increased mealtime support, a natural fluctuation in disease processes, or a spurious finding. Furthermore, it is possible that some decedents in our study experienced excess eating difficulties as a result of inadequate nutritional care. A thoughtfully designed prospective cohort study could tease out factors including care practices that contribute to or protect against eating-related decline in LTC residents. For example, nutritional factors that are associated with longer or shorter time to death could be identified through a comparison of various aspects of nutrition care in those who did and did not surpass 6-month life expectancy among participants originally recruited based on a combination of increased risk of 6-month mortality and nutrition-related challenges. Alternatively, a study to test the differential mortality of residents matched for eating challenges between LTC homes that have implemented purposeful nutrition or palliative care initiatives compared to control (non-intervention) homes could identify the potential impact of home-level factors on overall survival of residents. Such studies would help to identify potential home-level effects and identify residents that may be more likely to benefit from a restorative versus palliative approach to care and to inform decision-making in this regard. Indeed, a broader evidence base for best practice development is needed to optimize both restorative and palliative approaches to nutrition care in order to support decision-making and safeguard optimal outcomes.

Supported by the existing knowledge and ongoing efforts to strengthen the evidence base, intervention studies aimed towards integrating a palliative approach to care in LTC that specifically incorporate a nutrition component are warranted. In order to support innovations in relationship-centered comfort-focused nutrition care that are meaningful in the context of current LTC practice, a co-design approach that involves key champions throughout the process of design, implementation, evaluation, and spread is recommended (S. Caspar, 2020; Slattery et al., 2020). As discussed earlier, I propose that the involvement of dietitians and PSWs, as well as other members of the care team, in these efforts will improve the likelihood of intervention success. Success should not only be measured by residents' physical (e.g., comfort) indicators, but also by measures of psychosocial well-being (e.g., quality of life) of all members of the care relationship (e.g., residents, family, LTC team). Certainly, a social model of care that emphasizes resident outcomes is desirable, but it must be applicable to the specific needs and context of the people giving and receiving end-of-life nutrition care within the current LTC environment.

In light of the findings from this dissertation, some practical steps can be taken immediately to move towards a palliative approach to nutrition care for residents experiencing eating-related decline in LTC. Promisingly, our resident chart review demonstrated that comfort-focused nutrition orders were used in practice, though inconsistently. As such, dissemination of these findings and engagement of dietitians to champion further application of existing orders is recommended (Sheffer-Hilel et al., 2022). Creation of additional resources, including information pamphlets directed towards residents and families and discussion guides for care providers, can facilitate conversations about eating challenges and palliative nutrition care options. Integrating these conversations into existing advance care planning initiatives and multidisciplinary care conferences where possible may increase the uptake of comfort-focused nutrition care practices or at least serve to inform and manage caregivers' expectations around potential trajectories of eating-related decline (Harasym et al., 2020; Heckman et al., 2021). Ultimately, an acknowledgment of death as a reality in LTC is paramount to implementing palliative approaches to care more broadly (Cable-Williams & Wilson, 2017), so efforts to normalize death in this regard may be expected to increase the acceptance and earlier initiation of comfort-focused nutrition care as well.

9.8 Conclusion

In conclusion, this dissertation offers a novel contribution to the understanding of the intersection between nutrition care and end-of-life care in LTC homes. The findings can be used as a foundation for further studies to improve care practices that support residents with eating-related decline leading towards the end of life using a palliative approach to care. Certainly, palliative care principles are relevant and emerging within the LTC sector given the recognized need to support residents with complex life-limiting conditions; there is much to be learned from the field of palliative care. Concerning food and nutrition within the palliative literature, eating deficiencies are understood to represent a transitional phase between life and death requiring a holistic approach to support the comfort and quality of life of individuals with life-limiting conditions and their family caregivers (Pinho-Reis et al., 2022; Wallin et al., 2015, 2022). However, prior to this dissertation, the connection between eating challenges and end-of-life decline had not been explicitly made in the LTC literature. Nor had the implications on the development of a palliative approach to nutrition care been explored in the LTC context despite evidence that LTC care providers associate residents' eating challenges with end-of-life decline (Åvik Persson et al., 2018; Brandt, 2005; Cable-Williams & Wilson, 2014). An important step towards developing a palliative approach to nutrition care in LTC is to understand the current end-of-life nutrition care experiences of LTC residents and their care providers. To this end, we described nutrition-related documentation found within the resident charts from the final six month of life of deceased LTC residents as the basis of this dissertation. The research findings provide a novel description of the end-of-life nutrition care experience and highlight opportunities for potential growth and development of a palliative approach to nutrition care in LTC. First, this research provides quantitative evidence from several LTC homes in Ontario that eating challenges increase in prevalence and complexity over time with proximity to death, likely justifying a palliative approach to nutrition care. However, based on our findings comfort-focused nutrition care orders are used relatively infrequently and late in the end-of-life trajectory representing an opportunity for improvement. Furthermore, the results demonstrate that several eating-related challenges signal to care providers that residents are advancing towards the end of life but, except for dysphagia, the identification of these eating challenges is not consistently related to time to death. Nonetheless, such signs (e.g., decreased food intake, refusal to eat) may be leveraged to trigger comfort-focused care conversations as part of a broader palliative approach to nutrition care. Finally, the potential role of the dietitian in championing the integration of a palliative philosophy into nutrition care practices is implicated by the research findings. Altogether, these findings present a strong case for developing a palliative philosophy around nutrition care in LTC. Such an approach is important to empower care providers to confidently support residents with eating-related decline, thus supporting the psychosocial well-being of both care providers and residents while upholding the rich symbolism surrounding food when eating becomes challenging, undesirable, or impossible for residents. Innovation in palliative-focused nutrition care requires further studies to understand the specific end-of-life nutrition care needs of residents and the care practices that best address these needs to support the quality of life of the people who live and work in LTC.

References

Abbott, R. A., Whear, R., Thompson-Coon, J., Ukoumunne, O. C., Rogers, M., Bethel, A., Hemsley, A., & Stein, K. (2013). Effectiveness of mealtime interventions on nutritional outcomes for the elderly living in residential care: A systematic review and meta-analysis. *Ageing Research Reviews*, *12*(4), 967–981. https://doi.org/10.1016/j.arr.2013.06.002

Adams, C., Young, D., Gastañaduy, P. A., Paul, P., Marsh, Z., Hall, A. J., & Lopman, B. A. (2020). Quantifying the roles of vomiting, diarrhea, and residents vs. Staff in norovirus transmission in U.S. nursing home outbreaks. *PLoS Computational Biology*, *16*(3), e1007271. https://doi.org/10.1371/journal.pcbi.1007271

Agarwal, E., Marshall, S., Miller, M., & Isenring, E. (2016). Optimising nutrition in residential aged care: A narrative review. *Maturitas*, *92*, 70–78. https://doi.org/10.1016/j.maturitas.2016.06.013

Agarwal, E., Miller, M., Yaxley, A., & Isenring, E. (2013). Malnutrition in the elderly: A narrative review. *Maturitas*, *76*(4), 296–302. https://doi.org/10.1016/j.maturitas.2013.07.013

Alam, S., & Drakos, A. (2022). Staffing crisis: Addressing the high turnover rate of personal support workers in Ontario's long-term care sector. *The Meducator*, *1*(39). https://doi.org/10.15173/m.v1i39.3301

Allison, J. J., Wall, T. C., Spettell, C. M., Calhoun, J., Fargason, C. A., Kobylinski, R. W., Farmer, R., & Kiefe, C. (2000). The art and science of chart review. *The Joint Commission Journal on Quality Improvement*, *26*(3), 115–136. https://doi.org/10.1016/S1070-3241(00)26009-4

American Geriatrics Society [AGS] Ethics Committee and Clinical Practice and Models of Care Committee. (2014). American Geriatrics Society feeding tubes in advanced dementia position statement. *Journal of the American Geriatrics Society*, *62*(8), 1590–1593. https://doi.org/10.1111/jgs.12924

Anantapong, K., Barrado-Martín, Y., Nair, P., Rait, G., Smith, C. H., Moore, K. J., Manthorpe, J., Sampson, E. L., & Davies, N. (2021). How do people living with dementia perceive eating and drinking difficulties? A qualitative study. *Age and Ageing*, *50*(5), 1820–1828. https://doi.org/10.1093/ageing/afab108

Anantapong, K., Davies, N., Chan, J., McInnerney, D., & Sampson, E. L. (2020). Mapping and understanding the decision-making process for providing nutrition and hydration to people living with dementia: A systematic review. *BMC Geriatrics*, *20*(1), 520. https://doi.org/10.1186/s12877-020-01931-y

Anatchkova, M., Brooks, A., Swett, L., Hartry, A., Duffy, R. A., Baker, R. A., Hammer-Helmich, L., & Sanon Aigbogun, M. (2019). Agitation in patients with dementia: A systematic review of epidemiology and association with severity and course. *International Psychogeriatrics*, *31*(9), 1305–1318. https://doi.org/10.1017/S1041610218001898

Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative Performance Scale (PPS): A new tool. *Journal of Palliative Care*, *12*(1), 5–11. https://doi.org/10.1177/082585979601200102

Arcand, M. (2015). End-of-life issues in advanced dementia: Part 2: management of poor nutritional intake, dehydration, and pneumonia. *Canadian Family Physician*, *61*(4), 337–341.

Archbald-Pannone, L., Sevilleja, J. E., & Guerrant, R. (2010). Diarrhea, Clostridium difficile, and intestinal inflammation in residents of a long-term care facility. *Journal of the American Medical Directors Association*, *11*(4), 263–267. https://doi.org/10.1016/j.jamda.2009.09.006

Armstrong, P., Armstrong, H., & Bourgeault, I. L. (2023). Teaming up for long-term care: Recognizing all long-term care staff contribute to quality care. *Healthcare Management Forum*, *36*(1), 26–29. https://doi.org/10.1177/08404704221115811

Armstrong, P., Banerjee, A., Armstrong, H., Braedley, S., Choiniere, J., Lowndes, R., & Struthers, J. (2019). *Models for long-term residential care: A summary of the consultants' report to long-term care homes and services, City of Toronto.* https://www.toronto.ca/wp-content/uploads/2022/11/9118-Models-for-Long-term-Residential-Care-SSLTC-Council-Issue-Note-130891.pdf

Artiles, C. E., Regan, J., & Donnellan, C. (2021). Dysphagia screening in residential care settings: A scoping review. *International Journal of Nursing Studies*, *114*, 103813. https://doi.org/10.1016/j.ijnurstu.2020.103813

Åvik Persson, H., Sandgren, A., Fürst, C.-J., Ahlström, G., & Behm, L. (2018). Early and late signs that precede dying among older persons in nursing homes: The multidisciplinary team's perspective. *BMC Geriatrics*, *18*(1), 134. https://doi.org/10.1186/s12877-018-0825-0

Backhouse, T., Killett, A., Mioshi, E., & Khondoker, M. (2023). What are the factors associated with people with advanced dementia refusing assistance with personal care? *International Journal of Geriatric Psychiatry*, *38*(1), e5857. https://doi.org/10.1002/gps.5857

Baillie, J., Anagnostou, D., Sivell, S., Van Godwin, J., Byrne, A., & Nelson, A. (2018). Symptom management, nutrition and hydration at end-of-life: A qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliative Care*, *17*(1), 60. https://doi.org/10.1186/s12904-018-0314-4

Balint, E. (1969). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners*, *17*(82), 269–276.

Banerjee, A., & Armstrong, P. (2015). Centring care: Explaining regulatory tensions in residential care for older persons. *Studies in Political Economy*, *95*(1), 7–28. https://doi.org/10.1080/19187033.2015.11674944

Banerjee, A., Armstrong, P., Daly, T., Armstrong, H., & Braedley, S. (2015). "Careworkers don't have a voice:" epistemological violence in residential care for older people. *Journal of Aging Studies*, *33*, 28–36. https://doi.org/10.1016/j.jaging.2015.02.005

Banerjee, A., Daly, T., Armstrong, H., Armstrong, P., Lafrance, S., & Szebehely, M. (2008). *"Out of control": Violence against personal support workers in long-term care*. Longwoods.com. https://www.longwoods.com/articles/images/Violence_LTC_022408_Final.pdf

Banerjee, A., & Rewegan, A. (2017). Intensifying relational care: The challenge of dying in long-term residential care. *Journal of Canadian Studies*, *50*(2), 396–421. https://doi.org/10.3138/jcs.50.2.396

Banks, N. J. (1998). Designing medical record abstraction forms. *International Journal for Quality in Health Care*, *10*(2), 163–167. https://doi.org/10.1093/intqhc/10.2.163

Barclay, S., Froggatt, K., Crang, C., Mathie, E., Handley, M., Iliffe, S., Manthorpe, J., Gage, H., & Goodman, C. (2014). Living in uncertain times: Trajectories to death in residential care homes. *British Journal of General Practice*, *64*(626), e576–e583. https://doi.org/10.3399/bjgp14X681397

Barkema, W. S., Heckman, G. A., Slaughter, S. E., Carrier, N., Lengyel, C. O., & Keller, H. H. (2019). Medical diagnosis does not influence food intake in frail long-term care residents. *The Journal of Nursing Home Research*, *5*, 49–55.

Barken, R., Denton, M., Sayin, F. K., Brookman, C., Davies, S., & Zeytinoglu, I. U. (2018). The influence of autonomy on personal support workers' job satisfaction, capacity to care, and intention to stay. *Home Health Care Services Quarterly*, *37*(4), 294–312. https://doi.org/10.1080/01621424.2018.1493014

Barrado-Martín, Y., Hatter, L., Moore, K. J., Sampson, E. L., Rait, G., Manthorpe, J., Smith, C. H., Nair, P., & Davies, N. (2021). Nutrition and hydration for people living with dementia near the end of life: A qualitative systematic review. *Journal of Advanced Nursing*, *77*(2), 664–680. https://doi.org/10.1111/jan.14654

Barrado-Martín, Y., Nair, P., Anantapong, K., Aker, N., Moore, K. J., Smith, C. H., Rait, G., Sampson, E. L., Manthorpe, J., & Davies, N. (2022). Family caregivers' and professionals' experiences of supporting people living with dementia's nutrition and hydration needs towards the end of life. *Health & Social Care in the Community*, *30*(1), 307–318. https://doi.org/10.1111/hsc.13404

Bartrim, K., Moyle, W., Rigby, R., & Ball, L. (2023). Examining dietitians' knowledge, skills and attitudes regarding working with older adults in residential aged care facilities and home care services: An integrative review. *Journal of Human Nutrition and Dietetics*, *36*(1), 86–96. https://doi.org/10.1111/jhn.13073

Batchelor-Murphy, M. K., Kennerly, S. M., Horn, S. D., Barrett, R., Bergstrom, N., Boss, L., & Yap, T. L. (2019). Impact of cognition and handfeeding assistance on nutritional intake for nursing home residents. *Journal of Nutrition in Gerontology and Geriatrics*, *38*(3), 262–276. https://doi.org/10.1080/21551197.2019.1617221

Batchelor-Murphy, M. K., McConnell, E. S., Amella, E. J., Anderson, R. A., Bales, C. W., Silva, S., Barnes, A., Beck, C., & Colon-Emeric, C. S. (2017). Experimental comparison of efficacy for three handfeeding techniques in dementia. *Journal of the American Geriatrics Society*, *65*(4), e89–e94. https://doi.org/10.1111/jgs.14728

Beach, M. C., Inui, T., & and the Relationship-Centered Care Research Network. (2006). Relationship-centered care. A constructive reframing. *Journal of General Internal Medicine*, *21*(S1), S3–S8. https://doi.org/10.1111/j.1525-1497.2006.00302.x

Beck, A. M., Dent, E., & Baldwin, C. (2016). Nutritional intervention as part of functional rehabilitation in older people with reduced functional ability: A systematic review and meta-analysis of randomised controlled studies. *Journal of Human Nutrition and Dietetics*, *29*(6), 733–745. https://doi.org/10.1111/jhn.12382

Bell, C. L., Tamura, B. K., Masaki, K. H., & Amella, E. J. (2013). Prevalence and measures of nutritional compromise among nursing home patients: Weight loss, low body mass index, malnutrition, and feeding dependency, a systematic review of the literature. *Journal of the American Medical Directors Association*, *14*(2), 94–100. https://doi.org/10.1016/j.jamda.2012.10.012

Bennett, R. G., & Greenough, W. B. (1993). Approach to acute diarrhea in the elderly. *Gastroenterology Clinics of North America*, *22*(3), 517–533.

Bergland, Å., Johansen, H., & Sellevold, G. S. (2015). A qualitative study of professional caregivers' perceptions of processes contributing to mealtime agitation in persons with dementia in nursing home wards and strategies to attain calmness. *Nursing Open*, *2*(3), 119–129. https://doi.org/10.1002/nop2.24

Berkman, C., Ahronheim, J. C., & Vitale, C. A. (2019). Speech-language pathologists' views about aspiration risk and comfort feeding in advanced dementia. *American Journal of Hospice and Palliative Medicine*, *36*(11), 993–998. https://doi.org/10.1177/1049909119849003

Bern-Klug, M. (2006). Calling the question of "possible dying" among nursing home residents: Triggers, barriers, and facilitators. *Journal of Social Work in End-of-Life & Palliative Care*, *2*(3), 61–85. https://doi.org/10.1300/J457v02n03_06

Berridge, C., Lima, J., Schwartz, M., Bishop, C., & Miller, S. C. (2020). Leadership, staff empowerment, and the retention of nursing assistants: Findings from a survey of U.S. nursing homes. *Journal of the American Medical Directors Association*, *21*(9), 1254-1259.e2. https://doi.org/10.1016/j.jamda.2020.01.109

Beynon, C., Siegel, E. O., Supiano, K., & Edelman, L. S. (2022). Working dynamics of licensed nurses and nurse aides in nursing homes: A scoping review. *Journal of Gerontological Nursing*, *48*(5), 27–34. https://doi.org/10.3928/00989134-20220405-01

Beynon, C., Supiano, K., Siegel, E. O., Edelman, L. S., Hart, S. E., & Madden, C. (2021). It’s all about the nurse aides. *Journal of Long-Term Care*, 356–364. https://doi.org/10.31389/jltc.103

Borders, J. C., Blanke, S., Johnson, S., Gilmore-Bykovskyi, A., & Rogus-Pulia, N. (2020). Efficacy of mealtime interventions for malnutrition and oral intake in persons with dementia: A systematic review. *Alzheimer Disease and Associated Disorders*, *34*(4), 366–379. https://doi.org/10.1097/WAD.0000000000000387

Borkent, J. W., Van Hout, H. P. J., Feskens, E. J. M., Naumann, E., & De Van Der Schueren, M. A. E. (2023). Diseases, Health-Related Problems, and the Incidence of Malnutrition in Long-Term Care Facilities. *International Journal of Environmental Research and Public Health*, *20*(4), 3170. https://doi.org/10.3390/ijerph20043170

Boyd, M., Frey, R., Balmer, D., Robinson, J., McLeod, H., Foster, S., Slark, J., & Gott, M. (2019). End of life care for long-term care residents with dementia, chronic illness and cancer: Prospective staff survey. *BMC Geriatrics*, *19*(1), 137. https://doi.org/10.1186/s12877-019-1159-2

Brandt, H. E. (2005). Symptoms, signs, problems, and diseases of terminally ill nursing home patients: A nationwide observational study in the Netherlands. *Archives of Internal Medicine*, *165*(3), 314. https://doi.org/10.1001/archinte.165.3.314

Brink, P., & Kelley, M. L. (2015). Death in long-term care: A brief report examining factors associated with death within 31 days of assessment. *Palliative Care: Research and Treatment*, *9*, PCRT.S20347. https://doi.org/10.4137/PCRT.S20347

Brooke, J., & Ojo, O. (2015). Enteral nutrition in dementia: A systematic review. *Nutrients*, *7*(4), 2456–2468. https://doi.org/10.3390/nu7042456

Brown, M. A., Sampson, E. L., Jones, L., & Barron, A. M. (2013). Prognostic indicators of 6-month mortality in elderly people with advanced dementia: A systematic review. *Palliative Medicine*, *27*(5), 389–400. https://doi.org/10.1177/0269216312465649

Browne, C. V., & Braun, K. L. (2008). Globalization, women's migration, and the long-term-care workforce. *The Gerontologist*, *48*(1), 16–24. https://doi.org/10.1093/geront/48.1.16

Bükki, J., Neuhaus, P. M., & Paal, P. (2016). End of life care in nursing homes: Translating focus group findings into action. *Geriatric Nursing*, *37*(6), 440–445. https://doi.org/10.1016/j.gerinurse.2016.06.011

Bunn, D. K., Abdelhamid, A., Copley, M., Cowap, V., Dickinson, A., Howe, A., Killett, A., Poland, F., Potter, J. F., Richardson, K., Smithard, D., Fox, C., & Hooper, L. (2016). Effectiveness of interventions to indirectly support food and drink intake in people with dementia: Eating and Drinking Well in Dementia (EDWINA) systematic review. *BMC Geriatrics*, *16*(1), 89. https://doi.org/10.1186/s12877-016-0256-8

Burrows, A. B., Morris, J. N., Simon, S. E., Hirdes, J. P., & Phillips, C. (2000). Development of a Minimum Data Set-based Depression Rating Scale for use in nursing homes. *Age and Ageing*, *29*(2), 165–172. https://doi.org/10.1093/ageing/29.2.165

Busari, J. O., Moll, F. M., & Duits, A. J. (2017). Understanding the impact of interprofessional collaboration on the quality of care: A case report from a small-scale resource limited health care environment. *Journal of Multidisciplinary Healthcare*, *10*, 227–234. https://doi.org/10.2147/JMDH.S140042

Cable-Williams, B., & Wilson, D. (2014). Awareness of impending death for residents of long-term care facilities. *International Journal of Older People Nursing*, *9*(2), 169–179. https://doi.org/10.1111/opn.12045

Cable-Williams, B., & Wilson, D. M. (2017). Dying and death within the culture of long-term care facilities in Canada. *International Journal of Older People Nursing*, *12*(1), e12125. https://doi.org/10.1111/opn.12125

Cagle, J. G., Unroe, K. T., Bunting, M., Bernard, B. L., & Miller, S. C. (2017). Caring for dying patients in the nursing home: Voices from frontline nursing home staff. *Journal of Pain and Symptom Management*, *53*(2), 198–207. https://doi.org/10.1016/j.jpainsymman.2016.08.022

Canadian Hospice Palliative Care Association [CHPCA]. (2013). *A Model to Guide Hospice Palliative Care*. Canadian Hospice Palliative Care Association. https://www.chpca.ca/wp-content/uploads/2019/12/norms-of-practice-eng-web.pdf

Canadian Institute for Health Information [CIHI]. (2018). *Access to Palliative Care in Canada*. CIHI. https://www.cihi.ca/sites/default/files/document/access-to-palliative-care-in-canada-2023-report-en.pdf

Canadian Institute for Health Information [CIHI]. (2020). *Profile of Residents in Residential and Hospital-Based Continuing Care, 2018-2019* (Continuing Care Reporting System (CRS) Quick Stats). Canadian Institute for Health Information.

