**THE PALLIATIVE AND THERAPEUTIC HARMONIZATION (PATH) PROGRAM IN THE LONG TERM CARE HOME SETTING**

By

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**Abstract**

The Palliative and Therapeutic Harmonization (PATH) program was designed to help frail older adults and their family members prepare for and make medical decisions, in the context of frailty and dementia. This sandwich thesis includes three manuscripts that present the findings from a mixed methods study exploring the implementation and outcomes of the PATH program, in three long-term care (LTC) home settings. The purpose of the first sub study was to describe both the perceived need for the PATH program, and initial reactions following its training and implementation. Quantitative surveys and qualitative interviews with bereaved family members showed that prior to implementation, they were mostly satisfied with their relatives’ end-of-life care. Through qualitative interviews, clinical leaders shared a positive impression of the training and PATH principles. They also explained how the PATH program could help them improve palliative and end-of-life care planning and communication with residents and families. In the second sub study, qualitative interviews were conducted with family members to learn about their experiences with and perceived outcomes from the PATH program. All family members had a positive experience. They shared perceived outcomes such as, opportunities to share and learn about their relative’s health status and trajectory, creating a mutual understanding of directions for care, and receiving support and reassurance for health care decision making. Finally, the purpose of the third sub study was to describe both the perceived outcomes of the staff who implemented the PATH program, and differences in documenting residents’ advance care plans and discussions. Staff described both personal and practice related outcomes. In addition, documentation around advance care planning changed with the program’s implementation. Overall, the PATH program offered frail older adults, their family members and their professional caregivers an opportunity to communicate about and prepare to make decisions for palliative and end-of-life care.

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Thank you to all of the health care providers, administrators, assistants, family members and residents who participated in, or helped to facilitate this research study. My heartfelt thanks to all of you for welcoming me into the long-term care homes, providing logistical support, and your time in participating in the study. To the PATH team and administrators, your desire and dedication to improve the care of the residents and their families living in long-term care is to be commended. To the residents and their family members, thank you for your time in participating in the PATH program evaluation. It was my pleasure to engage with all of you in this process.

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To my friends and family, thank you for your continued support and encouragement during my doctoral studies. To my Mom, you and Dad always set the bar high. Thank you for everything. To Cory, my husband, my thoughts are best captured by Sarah McLachlan- “You stay the course. You hold the line. You keep it all together. You are the one true thing I know I can believe in.”