Canadian Institute for Health Information [CIHI]. (2021a). *Continuing Care Metadata*. https://www.cihi.ca/en/continuing-care-metadata

Canadian Institute for Health Information [CIHI]. (2021b). *How many long-term care beds are there in Canada?* https://www.cihi.ca/en/how-many-long-term-care-beds-are-there-in-canada#:~:text=In%20Canada%2C%20there%20are%202%2C076,of%20February%2028%2C%202021).

Canadian Institute for Health Information [CIHI]. (2021c). *Long-term care homes in Canada: How many and who owns them? [Infographic]*. https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them

Canadian Institute for Health Information [CIHI]. (2023). *Data Availability for CIHI Data Holdings (as of March 31, 2023)* [dataset]. CIHI.

Carpenter, I., & Hirdes, J. P. (2013). Using interRAI assessment systems to measure and maintain quality of long-term care. In *A Good Life in Old Age? Monitoring and Improving Quality in Long-Term Care* (pp. 93–139). OECD/European Commission 2013. https://doi.org/10.1787/9789264194564-7-en

Carrier, N., Villalon, L., Lengyel, C., Slaughter, S. E., Duizer, L., Morrison-Koechl, J., & Keller, H. (2019). Diet quality is associated with malnutrition and low calf circumference in Canadian long-term care residents. *BMC Nutrition*, *5*(1), 57. https://doi.org/10.1186/s40795-019-0314-7

Caspar, R. (1988). Food and water: Symbol and reality. *Health Progress (Saint Louis, Mo.)*, *69*(4), 54–58.

Caspar, S. (2020). Stakeholder engagement for successful practice change in long-term care: Evaluating the Feasible and Sustainable Culture Change Initiative (FASCCI) model: Supporting communities to deliver quality dementia care. *Alzheimer's & Dementia*, *16*(S8). https://doi.org/10.1002/alz.036917

Castillo, L. I. R., Hadjistavropoulos, T., & Beahm, J. (2022). Social media discussions about long-term care and the COVID-19 pandemic. *Journal of Aging Studies*, *63*, 101076. https://doi.org/10.1016/j.jaging.2022.101076

Cate, D., Ettema, R. G. A., Huisman-de Waal, G., Bell, J. J., Verbrugge, R., Schoonhoven, L., Schuurmans, M. J., the Basic Care Revisited Group (BCR), Zwakhalen, S., Vermeulen, H., Man-van Ginkel, J., Heinen, M., Metzelthin, S., Verstraten, C., Belle, E., Noort, H., Berg, G., & Manen, A. (2020). Interventions to prevent and treat malnutrition in older adults to be carried out by nurses: A systematic review. *Journal of Clinical Nursing*, *29*(11–12), 1883–1902. https://doi.org/10.1111/jocn.15153

Chaudhury, H., Hung, L., & Badger, M. (2013). The role of physical environment in supporting person-centered dining in long-term care: A review of the literature. *American Journal of Alzheimer's Disease and Other Dementias*, *28*(5), 491–500. https://doi.org/10.1177/1533317513488923

Chen, I., Lin, K., Hu, S. H., Chuang, Y., Long, C. O., Chang, C., & Liu, M. F. (2018). Palliative care for advanced dementia: Knowledge and attitudes of long-term care staff. *Journal of Clinical Nursing*, *27*(3–4), 848–858. https://doi.org/10.1111/jocn.14132

Choi, N., Garland, A., Ramsey, C., Steer, J., Keller, H. H., Heckman, G., Vucea, V., Bains, I., Kroetsch, B., Quail, P., King, S., Oshchepkova, T., Kalashnikova, T., Boscart, V., & Heyer, M. (2020). Problems with advance care planning processes and practices in nursing homes. *Journal of the American Medical Directors Association*, *21*(12), 2012–2013. https://doi.org/10.1016/j.jamda.2020.07.010

Chou, H.-H., Tsou, M.-T., & Hwang, L.-C. (2020). Nasogastric tube feeding versus assisted hand feeding in-home healthcare older adults with severe dementia in Taiwan: A prognosis comparison. *BMC Geriatrics*, *20*(1), 60. https://doi.org/10.1186/s12877-020-1464-9

Cichero, J. A. Y., Lam, P., Steele, C. M., Hanson, B., Chen, J., Dantas, R. O., Duivestein, J., Kayashita, J., Lecko, C., Murray, J., Pillay, M., Riquelme, L., & Stanschus, S. (2017). Development of international terminology and definitions for texture-modified foods and thickened fluids used in dysphagia management: The IDDSI framework. *Dysphagia*, *32*(2), 293–314. https://doi.org/10.1007/s00455-016-9758-y

Clarke, G., Fistein, E., Holland, A., Tobin, J., Barclay, S., & Barclay, S. (2018). Planning for an uncertain future in progressive neurological disease: A qualitative study of patient and family decision-making with a focus on eating and drinking. *BMC Neurology*, *18*(1), 115. https://doi.org/10.1186/s12883-018-1112-6

Cloutier, D., Stajduhar, K. I., Roberts, D., Dujela, C., & Roland, K. (2021). 'Bare-bones' to 'silver linings': Lessons on integrating a palliative approach to care in long-term care in Western Canada. *BMC Health Services Research*, *21*(1), 610. https://doi.org/10.1186/s12913-021-06606-x

College of Dietitians of Ontario. (2018). *Scope of practice for registered dietitians caring for clients with dysphagia in Ontario*. College of Dietitians of Ontario. https://www.collegeofdietitians.org/scope-of-practice/dysphagia/dysphagia-policy-(updated-2018).aspx

College of Dietitians of Ontario. (2021, May). *Long-term care dietitians: Your thoughts on documentation of oral food intake*. Regulation Matters 2020. https://www.collegeofdietitians.org/regulation-matters/2021-issue-1-may/are-you-a-dietitian-in-long-term-care.aspx#

Collingridge Moore, D., Payne, S., Van Den Block, L., Ling, J., Froggatt, K., Gatsolaeva, Y., Honinx, E., Pivodic, L., Miranda, R., Onwuteaka-Philipsen, B. D., Van Hout, H., Pasman, H. R. W., Oosterveld-Vlug, M., Ten Koppel, M., Piers, R., Van Den Noortgate, N., Engels, Y., Vernooij-Dassen, M., Hockley, J., … Wichmann, A. B. (2020). Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. *Palliative Medicine*, *34*(5), 558–570. https://doi.org/10.1177/0269216319893635

Collins, C., Tucker, C., Walton, C., Podbur, S., & Barrett, S. (2019). Pharmacy technician review of oral nutritional supplements (ONS) within care homes. *Pharmacy (Basel, Switzerland)*, *7*(1), 28. https://doi.org/10.3390/pharmacy7010028

Collins, L. M., & Lanza, S. T. (2010). *Repeated-Measures Latent Class Analysis and Latent Latent Transition Analysis* (pp. 181–224). John Wiley & Sons, Inc.

Cranley, L. A., Slaughter, S. E., Caspar, S., Heisey, M., Huang, M., Killackey, T., & McGilton, K. S. (2020). Strategies to facilitate shared decision-making in long-term care. *International Journal of Older People Nursing*, *15*(3), e12314. https://doi.org/10.1111/opn.12314

Cranley, L. A., Yeung, L., Tu, W., & McGillis Hall, L. (2022). Healthcare aide involvement in team decision-making in long-term care: A narrative review of the literature. *Journal of Clinical Nursing*, jocn.16573. https://doi.org/10.1111/jocn.16573

Darmon, P., Kaiser, M. J., Bauer, J. M., Sieber, C. C., & Pichard, C. (2010). Restrictive diets in the elderly: Never say never again? *Clinical Nutrition*, *29*(2), 170–174. https://doi.org/10.1016/j.clnu.2009.11.002

Davenport, J., & Yeung, H. (2019, June). *Comfort feeding only* [Online Learning Program]. Dietitians of Canada National Conference. https://members.dietitians.ca/DCMember/LearnProduct?id=01tf4000004O7KIAA0

del Río, M. I., Shand, B., Bonati, P., Palma, A., Maldonado, A., Taboada, P., & Nervi, F. (2012). Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff: perceptions toward hydration and nutrition at the end of life. *Psycho-Oncology*, *21*(9), 913–921. https://doi.org/10.1002/pon.2099

Dent, E., Wright, O. R. L., Woo, J., & Hoogendijk, E. O. (2023). Malnutrition in older adults. *The Lancet*, S0140673622026125. https://doi.org/10.1016/S0140-6736(22)02612-5

Dhand, N. K., & Khatkar, M. S. (2014). *Statulator: An online statistical calculator. Sample Size Calculator for Estimating a Single Proportion.* [Computer software]. http://statulator.com/SampleSize/ss1P.html

Dhedhi, S. A., Swinglehurst, D., & Russell, J. (2014). 'Timely' diagnosis of dementia: What does it mean? A narrative analysis of GPs' accounts. *BMJ Open*, *4*(3), e004439. https://doi.org/10.1136/bmjopen-2013-004439

Dietitians of Canada Ontario Long Term Care Action Group. (2016). *Ontario Long Term Care Dietitian Survey Report*. https://www.dietitians.ca/DietitiansOfCanada/media/Documents/Resources/12-2016-LTC-RD-Time-Survey-Report.pdf?ext=.pdf

Dodd, K. M. (2017, March). End-of-life care—Understanding the RD's role. *Today's Dietitian*, *19*(3), 36.

Donini, L. M., Stephan, B. C. M., Rosano, A., Molfino, A., Poggiogalle, E., Lenzi, A., Siervo, M., & Muscaritoli, M. (2020). What are the risk factors for malnutrition in older-aged institutionalized adults? *Nutrients*, *12*(9), 2857. https://doi.org/10.3390/nu12092857

Dorner, B., & Friedrich, E. K. (2018). Position of the Academy of Nutrition and Dietetics: Individualized nutrition approaches for older adults: long-term care, post-acute care, and other settings. *Journal of the Academy of Nutrition and Dietetics*, *118*(4), 724–735. https://doi.org/10.1016/j.jand.2018.01.022

Douglas, J. W., Jung, S. E., Noh, H., Ellis, A. C., & Ferguson, C. C. (2021). "If they don't like you, they are not going to eat for you": Individual and interpersonal factors affecting certified nursing assistants' ability to provide mealtime assistance to residents with dementia. *The Gerontologist*, *61*(4), 552–562. https://doi.org/10.1093/geront/gnaa145

Douglas, M. (1972). Deciphering a Meal. *Daedalus*, *101*(1), 61–81.

Douglas, M., & Gross, J. (1981). Food and culture: Measuring the intricacy of rule systems. *Social Science Information*, *20*(1), 1–35. https://doi.org/10.1177/053901848102000101

Druml, C., Ballmer, P. E., Druml, W., Oehmichen, F., Shenkin, A., Singer, P., Soeters, P., Weimann, A., & Bischoff, S. C. (2016). ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition (Edinburgh, Scotland)*, *35*(3), 545–556. https://doi.org/10.1016/j.clnu.2016.02.006

Duan, Y., Mueller, C. A., Yu, F., Talley, K. M., & Shippee, T. P. (2022). The relationships of nursing home culture change practices with resident quality of life and family satisfaction: Toward a more nuanced understanding. *Research on Aging*, *44*(2), 174–185. https://doi.org/10.1177/01640275211012652

Ducak, K., Keller, H. H., & Sweatman, G. (2015). Dining culture change in long-term care homes: Transitioning to resident-centered and relational meals. *Annals of Long-Term Care*, *23*(6). https://www.hmpgloballearningnetwork.com/site/altc/articles/dining-culture-change-long-term-care-homes-transitioning-resident-centered-and-relational

Dumic, I., Nordin, T., Jecmenica, M., Stojkovic Lalosevic, M., Milosavljevic, T., & Milovanovic, T. (2019). Gastrointestinal tract disorders in older age. *Canadian Journal of Gastroenterology and Hepatology*, *2019*, 1–19. https://doi.org/10.1155/2019/6757524

Durepos, P., Kaasalainen, S., Sussman, T., Parker, D., Brazil, K., Mintzberg, S., & Te, A. (2018). Family care conferences in long-term care: Exploring content and processes in end-of-life communication. *Palliative & Supportive Care*, *16*(5), 590–601. https://doi.org/10.1017/S1478951517000773

Durepos, P., Wickson-Griffiths, A., Hazzan, A. A., Kaasalainen, S., Vastis, V., Battistella, L., & Papaioannou, A. (2017). Assessing palliative care content in dementia care guidelines: A systematic review. *Journal of Pain and Symptom Management*, *53*(4), 804–813. https://doi.org/10.1016/j.jpainsymman.2016.10.368

Edahiro, A., Hirano, H., Yamada, R., Chiba, Y., Watanabe, Y., Tonogi, M., & Yamane, G. (2012). Factors affecting independence in eating among elderly with Alzheimer's disease: Eating in the elderly with AD. *Geriatrics & Gerontology International*, *12*(3), 481–490. https://doi.org/10.1111/j.1447-0594.2011.00799.x

Eisenmann, Y., Golla, H., Schmidt, H., Voltz, R., & Perrar, K. M. (2020). Palliative care in advanced dementia. *Frontiers in Psychiatry*, *11*, 699. https://doi.org/10.3389/fpsyt.2020.00699

Emodi, B. (1977). *A history of long-term care facilities for the elderly in Canada.* (4; CMHC Nursing Home and Hostels Design Guidelines Study). Government of Canada. https://publications.gc.ca/collections/collection_2016/schl-cmhc/NH18-25-4-1977-eng.pdf

Estabrooks, C. A., Straus, S. E., Flood, C. M., Keefe, J., Armstrong, P., Donner, G. J., Boscart, V., Ducharme, F., Silvius, J. L., & Wolfson, M. C. (2020). Restoring trust: COVID-19 and the future of long-term care in Canada. *FACETS*, *5*(1), 651–691. https://doi.org/10.1139/facets-2020-0056

Evans, C. (2005). Malnutrition in the elderly: A multifactorial failure to thrive. *The Permanente Journal*, *9*(3), 38–41. https://doi.org/10.7812/tpp/05-056

Farrell, T. W., Butler, J. M., Towsley, G. L., Telonidis, J. S., Supiano, K. P., Stephens, C. E., Nelson, N. M., May, A. L., & Edelman, L. S. (2022). Communication disparities between nursing home team members. *International Journal of Environmental Research and Public Health*, *19*(10), 5975. https://doi.org/10.3390/ijerph19105975

Fávaro-Moreira, N. C., Krausch-Hofmann, S., Matthys, C., Vereecken, C., Vanhauwaert, E., Declercq, A., Bekkering, G. E., & Duyck, J. (2016). Risk factors for malnutrition in older adults: A systematic review of the literature based on longitudinal data. *Advances in Nutrition*, *7*(3), 507–522. https://doi.org/10.3945/an.115.011254

Ferris, F. D., Gómez-Batiste, X., Fürst, C. J., & Connor, S. (2007). Implementing quality palliative care. *Journal of Pain and Symptom Management*, *33*(5), 533–541. https://doi.org/10.1016/j.jpainsymman.2007.02.033

Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*, *282*(14), 1365–1370. https://doi.org/10.1001/jama.282.14.1365

Firnhaber, G. C., Roberson, D. W., & Kolasa, K. M. (2020). Nursing staff participation in end-of-life nutrition and hydration decision-making in a nursing home: A qualitative study. *Journal of Advanced Nursing*, *76*(11), 3059–3068. https://doi.org/10.1111/jan.14491

Fleurke, M., Voskuil, D. W., & Beneken genaamd Kolmer, D. M. (2020). The role of the dietitian in the management of malnutrition in the elderly: A systematic review of current practices. *Nutrition & Dietetics*, *77*(1), 60–75. https://doi.org/10.1111/1747-0080.12546

Fong, R., Tsai, C.-F., Wong, W. H.-S., Yiu, O.-Y., & Luk, J. K. H. (2020). Speech therapy in palliative care and comfort feeding: Current practice and way ahead. *Asian Journal of Gerontology and Geriatrics*, *14*(2), 61–68. https://doi.org/10.12809/ajgg-2018-330-oa

Forbes, W. F., Jackson, J. A., & Kraus, A. S. (2013). *Institutionalization of the Elderly in Canada: Butterworths Perspectives on Individual and Population Aging Series*. Elsevier Science. https://books.google.ca/books?id=wkttBQAAQBAJ

Fries, B. E., Simon, S. E., Morris, J. N., Flodstrom, C., & Bookstein, F. L. (2001). Pain in U.S. nursing homes: Validating a pain scale for the Minimum Data Set. *The Gerontologist*, *41*(2), 173–179. https://doi.org/10.1093/geront/41.2.173

Fringer, A., Stängle, S., Büche, D., Ott, S. Ch., & Schnepp, W. (2020). The associations of palliative care experts regarding food refusal: A cross-sectional study with an open question evaluated by triangulation analysis. *PLOS ONE*, *15*(4), e0231312. https://doi.org/10.1371/journal.pone.0231312

Frissoni, G. B., Franzoni, S., Bellelli, G., Morris, J., & Warden, V. (1998). Overcoming eating difficulties in the severely demented. In L. Volicer & A. Hurley (Eds.), *Hospice Care for Patients with Advanced Progressive Dementia* (pp. 48–67). Springer Publishing Company.

Froggatt, K. A., Moore, D. C., Van den Block, L., Ling, J., Payne, S. A., Van den Block, L., Arrue, B., Baranska, I., Moore, D. C., Deliens, L., Engels, Y., Finne-Soveri, H., Froggatt, K., Gambassi, G., Honincx, E., Kijowska, V., Koppel, M. ten, Kylanen, M., Mammarella, F., … Vernooij-Dassen, M. (2020). Palliative care implementation in long-term care facilities: European Association for Palliative Care white paper. *Journal of the American Medical Directors Association*, *21*(8), 1051–1057. https://doi.org/10.1016/j.jamda.2020.01.009

Garland, A., Keller, H. H., Quail, P., Boscart, V., Heyer, M., Ramsey, C., Vucea, V., Choi, N., Bains, I., King, S., Oshchepkova, T., Kalashnikova, T., Kroetsch, B., Steer, J., & Heckman, G. (2022). BABEL (Better tArgeting, Better outcomes for frail ELderly patients) advance care planning: A comprehensive approach to advance care planning in nursing homes: a cluster randomised trial. *Age and Ageing*, *51*(3), afac049. https://doi.org/10.1093/ageing/afac049

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, *9*(2), 105–118. https://doi.org/10.1080/13607860412331310245

Gearing, R. E., Mian, I. A., Barber, J., & Ickowicz, A. (2006). A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *Journal of the Canadian Academy of Child and Adolescent Psychiatry = Journal De l'Academie Canadienne De Psychiatrie De L'enfant Et De L'adolescent*, *15*(3), 126–134.