**Table of Contents**

|  |  |
| --- | --- |
| **Abstract** | iii |
|  |  |
| **Acknowledgements** | v |
|  |  |
| **Table of Content** | vii |
|  |  |
| **List of Appendices** | x |
|  |  |
| **List of Tables** | xi |
|  |  |
| **List of Abbreviations** | xii |
|  |  |
| **Declaration of Academic Achievement** | xiii |
|  |  |
| **Chapter 1: Introduction** | 1 |
| Introduction | 1 |
| Why the need for palliative and end-of-life care strategies in Canada? | 3 |
| Why the need for palliative and end-of-life care strategies in LTC home settings? | 4 |
| What is advance care planning? | 5 |
| Statement of problem | 6 |
| Setting the context: What is PATH? | 8 |
| Overall research process | 9 |
| Research questions | 10 |
| Secondary research question | 10 |
| Thesis content | 11 |
| References | 13 |
|  |  |
| **Chapter 2: Implementing the PATH Program in the in Long-Term Care Home Setting** | 17 |
| Abstract | 18 |
| Introduction | 19 |
| Description of problem | 19 |
| Purpose statement & study rationale | 22 |
| Methods | 23 |
| Design | 23 |
| PATH program training | 23 |
| Settings and sample | 24 |
| Data collection procedures | 24 |
| Data analysis | 26 |
| Ethical considerations | 27 |
| Findings | 27 |
| Characteristics of the sample | 27 |
| Perceived need for PATH program- bereaved family caregiver perspectives | 28 |
| Staff perspectives | 30 |
| Initial reactions to the PATH training | 32 |
| Reaction to PATH program implementation and perceived barriers | 35 |
| Discussion | 36 |
| Study limitations | 40 |
| References | 42 |
|  |  |
| **Chapter 3: Family Members’ Perceptions and Experiences with the Palliative and Therapeutic Harmonization Program in the Long-Term Care Setting** | 50 |
| Abstract | 52 |
| Introduction | 53 |
| Methods | 55 |
| Design | 55 |
| Setting and sample | 55 |
| Data collection | 56 |
| Data analysis | 57 |
| Ethical considerations | 57 |
| Findings | 58 |
| Characteristics of the family members (interviewees) | 58 |
| Description of residents | 58 |
| Main themes | 59 |
| The PATH process | 59 |
| Perceived PATH outcomes | 61 |
| Participant recommendations related to PATH | 67 |
| Discussion of findings | 67 |
| Limitations | 70 |
| Conclusion | 71 |
| References | 72 |
|  |  |
| **Chapter 4:** **Exploring Staff and Resident Outcomes from the Implementation of the Palliative and Therapeutic Harmonization (PATH) Program in the Long-Term Care Home** | 77 |
| Abstract | 79 |
| Introduction | 80 |
| Purpose | 82 |
| Methods | 82 |
| Design | 82 |
| Setting and sample | 82 |
| Data collection procedures | 83 |
| Data analysis | 85 |
| Rigor | 87 |
| Ethical considerations | 89 |
| Qualitative Findings | 89 |
| Characteristics of the sample | 89 |
| Main themes | 90 |
| Practice outcomes | 90 |
| Personal outcomes | 95 |
| Quantitative Findings | 98 |
| Characteristics of the sample | 98 |
| Discussion | 100 |
| Study Limitations | 103 |
| Conclusion | 104 |
| References | 105 |
|  |  |
| **Chapter 5:** **Conclusions** | 115 |
| Triangulation of findings | 116 |
| Implications for LTC home practice | 118 |
| Implications for residents and family members | 120 |
| Implications for policy | 121 |
| Implications for future research | 122 |
| Limitation of PATH implementation and related implications | 125 |
| Study strengths & limitations | 128 |
| Concluding thoughts and lasting impression | 130 |
| References | 132 |
|  |  |
| **Appendix A: A Review of Advance Care Planning Programs in Long-Term Care Homes: Are They Dementia Friendly?** | 136 |
|  |  |
| **Appendix B: Revisiting Retrospective Chart Review: An Evaluation of Nursing Home Palliative and End-of-Life Care Research** | 174 |

**List of Appendices**

|  |  |
| --- | --- |
| Appendix A: A Review of Advance Care Planning Programs in Long-Term Care Homes: Are They Dementia Friendly? | 136 |
|  |  |
| Appendix B: Revisiting Retrospective Chart Review: An Evaluation of Nursing Home Palliative and End-of-Life Care Research | 174 |

**List of Tables**

|  |  |
| --- | --- |
| **Chapter 2** |  |
| Table 1. Summary of SWC EOLD total and item mean scores for (n=11)  bereaved family caregivers | 47 |
| Table 2. Summary of main themes and sub-themes | 49 |
|  |  |
| **Chapter 3** |  |
| Table 1. Main themes and sub-themes from family member interviews | 76 |
|  |  |
| **Chapter 4** |  |
| Table 1. Main themes and sub-themes | 110 |
| Table 2. Resident characteristics | 111 |
| Table 3. Summary of PATH discussion | 113 |

**List of Abbreviations**

|  |  |
| --- | --- |
| PATH | Palliative and Therapeutic Harmonization |
| LTC | Long-term care |
| OMOHLTC | Ontario Ministry of Health Long Term Care |
| CIHI | Canadian Institute for Health Information |
| NP | Nurse practitioner |
| FC | Family caregiver |
| CPR Program | Plan of Treatment for CPR Program |
| CGA | Comprehensive geriatric assessment |
| SWC EOLD | Satisfaction with Care at End of Life in Dementia |
| SD | Standard deviation |
| M | Mean |
| REB | Research Ethics Board |

**Declaration of Academic Achievement**

Abigail Wickson-Griffiths is the study lead and primary author of all of the chapters included in this sandwich thesis. As primary author, responsibilities included: collaborative study conception and design, data collection and analysis, interpretation of findings, and drafting and refining manuscripts.