Gieniusz, M., Sinvani, L., Kozikowski, A., Patel, V., Nouryan, C., Williams, M. S., Kohn, N., Pekmezaris, R., & Wolf-Klein, G. (2018). Percutaneous feeding tubes in individuals with advanced dementia: Are physicians "choosing wisely"? *Journal of the American Geriatrics Society*, *66*(1), 64–69. https://doi.org/10.1111/jgs.15125

Gilbert, E. H., Lowenstein, S. R., Koziol-McLain, J., Barta, D. C., & Steiner, J. (1996). Chart Reviews In Emergency Medicine Research: Where Are The Methods? *Annals of Emergency Medicine*, *27*(3), 305–308. https://doi.org/10.1016/S0196-0644(96)70264-0

Goddaer, J., & Abraham, I. L. (1994). Effects of relaxing music on agitation during meals among nursing home residents with severe cognitive impairment. *Archives of Psychiatric Nursing*, *8*(3), 150–158. https://doi.org/10.1016/0883-9417(94)90048-5

Goel, M. K., Khanna, P., & Kishore, J. (2010). Understanding survival analysis: Kaplan-Meier estimate. *International Journal of Ayurveda Research*, *1*(4), 274–278. https://doi.org/10.4103/0974-7788.76794

Gonella, S., Basso, I., Clari, M., Dimonte, V., & Di Giulio, P. (2021). A qualitative study of nurses' perspective about the impact of end-of-life communication on the goal of end-of-life care in nursing home. *Scandinavian Journal of Caring Sciences*, *35*(2), 502–511. https://doi.org/10.1111/scs.12862

Gonella, S., Basso, I., Dimonte, V., Martin, B., Berchialla, P., Campagna, S., & Di Giulio, P. (2019). Association between end-of-life conversations in nursing homes and end-of-life care outcomes: A systematic review and meta-analysis. *Journal of the American Medical Directors Association*, *20*(3), 249–261. https://doi.org/10.1016/j.jamda.2018.10.001

Hai, S., Cao, L., Yang, X., Wang, H., Liu, P., Hao, Q., & Dong, B. (2017). Association between nutrition status and cognitive impairment among Chinese nonagenarians and centenarians. *International Journal of Gerontology*, *11*(4), 215–219. https://doi.org/10.1016/j.ijge.2016.12.002

Hamburg, M. E., Finkenauer, C., & Schuengel, C. (2014). Food for love: The role of food offering in empathic emotion regulation. *Frontiers in Psychology*, *5*, 32. https://doi.org/10.3389/fpsyg.2014.00032

Hanson, L. C., Ersek, M., Gilliam, R., & Carey, T. S. (2011). Oral feeding options for people with dementia: A systematic review. *Journal of the American Geriatrics Society*, *59*(3), 463–472. https://doi.org/10.1111/j.1532-5415.2011.03320.x

Harasym, P. M., Afzaal, M., Brisbin, S., Sinnarajah, A., Venturato, L., Quail, P., Kaasalainen, S., Straus, S., Sussman, T., Virk, N., & Holroyd-Leduc, J. M. (2021). Multi-disciplinary supportive end of life care in long-term care: An integrative approach to improving end of life. *BMC Geriatrics*, *21*(1), 326. https://doi.org/10.1186/s12877-021-02271-1

Harasym, P. M., Brisbin, S., Afzaal, M., Sinnarajah, A., Venturato, L., Quail, P., Kaasalainen, S., Straus, S. E., Sussman, T., Virk, N., & Holroyd-Leduc, J. (2020). Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: A qualitative descriptive study of community-based and specialist palliative care physicians’ experiences, perceptions and perspectives. *BMJ Open*, *10*(8), e037466. https://doi.org/10.1136/bmjopen-2020-037466

Harper, A. E., Terhorst, L., Moscirella, M., Turner, R. L., Piersol, C. V., & Leland, N. E. (2021). The experiences, priorities, and perceptions of informal caregivers of people with dementia in nursing homes: A scoping review. *Dementia*, *20*(8), 2746–2765. https://doi.org/10.1177/14713012211012606

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., & Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, *95*, 103208. https://doi.org/10.1016/j.jbi.2019.103208

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Hasler, W. L., & Chey, W. D. (2003). Nausea and vomiting. *Gastroenterology*, *125*(6), 1860–1867. https://doi.org/10.1053/j.gastro.2003.09.040

Hawley, P. H. (2014). The bow tie model of 21st century palliative care. *Journal of Pain and Symptom Management*, *47*(1), e2–e5. https://doi.org/10.1016/j.jpainsymman.2013.10.009

Hawley, P. H. (2017). Barriers to access to palliative care. *Palliative Care*, *10*, 1178224216688887. https://doi.org/10.1177/1178224216688887

Heckman, G. A., Boscart, V., Quail, P., Keller, H. H., Ramsey, C., Vucea, V., King, S., Bains, I., Choi, N., & Garland, A. (2021). Applying the Knowledge-to-Action framework to engage stakeholders and solve shared challenges with person-centered advance care planning in long-term care homes. In *Canadian Journal on Aging / La Revue canadienne du vieillissement* (p. 1). https://doi.org/10.1017/s0714980820000410

Hector, P. (2022). Ageism in post-acute and long-term care: Is that possible? *Caring for the Ages*, *23*(7), 9–10. https://doi.org/10.1016/j.carage.2022.09.018

Hill, E., Savundranayagam, M. Y., Zecevic, A., & Kloseck, M. (2018). Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care. *American Journal of Alzheimer's Disease & Other Dementiasr*, *33*(5), 284–291. https://doi.org/10.1177/1533317518765124

Hirdes, J. P., Frijters, D. H., & Teare, G. F. (2003). The MDS-CHESS scale: A new measure to predict mortality in institutionalized older people. *Journal of the American Geriatrics Society*, *51*(1), 96–100. https://doi.org/jgs51017

Hirdes, J. P., Heckman, G. A., Morinville, A., Costa, A., Jantzi, M., Chen, J., & Hébert, P. C. (2019). One way out? A multistate transition model of outcomes after nursing home admission. *Journal of the American Medical Directors Association*, *20*(11), 1425-1431.e1. https://doi.org/10.1016/j.jamda.2019.02.010

Hoben, M., Chamberlain, S. A., Gruneir, A., Knopp-Sihota, J. A., Sutherland, J. M., Poss, J. W., Doupe, M. B., Bergstrom, V., Norton, P. G., Schalm, C., McCarthy, K., Kashuba, K., Ackah, F., & Estabrooks, C. A. (2019). Nursing home length of stay in 3 Canadian health regions: Temporal trends, jurisdictional differences, and associated factors. *Journal of the American Medical Directors Association*, *20*(9), 1121–1128. https://doi.org/10.1016/j.jamda.2019.01.144

Hopkinson, J., & Corner, J. (2006). Helping patients with advanced cancer live with concerns about eating: A challenge for palliative care professionals. *Journal of Pain and Symptom Management*, *31*(4), 293–305. https://doi.org/10.1016/j.jpainsymman.2005.09.005

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Hsu, A. T., Berta, W., Coyte, P. C., & Laporte, A. (2016). Staffing in Ontario's long-term care homes: Differences by profit status and chain ownership. *Canadian Journal on Aging / La*

Revue Canadienne Du Vieillissement, *35*(2), 175–189. https://doi.org/10.1017/S0714980816000192

Hughes, S. L., Greer, A. L., Elliot, A. J., McEwen, S. A., Young, I., & Papadopoulos, A. (2021). Epidemiology of norovirus and viral gastroenteritis in Ontario, Canada, 2009–2014. *Canada Communicable Disease Report*, *47*(10), 397–404. https://doi.org/10.14745/ccdr.v47i10a01

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., Kwon, J. H., Hutchins, R., Liem, C., & Bruera, E. (2014). Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": A systematic review. *Journal of Pain and Symptom Management*, *47*(1), 77–89. https://doi.org/10.1016/j.jpainsymman.2013.02.021

Hung, L. (2008). The dining experience of residents with dementia in long-term care facilities. *Seniors' Housing Update*, *17*, 1–4.

Iida, K., Ryan, A., Payne, S., Iida, K., Ryan, A., Payne, S., Hasson, F., & McIlfatrick, S. (2022). Palliative care in Japanese long-term care facilities. *International Journal of Palliative Nursing*, *28*(1), 28–37. https://doi.org/10.12968/ijpn.2022.28.1.28

Ijaopo, E. O., & Ijaopo, R. O. (2019). Tube feeding in individuals with advanced dementia: A review of its burdens and perceived benefits. *Journal of Aging Research*, *2019*, 7272067. https://doi.org/10.1155/2019/7272067

Iyamu, I., Plottel, L., Snow, M. E., Zhang, W., Havaei, F., Puyat, J., Sawatzky, R., & Salmon, A. (2022). Culture change in long-term care-post COVID-19: Adapting to a new reality using established ideas and systems. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, 1–8. https://doi.org/10.1017/S0714980822000344

Jeejeebhoy, K. N. (2012). Malnutrition, fatigue, frailty, vulnerability, sarcopenia and cachexia: Overlap of clinical features. *Current Opinion in Clinical Nutrition and Metabolic Care*, *15*(3), 213–219. https://doi.org/10.1097/MCO.0b013e328352694f

Jefferies, D., Johnson, M., & Griffiths, R. (2010). A meta-study of the essentials of quality nursing documentation. *International Journal of Nursing Practice*, *16*(2), 112–124. https://doi.org/10.1111/j.1440-172X.2009.01815.x

Johnson, S., Nasser, R., Banow, T., Cockburn, T., Voegeli, L., Wilson, O., & Coleman, J. (2009). Use of oral nutrition supplements in long-term care facilities. *Canadian Journal of Dietetic Practice and Research*, *70*(4), 194–198. https://doi.org/10.3148/70.4.2009.194

Johnson, S., Nasser, R., Rustad, K., Chan, J., Wist, C., Siddique, A., & Tulloch, H. (2018). Review of nutrition screening and assessment practices for long-term care residents. *Journal of Nutrition in Gerontology and Geriatrics*, *37*(3–4), 169–182. https://doi.org/10.1080/21551197.2018.1482811

Jones, M. O. (2007). Food choice, symbolism, and identity: Bread-and-butter issues for folkloristics and nutrition studies (American Folklore Society presidential address, October 2005). *The Journal of American Folklore*, *120*(476), 129–177.

Jordan, R. I., Allsop, M. J., ElMokhallalati, Y., Jackson, C. E., Edwards, H. L., Chapman, E. J., Deliens, L., & Bennett, M. I. (2020). Duration of palliative care before death in international routine practice: A systematic review and meta-analysis. *BMC Medicine*, *18*(1), 368. https://doi.org/10.1186/s12916-020-01829-x

Jørgensen, T. L., Hallas, J., Friis, S., & Herrstedt, J. (2012). Comorbidity in elderly cancer patients in relation to overall and cancer-specific mortality. *British Journal of Cancer*, *106*(7), 1353–1360. https://doi.org/10.1038/bjc.2012.46

Julkunen, L., Hiltunen, K., Kautiainen, H., Saarela, R. K. T., Pitkälä, K. H., & Mäntylä, P. (2021). Oral disease burden of dentate older adults living in long-term care facilities: FINORAL study. *BMC Oral Health*, *21*(1), 624. https://doi.org/10.1186/s12903-021-01984-4

Jung, D., Lee, K., Gagne, J. C. D., Lee, M., Lee, H., Yoo, L., Won, S., & Choi, E. (2021). Eating difficulties among older adults with dementia in long-term care facilities: A scoping review. *International Journal of Environmental Research and Public Health*, *18*(19), 10109. https://doi.org/10.3390/ijerph181910109

Kaasalainen, S., Brazil, K., & Kelley, M. L. (2014). Building capacity in palliative care for personal support workers in long-term care through experiential learning. *International Journal of Older People Nursing*, *9*(2), 151–158. https://doi.org/10.1111/opn.12008

Kaasalainen, S., Sussman, T., Durepos, P., McCleary, L., Ploeg, J., Thompson, G., & the SPA-LTC Team. (2019). What are staff perceptions about their current use of emergency departments for long-term care residents at end of life? *Clinical Nursing Research*, *28*(6), 692–707. https://doi.org/10.1177/1054773817749125

Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Hunter, P. V., Wickson-Griffiths, A., Cook, R., Bello-Haas, V. D., Venturato, L., Papaioannou, A., You, J., & Parker, D. (2019). A stakeholder analysis of the Strengthening a Palliative Approach in Long-Term Care model. *Nursing Leadership (Toronto, Ont.)*, *32*(3), 27–39. https://doi.org/10.12927/cjnl.2019.25974

Kaasalainen, S., Sussman, T., Neves, P., & Papaioannou, A. (2016). Strengthening a Palliative Approach in Long-Term Care (SPA-LTC): A new program to improve quality of living and dying for residents and their family members. *Journal of the American Medical Directors Association*, *17*(3), B21. https://doi.org/10.1016/j.jamda.2015.12.067

Kaasalainen, S., Sussman, T., Thompson, G., McCleary, L., Hunter, P. V., Venturato, L., Wickson-Griffiths, A., Ploeg, J., Parker, D., Sinclair, S., Dal Bello-Haas, V., Earl, M., You, J. J., & the

SPA-LTC team. (2020). A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program. *BMC Palliative Care*, *19*(1), 107. https://doi.org/10.1186/s12904-020-00599-w

Kai, K., Hashimoto, M., Amano, K., Tanaka, H., Fukuhara, R., & Ikeda, M. (2015). Relationship between Eating Disturbance and Dementia Severity in Patients with Alzheimer's Disease. *PloS One*, *10*(8), e0133666. https://doi.org/10.1371/journal.pone.0133666

Kaiser, M. J., Bauer, J. M., Ramsch, C., Uter, W., Guigoz, Y., Cederholm, T., Thomas, D. R., Anthony, P., Charlton, K. E., Maggio, M., Tsai, A. C., Grathwohl, D., Vellas, B., Sieber, C. C., & MNA-International Group. (2009). Validation of the Mini Nutritional Assessment short-form (MNA-SF): A practical tool for identification of nutritional status. *The Journal of Nutrition, Health & Aging*, *13*(9), 782–788. https://doi.org/10.1007/s12603-009-0214-7

Kazemi, S., Savabi, G., Khazaei, S., Savabi, O., Esmaillzadeh, A., Keshteli, A. H., & Adibi, P. (2011). Association between food intake and oral health in elderly: SEPAHAN systematic review no. 8. *Dental Research Journal*, *8*(Suppl1), S15–S20.

Keller, H. H. (1993). Malnutrition in institutionalized elderly: How and why? *Journal of the American Geriatrics Society*, *41*(11), 1212–1218. https://doi.org/10.1111/j.1532-5415.1993.tb07305.x

Keller, H. H. (2016). Improving food intake in persons living with dementia. *Annals of the New York Academy of Sciences*, *1367*(1), 3–11. https://doi.org/10.1111/nyas.12997

Keller, H. H., Carrier, N., Duizer, L., Lengyel, C., Slaughter, S., & Steele, C. (2014). Making the Most of Mealtimes (M3): Grounding mealtime interventions with a conceptual model. *Journal of the American Medical Directors Association*, *15*(3), 158–161. https://doi.org/10.1016/j.jamda.2013.12.001

Keller, H. H., Carrier, N., Slaughter, S. E., Lengyel, C., Steele, C. M., Duizer, L., Morrison, J., Brown, K. S., Chaudhury, H., Yoon, M. N., Duncan, A. M., Boscart, V., Heckman, G., & Villalon, L. (2017). Prevalence and determinants of poor food intake of residents living in long-term care. *Journal of the American Medical Directors Association*, *18*(11), 941–947. https://doi.org/10.1016/j.jamda.2017.05.003

Keller, H. H., Carrier, N., Slaughter, S., Lengyel, C., Steele, C. M., Duizer, L., Brown, K. S., Chaudhury, H., Yoon, M. N., Duncan, A. M., Boscart, V. M., Heckman, G., & Villalon, L. (2017). Making the Most of Mealtimes (M3): Protocol of a multi-centre cross-sectional study of food intake and its determinants in older adults living in long term care homes. *BMC Geriatrics*, *17*(1), 15. https://doi.org/10.1186/s12877-016-0401-4

Keller, H. H., Edward, H. G., & Cook, C. (2006). Mealtime experiences of families with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, *21*(6), 431–438. https://doi.org/10.1177/1533317506294601

Keller, H. H., Gibbs-Ward, A., Randall-Simpson, J., Bocock, M.-A., & Dimou, E. (2006). Meal rounds: An essential aspect of quality nutrition services in long-term care. *Journal of the American Medical Directors Association*, *7*(1), 40–45. https://doi.org/10.1016/j.jamda.2005.06.009

Keller, H. H., Slaughter, S., Gramlich, L., Namasivayam-MacDonald, A., & Bell, J. J. (2021). Multidisciplinary nutrition care: Benefitting patients with malnutrition across healthcare sectors. In Ó. G. Geirsdóttir & J. J. Bell (Eds.), *Interdisciplinary Nutritional Management and Care for Older Adults* (pp. 177–188). Springer International Publishing. https://doi.org/10.1007/978-3-030-63892-4_13

Keller, H. H., Syed, S., Dakkak, H., Wu, S. A., & Volkert, D. (2022). Reimagining nutrition care and mealtimes in long-term care. *Journal of the American Medical Directors Association*, *23*(2), 253-260.e1. https://doi.org/10.1016/j.jamda.2021.12.021

Keller, H. H., Vucea, V., Slaughter, S. E., Jager-Wittenaar, H., Lengyel, C., Ottery, F. D., & Carrier, N. (2019). Prevalence of malnutrition or risk in residents in long term care: Comparison of four tools. *Journal of Nutrition in Gerontology and Geriatrics*, *38*(4), 329–344. https://doi.org/10.1080/21551197.2019.1640165

Kelley, M. L. (2015). *Implementing a palliative approach to care in long term care homes (Figure)*. https://www.palliativealliance.ca/assets/files/initiate-7-palliative-care-processes.jpg

Kiely, D., Simon, S., Jones, R., & Morris, J. (2000). The protective effect of social engagement on mortality in long-term care. *Journal of the American Geriatrics Society*, *48*, 1367–1372. https://doi.org/10.1111/j.1532-5415.2000.tb02624.x

Kiesswetter, E., Pohlhausen, S., Uhlig, K., Diekmann, R., Lesser, S., Heseker, H., Stehle, P., Sieber, C. C., & Volkert, D. (2013). Malnutrition is related to functional impairment in older adults receiving home care. *The Journal of Nutrition, Health & Aging*, *17*(4), 345–350. https://doi.org/10.1007/s12603-012-0409-1

Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first* (Vol. 20). Open university press Buckingham.

Koggel, C. M., Harbin, A., & Llewellyn, J. J. (2022). Feminist relational theory. *Journal of Global Ethics*, *18*(1), 1–14. https://doi.org/10.1080/17449626.2022.2073702

Koh, R. T. G., Thirumanickam, A., & Attrill, S. (2022). How are the mealtime experiences of people in residential aged care facilities informed by policy and best practice guidelines? A scoping review. *BMC Geriatrics*, *22*(1), 737. https://doi.org/10.1186/s12877-022-03340-9

Kojima, G. (2015). Prevalence of Frailty in Nursing Homes: A Systematic Review and Meta-Analysis. *Journal of the American Medical Directors Association*, *16*(11), 940–945. https://doi.org/10.1016/j.jamda.2015.06.025

Komici, K., Guerra, G., Addona, F., & Fantini, C. (2022). Delirium in Nursing Home Residents: A Narrative Review. *Healthcare (Basel, Switzerland)*, *10*(8), 1544. https://doi.org/10.3390/healthcare10081544

Kontos, P. C., Miller, K.-L., & Mitchell, G. J. (2010). Neglecting the importance of the decision making and care regimes of personal support workers: A critique of standardization of care planning through the RAI/MDS. *The Gerontologist*, *50*(3), 352–362. https://doi.org/10.1093/geront/gnp165

Kontos, P. C., Miller, K.-L., Mitchell, G. J., & Cott, C. A. (2011). Dementia care at the intersection of regulation and reflexivity: A critical realist perspective. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *66B*(1), 119–128. https://doi.org/10.1093/geronb/gbq022

Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs (Project Hope)*, *29*(2), 312–317. https://doi.org/10.1377/hlthaff.2009.0966

Lam, R. E., & Lam, P. J. (2014). Nutrition in Dementia. *Canadian Medical Association Journal*, *186*(17), 1319–1319. https://doi.org/10.1503/cmaj.141217

Lan, S.-H., Lu, L.-C., Yen, Y., Hsieh, Y., Chen, J., Wu, W., Lan, S.-J., & Lin, L. (2016). Tube feeding among elder in long-term care facilities: A systematic review and meta-analysis. *The Journal of Nutrition, Health & Aging*, *21*. https://doi.org/10.1007/s12603-016-0717-y

Landi, F., Liperoti, R., Lattanzio, F., Russo, A., Tosato, M., Barillaro, C., Bernabei, R., & Onder, G. (2012). Effects of anorexia on mortality among older adults receiving home care: An observational study. *The Journal of Nutrition, Health & Aging*, *16*(1), 79–83. https://doi.org/10.1007/s12603-011-0064-y

Lee, J., Cheng, J., Au, K., Yeung, F., Leung, M., Ng, J., Hui, E., Lo, R., & Woo, J. (2013). Improving the quality of end-of-life care in long-term care institutions. *Journal of Palliative Medicine*, *16*(10), 1268–1274. https://doi.org/10.1089/jpm.2013.0190

Lee, J. Y., Lee, K. H., & McConnell, E. S. (2021). Mealtime caregiving approaches and behavioral symptoms in persons living with dementia: A longitudinal, observational study. *BMC Nursing*, *20*(1), 104. https://doi.org/10.1186/s12912-021-00621-3

Li, B., Lingsma, H. F., Steyerberg, E. W., & Lesaffre, E. (2011). Logistic random effects regression models: A comparison of statistical packages for binary and ordinal outcomes. *BMC Medical Research Methodology*, *11*(1), 77. https://doi.org/10.1186/1471-2288-11-77

Lindmark, T., Engström, M., & Trygged, S. (2023). Psychosocial work environment and well-being of direct-care staff under different nursing home ownership types: A systematic review. *Journal of Applied Gerontology: The Official Journal of the Southern Gerontological Society*, *42*(2), 347–359. https://doi.org/10.1177/07334648221131468

Liu, W., Perkhounkova, Y., & Hein, M. (2022). Person-centered and task-centered care and mealtime behaviors in nursing home residents with dementia: Impact on food intake. *Innovation in Aging*, *6*(6), igac025. https://doi.org/10.1093/geroni/igac025

Löfmark, R., Nilstun, T., & Bolmsjö, I. A. (2007). From cure to palliation: Concept, decision and acceptance. *Journal of Medical Ethics*, *33*(12), 685–688. https://doi.org/10.1136/jme.2006.018895

Long-Term Care Staffing Study Advisory Group. (2020). *Long-term care staffing study*. Ontario Ministry of Long-Term Care. https://www.ontario.ca/page/long-term-care-staffing-study#section-4

Loofs, T. S., & Haubrick, K. (2021). End-of-life nutrition considerations: Attitudes, beliefs, and outcomes. *American Journal of Hospice and Palliative Medicine®*, *38*(8), 1028–1041. https://doi.org/10.1177/1049909120960124

Lopez, R. P., & Amella, E. J. (2011). Time travel: The lived experience of providing feeding assistance to a family member with dementia. *Research in Gerontological Nursing*, *4*(2), 127–134. https://doi.org/10.3928/19404921-20100729-02

Lowndes, R., Armstrong, P., & Daly, T. (2015). The meaning of "dining": The social organization of food in long-term care. *Food Studies*, *4*(1), 19–34.

Luca, A., Luca, M., & Calandra, C. (2014). Eating disorders in late-life. *Aging and Disease*, *6*(1), 48–55. https://doi.org/10.14336/AD.2014.0124 [doi]

Lunney, J. R. (2003). Patterns of functional decline at the end of life. *JAMA*, *289*(18), 2387. https://doi.org/10.1001/jama.289.18.2387

Lynch, M. C. (2016). Is tube feeding futile in advanced dementia? *The Linacre Quarterly*, *83*(3), 283–307. https://doi.org/10.1080/00243639.2016.1211879

Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. *The Hastings Center Report*, *Spec No*, S14-18. https://doi.org/10.1353/hcr.2005.0096

Madden, C., Clayton, M., Canary, H. E., Towsley, G., Cloyes, K., & Lund, D. (2017). Rules of performance in the nursing home: A grounded theory of nurse-CNA communication. *Geriatric Nursing (New York, N.Y.)*, *38*(5), 378–384. https://doi.org/10.1016/j.gerinurse.2016.12.013

Mahmoodpoor, A., Shadvar, K., Saghaleini, S., Dehghan, K., & Ostadi, Z. (2018). Pressure ulcer and nutrition. *Indian Journal of Critical Care Medicine*, *22*(4), 283–289. https://doi.org/10.4103/ijccm.IJCCM_277_17

Malafarina, V., Uriz-Otano, F., Gil-Guerrero, L., & Iniesta, R. (2013). The anorexia of ageing: Physiopathology, prevalence, associated comorbidity and mortality. A systematic review. *Maturitas*, *74*(4), 293–302. https://doi.org/10.1016/j.maturitas.2013.01.016

Mangoni, A. A., & Woodman, R. J. (2019). The potential value of person-centred statistical methods in ageing research. *Age and Ageing*, *48*(6), 783–784. https://doi.org/10.1093/ageing/afz140

Mann, K., Lengyel, C. O., Slaughter, S. E., Carrier, N., & Keller, H. H. (2019). Resident and staff mealtime actions and energy intake of long-term care residents with cognitive impairment: Analysis of the Making the Most of Mealtimes study. *Journal of Gerontological Nursing*, *45*(8), 32–42. https://doi.org/10.3928/00989134-20190709-04

Marcella, J., & Kelley, M. L. (2015). "Death is part of the job" in long-term care homes: Supporting direct care staff with their grief and bereavement. *SAGE Open*, *5*(1), 215824401557391. https://doi.org/10.1177/2158244015573912

Martone, A., Onder, G., Vetrano, D., Ortolani, E., Tosato, M., Marzetti, E., & Landi, F. (2013). Anorexia of aging: A modifiable risk factor for frailty. *Nutrients*, *5*(10), 4126–4133. https://doi.org/10.3390/nu5104126

Matthews, D. C., Clovis, J. B., Brillant, M. G. S., Filiaggi, M. J., McNally, M. E., Kotzer, R. D., & Lawrence, H. P. (2012). Oral health status of long-term care residents-a vulnerable population. *Journal (Canadian Dental Association)*, *78*, c3.

McCann, R. M., Hall, W. J., & Groth-Juncker, A. (1994). Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA*, *272*(16), 1263–1266. https://doi.org/10.1001/jama.272.16.1263

McCleary, L., Thompson, G. N., Venturato, L., Wickson-Griffiths, A., Hunter, P., Sussman, T., & Kaasalainen, S. (2018). Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry*, *18*(1), 307. https://doi.org/10.1186/s12888-018-1882-9

McCormack, B. (2001). *Negotiating Partnership with Older People—A Person-Centred Approach*. Ashgate Publishing.

Mehta, A., & Chan, L. S. (2008). Understanding of the concept of "total pain": A prerequisite for pain control. *Journal of Hospice & Palliative Nursing*, *10*(1), 26–32. https://doi.org/10.1097/01.NJH.0000306714.50539.1a

Menec, V. H., Nowicki, S., Blandford, A., & Veselyuk, D. (2009). Hospitalizations at the end of life among long-term care residents. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *64A*(3), 395–402. https://doi.org/10.1093/gerona/gln034

Merino, G., Marín-Arroyo, M. R., Beriain, M. J., & Ibañez, F. C. (2021). Dishes adapted to dysphagia: Sensory characteristics and their relationship to hedonic acceptance. *Foods (Basel, Switzerland)*, *10*(2), 480. https://doi.org/10.3390/foods10020480

Milte, R., Petersen, J., Boylan, J., Henwood, T., Hunter, S., Lange, B., Lawless, M., Torode, S., & Lewis, L. K. (2022). Prevalence and determinants of physical frailty among people living in residential aged care facilities: A large-scale retrospective audit. *BMC Geriatrics*, *22*(1), 424. https://doi.org/10.1186/s12877-022-03101-8

Mitchell, G., Agnelli, J., McGreevy, J., Diamond, M., Roble, H., McShane, E., & Strain, J. (2016). Palliative and end-of-life care for people living with dementia in care homes: Part 2. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, *30*(44), 54–63. https://doi.org/10.7748/ns.2016.e10582

Mitchell, G. J., Dupuis, S. L., & Kontos, P. (2013). Dementia discourse: From imposed suffering to knowing other-wise. *Journal of Applied Hermeneutics*, *2013*(1).

Mitchell, S. L., Kiely, D. K., Jones, R. N., Prigerson, H., Volicer, L., & Teno, J. M. (2006). Advanced dementia research in the nursing home: The CASCADE study. *Alzheimer Disease and Associated Disorders*, *20*(3), 166–175. https://doi.org/10.1097/00002093-200607000-00008

Mitchell, S. L., Mor, V., Gozalo, P. L., Servadio, J. L., & Teno, J. M. (2016). Tube feeding in US nursing home residents with advanced dementia, 2000-2014. *JAMA*, *316*(7), 769. https://doi.org/10.1001/jama.2016.9374

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L., & Hamel, M. B. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, *361*(16), 1529–1538. https://doi.org/10.1056/NEJMoa0902234

Molloy, U., & Phelan, A. (2022). Living, loving and letting go-navigating the relational within palliative care of older people in long-term care facilities: An action research study. *International Journal of Older People Nursing*, *17*(2). https://doi.org/10.1111/opn.12424

Morley, J. E. (2011). End-of-life care in the nursing home. *Journal of the American Medical Directors Association*, *12*(2), 77–83. https://doi.org/10.1016/j.jamda.2010.11.012

Morley, J. E., & Silver, A. J. (1988). Anorexia in the elderly. *Neurobiology of Aging*, *9*(1), 9–16. https://doi.org/10.1016/s0197-4580(88)80004-6

Morley, J. E., & Steinberg, K. E. (2009). Diarrhea in long-term care: A messy problem. *Journal of the American Medical Directors Association*, *10*(4), 213–217. https://doi.org/10.1016/j.jamda.2009.01.007

Morris, J. N., Fries, B. E., Mehr, D. R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. A. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology*, *49*(4), 174. https://doi.org/10.1093/geronj/49.4.m174

Morris, J. N., Fries, B. E., & Morris, S. A. (1999). Scaling ADLs within the MDS. *The Journals of Gerontology.Series A, Biological Sciences and Medical Sciences*, *54*(11), 546. https://doi.org/10.1093/gerona/54.11.m546

Morrison, J. M., Wu, S. A., & Keller, H. H. (2019). Beyond tube-feeding: Relationship-centered, comfort care for individuals with eating challenges in dementia. *Journal of the American Geriatrics Society*, *67*(1), 185–186. https://doi.org/10.1111/jgs.15571

Morrison-Koechl, J., Wu, S. A., Slaughter, S. E., Lengyel, C. O., Carrier, N., & Keller, H. H. (2021). Hungry for more: Low resident social engagement is indirectly associated with poor energy intake and mealtime experience in long-term care homes. *Appetite*, *159*, 105044. https://doi.org/10.1016/j.appet.2020.105044

Munshi, M. N., Florez, H., Huang, E. S., Kalyani, R. R., Mupanomunda, M., Pandya, N., Swift, C. S., Taveira, T. H., & Haas, L. B. (2016). Management of diabetes in long-term care and skilled nursing facilities: A position statement of the American Diabetes Association. *Diabetes Care*, *39*(2), 308–318. https://doi.org/10.2337/dc15-2512 [doi]

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*, *330*(7498), 1007–1011. https://doi.org/10.1136/bmj.330.7498.1007

Muthén, B., & Muthén, L. K. (2000). Integrating person-centered and variable-centered analyses: Growth mixture modeling with latent trajectory classes. *Alcoholism, Clinical and Experimental Research*, *24*(6), 882–891.

Namasivayam, A. M., & Steele, C. M. (2015). Malnutrition and dysphagia in long-term care: A systematic review. *Journal of Nutrition in Gerontology and Geriatrics*, *34*(1), 1–21. https://doi.org/10.1080/21551197.2014.1002656

Neloska, L., Damevska, K., Nikolchev, A., Pavleska, L., Petreska-Zovic, B., & Kostov, M. (2016). The association between malnutrition and pressure ulcers in elderly in long-term care facility. *Open Access Macedonian Journal of Medical Sciences*, *4*(3), 423–427. https://doi.org/10.3889/oamjms.2016.094

Newman, R. D., Ray, R., Woodward, L., & Glass, B. (2020). Factors contributing to the preferred method of feeding in end-stage dementia: A scoping review. *Dysphagia*, *35*(4), 616–629. https://doi.org/10.1007/s00455-019-10072-3

Ng, R., Lane, N., Tanuseputro, P., Mojaverian, N., Talarico, R., Wodchis, W. P., Bronskill, S. E., & Hsu, A. T. (2020). Increasing complexity of new nursing home residents in Ontario, Canada: A serial cross-sectional study. *Journal of the American Geriatrics Society*, *68*(6), 1293–1300. https://doi.org/10.1111/jgs.16394

Niedert, K. C., & American Dietetic Association. (2005). Position of the American Dietetic Association: Liberalization of the diet prescription improves quality of life for older adults in long-term care. *Journal of the American Dietetic Association*, *105*(12), 1955–1965. https://doi.org/10.1016/j.jada.2005.10.004

Nijs, K., De Graaf, C., Van Staveren, W. A., & De Groot, L. C. P. G. M. (2009). Malnutrition and mealtime ambiance in nursing homes. *Journal of the American Medical Directors Association*, *10*(4), 226–229. https://doi.org/10.1016/j.jamda.2009.01.006

Njegovan, V., Man-Son-Hing, M., Mitchell, S. L., & Molnar, F. J. (2001). The hierarchy of functional loss associated with cognitive decline in older persons. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *56*(10), M638–M643. https://doi.org/10.1093/gerona/56.10.M638

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(s1), 45–53. https://doi.org/10.1111/j.1365-2702.2004.00926.x

Nylund, K. L., Asparouhov, T., & Muthén, B. O. (2007). Deciding on the number of classes in latent class analysis and growth mixture modeling: A Monte Carlo simulation study. *Structural Equation Modeling*, *14*(4), 535–569. https://doi.org/10.1080/10705510701575396

Nylund-Gibson, K., & Choi, A. Y. (2018). Ten frequently asked questions about latent class analysis. *Translational Issues in Psychological Science*, *4*(4), 440–461. https://doi.org/10.1037/tps0000176

Öhlén, J., Reimer-Kirkham, S., Astle, B., Håkanson, C., Lee, J., Eriksson, M., & Sawatzky, R. (2017). Person-centred care dialectics-Inquired in the context of palliative care. *Nursing Philosophy*, *18*(4), e12177. https://doi.org/10.1111/nup.12177

O'Keeffe, M., Kelly, M., O'Herlihy, E., O'Toole, P. W., Kearney, P. M., Timmons, S., O'Shea, E., Stanton, C., Hickson, M., Rolland, Y., Sulmont Rossé, C., Issanchou, S., Maitre, I., Stelmach-Mardas, M., Nagel, G., Flechtner-Mors, M., Wolters, M., Hebestreit, A., De Groot, L. C. P. G. M., … O'Connor, E. M. (2019). Potentially modifiable determinants of malnutrition in older adults: A systematic review. *Clinical Nutrition*, *38*(6), 2477–2498. https://doi.org/10.1016/j.clnu.2018.12.007

O'Keeffe, S. T., Leslie, P., Lazenby-Paterson, T., McCurtin, A., Collins, L., Murray, A., Smith, A., Mulkerrin, S., & SPARC (Swallow Perspectives, Advocacy and Research Collective). (2023). Informed or misinformed consent and use of modified texture diets in dysphagia. *BMC Medical Ethics*, *24*(1), 7. https://doi.org/10.1186/s12910-023-00885-1

Ontario Long Term Care Association [OLTCA]. (2019). *This is Long-Term Care 2019* (pp. 1–16). Ontario Long Term Care Association. https://www.oltca.com/OLTCA/Documents/Reports/TILTC2019web.pdf

Ontario Long Term Care Association [OLTCA]. (2023). *The Data: Long-Term Care in Ontario*. Ontario Long Term Care Association. https://www.oltca.com/about-long-term-care/the-data/

Ontario's Long-Term Care COVID-19 Commission, Final Report. (2021). http://www.ltccommission-commissionsld.ca/

Orrevall, Y. (2015). Nutritional support at the end of life. *Nutrition (Burbank, Los Angeles County, Calif.)*, *31*(4), 615–616. https://doi.org/10.1016/j.nut.2014.12.004

Palecek, E. J., Teno, J. M., Casarett, D. J., Hanson, L. C., Rhodes, R. L., & Mitchell, S. L. (2010). Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *Journal of the American Geriatrics Society*, *58*(3), 580–584. https://doi.org/10.1111/j.1532-5415.2010.02740.x

Palese, A., Bressan, V., Kasa, T., Meri, M., Hayter, M., & Watson, R. (2018). Interventions maintaining eating independence in nursing home residents: A multicentre qualitative study. *BMC Geriatrics*, *18*(1), 292. https://doi.org/10.1186/s12877-018-0985-y

Palese, A., Gonella, S., Grassetti, L., Longobardi, M., De Caro, A., Achil, I., Hayter, M., & Watson, R. (2020). What nursing home environment can maximise eating independence among residents with cognitive impairment? Findings from a secondary analysis. *Geriatric Nursing (New York, N.Y.)*, *41*(6), 709–716. https://doi.org/10.1016/j.gerinurse.2020.03.020

Palese, A., Gonella, S., Kasa, T., Caruzzo, D., Hayter, M., & Watson, R. (2019). Negative prompts aimed at maintaining eating independence. *Nursing Ethics*, *26*(7–8), 2158–2171. https://doi.org/10.1177/0969733018819124

Palliative Alliance. (2017). *Quality Palliative Care in Long Term Care: Tools and Resources for Organizational Change*. palliativealliance.ca

Pasman, H. R. W., Onwuteaka-Philipsen, B. D., Kriegsman, D. M. W., Ooms, M. E., Ribbe, M. W., & van der Wal, G. (2005). Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is forgone. *Archives of Internal Medicine*, *165*(15), 1729. https://doi.org/10.1001/archinte.165.15.1729

Peduzzi, P., Concato, J., Kemper, E., Holford, T. R., & Feinstein, A. R. (1996). A simulation study of the number of events per variable in logistic regression analysis. *Journal of Clinical Epidemiology*, *49*(12), 1373–1379. https://doi.org/10.1016/S0895-4356(96)00236-3

Perlman, C. M., & Hirdes, J. P. (2008). The Aggressive Behavior Scale: A new scale to measure aggression based on the Minimum Data Set. *Journal of the American Geriatrics Society*, *56*(12), 2298–2303. https://doi.org/10.1111/j.1532-5415.2008.02048.x

Pezzana, A., Cereda, E., Avagnina, P., Malfi, G., Paiola, E., Frighi, Z., Capizzi, I., Sgnaolin, E., & Amerio, M. L. (2015). Nutritional care needs in elderly residents of long-term care institutions: Potential implications for policies. *The Journal of Nutrition, Health & Aging*, *19*(9), 947–954. https://doi.org/10.1007/s12603-015-0537-5

Phillips, C., Polakoff, D., Maue, S. K., & Mauch, R. (2001). Assessment of constipation management in long-term care patients. *Journal of the American Medical Directors Association*, *2*(4), 149–154. https://doi.org/10.1016/S1525-8610(04)70190-5

Pilgrim, A. L., Robinson, S. M., Sayer, A. A., & Roberts, H. C. (2015). An overview of appetite decline in older people. *Nursing Older People*, *27*(5), 29–35. https://doi.org/10.7748/nop.27.5.29.e697

Pinho-Reis, C., Pinho, F., & Reis, A. M. (2022). Food and nutrition as part of the total pain concept in palliative care [Alimentação e nutrição como parte do conceito de dor total em cuidados paliativos]. *Acta Portuguesa de Nutrição*, *28*(2022), 52–58. https://doi.org/10.21011/apn.2022.2810

Pinto, I., Pereira, J., Campos, C., & Thompson, J. (2016). The dietitian’s role in palliative care: A qualitative study exploring the scope and emerging competencies for dietitians in palliative care. *Journal of Palliative Care & Medicine*, *06*(02). https://doi.org/10.4172/2165-7386.1000253

Pott, K., Chan, K., Leclerc, A., Bernard, C., Song, A., Puyat, J., & Rodney, P. (2020). Death in long-term care: Focus groups and interviews identify strategies to alleviate staff burnout. *Journal of Long Term Care*, 131–143. https://doi.org/10.31389/jltc.34

Pu, D., Choi, Y.-Y., Chan, K. M.-K., & Poon, M. M.-W. (2021). Modifying puree meals in residential aged care facilities: A multi-centre feasibility and acceptability study. *Geriatrics (Basel, Switzerland)*, *6*(4), 108. https://doi.org/10.3390/geriatrics6040108

Puurveen, G., Baumbusch, J., & Gandhi, P. (2018). From family involvement to family inclusion in nursing home settings: A critical interpretive synthesis. *Journal of Family Nursing*, *24*(1), 60–85. https://doi.org/10.1177/1074840718754314

Qureshi, D., Tanuseputro, P., Perez, R., Pond, G. R., & Seow, H.-Y. (2019). Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study. *Palliative Medicine*, *33*(2), 150–159. https://doi.org/10.1177/0269216318815794

Rahman, A. N., & Schnelle, J. F. (2008). The nursing home culture-change movement: Recent past, present, and future directions for research. *The Gerontologist*, *48*(2), 142–148. https://doi.org/10.1093/geront/48.2.142

Ranganathan, A., Dougherty, M., Waite, D., & Casarett, D. (2013). Can palliative home care reduce 30-day readmissions? Results of a propensity score matched cohort study. *Journal of Palliative Medicine*, *16*(10), 1290–1293. https://doi.org/10.1089/jpm.2013.0213

Rasheed, S., & Woods, R. T. (2013). Malnutrition and quality of life in older people: A systematic review and meta-analysis. *Ageing Research Reviews*, *12*(2), 561–566. https://doi.org/10.1016/j.arr.2012.11.003

Rawal, G., & Yadav, S. (2015). Nutrition in chronic obstructive pulmonary disease: A review. *Journal of Translational Internal Medicine*, *3*(4), 151–154. https://doi.org/10.1515/jtim-2015-0021

Reid, C. M., Gibbins, J., McCoubrie, R., & Forbes, K. (2011). Palliative care is not same as end of life care. *BMJ (Clinical Research Ed.)*, *342*, d2735. https://doi.org/10.1136/bmj.d2735

Reimer, H. D., & Keller, H. H. (2009). Mealtimes in nursing homes: Striving for person-centered care. *Journal of Nutrition For the Elderly*, *28*(4), 327–347. https://doi.org/10.1080/01639360903417066

Relias Media. (2014, August 1). *Controversy over "comfort feeding only" for dementia patients* [Newsletter]. Medical Ethics Advisor. https://www.reliasmedia.com/articles/17116-controversy-over-comfort-feeding-only-for-dementia-patients

Resnick, B., Gruber-Baldini, A. L., Galik, E., Pretzer-Aboff, I., Russ, K., Hebel, J. R., & Zimmerman, S. (2009). Changing the philosophy of care in long-term care: Testing of the restorative care intervention. *The Gerontologist*, *49*(2), 175–184. https://doi.org/10.1093/geront/gnp026

Ribeiro Salomon, A. L., & Carvalho Garbi Novaes, M. R. (2015). Outcomes of enteral nutrition for patients with advanced dementia: A systematic review. *The Journal of Nutrition, Health & Aging*, *19*(2), 169–177. https://doi.org/10.1007/s12603-014-0517-1

Robinson, J., Frey, R., Boyd, M., McLeod, H., Meehan, B., & Gott, M. (2021). InterRAI assessments: Opportunities to recognise need for and implementation of palliative care interventions in the last year of life? *Australasian Journal on Ageing*, *40*(1). https://doi.org/10.1111/ajag.12840

Rofes, L., Arreola, V., Almirall, J., Cabré, M., Campins, L., García-Peris, P., Speyer, R., & Clavé, P. (2011). Diagnosis and management of oropharyngeal dysphagia and its nutritional and respiratory complications in the elderly. *Gastroenterology Research and Practice*, *2011*, 1–13. https://doi.org/10.1155/2011/818979

Rogus-Pulia, N., Malandraki, G. A., Johnson, S., & Robbins, J. (2015). Understanding dysphagia in dementia: The present and the future. *Current Physical Medicine and Rehabilitation Reports*, *3*(1), 86–97. https://doi.org/10.1007/s40141-015-0078-1

Romaniw, O. C., Rajpal, R., Duncan, A. M., Keller, H. H., & Duizer, L. M. (2020). Nutrition in Disguise: Effects of food neophobia, healthy eating interests and provision of health information on liking and perceptions of nutrient-dense foods in older adults. *Foods*, *10*(1), 60. https://doi.org/10.3390/foods10010060

Rousseau, P. (2018). To feed(ing tube) or not. *Journal of the American Geriatrics Society*, *66*(8), 1647–1647. https://doi.org/10.1111/jgs.15380

Sachs, G. A., Carter, R., Holtz, L. R., Smith, F., Stump, T. E., Tu, W., & Callahan, C. M. (2011). Cognitive Impairment: An Independent Predictor of Excess Mortality: A Cohort Study. *Annals of Internal Medicine*, *155*(5), 300. https://doi.org/10.7326/0003-4819-155-5-201109060-00007

Sakamoto, M., Watanabe, Y., Edahiro, A., Motokawa, K., Shirobe, M., Hirano, H., Ito, K., Kanehisa, Y., Yamada, R., & Yoshihara, A. (2018). Self-feeding ability as a predictor of mortality Japanese nursing home residents: A two-year longitudinal study. *The Journal of Nutrition, Health & Aging*, *23*(2), 157–164. https://doi.org/10.1007/s12603-018-1125-2

Sampson, E. L., Candy, B., & Jones, L. (2009). Enteral tube feeding for older people with advanced dementia. *The Cochrane Database of Systematic Reviews*, *2009*(2), CD007209. https://doi.org/10.1002/14651858.CD007209.pub2

Sanders, C., Behrens, S., Schwartz, S., Wengreen, H., Corcoran, C. D., Lyketsos, C. G., & Tschanz, J. T. (2016). Nutritional status is associated with faster cognitive decline and worse functional impairment in the progression of dementia: The Cache County Dementia Progression Study. *Journal of Alzheimer's Disease*, *52*(1), 33–42. https://doi.org/10.3233/JAD-150528