Sharon Kaasalainen, Carrie McAiney and Jenny Ploeg were co-authors. Sharon Kaasalainen supervised the study. All were involved with collaboratively designing the study, data analysis and refining the manuscripts.

**Chapter 1**

**Introduction**

It is estimated that 39% of the Canadian population dies in long-term care (LTC) homes, and accordingly, these facilities are recognized as necessary places for providing palliative and end-of-life care (Canadian Healthcare Association, 2009). A key component in providing resident-centred, palliative and end-of-life care is advance care planning (Canadian Hospice Palliative Care Association, 2012); a process where the resident’s future care preferences are discussed (Patel, Sinuff, & Cook, 2004). However, the healthcare wishes and goals of residents affected by dementia are not always known, which can lead to burdensome treatments that are inconsistent with a palliative care approach (Di Giulio et al., 2008; Mitchell, Kiely, & Hamel, 2004). In addition, family members who do not know the wishes or preferences of their relatives are left to make uniformed decisions on their behalf (Lopez, 2009). Therefore, appropriate strategies and interventions for meeting the residents’ and their family members’ planning needs are essential in this setting. The Palliative and Therapeutic Harmonization (PATH) process (Mallery & Moorhouse, 2010; Moorhouse & Mallery, 2010), which was developed for frail older adults including those with dementia, offers a promising approach to advance care planning for people living in LTC homes. However, the PATH process has not been evaluated in LTC, which is necessary to assess its outcomes and feasibility for use in this unique setting.

The purpose of the overall study is to explore the implementation and outcomes of the PATH program in the LTC home setting. The findings of this study will contribute to the literature by evaluating the PATH program for the first time in the LTC home setting. It is important to examine the PATH program in this setting because it was designed to address the care planning needs of older adults (and their family members and professional caregivers) with health issues that are common in LTC homes, such as frailty and dementia (Mallery & Moorhouse, 2010). This approach also lends itself well to the process of advance care planning, in that it helps older adults and their family members understand their health conditions and trajectories, and consider options for current and future care. Collectively, the findings of this study advance knowledge of the PATH program in LTC home setting around (a) the perceived need for the program and initial reactions to training, (b) barriers to address in implementing the program, (c) family members’ experiences and perceived outcomes, and (d) staff and resident outcomes associated with the implementation of the PATH program.

The following presents a “sandwich” thesis, which consists of at least three manuscripts developed from the research study that are either published or prepared for publication (Nursing Graduate Program, 2013). This sandwich thesis includes three manuscripts that have been prepared for submission for publication in nursing or gerontological journals. Collectively the three manuscripts (Chapters 2-4) highlight the findings from a study looking at the implementation and outcomes of the PATH program in the LTC home setting. The PATH program was designed by two Canadian geriatricians to help older adults and their family members prepare and make medical decisions, in the context of frailty and dementia. A fourth published article (Appendix A) is included, which provides an evaluation of the impacts and dementia-friendliness of advance care planning programs that have been implemented in the LTC home setting. The purpose of including this chapter is to provide background information on the rationale for the need of advance care planning in the LTC home setting, and describe initiatives that have been previously implemented to address this gap in care. A fifth published article (Appendix B) is included, which evaluates the validity and reliability of the retrospective chart review data collection method in articles with a palliative and/or end-of-life care focus in the LTC home setting. This article is included to help frame the methodological issues with one of the quantitative data collection methods used in this research study.