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, *15*(1), 5. https://doi.org/10.1186/s12904-016-0076-9

Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham, S., Pesut, B., Schalkwyk, T., Stajduhar, K., Tayler, C., Baumbusch, J., & Thorne, S. (2017). Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *ANS. Advances in Nursing Science*, *40*(3), 261–277. https://doi.org/10.1097/ANS.0000000000000163

Schwartz, M. L., Lima, J. C., Clark, M. A., & Miller, S. C. (2019). End-of-life culture change practices in U.S. nursing homes in 2016/2017. *Journal of Pain and Symptom Management*, *57*(3), 525–534. https://doi.org/10.1016/j.jpainsymman.2018.12.330

Seow, H., Guthrie, D. M., Stevens, T., Barbera, L. C., Burge, F., McGrail, K., Chan, K. K. W., Peacock, S. J., & Sutradhar, R. (2021). Trajectory of end-of-life pain and other physical symptoms among cancer patients receiving home care. *Current Oncology (Toronto, Ont.)*, *28*(3), 1641–1651. https://doi.org/10.3390/curroncol28030153

Sgrò, G., Caruso, C., Ceravolo, F., Curinga, G., Renda, G. F., Rispoli, V., Spadea, F., Malara, A., & Garo, M. (2014). Relationship between cognitive impairment and nutritional assessment on functional status in Calabrian long-term-care. *Clinical Interventions in Aging*, 105. https://doi.org/10.2147/CIA.S54611

Sheffer-Hilel, G., Drach-Zahavy, A., & Endevelt, R. (2022). The informal champion’s role in promoting the care of inter-professional teams. *Small Group Research*, 104649642210996. https://doi.org/10.1177/10464964221099635

Sieber, C. C. (2019). Malnutrition and sarcopenia. *Aging Clinical and Experimental Research*, *31*(6), 793–798. https://doi.org/10.1007/s40520-019-01170-1

Simmons, S. F., Lam, H. Y., Rao, G., & Schnelle, J. F. (2003). Family members' preferences for nutrition interventions to improve nursing home residents' oral food and fluid intake. *Journal of the American Geriatrics Society*, *51*(1), 69–74. https://doi.org/10.1034/j.1601-5215.2002.51012.x

Simmons, S. F., & Schnelle, J. F. (2004). Individualized feeding assistance care for nursing home residents: Staffing requirements to implement two interventions. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, *59*(9), M966-973. https://doi.org/10.1093/gerona/59.9.m966

Sims, R. V., Hauser, R. J., Adewale, A. O., Maislin, G., Skeie, S., Lavizzo-Mourey, R. J., & Rubin, H. (1995). Acute gastroenteritis in three community-based nursing homes. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *50A*(5), M252–M256. https://doi.org/10.1093/gerona/50A.5.M252

Slattery, P., Saeri, A. K., & Bragge, P. (2020). Research co-design in health: A rapid overview of reviews. *Health Research Policy and Systems*, *18*(1), 17. https://doi.org/10.1186/s12961-020-0528-9

Slaughter, S. E., Eliasziw, M., Morgan, D., & Drummond, N. (2011). Incidence and predictors of eating disability among nursing home residents with middle-stage dementia. *Clinical Nutrition*, *30*(2), 172–177. https://doi.org/10.1016/j.clnu.2010.09.001

Slaughter, S. E., & Hayduk, L. A. (2012). Contributions of environment, comorbidity, and stage of dementia to the onset of walking and eating disability in long-term care residents. *Journal of the American Geriatrics Society*, *60*(9), 1624–1631. https://doi.org/10.1111/j.1532-5415.2012.04116.x

Slaughter, S. E., Morrison-Koechl, J. M., Chaudhury, H., Lengyel, C. O., Carrier, N., & Keller, H. H. (2020). The association of eating challenges with energy intake is moderated by the mealtime environment in residential care homes. *International Psychogeriatrics*, *32*(7), 863–873. https://doi.org/10.1017/S1041610219001959

Sloane, P. D., Ivey, J., Helton, M., Barrick, A. L., & Cerna, A. (2008). Nutritional issues in long-term care. *Journal of the American Medical Directors Association*, *9*(7), 476–485. https://doi.org/10.1016/j.jamda.2008.03.005

Smith, K. M., Thomas, K. S., Johnson, S., Meng, H., & Hyer, K. (2019). Dietary service staffing impact nutritional quality in nursing homes. *Journal of Applied Gerontology*, *38*(5), 639–655. https://doi.org/10.1177/0733464816688309

Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine*, *28*(2), 130–150. https://doi.org/10.1177/0269216313493466

Soar, N., Birns, J., Sommerville, P., Fitzgerald, A., & Archer, S. (2023). Readmissions to hospital following a decision to eat and drink with acknowledged risk. *Geriatric Nursing*, *50*, 90–93. https://doi.org/10.1016/j.gerinurse.2022.12.017

Soar, N., Birns, J., Sommerville, P., Lang, A., & Archer, S. (2021). Approaches to eating and drinking with acknowledged risk: A systematic review. *Dysphagia*, *36*(1), 54–66. https://doi.org/10.1007/s00455-020-10107-0

Söderström, L., Rosenblad, A., Thors Adolfsson, E., & Bergkvist, L. (2017). Malnutrition is associated with increased mortality in older adults regardless of the cause of death. *British Journal of Nutrition*, *117*(4), 532–540. https://doi.org/10.1017/S0007114517000435

Sommerville, P., Lang, A., Archer, S., Woodcock, T., & Birns, J. (2019). FORWARD (Feeding via the Oral Route With Acknowledged Risk of Deterioration): Evaluation of a novel tool to support patients eating and drinking at risk of aspiration. *Age and Ageing*, *48*(4), 553–558. https://doi.org/10.1093/ageing/afz050

Sørensen, D., Wieghorst, A. R., Elbek, J. A., & Mousing, C. A. (2020). Mealtime challenges in patients with chronic obstructive pulmonary disease: Who is responsible? *Journal of Clinical Nursing*, *29*(23–24), 4583–4593. https://doi-org.proxy.lib.uwaterloo.ca/10.1111/jocn.15491

Squires, J. E., Hoben, M., Linklater, S., Carleton, H. L., Graham, N., & Estabrooks, C. A. (2015). Job satisfaction among care aides in residential long-term care: A systematic review of contributing factors, both individual and organizational. *Nursing Research and Practice*, *2015*, 1–24. https://doi.org/10.1155/2015/157924

Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *American Psychologist*, *47*(1), 6–22. https://doi.org/10.1037/0003-066X.47.1.6

Stuart, B. (1999). The NHO *Medical Guidelines for Non-Cancer Disease* and Local Medical Review Policy: Hospice Access for Patients with Diseases Other Than Cancer. *The Hospice Journal*, *14*(3–4), 139–154. https://doi.org/10.1080/0742-969X.1999.11882934

Sumida, K., Molnar, M. Z., Potukuchi, P. K., Thomas, F., Lu, J. L., Yamagata, K., Kalantar-Zadeh, K., & Kovesdy, C. P. (2019). Constipation and risk of death and cardiovascular events. *Atherosclerosis*, *281*, 114–120. https://doi.org/10.1016/j.atherosclerosis.2018.12.021

Sussman, T., Kaasalainen, S., Mintzberg, S., Sinclair, S., Young, L., Ploeg, J., Bourgeois-Guérin, V., Thompson, G., Venturato, L., Earl, M., Strachan, P., You, J. J., Bonifas, R., & McKee, M. (2017). Broadening end-of-life comfort to improve palliative care practices in long term care. *Canadian Journal on Aging*, *36*(3), 306–317. https://doi.org/10.1017/S0714980817000253

Tang, S., Finlayson, G., Dahl, P., Bertone, M. F., Schroth, R. J., & Manitoba Dental Association. (2019). Dentists' views on providing care for residents of long-term care facilities. *Journal of the Canadian Dental Association*, *85*, j8.

Tanuseputro, P., Hsu, A., Kuluski, K., Chalifoux, M., Donskov, M., Beach, S., & Walker, P. (2017). Level of need, divertibility, and outcomes of newly admitted nursing home residents. *Journal of the American Medical Directors Association*, *18*(7), 616–623. https://doi.org/10.1016/j.jamda.2017.02.008

Tariq, S. H. (2007). Constipation in long-term care. *Journal of the American Medical Directors Association*, *8*(4), 209–218. https://doi.org/10.1016/j.jamda.2007.02.009

The National Hospice Organization. (1996). Medical guidelines for determining prognosis in selected non-cancer diseases. *The Hospice Journal*, *11*(2), 47–63. https://doi.org/10.1080/0742-969X.1996.11882820

Thompson, G. N., & McClement, S. E. (2019). Critical nursing and health care aide behaviors in care of the nursing home resident dying with dementia. *BMC Nursing*, *18*(1), 59. https://doi.org/10.1186/s12912-019-0384-5

Thompson, G. N., McClement, S. E., Labun, N., & Klaasen, K. (2018). Developing and testing a nursing home end -of -life care chart audit tool. *BMC Palliative Care*, *17*(1), 49. https://doi.org/10.1186/s12904-018-0301-9

Thompson, S., & Oliver, D. P. (2008). A new model for long-term care: Balancing palliative and restorative care delivery. *Journal of Housing for the Elderly*, *22*(3), 169–194. https://doi.org/10.1080/02763890802232014

Toscani, F., Finetti, S., Giunco, F., Basso, I., Rosa, D., Pettenati, F., Bussotti, A., Villani, D., Gentile, S., Boncinelli, L., Monti, M., Spinsanti, S., Piazza, M., Charrier, L., & Di Giulio, P. (2019).

The last week of life of nursing home residents with advanced dementia: A retrospective study. *BMC Palliative Care*, *18*(1), 117. https://doi.org/10.1186/s12904-019-0510-x

Towsley, G. L., Hirschman, K. B., & Madden, C. (2015). Conversations about end of life: Perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine*, *18*(5), 421–428. https://doi.org/10.1089/jpm.2014.0316

Unroe, K. T., Cagle, J. G., Lane, K. A., Callahan, C. M., & Miller, S. C. (2015). Nursing home staff palliative care knowledge and practices: Results of a large survey of frontline workers. *Journal of Pain and Symptom Management*, *50*(5), 622–629. https://doi.org/10.1016/j.jpainsymman.2015.06.006

Van Bokhorst-de Van Der Schueren, M. A. E., Guaitoli, P. R., Jansma, E. P., & De Vet, H. C. W. (2014). Nutrition screening tools: Does one size fit all? A systematic review of screening tools for the hospital setting. *Clinical Nutrition*, *33*(1), 39–58. https://doi.org/10.1016/j.clnu.2013.04.008

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., Francke, A. L., Jünger, S., Gove, D., Firth, P., Koopmans, R. T., Volicer, L., & on behalf of the European Association for Palliative Care (EAPC). (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, *28*(3), 197–209. https://doi.org/10.1177/0269216313493685

Vandewoude, M. F. J., Van Wijngaarden, J. P., De Maesschalck, L., Luiking, Y. C., & Van Gossum, A. (2019). The prevalence and health burden of malnutrition in Belgian older people in the community or residing in nursing homes: Results of the NutriAction II study. *Aging Clinical and Experimental Research*, *31*(2), 175–183. https://doi.org/10.1007/s40520-018-0957-2

Vassar, M., & Matthew, H. (2013). The retrospective chart review: Important methodological considerations. *Journal of Educational Evaluation for Health Professions*, *10*, 12. https://doi.org/10.3352/jeehp.2013.10.12

Villalon, L., Laporte, M., & Carrier, N. (2011). Nutrition screening for seniors in health care facilities: A survey of health professionals. *Canadian Journal of Dietetic Practice and Research*, *72*(4), 162–169. https://doi.org/10.3148/72.4.2011.162

Visser, M., Volkert, D., Corish, C., Geisler, C., de Groot, L. C., Cruz-Jentoft, A. J., Lohrmann, C., O'Connor, E. M., Schindler, K., de van der Schueren, M. A., & on behalf of the MaNuEL consortium. (2017). Tackling the increasing problem of malnutrition in older persons: The Malnutrition in the Elderly (MaNuEL) Knowledge Hub. *Nutrition Bulletin*, *42*(2), 178–186. https://doi.org/10.1111/nbu.12268

Volicer, L., Seltzer, B., Rheaume, Y., Karner, J., Glennon, M., Riley, M. E., & Crino, P. (1989). Eating difficulties in patients with probable dementia of the Alzheimer type. *Journal of Geriatric Psychiatry and Neurology*, *2*(4), 188–195. https://doi.org/10.1177/089198878900200404

Volicer, L., & Simard, J. (2015). Palliative care and quality of life for people with dementia: Medical and psychosocial interventions. *International Psychogeriatrics*, *27*(10), 1623–1634. https://doi.org/10.1017/S1041610214002713

Volkert, D., Beck, A. M., Cederholm, T., Cruz-Jentoft, A., Goisser, S., Hooper, L., Kiesswetter, E., Maggio, M., Raynaud-Simon, A., Sieber, C. C., Sobotka, L., van Asselt, D., Wirth, R., & Bischoff, S. C. (2019). ESPEN guideline on clinical nutrition and hydration in geriatrics. *Clinical Nutrition*, *38*(1), 10–47. https://doi.org/10.1016/j.clnu.2018.05.024

Volkert, D., Chourdakis, M., Faxen-Irving, G., Frühwald, T., Landi, F., Suominen, M. H., Vandewoude, M., Wirth, R., & Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*, *34*(6), 1052–1073. https://doi.org/10.1016/j.clnu.2015.09.004

Volkert, D., Kiesswetter, E., Cederholm, T., Donini, L. M., Eglseer, D., Norman, K., Schneider, S. M., Ströbele-Benschop, N., Torbahn, G., Wirth, R., & Visser, M. (2019). Development of a model on determinants of malnutrition in aged persons: A MaNuEL project. *Gerontology & Geriatric Medicine*, *5*, 2333721419858438. https://doi.org/10.1177/2333721419858438

Vucea, V., Keller, H. H., Morrison, J. M., Duizer, L. M., Duncan, A. M., Carrier, N., Lengyel, C. O., Slaughter, S. E., & Steele, C. M. (2018). Modified texture food use is associated with malnutrition in long term care: An analysis of Making the Most of Mealtimes (M3) project. *The Journal of Nutrition, Health & Aging*, *22*(8), 916–922. https://doi.org/10.1007/s12603-018-1016-6

Wallin, V., Carlander, I., Sandman, P.-O., & Håkanson, C. (2015). Meanings of eating deficiencies for people admitted to palliative home care. *Palliative and Supportive Care*, *13*(5), 1231–1239. https://doi.org/10.1017/S1478951514001199

Wallin, V., Mattsson, E., Omerov, P., & Klarare, A. (2022). Caring for patients with eating deficiencies in palliative care—Registered nurses' experiences: A qualitative study. *Journal of Clinical Nursing*, *31*(21–22), 3165–3177. https://doi.org/10.1111/jocn.16149

Wang, M. C., Deng, Q., Bi, X., Ye, H., & Yang, W. (2017). Performance of the entropy as an index of classification accuracy in latent profile analysis: A Monte Carlo simulation study. *Acta Psychologica Sinica*, *49*(11), 1473–1482. https://doi.org/10.3724/SP.J.1041.2017.01473

Wang, N., Hailey, D., & Yu, P. (2011). Quality of nursing documentation and approaches to its evaluation: A mixed-method systematic review. *Journal of Advanced Nursing*, *67*(9), 1858–1875. https://doi.org/10.1111/j.1365-2648.2011.05634.x

Ward, G., & Rogan, E. (2021). Perceptions of long-term care nurses and nursing assistants about communication related to residents' care. *Journal of Long Term Care*, 70–76. https://doi.org/10.31389/jltc.37

Wassink, H. L., & Chapman, G. E. (2010). Vancouver dietitians' perspectives on their roles in long-term care. *Canadian Journal of Dietetic Practice and Research*, *71*(1), e12-17. https://doi.org/10.3148/71.1.2010.26

Watkins, R., Goodwin, V. A., Abbott, R. A., Hall, A., & Tarrant, M. (2017). Exploring residents' experiences of mealtimes in care homes: A qualitative interview study. *BMC Geriatrics*, *17*(1), 141. https://doi.org/10.1186/s12877-017-0540-2

Watson, R. (1994). Measuring feeding difficulty in patients with dementia: Developing a scale. *Journal of Advanced Nursing*, *19*(2), 257–263. https://doi.org/10.1111/j.1365-2648.1994.tb01079.x [doi]

Webber, C., Milani, C., Clarke, A., R Isenberg, S., Downar, J., Kobewka, D., Hsu, A., Lau, J., Sinnarajah, A., Simon, J., Boese, K., Arya, A., Hannon, B., Roberts, R., Turcotte, L., Howard, M., Maxwell, C., & Tanuseputro, P. (2022). Using linked administrative data to evaluate and improve the quality of end-of-life care in nursing homes. *International Journal of Population Data Science*, *7*(3). https://doi.org/10.23889/ijpds.v7i3.2006

Weller, B. E., Bowen, N. K., & Faubert, S. J. (2020). Latent class analysis: A guide to best practice. *Journal of Black Psychology*, *46*(4), 287–311. https://doi.org/10.1177/0095798420930932

Wendland, B. E., Greenwood, C. E., Weinberg, I., & Young, K. W. H. (2003). Malnutrition in institutionalized seniors: The iatrogenic component. *Journal of the American Geriatrics Society*, *51*(1), 85–90. https://doi.org/10.1034/j.1601-5215.2002.51015.x

Whear, R., Abbott, R., Thompson-Coon, J., Bethel, A., Rogers, M., Hemsley, A., Stahl-Timmins, W., & Stein, K. (2014). Effectiveness of mealtime interventions on behavior symptoms of people with dementia living in care homes: A systematic review. *Journal of the American Medical Directors Association*, *15*(3), 185–193. https://doi.org/10.1016/j.jamda.2013.10.016

Wickson-Griffiths, A., Kaasalainen, S., Ploeg, J., & McAiney, C. (2014). Revisiting Retrospective Chart Review: An Evaluation of Nursing Home Palliative and End-of-Life Care Research. *Palliative Medicine & Care Open Access*, *1*(2). https://symbiosisonlinepublishing.com/palliative-medicine-care/

Wiersma, E., Marcella, J., McAnulty, J., & Kelley, M. L. (2019). 'That just breaks my heart': Moral concerns of direct care workers providing palliative care in LTC homes. *Canadian Journal on Aging*, *38*(03), 268–280. https://doi.org/10.1017/S0714980818000624

Williams, N., Hermans, K., Cohen, J., Declercq, A., Jakda, A., Downar, J., Guthrie, D. M., & Hirdes, J. P. (2022). The interRAI CHESS scale is comparable to the Palliative Performance Scale in predicting 90-day mortality in a palliative home care population. *BMC Palliative Care*, *21*(1), 174. https://doi.org/10.1186/s12904-022-01059-3

Williams, S. W., Zimmerman, S., & Williams, C. S. (2012). Family caregiver involvement for long-term care residents at the end of life. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *67*(5), 595–604. https://doi.org/10.1093/geronb/gbs065

Winter, S. M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *The American Journal of Medicine*, *109*(9), 723–726. https://doi.org/10.1016/s0002-9343(00)00609-4

Wirth, R., Dziewas, R., Beck, A. M., Clave, P., Heppner, H. J., Langmore, S., Leischker, A., Martino, R., Pluschinski, P., Rösler, A., Shaker, R., Warnecke, T., Sieber, C. C., Volkert, D., & Hamdy, S. (2016). Oropharyngeal dysphagia in older persons—From pathophysiology to adequate intervention: A review and summary of an international expert meeting. *Clinical Interventions in Aging*, 189. https://doi.org/10.2147/CIA.S97481

Wirth, R., Pourhassan, M., Streicher, M., Hiesmayr, M., Schindler, K., Sieber, C. C., & Volkert, D. (2018). The impact of dysphagia on mortality of nursing home residents: Results from the nutritionDay project. *Journal of the American Medical Directors Association*, *19*(9), 775–778. https://doi.org/10.1016/j.jamda.2018.03.016

Wirth, R., Streicher, M., Smoliner, C., Kolb, C., Hiesmayr, M., Thiem, U., Sieber, C. C., & Volkert, D. (2016). The impact of weight loss and low BMI on mortality of nursing home residents – Results from the nutritionDay in nursing homes. *Clinical Nutrition*, *35*(4), 900–906. https://doi.org/10.1016/j.clnu.2015.06.003

Worster, A., & Haines, T. (2004). Advanced statistics: Understanding medical record review (MRR) studies. *Academic Emergency Medicine: Official Journal of the Society for Academic Emergency Medicine*, *11*(2), 187–192. https://doi.org/10.1111/j.1553-2712.2004.tb01433.x

Wu, S. A., Keller, H. H., Donnelly, R., Lambe, E., & Dunn-Ridgeway, H. (2021). Developmental evaluation of the CHOICE+ champion training program. *Journal of Long Term Care*, 230–244. https://doi.org/10.31389/jltc.61

Wu, S. A., Morrison, J. M., Dunn-Ridgeway, H., Vucea, V., Iuglio, S., & Keller, H. H. (2018). Mixed methods developmental evaluation of the CHOICE program: A relationship-centred mealtime intervention for long-term care. *BMC Geriatrics*, *18*(1), 277. https://doi.org/10.1186/s12877-018-0964-3

Wu, S. A., Morrison-Koechl, J., Lengyel, C., Carrier, N., Awwad, S., & Keller, H. H. (2020). Are therapeutic diets in long-term care affecting resident food intake and meeting their nutritional goals? *Canadian Journal of Dietetic Practice and Research*, *81*(4), 186–192. https://doi.org/10.3148/cjdpr-2020-015

Wu, S. A., Morrison-Koechl, J., Slaughter, S. E., Middleton, L. E., Carrier, N., McAiney, C., Lengyel, C., & Keller, H. (2020). Family member eating assistance and food intake in long-term care: A secondary data analysis of the M3 Study. *Journal of Advanced Nursing*, *76*(11), 2933–2944. https://doi.org/10.1111/jan.14480

Wu, Sarah A. (2021). *Relational mealtimes in long-term care: Understanding the context of care at mealtimes for residents with eating and other mealtime challenges* [PhD Dissertation, UWSpace]. http://hdl.handle.net/10012/17444

Xiong, B., Freeman, S., Banner, D., & Spirgiene, L. (2019). Hospice use and one-year survivorship of residents in long-term care facilities in Canada: A cohort study. *BMC Palliative Care*, *18*(1), 100. https://doi.org/10.1186/s12904-019-0480-z

Yang, R.-Y., Yang, A.-Y., Chen, Y.-C., Lee, S.-D., Lee, S.-H., & Chen, J.-W. (2022). Association between Dysphagia and Frailty in Older Adults: A Systematic Review and Meta-Analysis. *Nutrients*, *14*(9), 1812. https://doi.org/10.3390/nu14091812

Yarnall, A. J., Sayer, A. A., Clegg, A., Rockwood, K., Parker, S., & Hindle, J. V. (2017). New horizons in multimorbidity in older adults. *Age and Ageing*, *46*(6), 882–888. https://doi.org/10.1093/ageing/afx150

Ye, L., & Richards, K. C. (2018). Sleep and long-term care. *Sleep Medicine Clinics*, *13*(1), 117–125. https://doi.org/10.1016/j.jsmc.2017.09.011

Ying, I. (2015). Artificial nutrition and hydration in advanced dementia. *Canadian Family Physician*, *61*(3), 245–248, e125-128.

Yoon, M. N., Ickert, C., Slaughter, S. E., Lengyel, C. O., Carrier, N., & Keller, H. H. (2018). Oral health status of long-term care residents in Canada: Results of a national cross-sectional study. *Gerodontology*, *35*(4), 359–364. https://doi.org/10.1111/ger.12356

You, K., Li, Y., Intrator, O., Stevenson, D., Hirth, R., Grabowski, D., & Banaszak-Holl, J. (2016). Do nursing home chain size and proprietary status affect experiences with care? *Medical Care*, *54*(3), 229–234. https://doi.org/10.1097/MLR.0000000000000479

Zhang, Z. (2016). Model building strategy for logistic regression: Purposeful selection. *Annals of Translational Medicine*, *4*(6), 111–111. https://doi.org/10.21037/atm.2016.02.15

Zimmerman, S., Cohen, L. W., Reed, D., Gwyther, L. P., Washington, T., Cagle, J. G., Sloane, P. D., & Preisser, J. S. (2013). Families matter in long-term care: Results of a group-randomized trial. *Seniors Housing & Care Journal*, *21*(1), 3–20.

Zimmerman, S., Shier, V., & Saliba, D. (2014). Transforming nursing home culture: Evidence for practice and policy. *The Gerontologist*, *54 Suppl 1*, S1-5. https://doi.org/10.1093/geront/gnt161

Appendix A

Supplemental Materials for the Literature Review (Chapter 2)

Contents of Appendix A:

A.1 Nutrition Care Practices in LTC

Nutrition care plans are developed in response to the specific challenges of the resident through consultation with the chart, the resident if able, the long-term care (LTC) team, and family members (Johnson et al., 2018). These are discussed in more detail (i.e., description and prevalence) in the following sections as background and justification for inclusion in the data collection.

Therapeutic diets

Therapeutic diets are diet prescriptions that restrict or promote specific food items or macro/micronutrients in response to specific diagnoses. For example, a diabetic diet may limit food items containing simple sugars and a cardiovascular diet may involve reduced sodium (Darmon et al., 2010). Alternatively, a high fibre or potassium diet focuses on increasing these in the diet. In a survey of several LTC homes across Canada, 42% of residents had some form of therapeutic diet, the most prevalent being diabetic (21%), promoting weight gain (10%), 'other' restrictive (7%), and no salt added (4%) (Wu, Morrison-Koechl, Lengyel, et al., 2020). Some studies have argued that therapeutic diets may discourage food intake and increase the risk of malnutrition by reducing the palatability of food and limiting enjoyable food items such as sweets and desserts (Darmon et al., 2010; Sloane et al., 2008). However, therapeutic diets do meet a need and are relevant in some residents to manage their conditions (Wu, Morrison-Koechl, Lengyel, et al., 2020).

Modified texture diets

Modified texture diets and thickened fluids are prescribed to residents who have dysphagia or poor oral health and dentition (Agarwal et al., 2016). Various consistencies of food (e.g., pureed, minced) and fluid (e.g., thin, mildly thick) are offered depending on the need of the resident (Cichero et al., 2017). One third (33%) of residents in a purposive sample of LTC homes across Canada received a modified texture diet (Vucea et al., 2018).

Oral nutritional supplements

Oral nutritional supplements (ONS) are energy- and nutrient-dense beverages (e.g., milkshake) or food additives (e.g., powder) that enhance overall nutritional intake. ONS is widely used across LTC facilities to address eating challenges among residents and are typically used in response to unintentional weight loss, decreased food intake, and pressure ulcers (Agarwal et al., 2016; Johnson et al., 2009). The use of ONS in LTC can vary with estimates ranging from 8% to 31% of residents prescribed an ONS (C. Collins et al., 2019; Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017; Vandewoude et al., 2019).

Adaptive aids

Many residents of LTC experience loss of independence as a result of functional decline (Ontario Long Term Care Association [OLTCA], 2019). The goal of care is to support independence for as long as possible by allowing residents to perform tasks as they are able. Adaptive aids such as rimmed plates, finger foods, cups with handles or spouts can all help residents to continue to participate in mealtime activities in the early stages of eating challenges (Frissoni et al., 1998). Proper positioning in an upright position is also important for allowing residents to participate in meals and assists in ease and safety of swallowing (Rogus-Pulia et al., 2015).

Physical and verbal assistance

Assistance during mealtimes is offered to varying degrees to further support residents during mealtimes. Assistance may range from verbal, in the case of residents with cognitive impairment who require reminders and encouragement to eat; set up only, which entails cutting food and opening packages; occasional, if the resident only needs assistance some of the time; to extensive, in the case of residents who have lost the ability to feed themselves (Keller, Carrier, Slaughter, Lengyel, Steele, Duizer, Morrison, et al., 2017). Interventions that increase the one-on-one assistance offered to residents in LTC at mealtimes and snacks show major potential to improve food and fluid intake, though time and staffing are often cited as barriers to offering eating assistance at mealtimes (Simmons & Schnelle, 2004).

Dining environment

Multiple components of the dining environment, including the ambiance, psychosocial support, cues toward mealtime, and food service have the potential to positively impact food intake and dementia-related responsive expressions in residents of LTC (Abbott et al., 2013; Whear et al., 2014). Many changes can be made to enhance the dining room environment, such as using decorations, wall hangings and furniture to create an inviting homelike atmosphere (Ducak et al., 2015). As mentioned previously, activity and noise in the dining room can be distracting to residents and may contribute to low food intake, but eating alone in the bedroom may also have a negative effect. As such, alternative dining environments that are quieter and have less people may contribute to a more enjoyable and effective mealtime experience for certain residents (Sloane et al., 2008).

A.2 Discourse Around Artificial Nutrition for Persons Living with Dementia

Historically, a large portion of the discourse around nutrition care options for severe eating challenges among older adults nearing the end of life focuses on enteral and parenteral nutrition, generally referred to as artificial nutrition, as a last resort for maintaining nutritional status (Brooke & Ojo, 2015; Ijaopo & Ijaopo, 2019; Lan et al., 2016; Lynch, 2016; Ribeiro Salomon & Carvalho Garbi Novaes, 2015). Artificial nutrition was created to deliver all nutrients and fluid directly to the gastrointestinal tract when a person is unable to swallow or if oral intake is otherwise compromised. For several decades, artificial nutrition has been the emphasis of discussion for addressing eating difficulties in persons in advanced stages of diseases such as dementia (e.g., Finucane et al., 1999; Volicer et al., 1989). Many have concluded that the burdens imposed by this form of nutrition on an individual with advanced dementia outweighs its benefits; there is no convincing evidence that artificial nutrition improves desired outcomes such as nutritional status, survival, or risk of pressure sores and aspiration pneumonia in this population (Chou et al., 2020; Finucane et al., 1999; Lan et al., 2016; Sampson et al., 2009). In response, both the American Geriatrics Society [AGS] (2014) and the Canadian Geriatrics Society (Lam & Lam, 2014) recommend against the use of artificial nutrition for individuals with advanced dementia, opting rather for gentle hand feeding and verbal prompting to encourage adequate oral intake.

Despite this seemingly convincing body of literature, others still maintain that artificial nutrition should not be dismissed as a worthwhile treatment option (Brooke & Ojo, 2015; Ijaopo & Ijaopo, 2019; Ribeiro Salomon & Carvalho Garbi Novaes, 2015). Support for artificial nutrition centers around the argument that although no consistent benefits have been shown, there is also no evidence to suggest that artificial nutrition negatively impacts the nutritional status in these individuals, so there is no harm in offering it and furthermore it would be inappropriate to withhold it as a potential treatment option (Ribeiro Salomon & Carvalho Garbi Novaes, 2015). Furthermore, many of the studies cited by the American Geriatrics Society to form their position statement against artificial nutrition use in advanced dementia have been criticized for lacking methodological rigor (Lynch, 2016). In this critique, Lynch (2016) argues that "It is inappropriate for guidelines to issue a blanket statement against the use of feeding tubes when in fact feeding tubes help some people" (p. 301). Instead, proponents of artificial nutrition as a care option for persons in advanced stages of dementia suggest that the decision should be considered on a case-by-case basis (Ijaopo & Ijaopo, 2019; Lynch, 2016; Ribeiro Salomon & Carvalho Garbi Novaes, 2015). While this stance may be defensible, it is not helpful in supporting members of the care network to arrive at the most appropriate care decisions when long-term care (LTC) residents experience severe eating challenges.

This recommendation to offer artificial nutrition on a case-by-case basis is problematic in that it lacks clarity and decisiveness. As a result, health professionals, members of the LTC care team, family carers, and other decision-makers are left to question whether artificial nutrition is the best option to deliver nutrients to the resident when in the vast majority of cases, it is not appropriate (Gieniusz et al., 2018; Palecek et al., 2010; Rousseau, 2018). Furthermore, though outcomes such as potential increase in survival rate and decreased risk of aspiration pneumonia have been cited as perceived benefits, an important outcome that has not been explored is the quality of life of both the resident and the care network. Artificial nutrition can be highly burdensome and may cause undue stress and anxiety on residents with cognitive impairment in particular, who may require restraints to prevent them from removing the tube (Volicer & Simard, 2015). While some have argued in favour of artificial nutrition because of the sense of relief family carers have reported once it is initiated (Ijaopo & Ijaopo, 2019), evidence suggests that relief is also gained through education on, and implementation of, relationship-centered practices like careful hand feeding that encourage oral intake ([AGS], 2014; Druml et al., 2016; Hanson et al., 2011; Keller, Edward, et al., 2006; Lam & Lam, 2014; Palecek et al., 2010). As such, there is a great need to shift the focus of the debate beyond “to tube-feed or not” in advanced stages of eating challenges to develop and emphasize alternatives (e.g., comfort feeding) and raise awareness of these alternatives among members of the care network (Morrison et al., 2019; Rousseau, 2018).

Appendix B

Codebook with List of Variables and Definitions

The codebook as it appears here contains extracted and derived variables that were used in the four studies within this dissertation and is not an exhaustive list of variables that were extracted from the retrospective chart review.

Demographics variables Obtained from res charts (Home Chain) and from BABEL data collection.		
Record_id	Record ID	
Site_id	Site ID	
Data_source	Source of data – HC or BABEL	0= Home Chain; 1= BABEL
Age_death	Resident's age at death	Years (death date – birth date)
Admit_time	Length of admission	Number of months, from admission date to date of death
Admit6	Was residents admitted to the home for at least 6 months prior to death?	if admit_time >=6 then admit6 = 1; if admit_time <6 then admit6 = 0;
Admit_date	Date of admission	
dem_sex	Sex	1= male; 2= female
MDS variables **NOTE: for Home Chain variables, the third last assessment was used (mean 206 days prior to death) to match up with BABEL, which were mean 257 days prior to death** Obtained from res charts (Home Chain) and from BABEL data collection.		
Mds_date	Date MDS was collected	
Mds_timetodeath	Number of days prior to death MDS data were collected	(Date of death) – (MDS date)
Res_heightcm	Resident Height, cm (from resident chart, date of MDS data collection)	Numerical, cm

Rai_abs_any	Any aggressive behaviour displayed; Modified ABS Score (sum of physical, verbal abuse, socially inappropriate/disruptive, resists care)	0= no; 1= yes *note: the way the data was collected, with y/n expression occured or did not, the sum of the 4 scores will have a max score of 4. 0= no aggressive behaviour, >=1- 4 would be the same as ABS >=1 on the regular score, so just have to use dichotomous yes/no variable.
mds_b4_cogskills	B4. Cognitive skills for daily decision making	0= independent, 1= modified, 2= moderately impaired, 3= severely impaired
mds_k4_nutrprob_y___3	Leaves >25% of food uneaten at most meals	0= no; 1= yes.
MDS SCORES		
Rai_adl_score	Activities of daily living (ADL) heirarchy scale Morris JN, Fries BE, Morris SA. (1999) Scaling ADLs within the MDS. Journals of Gerontology: Medical Sciences 54(11):M546-M553.	0 = independent; 1= supervision; 2= limited; 3= extensive; 4= maximal; 5= dependent; 6= total dependence.
Adl_extensive	Collapsed ADL score, <3 and 3+	if Rai_adl_score in (0,1,2) then adl_extensive =0; if rai_adl_score in (3,4,5,6) then adl_extensive = 1;
rai_abs_scale	Aggressive Behaviour Scale (ABS) Perlman CM, Hirdes JP. The aggressive behavior scale: a new scale to measure aggression based on the minimum data set. J Am Geriatr Soc. 2008 Dec;56(12):2298-303. doi: 10.1111/j.1532-5415.2008.02048.x. PMID: 19093929.	0 (none) to 12 (severe)
abs_severe	ABS categorical	0, None; 1, mild to moderate aggressive behaviour (ABS 1-4); 2, more severe (ABS 5+)
rai_cps_score	Cognitive Performance Scale (CPS) score Morris JN, Fries BE, Mehr DR, Hawes C, Philips C, Mor V, Lipsitz L. (1994) MDS Cognitive Performance Scale. Journal of Gerontology: Medical Sciences 49 (4): M174-M182.	0, intact; 1, borderline intact; 2, mild impairment; 3, moderate impairment; 4, moderately severe impairment; 5, severe impairment; 6, very severe impairment

Cps_modhi	CPS categorical	0, intact/mild impairment (CPS 0-2); 1, moderate/severe impairment (CPS 3+)
rai_drs_score	Depression Rating Scale (DRS) Burrows A, Morris JN, Simon S, Hirdes JP, Phillips C. (2000) Development of a Minimum Data Set-based Depression Rating Scale for Use in Nursing Homes. Age and Ageing 29(2): 165-172.	0, no mood symptoms; to 14, all mood symptoms present in last 3 days
Drs_risk	DRS categorical	0, low/no depression risk (DRS 0-2); 1, minor or major depressive disorders (DRS 3+)
rai_painscale	Pain Scale **Fries BE, Simon SE, Morris JN, Flodstrom C, Bookstein FL**. 2001. Pain in U.S. Nursing Homes: Validating a Pain Scale for the Minimum Data Set. *Gerontologist* 41(2): 173–79.	0, no pain; 1, less than daily pain; 2, daily pain, but not severe; 3, daily severe pain
Any_pain		if rai_painscale = 0 then any_pain =0; if rai_painscale in (1,2,3) then any_pain = 1;
Daily_pain		if rai_painscale in (0,1) then daily_pain = 0; if rai_painscale in (2,3) then daily_pain = 1;
res_chess	Changes in Health, End-stage disease, Signs, and Symptoms (CHESS) scale – 'health instability' **Hirdes JP, Frijters D, Teare G**. 2003.The MDS CHESS Scale: A New Measure to Predict Mortality in the Institutionalized Elderly. *Journal of the American Geriatrics Society* 51(1): 96–100.	0, No health instability; 1, minimal instability; 2, low instability; 3, Moderate; 4, High; 5, very high
Chess_modhi	Collapsed CHESS score <3 and 3+	if res_chess in (0,1,2) then chess_modhi =0; if res_chess in (3,4,5) then chess_modhi = 1;

Diagnoses obtained from MDS
Matched up from Home Chain and BABEL data

res_diag_canc	Cancer	0 = no; 1 = yes
res_diag_diabetes	Diabetes	
res_diag_hypothyroid	Hypothyroidism	
res_diag_cardio	CVD (e.g., HTN, arteriosclerosis, DVT, PVD)	
res_diag_chf	Congestive heart failure	
res_diag_arthr	Arthritis	
res_diag_hipfract	Hip fracture	
res_diag_osteopor	Osteoporosis	
res_diag_alz	Alzheimer’s disease	
res_diag_aphasia	Aphasia	
res_diag_cp	Cerebral palsy	
res_diag_stroke	Stroke/TIA/CVA	
res_diag_nonADdem	Non-AD dementia	
res_diag_hemiplegia	Hemiplegia/hemiparesis	
res_diag_ms	Multiple sclerosis	
res_diag_paraplegia	Paraplegia	
res_diag_parkin	Parkinson’s	
res_diag_quadripleg	Quadriplegia	
res_diag_seizure	Seizure disorder	
res_Diag_braintrauma	Traumatic brain injury	
res_diag_anxiety	Anxiety disorder	

res_diag_depr	Depression	0 = no; 1 = yes	
res_diag_bipolar	Bipolar disorder		
res_diag_schizo	Schizophrenia		
res_diag_asthma	Asthma		
res_diag_copd	COPD/Emphysema		
res_diag_sensory	Sensory conditions (e.g., glaucoma, cataracts, macular degeneration)		
res_diag_renalcond	Renal failure/disorder		
Res_diag_alldem	All-cause dementia (AD + nonAD combined)		
Nutrition interventions – found in the care plan			
Note: for variables 31-99, these are the root variable name with ___0, ___1…. Etc added to the end to signify # months prior to death. So, each will have 4 variables associated with the root variable as in the example for #31.		0= No 1= Yes (unless otherwise specified)	The variables for care plans are coded based on the nearest care plan preceding the 6/3/1 month/2 wk time point. Descriptions/definitions provided:
ncc_int_nochange	No changes (Not applicable for 6 month time point)	ncc_int_nochange___0 6 months ncc_int_nochange___1 3 months ncc_int_nochange___2 1 month ncc_int_nochange___3 2 weeks	No changes in the care plan since previous time point. Not applicable for 6 month time point, since this is considered baseline for the study.
ncc_int_phys	Increase in physical eating assistance	See note above #31 – 4 variations	Physical assist provided to a greater extent than previous recorded, as per levels, e.g., None → Limited → extensive → total. “Cut up” food, or help with set up would be included - Does not include “SUPERVISION with minimal set up or assistance”
ncc_int_encourage	Increased encouragement (verbal or other support)	“”	Required oversight of meals required but not necessarily physical assistance. Noted as “encouragement”, “supervision”, “support” etc. indicating that additional support or verbal prompting is

			required – could be coupled with none or some phys assist. - Flag “encourage specific food items” or “push nutrient dense foods” as encouragement. This should be a new item and not just altering the specifics of what is being encouraged (e.g., if changed from “encourage nutrient dense foods”, to “encourage nutrient dense foods including eggs.. etc.” then this is not increased encouragement).
ncc_int_adaptaid	Adaptive aid	“”	Adaptive aids (e.g., lip plate, special utentils, nosey cup etc.) in place to assist with eating - Capture all changes to adaptive aids used (e.g., lip plate changed to blue lip plate would be flagged), mug for cereal or soup,
ncc_int_mtd	Texture modification introduced	“”	Texture modification noted (e.g., pureed, minced) but NOT including “cut up” as this is set up assistance and not texture mod. Thickened liquid is also included here
ncc_int_mtd_alt	Alteration of existing texture modification	“”	Change to texture in either direction (e.g., minced to pureed or vice versa)
ncc_int_mtd_wd	Withdrawal of texture modification diet	“”	Change any mod back to regular texture
ncc_int_dietpres	Therapeutic diet prescription	“”	Any therapeutic diet prescription that alters/limits types of food allowed, e.g., diabetic, renal, low sodium, high energy/protein. Note: if specific high energy/protein food items are suggested as offerings, but not a formal diet order this does not count.
ncc_int_dietpres_wd	Cessation of therapeutic diet prescription	“”	Removal of therapeutic diet or liberalization, so that specific foods are no longer restricted
ncc_int_ons	ONS introduction	“”	Oral nutritional supplement introduced. Can be at medpass or during meals, and can be a commercial product (e.g., Resource 2.0, Boost) or made in-house (e.g., high-protein shake, protein powder added to cereal etc.)

ncc_int_ons_alt	Alteration of existing ONS prescription	See note above #31 – 4 variations	Any change to an existing oral nutritional supplement prescription, such as change in product or dosage
ncc_int_ons_wd	Withdrawal of ONS	“”	Cessation of all oral nutritional supplements
ncc_int_fluid	Fluid protocol to increase fluid intake	“”	Specific program to enhance fluid intake, e.g. CHEERS program. “Push fluids” does not count, as it should be a more formalized intervention, nor does listing of specific fluid items to be served at meals/snacks. Must be a formalized program.
ncc_int_hypoderm	Hypodermoclysis	“”	Subcutaneous administration of fluids
ncc_int_wt_monitor	Increased weight monitoring	“”	Weight monitoring more frequent than was in place previously. Assumed that 1x per month is standard so if not specified in the care plan, then ‘no’
ncc_int_wtmon_wd	Cessation of weight monitoring as per care plan	“”	If not specified in the care plan, then ‘no’
ncc_int_fi_mon	Food intake flagged for monitoring and follow-up	“”	Any comment of monitoring and/or notifying RD of changes to food intake (if ‘food/fluid’ not specified, assume both)
ncc_int_flu_mon	Fluid intake flagged for monitoring and follow-up	“”	Any comment of monitoring and/or notifying RD of changes to fluid intake (if ‘food/fluid’ not specified, assume both) - NOT if already flagged for monitoring and recommended/”don’t go below” amounts have changed
ncc_int_fimon_wd	Cessation of routine mealtime food intake tracking	“”	Any comment to stop monitoring food intake during meals
ncc_int_flex	Eating in room or outside of mealtimes	“”	Meal delivered to room or meal taken in different dining area (e.g., TV room)
ncc_int_environ	Other environmental/dining change	“”	Any other specification in dining environment other than location outside of dining room (e.g., beside window, alone at table etc.) - Specification of meal service (e.g., deliver meal to resident first to mitigate wandering etc.)