**Why the Need for Palliative and End-of-Life Care Strategies in Canada?**

Society is aging, and the proportion of adults over the age of 65 will continue to grow over the coming decades (Public Health Agency of Canada, 2010). However, medical advances have meant that individuals are living longer with complex diseases (Canadian Hospice Palliative Care Association, 2012). Indeed, in 2009, 37% of Canadians over the age of 80 years reported having four or more chronic health conditions (Public Health Agency of Canada, 2010). In fact, 73% of all Canadian deaths result from chronic conditions (Canadian Hospice and Palliative Care Association, 2012). A palliative approach to care is encouraged for life-limiting chronic illnesses (Bacon, 2012). Therefore, it is important to explore strategies that will help older adults and their family members understand their chronic health conditions, in order to assist them with making health care decisions as they approach end-of-life.

**Why the Need for Palliative and End-of-Life Care Strategies in the LTC Home Setting?**

In the province of Ontario, and for the purposes of this study, LTC homes are residential facilities that provide nursing and personal care on a 24-hour basis to the individuals residing in them (Ontario Ministry of Health and LTC (OMOHLTC), 2013). In Ontario, a placement coordinator determines an individual’s eligibility for LTC admission based upon the following criteria: (a) being 18 years or older; (b) being insured under the Health Insurance Act; (c) requiring access to nursing care on a 24-hour basis; (d) requiring frequent assistance with activities of daily living (e.g. personal hygiene, toileting, eating) and supervision or monitoring for safety; and (e) having needs that cannot be met through community-based services but can be met in a LTC home (Meadus, 2010). Thus, individuals residing in LTC homes tend to have multiple chronic health conditions making them eligible to live in this setting.

A common chronic condition that affects individuals living in LTC homes is Alzheimer’s disease or other related dementias causing cognitive impairment (Alzheimer Society, 2010). Broadly, dementia can be described as a syndrome caused by irreversible neuro-degeneration, which over time causes cognitive and functional impairments, and eventual death (Arcand et al., 2009; Sampson, 2010). Common manifestations of dementia include changes in social behaviours and impaired and/or loss of memory, judgement, communication and ability to perform activities of daily living (Alzheimer Society, 2010; The Swedish Council on Technology Assessment in Health Care, 2008).

Residents who live in LTC homes represent one of the frailest groups of older adults (Gillick, 2004). Generally, frailty can be thought of in terms of loss of an individual’s reserves (energy, health, physical and mental), where multiple disease processes may interact and lead to dependence on others for activities of daily living (Rockwood et al., 1994; Rockwood et al., 2005). Given the frailty of many residents, including those with dementia, LTC homes have become recognized as appropriate and necessary places for providing palliative and end-of-life care (Alzheimer Society, 2010; Hertogh, 2006; Sampson, 2010). Thus, strategies or processes for helping residents and their family members understand their health conditions and prepare to make health care decisions in this context are essential.

**What is Advance Care Planning?**

In recognizing that everyone should have a choice in determining their health care, the importance of engaging in advance care planning discussions with residents living in LTC homes is paramount (Lyon, 2007). Advance care planning is a process in which individuals with decision-making capacity reflect on their values and share their wishes for future health care treatments with family members and/or health care providers (Canadian Hospice Palliative Care Association, 2012). During this process an individual identifies a substitute decision maker who will make decisions on their behalf, should they lose their decision-making capacity (Canadian Hospice Palliative Care Association, 2012). Therefore, the main purpose of an advance care planning discussion is to create an understanding of an individual's future treatment preferences, so that should they no longer be able to make health care decisions, family members and health care professionals can make informed decisions on their behalf that are consistent with their previously expressed values and wishes (Dobalian, 2006; Karel, Moye, Bank, & Azar, 2007; Patel et al., 2004). It is important to note that health care providers can play an important role in this process, as they can be relied upon to offer their expertise (Canadian Hospice Palliative Care Association, 2012).

Although not necessary, following the advance care planning discussion, it is common for an advance directive or plan to be produced, which specifically documents the preferences of residents (Patel et al., 2004). The discussion and subsequent documentation may centre on the person's understanding of their health condition and illness trajectories, goals of care (e.g. life sustaining vs. palliative approach), and places to receive care (e.g. home vs. hospital) (Gillick, 2004; Moorhouse & Mallery, 2010). In the LTC home setting, the convenience of documented preferences may be preferred, however it is recognized that the discussion and understanding of a resident's values may be more beneficial as not all treatment options can be planned and documented (Sampson, 2010). It is also recommended that advance care planning should be based on a person’s current health condition and realistic illness trajectory; therefore, it is important to note that plans can change (Canadian Hospice Palliative Care Association, 2012; Gillick, 2004; Moorhouse & Mallery, 2010).

**Statement of Problem**

Given the health concerns of persons residing in LTC homes, appropriate strategies are needed to help meet residents’, family members’, and health care providers’ care planning needs. However, it is recognized that residents may not be able to participate in making health care decisions, in which case, family members must engage in the process with health care providers. In preparing for this research study, a literature review revealed a number of initiatives that have been used to promote or enhance advance care planning in this setting (Appendix A). The following summarizes the key points from reviewing the literature in preparation for the study.

This preparatory work helped to determine a program (i.e., PATH) to implement and evaluate in the LTC home setting, and offers several points of guidance in moving the evidence base forward. First, the majority of residents are affected by a combination of frailty and dementia, conditions for which advance care planning is essential. Second, a prominent feature of the advance care planning process is having all interested parties (resident, family members and healthcare providers) knowledgeable of health conditions and future treatment plans. Third, designated healthcare providers should be knowledgeable about, and involved in the advance care planning process. Fourth, as a whole, the literature describing advance care planning program implementation is largely based on international studies. Fifth, the potential outcomes of engaging in advance care planning are well documented in the evaluation studies; however the actual process of engaging in advance care planning is not as well explored. Based on these observations, it is fitting that a program developed in the Canadian context, that addresses the care planning needs of frail older adults, their family members and health care providers be piloted and evaluated in this setting. The PATH program offers a promising and unique approach because of its emphasis on facilitating a mutual understanding among the resident (if able), their family member(s), and health care provider(s) about the resident’s health trajectory in the context of frailty and dementia, with the goal of informed decision-making at the end-of-life.

**Setting the Context: What is PATH?**

The PATH process is a 3-step approach to help frail older adults and their family members (or substitute decision makers) make medical care decisions (Mallery & Moorhouse, 2010). The unique feature of the PATH program is that it aids frail older adults and their family members in making informed health care decisions in the context of their frailty, and resulting health prognosis and outcomes (Moorhouse & Mallery, 2010). The informed decision making is the result of three main processes that the older adult, family members and (PATH trained) healthcare provider engage in. These processes include: helping the older adult and family members *understand* their health conditions in the context of frailty through a comprehensive geriatric assessment; next the parties *communicate* about the results of the older adult’s assessment; and finally, the older adult and family members are *empowered* to make medical decisions (Moorhouse & Mallery, 2010). The PATH process, which was a newly developed program for frail older adults including those with dementia, offers a promising approach for making medical decisions. While PATH has been used in geriatric medicine clinics, it has not been implemented or evaluated in the LTC home setting.

The purpose of the overall study is to explore the implementation and outcomes of the PATH program in the LTC home setting (Mallery & Moorhouse, 2010; Moorhouse & Mallery, 2010). The findings of this study will contribute to the literature by evaluating the PATH program for the first time in the LTC home setting.

**Overall Research Process**

The overall study used an embedded mixed methods design (Creswell & Plano Clark, 2011). Due to the complexity of examining the experiences, implementation and perceived outcomes of the PATH program, relying on one method would not adequately address the research purpose. The embedded design was selected to answer both qualitative and quantitative research questions; however the quantitative data was considered to be secondary (i.e., embedded) in the primary qualitative data. This mixed methods research design is noted as QUAL(quan) (Creswell & Plano Clark, 2011). As such, the qualitative and quantitative findings do not have equal weighting in the interpretation and reporting of the results of this overall study. Unlike other mixed method designs, the qualitative and quantitative data are not intended to be merged nor does one data set have to inform its counterpart (Creswell & Plano Clark, 2011).