			- “serve first” - Seated at assistive table.
ncc_int_bowel	Bowel protocol	“”	Any intervention to improve bowel motility (e.g., prunes/prune juice, OTC or prescription medications, laxatives, suppositories etc.); protocol regarding constipation.
ncc_int_preference	Care plan adjusted according to preference	“”	Any specification of resident’s preferences during mealtimes, concerning food items, time of meals, likes/dislikes etc.
ncc_int_comfort	Comfort focus	See note above #31 – 4 variations	Comfort feeding and/or measures directed towards food and mealtimes specifically (e.g., “Provide food/fluid as desired and tolerated by resident”)
ncc_int_tube	Tube feeding introduced	“”	PEG, NG, or other non-oral source of nutrition initiated
ncc_int_tube_wd	Tube feeding ceased	“”	PEG, NG, or other non-oral source of nutrition withdrawn
ncc_int_other	Other care plan?	“”	Any other care plan that specifies food/mealtime protocol that does not fit in categories above; Include other interventions (e.g., large/small portions) that don’t fit into the categories above.
ncc_int_other_detail6	Describe other interventions, 6 months	Text	Other intervention, specified (6 months)
ncc_int_other_detail3	Describe other interventions, 3 months	Text	Other intervention, specified (3 months)
ncc_int_other_detail1	Describe other interventions, 1 month	Text	Other intervention, specified (1 month)
ncc_int_other_detail2wk	Describe other interventions, 2 weeks	Text	Other intervention, specified (2 weeks)
History of conditions that challenge good intake as specified in the care plan:			
ncc_ec_history___1	Cognitive difficulties	0=no, 1= yes	
ncc_ec_history___2	Physical difficulties	“”	Weakness, arthritis, other musculoskeletal condition with indication that physical help is required during meals.

ncc_ec_history___3	Dysphagia/swallowing difficulties	“”	
ncc_ec_history___4	Chewing or oral health issues	“”	
ncc_ec_history___5	Other	“”	
ncc_ec_history_other	Specify, if history of other condition/chronic eating challenge specified in care plan	Text	
EATING CHALLENGES – noted in progress notes			
ncc_ec_decr_fi	Decreased food intake	See note above #31 – 4 variations	Any note of “low food intake”, or “decreased”, “lower than usual” etc. Applicable if this is noted at least once during the respective two week observation period. Synonyms: “not eating”, “decreased intake”, “less than usual”. Missing one meal should not be considered decreased food intake, but if they miss several meals (e.g., >=1 per day for 3 or more days in a row or all meals in 1 day), then that should be considered decreased food intake. But just missing a meal in itself shouldn’t be considered decreased FI, unless specified that the res is eating less than usual.
ncc_ec_dehydr	Dehydration/decreased fluid intake	“”	“Poor fluid intake”, any signs of dehydration reported, decreased fluids, not drinking well, refused fluids etc
ncc_ec_poor_app	Poor appetite	“”	“decreased appetite”, “not hungry”, ‘not willing to eat’ Note: this has to be explicitly stated in the progress notes and not implied by not eating meal. Resident declines food when offered if no other explanation provided (e.g., “resident shook his head no to food and fluid when offered”) - Flag if there is an indication that poor appetite is the reason for not eating (e.g., resident not feeling well).
ncc_ec_lowenergy	Low energy	“”	Any indication that the resident is too tired or lack of energy to eat - “Low energy”, “sleeping at meal”, “lethargic”, “sleepy”, “too tired to come to meal”, “remained in bed”, “leaning over in chair during meal”, “weak” - Remained in bed (for meal) indicates low energy.

ncc_ec_refusal	Refusal to eat	“”See note above #31 – 4 variations	Uncharacteristic refusal of mealtime (e.g., if indicated that res usually misses a specific meal such as breakfast, this doesn’t count). Refusal could indicate didn’t want to come to the dining room or refused to eat when in the dining room and offered food, and could be paired with another eating challenge – e.g., “Too tired, refused to come to the dining room.” Would be coded as low energy AND refusal to eat -Implies a choice/action originating from the resident. Refusal can also indicate that the res declined any food/meal offered even if care adjusted and the res was offered another meal or other strategy with success.
ncc_ec_conc	Poor concentration		Any indication that the resident is unable to focus or lacks attention to meal, e.g. “distracted”, “low concentration”, “wandering during mealtime”, “restless”
ncc_ec_prompt	Verbal or physical prompting required	“”	Noted that the person needed help with meal, e.g., “needed encouragement”, prompting, help with set up. This should be prompting in the sense of actually performing the mealtime/eating tasks and not just encouragement to attend the meal. E.g. if res is not swallowing and prog note indicates that they were prompted to swallow with good effect.
ncc_ec_cogn	Cognitive difficulties that challenge self-feeding	“”	Any cognitive challenges noted that make mealtimes difficult (usually included in the care plan, but could also be a progress note, if, for example, the reason for refusal to eat was cognitive impairment or misjudgment); “requires prompting”, “[any challenge with meal] due to cognitive factors”, “requires orienting”. Applies only to food intake and not meds. Must be challenges explicitly due to cognitive impairment and not questionable whether the challenge is cause by cog or physical impairment. “Confused” that leads to decreased intake.

ncc_ec_phys_diff	Physical difficulties with self-feeding	“”	Any physical challenges that make mealtimes/self-feeding difficult (usually included in the care plan, but could also be a progress note, if, for example, the person is experiencing pain or physical help required) – could be paired with cognitive difficulties. E.g., “needed help with meal”, “[physical disability/injury/condition] that makes eating challenging”, “requires physical assistance”, including physical challenges that prevent set up/opening containers. Flag if resident is noted to have difficulty in the act of self feeding (e.g., spillage).
ncc_ec_frustration	Aggression or expression of frustration during mealtime	“”	Any expression of anger/frustration during mealtime. E.g., Aggression, “physical contact”, “hitting”, “slapped”, “punched”, kicked, “resistive” all in the act of mealtime or snack (e.g., during dinner service, when being helped with meal) or if interrupts mealtime (e.g., if res isn’t able to attend dining room because of expression). NOT if food is offered to distract from expressions, only if it hinders the meal/snack service.This doesn’t include when administering medications even if at mealtimes if there is no disturbance with the meal (e.g., “resistive to taking meds at lunch” would not count here). Any expression of frustration with mealtime (e.g., calling out “I don’t want to be here, get me out of here!”)
ncc_ec_unusual	Inappropriate or unusual behaviour (e.g., eating table mates' food)	“”	Any action that is out of the ordinary for general social norms but not necessarily wrong concerning interactions during meal service or with mealtimes (e.g., eating a table mates’ food, grabbing at cups and plates, eating breakfast in middle of night, refusing meal because convinced had already eating or incorrectly anticipating family taking out to dinner etc). Must occur during mealtime
ncc_ec_dysphagia	Dysphagia	See note above #31 – 4 variations	“Dysphagia”, “problems swallowing”, coughing/choking at meals; Not swallowing/holding

			food in mouth does not imply dysphagia. To be dysphagia, there must be some exhibited signs of swallowing problems, e.g., coughing/choking. Coughing must be explicitly noted to be related to food/fluid/meds intake. Difficulty swallowing meds can also indicate dysphagia.
ncc_ec_dental	Dental or chewing issues	“”	Dental problems, broken teeth, dry mouth, missing dentures, won’t wear dentures, problem chewing; Can be obtained from 6-month care plan if significant dental issues are reported to compromise food intake.
ncc_ec_hold_food	Holding food in mouth	“”	“Wouldn’t swallow”, “pocketing food in cheek”, etc. Spitting food out could also count – essentially anything that indicates that the resident was able to get food in mouth but wouldn’t swallow; Only if reported in progress note, and not “history of” holding food in mouth in care plan. Does not include meds “wiping food off of tongue”
ncc_ec_recogn	Eating inedibles	“”	Inappropriately put something in mouth that was not a food item (e.g., napkin)
ncc_ec_vomit_acute	Emesis - short term	“”	Vomiting/emesis/dry heaving reported on an occasional basis – 1-3 days within a week, non recurrent
ncc_ec_vomit_chronic	Emesis - chronic / long-term	“”	Vomiting/emesis/dry heaving reported repeatedly (e.g., >3 days in 1 week OR recurrent over > 1 week)
ncc_ec_consti	Constipation	“”	No BM >2 days Not to be obtained from care plan
ncc_ec_diarr_acute	Diarrhea - short term	“”	Diarrhea/loose stool reported on occasion – 1-3 days in a week, non recurrent
ncc_ec_diarr_chronic	Diarrhea - chronic / long term	“”	Diarrhea/loose stool reported repeatedly >3 days in a week, or recurrent >1 week, or indicated as “ongoing” in progress notes

ncc_ec_skin	Skin breakdown/pressure ulcers	“”	Any ongoing issues with compromised skin, beyond rashes and redness, or what can be explained by a fall or other injury.
ncc_ec_other	Other eating challenges?	“”	Any challenges with eating that do not fit into the categories specified above – more details provided in text boxes (below) - E.g., weepy, sadness, unhappy, depressed.
ncc_ec_other_detail6	Describe other challenges, 6 months	notes	Other eating challenge, specified (6 months)
ncc_ec_other_detail3	Describe other challenges, 3 months	notes	Other eating challenge, specified (3 months)
ncc_ec_other_detail1	Describe other challenges, 1 month	notes	Other eating challenge, specified (1 month)
ncc_ec_other_detail2wk	Describe other challenges, 2 weeks	notes	Other eating challenge, specified (2 weeks)

Summary of eating challenges and nutrition interventions (derived)

t1_ec15 t2_ec15 t3_ec15 t4_ec15	Summary score of eating challenges, 15 in total: 1. Decreased food intake 2. Decreased fluid intake/dehydration 3. Poor appetite 4. Low energy 5. Refusal to eat 6. Distractibility 7. Demonstrated need of verbal or physical prompting 8. Cognitive difficulties that challenge self-feeding 9. Physical difficulties that challenges self-feeding 10. Frustration/expressive behaviours during mealtime 11. Socially inappropriate behaviour (e.g., eating table mates’ food) 12. Swallowing difficulties 13. Dental or chewing issues 14. Holding food in mouth 15. Eating inedibles	t1_ec15 = sum(ncc_ec_decr_fi___0, ncc_ec_dehydr___0, ncc_ec_poor_app___0, ncc_ec_lowenergy___0, ncc_ec_refusal___0, ncc_ec_conc___0, ncc_ec_prompt___0, ncc_ec_cogn___0, ncc_ec_phys_diff___0, ncc_ec_frustration___0, ncc_ec_unusual___0, ncc_ec_dysphagia___0, ncc_ec_dental___0, ncc_ec_hold_food___0, ncc_ec_recogn___0);

Sum_ec15	Total number of eating challenges recorded across the four time points	= sum(t1_ec15, t2_ec15, t3_ec15, t4_ec15);
Sum of 8 restorative inter ventions:	Increased physical assistance Increased encouragement Adaptive aid Modified texture Therapeutic diet prescription ONS Fluid protocol Hypodermoclysis	ncc_int_phys___0, ncc_int_encourage___0 , ncc_int_adaptaid___0 , ncc_int_mtd___0 , ncc_int_dietpres___0, ncc_int_ons___0 , ncc_int_fluid___0, ncc_int_hypoderm___0
T1_int8 (… t4_int8)	Total number of restorative interventions in place of 8 most common at baseline (6 months)	t1_int8 = sum(ncc_int_phys___0, ncc_int_encourage___0 , ncc_int_adaptaid___0 , ncc_int_mtd___0 , ncc_int_dietpres___0, ncc_int_ons___0 , ncc_int_fluid___0, ncc_int_hypoderm___0);
T2_intchg_yn T3_intchg_yn T4_intchg_yn	Any changes made to the care plans at subsequent timepoints (bivariate) based on 8 interventions (counting alterations to MTD and ONS)	
Int_any_withdrawal	Withdrawal of ONS, MTD, or diet prescription	if ncc_int_mtd_wd = 1 or ncc_int_dietpres_wd = 1 or ncc_int_ons_wd = 1 then int_any_withdrawal = 1; else int_any_withdrawal = 0;
Ncc_ec_none___(0,1,2,3)	No eating challenges during the specified time point (does not include "other" eating challenges)	
Ncc_ec_none	No eating challenges at any time point *NOTE: this is same format for all "ever" eating challenge variables - ___# removed from variable root	
Wt1 – wt6	Weight (kg) at each time point Wt1 is 6 months prior to death	Wt1 = ncc_wt_6mo, wt2= ncc_wt_5mo… etc.

Wtchg1 – wtchg6	Weight change (%) in relation to wt at time 6, las tmonth prior to death	Wtchg1 = pctdiff_6mo

Bmi1- bmi6	BMI at each time point, based on height found on first MDS collected (~6months)	bmi1 = ncc_wt_6mo/((Res_heightcm*0.01)**2);
		bmi2 = ncc_wt_5mo/((Res_heightcm*0.01)**2);
		bmi3 = ncc_wt_4mo/((Res_heightcm*0.01)**2);
		bmi4 = ncc_wt_3mo/((Res_heightcm*0.01)**2);
		bmi5 = ncc_wt_2mo/((Res_heightcm*0.01)**2);
		bmi6 = ncc_wt_1mo/((Res_heightcm*0.01)**2);

t2_prevmo_wtloss	% weight loss from previous month at 3 (t2) months, 1 (t3) months, and 2 weeks (t4) prior to death	t2_prevmo_wtloss = ((wt2-wt3)/wt2)*100;
		t3_prevmo_wtloss = ((wt4-wt5)/wt4)*100;
		t4_prevmo_wtloss = ((wt5-wt6)/wt5)*100;

t2_5wtloss
t3_5wtloss
t4_5wtloss
	Weight loss >=5% in past month	e.g.,
		t2_5wtloss =0;
		if t2_prevmo_wtloss >=5 then t2_5wtloss = 1;
		if t2_prevmo_wtloss =. then t2_5wtloss =.;

t1_pall_des
t2_pall_des
t3_pall_des
t4_pall_des
	Palliative designation occurred prior to time point and after previous timepoint (e.g., t1 indicates that a palliative conversation had already occurred prior to 6 months before death); t4 includes and conversation that happened within a month of death, since care plan changes were recorded at any point within the last two weeks for the 2 week time point	t1_pall_des = 0;
		t2_pall_des = 0;
		t3_pall_des = 0;
		t4_pall_des = 0;
		if palliative_diff > 180 then t1_pall_des = 1 ;
		if 90<palliative_diff <=180 then t2_pall_des =1;
		if 30<palliative_diff <=90 then t3_pall_des = 1;
		if 0<=palliative_diff <=30 then t4_pall_des = 1;

Palliative/EOL Phase (Study 3) – identified by CTRL-F of entire 6 month period leading up to death and notes from that point on scanned for actions/care provided

ncc_palliat_date	Date of first formal or informal mention of resident nearing death	Date, m-d-y	Key words could include “end-of-life”, “end of life”, “EOL”, “end”, “palliative”, “terminal”, “declin”*, “deterior”*, “death”, “dying”, “comfort measures”, and note the first date any of these are reported if it pertains directly to, or implies suspected end of life; **Note:** does not have to be an explicit mention of death/EOL if it is clear that there is a choice to be made between treating/diagnosing or providing comfort care.

			Also, if palliative status implemented previously and then lifted d/t improved status, then this does not count as the palliative date, but should be noted in the description. Ex. res palliative in 2015 but then no longer palliative in 2016, but then palliative again 7 months before death. Most recent and final palliative order would be noted.
palliative_diff	Number of days between date formal/informal mention of palliative or comfort focused care and death	palliative_diff = intck('day', ncc_palliat_date, death_date);	
Any_palliative	Was the resident flagged as palliative/declining/EOL prior to death?	1= yes, 0= no; based on whether or not mention of death/palliative etc was present (i.e. if ncc_palliat_date not missing)	
Palliat_length	Number of days between pallaitve date and death, categorized	0= 0-14 days (within 2 weeks of death); 1=15-30 days (within 1 month of death); 2= 31-90 days (within 3 months of death); 3= 91-180 days (within 6 months of death); 4= 180-365 days (within 1 year of death); 5= >365 days (more than 1 year prior to death).	
Pall_provider	Updated role of person who initiated EOL convo	0 Physician/Nurse practitioner 1 Nursing 2 Family 3 Dietitian 4 Hospital MD/team 5 Resident 6 Other	
ncc_palliat_provother	Specify, if other	text	Other provider role of first documented EOL
ncc_palliat_reasn	Details around first mention of comfort/palliative care	Text	Details leading up to and around first mention of EOL – e.g., conversations, illness, symptoms etc.

ncc_palliat	Formal palliative care order initiated?	0= no 1= yes	Yes, if care order entered into care plan for palliative/EOL care initiation
ncc_palliat_formal	If yes, date formal palliative care order initiated:	Date, m-d-y	Date of palliative/EOL care order Formal decision to focus on comfort, not necessarily an EOL order as this is more close to death. The former should be reported over the latter though if EOL is only formal order given, then this would be specified.
formalpall_diff	Difference in formal palliative order (in care plan, or EOL order from physician) until death, number of days	formalpall_diff = intck('day', ncc_palliat_formal, death_date);	
formpall_length	Categorical, difference in formal palliative order to death, days	0= 0-14 days (within 2 weeks of death); 1=15-30 days (within 1 month of death); 2= 31-90 days (within 3 months of death); 3= 91-180 days (within 6 months of death); 4= 180-365 days (within 1 year of death); 5= >365 days (more than 1 year prior to death).	

Palliative Predictors (events leading up to first mention of palliative/comfort/EOL, informally) – coded from the ncc_palliat_reasn text box

pr_lowintake	Low food/fluid intake	Predictor of EOL/palliative period – yes=1 , no= 0
pr_physassist	Physical assistance with eating required	‘’
pr_dysphagia	Dysphagia/swallowing problems	
pr_refuseat	Resident refusal to eat	
pr_gisymptoms	GI Symptoms	
pr_skin	Skin integrity issue/unhealable wound	
Pr_any_ec	Any eating challenges, with the exception of weight loss	Code: if pr_lowintake = 1 or pr_physassist = 1 or pr_dysphagia = 1 or pr_refuseat = 1 or

		pr_gisymptoms = 1 or pr_skin= 1 then pr_any_ec = 1;
pr_wtloss	Weight loss	
pr_abnlabs	Abnormal lab results	
pr_edema	Edema	
pr_lethargy	Lethargy/remains in bed	
pr_gendecline	General decline	
pr_cogdecline	Cognitive decline	
pr_delirium	Delirium	
pr_anxiety	Anxiety, aggression, restlessness, mental health issue	
pr_pain	Pain	
pr_socwithdraw	Social withdrawal/non-responsive	
pr_resrefus	Resident refusal of care/treatment	
pr_poadecline	POA declined treatment	
pr_infection	Infection	
pr_fallinj	Fall/injury	
pr_unstable	Unstable condition/vitals (e.g., BP, RR, HR, O_2 sats, temperature)	
pr_cancprog	Cancer or other progressive condition	
pr_sudden	CVA/TIA/Heart attack/Organ failure/Sudden decline	
pr_unclear	Unclear reason	

Appendix C

Supplemental Materials for Study 1 (Chapter 5)

Contents of Appendix C:

C.1 Bivariate Comparison of Eating Challenges by Sampling Frame Across the Four Time Points

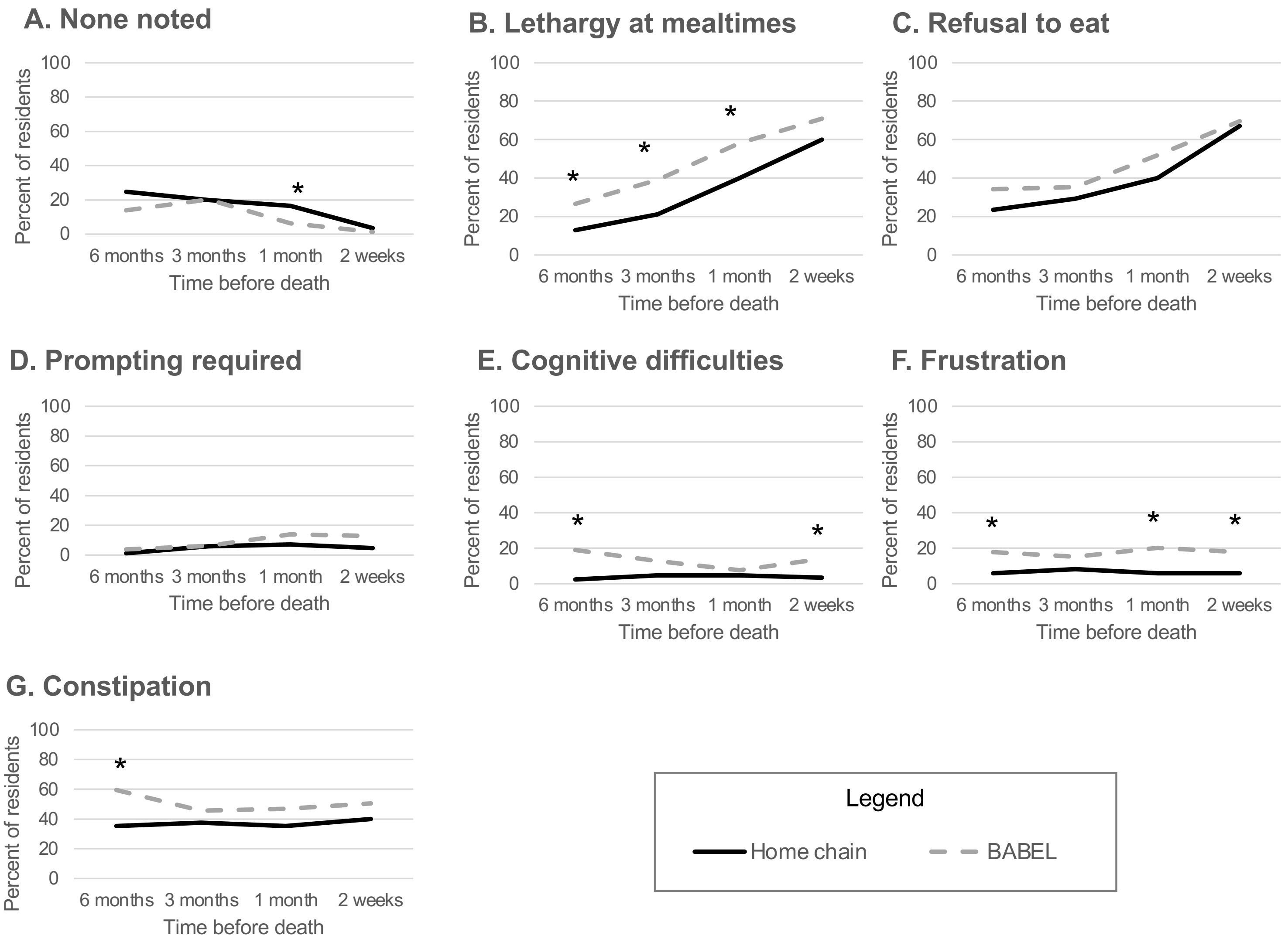
Several eating challenges (i.e., none, lethargy at mealtimes, refusal to eat, prompting required to eat, cognitive difficulties, frustration, and constipation) were significantly different between the home chain and BABEL samples in the mixed effects logistic regression analysis (Table 5.2). Figure C.1 provides a visual description and bivariate analysis of these differences across the two sampling frames. Of note, the BABEL sample had a higher prevalence of these eating challenges as expected given the recruitment criteria but the trends of each eating challenge with proximity to death were similar between the two sampling frames.