The QUAL(quan) design was selected so that emphasis could be placed on learning about the PATH program’s implementation, perceived outcomes and feasibility in the LTC home setting, as appropriate quantifiable measures were difficult to establish prior to the start of the study period. Also, the primary author largely approaches research inquiry from a naturalistic paradigm, where multiple realities exist, subjective experiences are valued, and knowledge is built from an inductive process (Loiselle & Profetto-McGrath, 2011). Therefore, more emphasis was also put on the qualitative component due to the primary author`s naturalistic worldview.

The study research questions and the chapter they are addressed in were:

**Research Questions**

* What are the experiences of and satisfaction with end-of-life care among bereaved family members of residents, prior to the PATH program implementation? (Chapter 2)
* What are the initial experiences of LTC home staff implementing and using the PATH program processes? (Chapter 2)
* What are the experiences, perceived outcomes and impressions of residents and their family members participating in the PATH program? Does (and if so, how) the use of the PATH program influence the communication and understanding of residents’ health status as well as decision making, and advance care planning among family members and residents? (Chapter 3)
* What are the experiences, perceived outcomes and impressions of LTC home staff implementing and using the PATH program? Does (and if so, how) the use of the PATH program influence the communication and understanding of residents’ health status as well as decision making, and advance care planning among LTC home staff? (Chapter 4)

**Secondary Research Question**

* What are the differences in the documentation related to resident health status, advance care planning discussions and decisions between the charts of residents at the intervention and comparison sites during the pre and post PATH program implementation periods? (Chapter 4)

**Thesis Content**

To answer the research questions, three manuscripts were written, each with a different focus. They are summarized in the following:

**Chapter 2: Implementing the Palliative and Therapeutic Harmonization Program in the long-term care home setting**

This was the first sub study conducted about the PATH program in LTC home setting. Originally implemented in a community clinic setting, attended by two geriatricians, it was important to assess the suitability and need to use the program in the LTC home setting.

The main purposes of this sub study were to describe the:

perceived need to implement the PATH program from both staff and bereaved family caregiver perspectives;

staff perceptions of the PATH program training; and

initial experiences and perceptions of staff with implementing the PATH program.

**Chapter 3: Family members’ experiences and perceived outcomes to the Palliative and Therapeutic Harmonization Program in the long-term care home setting**

As the PATH program had been newly implemented by staff members, it was important to understand the experiences of family members in going through the PATH discussion and in identifying the perceived impacts of their participation in the process. As key participants in helping to plan for and make decisions on behalf of their relatives, it was important to learn if and how the PATH program could facilitate these important aspects of care from the perspective of family members. Therefore, the main purpose of this sub study was to describe family members’ experiences and perceived outcomes of the PATH program.

**Chapter 4: Exploring staff and resident outcomes from the implementation of the Palliative and Therapeutic Harmonization program in long-term care home**

After the PATH program had been used in practice for approximately one year, it was important to understand outcomes related to the program’s implementation. Therefore, the purpose of this sub study was to evaluate the PATH program outcomes in the LTC home setting. The main objectives were to:

* describe the perceived outcomes and experiences of LTC home staff members using the PATH program; and
* describe the differences in the documentation related to resident health status, advance care planning discussion and decisions between the charts of residents at the intervention (PATH and non PATH participants) and comparison sites.

Note to Reader: As noted, three manuscripts have been prepared or submitted for

publication. All of the manuscripts provide some overlap in the description of the PATH program and the methods employed to address the respective research questions.

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**Chapter 2**

**Implementing the PATH Program in the in Long-Term Care Home Setting**

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**Abstract**

The purpose of this mixed-methods study was to describe the perceived need for the Palliative and Therapeutic Harmonization (PATH) program, as well as initial perspectives following the program’s training and introduction in three long-term care (LTC) homes. Quantitative surveys and qualitative interviews with bereaved family caregivers revealed that they were generally satisfied with their relatives’ end-of-life care experiences prior to the PATH program’s introduction. Clinical leaders who completed the PATH program training and implemented it in their practice, participated in semi-structured, qualitative interviews. They reacted positively to the training and PATH principles, and shared that the program would help them to address gaps in care around improving palliative and end-of-life care planning and communication with residents and families. As the staff implemented this promising program, they recognized initial barriers, which need to be addressed before the PATH program is introduced in other LTC homes.