(Following page):

Figure C.1

Differences in eating challenges between the home chain (n=85) and BABEL (n=79) samples over time

Note. Bivariate analysis comparing eating challenges that were significantly different between the two sampling frames in the mixed effects logistic regression analysis (Table 5.2). The lines describe the change in prevalence of each eating challenge over time with statistical comparison at each timepoint using χ^2 analysis; asterisks (*) represent statistical significance between the sampling frame at the corresponding time points, $p<0.05$.


A. None noted
B. Lethargy at mealtimes
C. Refusal to eat
D. Prompting required
E. Cognitive difficulties
F. Frustration
G. Constipation
Percent of residents
0
20
40
60
80
100
6 months
3 months
1 month
2 weeks
Time before death
*
Legend
Home chain
BABEL

C.2 Repeated Measures Latent Class Analysis (RMLCA) Model Building

Table C.1

Comparison of fit statistics of modeled 5-item and 6-item versions of the repeated measures latent class analysis with one to eight classes (n=164)

Number of classes	Df	AIC	BIC	CAIC	ABIC	Entropy
			5-item version[a]			
1	1048555	1344.62	1406.62	1426.62	1343.30	1.00
2	1048534	1155.39	**1282.49**	**1323.49**	1152.68	0.85
3	1048513	1134.74	1326.93	1388.93	1130.64	0.88
4	1048492	**1132.73**	1390.02	1473.02	**1127.25**	0.83
5	1048471	1138.94	1461.32	1565.32	1132.07	0.85
6	1048450	1144.02	1531.50	1656.50	1135.76	0.89
7	1048429	1153.45	1606.03	1752.03	1143.80	0.86
8	1048408	1168.75	1686.43	1853.43	1157.72	0.90
			6-item version[a]			
1	16777191	2053.71	2128.11	2152.11	2052.12	1.00
2	16777166	1820.61	**1972.50**	**2021.50**	1817.37	0.81
3	16777141	1792.64	2022.03	2096.03	1787.75	0.81
4[b]	16777116	1779.71	2086.59	2185.59	1773.17	0.84
5	16777091	1778.36	2162.75	2286.75	1770.17	0.87
6	16777066	**1773.72**	2235.60	2384.60	**1763.88**	0.90
7	16777041	1780.99	2320.37	2494.37	1769.50	0.92
8	16777016	1796.32	2413.19	2612.19	1783.17	0.91

Note. Bolded values indicate the lowest value indicating best fit for the respective criterion. AIC, Akaike information criterion; ABIC, adjusted Bayesian information criteria; BIC, Bayesian information criterion; CAIC, consistent Akaike information criterion; Df, degrees of freedom.

[a] Eating challenges included in the repeated measures latent class analysis: frustration, self-feeding challenges, distractibility, dysphagia, and refusal to eat; the 6-item version included low energy.

[b] Final selected model.

C.3 Sensitivity Analysis: Multi-Group RMLCA

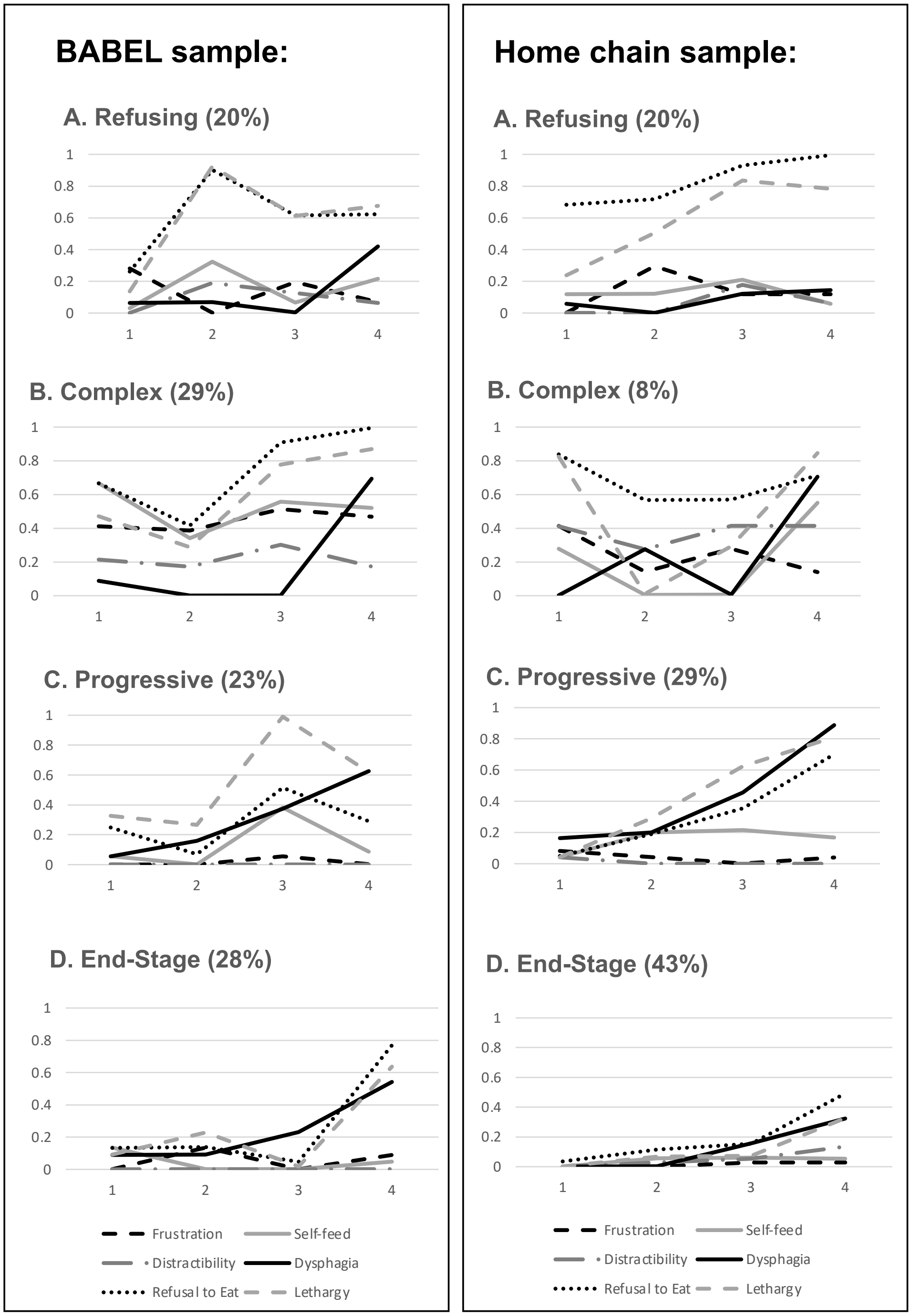
A sensitivity analysis was performed to assess the reliability of the classes that were identified in the repeated measures latent class analysis (RMLCA) using the entire sample. For the sensitivity analysis, a multi-group RMLCA, which allowed for item means and class probabilities to vary by sampling frame, was tested to check for consistency in class definitions between BABEL and home chain participants. For this analysis, the identified classes had similar patterns, with notable differences and potential cross-contamination of classes likely due to the bias towards more eating challenges in general in the BABEL sample due to recruitment criteria (Figure C.2). An improvement to this sensitivity analysis would be to use the class probabilities identified using the home chain sample (i.e., a random sample that is, at least in theory, representative of a variety of eating challenges) and apply them to the BABEL sample to test the average fit of individual participants into one of the four classes. Ideally, participants would show distinct membership in one of the four classes as determined by average latent class posterior probability closer to 1 and no less than 0.8 (Weller et al., 2020).

(Following page):

Figure C.2

Multi-group repeated measures latent class analysis (RMLCA) allowing response probabilities to vary across the sampling frames, BABEL (n=79) and home chain (n=85).

Note. The general patterns produced by each sampling frame were similar, although the patterns were less clear in the BABEL sample, likely due to the differing recruitment criteria (i.e., death expected in 6-12 months; decreased food intake as one of several criteria). Fit statistics: average latent class posterior probability=0.96, entropy=0.91.



BABEL sample:

A. Refusing (20%)

B. Complex (29%)

C. Progressive (23%)

D. End-Stage (28%)

Home chain sample:

A. Refusing (20%)

B. Complex (8%)

C. Progressive (29%)

D. End-Stage (43%)

C.4 Bivariate Analyses of Resident Characteristics by Latent Classes

Table C.2

Bivariate comparison of resident characteristics across classes of eating challenges (n=164)

	Eating challenge class			
	Complex	**End-stage**	**Progressive**	**Refusing**
	Descriptive, % (n)[a]			
Class statistics				
N (%)	31 (18.9%)	50 (30.5%)	50 (30.5%)	33 (20.1%)
Average Latent Class Posterior Probability, mean ± SD	0.98 ± 0.07	0.93 ± 0.08	0.90 ± 0.11	0.92 ± 0.11
Data source				
Home Chain Sample	**22.6 (7)**	**68.0 (34)**	**52.0 (26)**	**54.6 (18)**
BABEL Sample	**77.4 (24)**	**32.0 (16)**	**48.0 (24)**	**45.5 (15)****
Resident demographics				
Age at death, years, mean ± SD	89.4 ± 6.3	89.2 ± 7.8	87.1 ± 8.3	87.7 ± 6.2
Sex, female	67.7 (21)	68.0 (34)	58.0 (29)	48.5 (16)
Length of admission, months, Median [Q1, Q3]	27 [12, 37]	46 [26, 62]	37 [19, 48]	24 [17, 38]
MDS Scores[b]				
Leaves >25% of food uneaten at most meals	**80.6 (25)**	**56.0 (28)**	**42.0 (21)**	**66.7 (22)****
Cognitive impairment, moderate/severe (CPS ≥3)	77.4 (24)	80.0 (40)	82.0 (41)	75.8 (25)
Health Instability, moderate/high (CHESS≥3)	**32.3 (10)**	**6.0 (3)**	**12.0 (6)**	**9.1 (3)***
Significant loss of independence (ADL≥3)	77.4 (24)	94.0 (47)	94.0 (47	84.8 (28)
Depression risk (DRS≥3)	61.3 (19)	42.0 (21)	44.0 (22)	45.4 (15)
Exhibits responsive behaviours (ABS≥1)	**74.2 (23)**	**44.0 (22)**	**50.0 (25)**	**60.6 (20)***
Pain Scale, daily	3.2 (1)	6.0 (3)	6.0 (3)	3.0 (1)
Diagnoses[b]				
Cancer	25.8 (8)	12.0 (6)	14.0 (7)	27.3 (9)
Diabetes mellitus	12.9 (4)	28.0 (14)	30.0 (15)	21.2 (7)
Hypothyroidism	25.8 (8)	28.0 (14)	14.0 (7)	30.3 (10)
Cardiovascular disorders[c]	83.9 (26)	76.0 (38)	82.0 (41)	75.8 (25)
Congestive heart failure	6.4 (2)	14.0 (7)	24.0 (12)	18.2 (6)
Arthritis	61.3 (19)	44.0 (22)	42.0 (21)	45.4 (15)
Osteoporosis	35.5 (11)	28.0 (14)	22.0 (11)	21.2 (7)
Alzheimer's	22.6 (7)	12.0 (6)	12.0 (6)	18.2 (6)

	Eating challenge class			
	Complex	**End-stage**	**Progressive**	**Refusing**
Non-Alzheimer's dementia	77.4 (24)	56.0 (28)	58.0 (29)	63.6 (21)
Aphasia	**48.4 (15)**	**12.0 (6)**	**16.0 (8)**	**15.2 (5)*****
Stroke/cerebrovascular accident	29.0 (9)	20.0 (10)	24.0 (12)	24.2 (8)
Parkinson's	9.7 (3)	10.0 (5)	16.0 (8)	0.0 (0)
Seizure disorder	6.4 (2)	12.0 (6)	2.0 (1)	6.1 (2)
Anxiety disorder	**32.3 (10)**	**10.0 (5)**	**14.0 (7)**	**6.1 (2)***
Depression	38.7 (12)	38.0 (19)	28.0 (14)	24.2 (8)
Asthma	6.4 (2)	6.0 (3)	2.0 (1)	3.0 (1)
COPD/emphysema	6.4 (2)	16.0 (8)	18.0 (9)	27.3 (9)
Sensory condition[d]	38.7 (12)	30.0 (15)	16.0 (8)	27.3 (9)
Renal condition	12.9 (4)	6.0 (3)	10.0 (5)	9.1 (3)

Note. ABS, Aggressive Behaviour Scale (max. 12); ADL, Activities of Daily Living Self Performance Hierarchy Scale (max. 6); BABEL: 'Better Targeting for Better Outcomes'; CHESS, Changes in Health, End-stage Disease and Signs and Symptoms (max. 5); COPD, chronic obstructive pulmonary disease; CPS, Cognitive Performance Scale (max. 6); DRS, Depression Risk Scale (max. 14); MDS, InterRAI Minimum Dataset 2.0.

[a] Descriptives are % (n) unless otherwise specified.

[b] MDS scores and diagnoses recorded at the time of entry into the study for BABEL participants (mean = 256 ±131 days) and at third last data entry prior to death for home chain participants (mean = 206±34 days).

[c] e.g., hypertension, deep vein thrombosis, peripheral vascular disease, arteriosclerosis, etc.

[d] e.g., macular degeneration, cataracts, glaucoma

**p*<0.05; ***p*<0.01; ***p<0.001

Appendix D

Supplemental Materials for Study 3 (Chapter 7)

Contents of Appendix D:

D.1 Tables Describing the Change in Status Event Leading to Suspected End-of-Life Decline

Table D.1

Process for identifying the change in status event

Step 1: Date range	Progress Notes tab → "View All" → "Custom" → Select date range beginning at 6 month prior, ending on date of death
Step 2: Text search (ctrl-F) keywords	Text search (ctrl-F) for "end-of-life", "end of life", "EOL", "end", "palliative", "terminal", "declin"*, "deterior"*, "death", "dying", "comfort", "comfort measures"
Step 3: Identify consideration of end-of-life decline	Note the first date any of these are reported if it pertains directly to, or implies suspected end of life;
Step 4: Expand search where necessary	If no indication of end-of-life/comfort focus, or indication that management of change of status was already established at 6 months prior to death, the search was expanded by 6 month increments to identify the first mention, or absence, of anticipated end-of-life.

*Words intentionally left incomplete to account for various suffixes

Table D.2

Codes of signs and symptoms indicating a change in status indicative of potential terminal decline

Signs and symptoms	Definition with examples extracted from the text
Nutrition related	
Low food/fluid intake	Any indication that the resident's intake has decreased, e.g., "poor food intake", "eating has declined over past month", "poor appetite"
Physical assistance with eating required	Indication that the resident is no longer able to eat independently and requires help , e.g., "resident is no longer able to feed himself", "requires ++ cuing/assistance to eat", "difficulty getting food to mouth"
Dysphagia	Swallowing difficulty, choking when eating, or diagnosis of dysphagia, e.g., "difficulty swallowing", "dysphagia"
Food refusal	Resident refuses to eat or attend one or more meals, resistant to eating, e.g., "often refuses to eat at all", "keeps resisting/refusing to eat", "missing more meals", "several meals refused", "resistant to eating and drinking", "routinely declining food"
GI symptoms	Any issues or irregularity with the gastrointestinal system, e.g., "sore stomach", "coffee ground emesis", "watery stools", "gastric outlet obstruction", "rectal bleeding"
Poor wound healing	Abnormal and notable skin conditions, e.g., "open and rapidly progressing wound on coccyx", "worsening skin condition", "pressure ulcers developing", "open cancerous wound on hand that will not heal"
Weight loss	Noted decreased weight from a previous measurement, e.g., "decreased weight", "weight loss", "10% weight loss in past year"
Non-nutrition related	
Abnormal lab results	Irregular blood or urine samples, e.g., "profound anemia", "low hemoglobin", "sodium levels increased", "hematuria", "high blood sugars", "recent blood work indicated malnutrition"
Edema	Indication of swelling or fluid retention, e.g., "swelling in face", "fluid in abdomen", "diagnosis of pulmonary oedema", "assessed lower legs, remain edematous", "fluid retention due to renal insufficiency"
Lethargy	Indication that the resident has experienced a decrease in energy, e.g., "increasingly lethargic", "fatigue", "resident remains in bed", "too tired to come to meals", "longer periods sleeping", "fatigues quickly", "very sleepy", "less energy"
General decline	Unspecified deterioration of condition e.g., "overall decline", "overall deterioration", "decline over past several months", "feeling generally unwell", "decline in condition", "overall poor", "frail state", "more support required"

Signs and symptoms	Definition with examples extracted from the text
Cognitive decline	Any report of change in cognition, e.g., “cognitive deterioration”, “experiencing confusion”, “increased CPS [cognitive performance scale] score”, “difficulties appropriately responding to environment”, “complications given cognitive state”, “diagnosis of dementia”, “continued decline in mentation”,
Delirium	Report of delirium specifically, e.g., “possible palliative delirium”, “delirious”
Mental health issue	Any issues with mental health, e.g., “anxiety”, “restless”, “agitated behaviours”, “resistive to care, wandering, insomnia”, “depressed”
Pain	Any signs, complaint, or management of pain, e.g., “family informed of increased dilaudid for pain”, “mouth/face/jaw pain”, “experiencing more pain”, “signs of pain”, “pain meds initiated for resident moaning”
Social withdrawal	Note that resident is less engaged in the social life of the home, e.g., “little conversing”, “less engaged in environment”, “not as bright or communicative”, “withdrawn from social life, rarely participates in activities or 1:1 visits”, “seems resident has given up”
Resident declined treatment/care	Verbal or non-verbal refusal of offered support, care or treatment, e.g., “refuses meds”, “resident stated they did not want to go to hospital”, “resistive to care”, “refuses eating assistance” (note: this was not interpreted as food refusal because it was the act of assistance that was noted and not the food itself).
Infection	Any indication of an infection, e.g., “UTI”, “sepsis”, “pneumonia”, “meningitis”, “eye infection”, “cellulitis”, “osteomyelitis”, “infected wound”
Falls	Reported falls, not necessarily resulting in injury, “noted several recent falls”, “symptoms started with 2 falls”, “increase in falls with poor balance”, “had fall and hit head”, “admitted to hospital due to fall”
Injury	Any trauma or damage to bodily tissue, e.g., “fracture”, “recent shin injury”, “had fall and hit head with visible trauma (hematoma and wound)”,
Unstable/irregular vitals	Vital signs, including blood pressure, respiratory rate, heart rate, O_2 saturation, temperature, outside of normal limits, e.g., “respiratory distress”, “fever”, “low oxygen levels”, “declining lung function”, “low blood pressure”, “irregular heart rate”
Cancer	Any mention of cancer, metastases, tumour etc., “cancer”, “metastatic prostate cancer”, “cancerous lumps on ears”, “cancerous lesions”, “metastatic liver disease”
Progressive condition	Note of a non-cancer progressive condition that has progressed over a long term, e.g., “COPD”, “Renal disease”, “cardiac condition”, “terminal decline due to dementia”, “decreased kidney function”, “advanced Parkinson’s”, “progression of medical conditions”
Organ failure	Indication of organ (e.g., heart, kidneys, liver, lungs) failure that may or may not be progressive, e.g., “renal disease”, “complication as result of liver”, “acute renal failure”, “CHF”

Signs and symptoms	Definition with examples extracted from the text
Sudden decline	Sudden change in status, occurring over several hours or severe decline over one or two days, e.g., "change in condition and severe deterioration in prior day", "significant decline… possible TIAs", "rapid decline", "up and well … checked a short time later he was mostly unresponsive… probably CVA"

Table D.3

Frequency of total nutrition-related, non-nutrition, and overall signs and symptoms noted (n=76)

	Nutrition-related (max. 7)	Non-nutrition related (max. 18)	Overall (max. 25)
Number of reasons cited	**% (n)**	**% (n)**	**% (n)**
0	23.7 (18)	2.6 (2)	0.0 (0)
1	39.5 (30)	19.7 (15)	6.6 (5)
2	25.0 (19)	30.3 (23)	18.4 (14)
3	9.2 (7)	22.4 (17)	21.0 (16)
4	2.6 (2)	15.8 (12)	18.4 (14)
5		4.0 (3)	17.1 (13)
6		2.6 (2)	10.5 (8)
7		2.6 (2)	4.0 (3)
8			1.3 (1)
9			1.3 (1)
10			1.3 (1)

Note. Frequencies are based on sums of nutrition-related signals, non-nutrition related signals, and all signals noted in the change of status conversation. Blank cells indicate a count of zero (0)