**Key Words**

end-of-life care, palliative care, program implementation, mixed methods research

Long-term care (LTC) homes are challenged with providing high-quality care for residents, who oftentimes have advanced age and multiple chronic conditions (Canadian Institute of Health Information (CIHI), 2011). Given the profile of this population, planning for high-quality palliative and end-of-life care has become a priority (Canadian Health Association, 2009; Frogatt et al., 2013; World Health Organization, 2011).Although a variety of strategies have been used in LTC homes to guide planning for end-of-life care (Wickson-Griffiths, Kaasalainen, Ploeg & McAiney, 2014), the Palliative and Therapeutic Harmonization (PATH) program offers a promising approach in preparing for end-of-life care decision making for frail older adults (Moorhouse & Mallery, 2010). In order to address current gaps in care, a small group of LTC homes received PATH training and implemented this approach. Hence, the purpose of this paper is to describe the perceived need for the PATH program from the perspective of bereaved family caregivers and staff members, as well as the initial perspectives of staff following the introduction of the program, reactions to training, and implementation barriers.

**Description of the Problem**

**Residents Living in LTC**

LTC homes have 24-hour nursing and personal care available to residents who live there (Ontario Ministry of Health and Long-Term Care (OMOHLTC), 2013). Recently, the percentage of older adults (≥65 years) residing in LTC homes has declined, which is partly due to an emphasis on and improvement to accessible community care and support (CIHI, 2011). However, with this decline, both the level and complexity of care provided to the population in LTC homes has increased (Alzheimer Society, 2010). Some of the oldest and most vulnerable adults reside in LTC homes (CIHI, 2011). For example, 57% of the Canadian population over 85 years is living in this setting, with about 60% of residents having moderate to severe cognitive impairment, and 74% requiring extensive assistance or are dependent on caregivers to perform activities of daily living (CIHI, 2011). In addition, many residents living in LTC homes are referred to as being frail (Gillick, 2004). The characteristics of frailty can be used as determinants for admission to facility-based care (Rockwood et al., 2005). Due to both the complexity and general health decline of these frail residents, discussing and knowing their health care preferences is advisable in preparing for eventual end-of-life care.

Indeed, family caregivers are encouraged to engage in end-of-life care planning with the resident and/or on their behalf with health care providers (Moorhouse & Mallery, 2012). Family caregivers’ participation is especially important, as they may become the persons responsible for the end-of-life care decision making and communication, if a resident has cognitive impairments precluding them from this process (Shalowitz, Garrett-Mayer, & Wendler, 2006). However, some studies have shown that communication around end-of-life care in LTC homes need improvements (Vohra, Brazil, & Szala-Meneok, 2006), which may ultimately effect bereaved family caregivers’ satisfaction with this experience (Thompson, Menec, Chochinov & McClement, 2008; Vohra, Brazil, Hanna & Abelson, 2004). Thus, it is important to be able to adequately prepare and communicate about end-of-life care and decision-making with this group.

**PATH Program Description**

The PATH approach was developed in response to the growing need for a strategy that would address the decision making and care planning needs of older adults experiencing frailty and dementia (Moorhouse & Mallery, 2010). Moorhouse and Mallery, both geriatricians, recognized that end-of-life care planning guides are often disease specific, do not account for the potential number of health deficits, and often put the onus on the older adult or family caregiver to express their values (Moorhouse & Malley, 2010). As a result of these deficiencies, they developed a three-step PATH process, which is engaged in by the health care provider, the older adult and their family caregiver (Moorhouse & Mallery, 2010). First, in addition to providing educational materials around frailty, dementia, and prognosis, *understanding* of the older adult's illness severity and trajectory is established through a comprehensive geriatric assessment (CGA) (Moorhouse & Mallery, 2010). Second, the older adult and family caregiver engage in a structured interview with the health care provider, which is designed to *communicate* the findings of the CGA, and explain the anticipated illness trajectory for each co-morbidity. The third step is to *empower* the older adult and family caregiver to make future health care choices, which are documented in an individualized plan of care. A list of relevant questions to ask in a health crisis is provided to program participants to aid in future decision making (Moorhouse & Mallery, 2010). Thus far, the PATH program has been implemented in an outpatient clinic setting (PATH Clinic, 2013). For a more detailed description of the PATH program and the evaluative work to date, please refer to the website and published articles by the developers (Moorhouse & Mallery, 2010; Mallery & Moorhouse, 2010; Moorhouse & Mallery 2012).

**Purpose Statement & Study Rationale**

Given that the PATH program was specifically designed to meet the needs of persons with conditions prevalent in LTC homes and their family caregivers, it is highly relevant for an investigation in this setting. In addition, it is standard practice for LTC residents to have an annual physical exam as well as care conference to discuss their health status and reassess goals of care (OMOHLTC, 2010). The steps in the PATH process seem congruent to those occurring in LTC homes. Therefore, a new investigation seeking to learn how the PATH program can be introduced in the LTC home setting is warranted.

This study has three main purposes, to describe the: 1) perceived need to implement the PATH program from both staff and bereaved family caregiver perspectives; 2) staff perceptions of the PATH program training; and, 3) staff’s initial experiences and perceptions of implementing the PATH program. This is the first study conducted about the PATH program in LTC home setting, and provides valuable information for future implementation and evaluation of this program. As such, it was important to assess LTC staff’s perspectives about its suitability for implementation in the LTC setting and any related barriers. In this manner, any refinements could be made to make it more feasible and perhaps more effective in the LTC home setting.

**Methods**

**Design**

This study used a mixed-method, embedded design (Creswell & Plano Clark, 2007). To help understand the need to implement the PATH program, both qualitative and quantitative methods were used to understand bereaved family caregivers’ satisfaction with end-of-life care provided to their relatives prior to its implementation. Qualitative methods were used to learn about staff’s perception of the PATH program training and experiences with the implementation.

**PATH Program Training**

In May 2012, training was provided over two full days, to some clinical leaders from three LTC homes, by the two geriatricians that developed the PATH program. The training was provided to the clinical leaders who were intended to be most responsible for engaging in the PATH process with residents and family caregivers. Persons receiving the training included the nurse practitioner (NP), physiotherapist, social worker, pharmacist and five nurse managers. The primary author also attended as an observer. Some personnel were unable to attend, including the medical directors, administrator, director of care and other managers. The NP later provided a presentation to these persons, summarizing the PATH principles and implementation plan.

The training session included an introduction to key concepts such as frailty, the consideration and effect of co-morbidities on health and illness, and dementia in the older adult. The PATH program developers used a variety of methods to impart knowledge about the approach including didactic lecture style, reflection periods, paper case-based studies and case scenarios with residents and family caregivers at the LTC homes. The training built an understanding of the palliative and therapeutic approach for the frail older adult. The staff were also provided with training and a structure for completing a CGA and resident history, engaging in advance care planning discussion with family and residents, and worksheets for resident-centered goal setting and funeral planning.

**Settings and Sample**

Using purposive sampling, data were collected from participants at three not-for-profit LTC homes in Ontario, Canada. The LTC homes were under the same management, ranged in size from less than 50 to over 150 beds, and were in (n=1) suburban and (n=2) rural settings.

**Data Collection Procedures**

**Bereaved family caregiver questionnaire and interview.** Personnel from the LTC homes identified family caregivers whose relatives had died prior to the PATH program implementation. To be sensitive to potential participants but also to accurate recall, we requested that family caregivers thought to be experiencing complicated grieving, or those whose relatives had died within three months or more than one year prior to the implementation, not be identified (Addington-Hall & McPherson, 2001). LTC home personnel recruited potential participants by phone. Potential participants agreed to receive the Satisfaction with Care at the End of Life in Dementia (SWC EOLD) questionnaire (Volicer, Hurley, & Blasi, 2001) and information about participating in a follow-up interview with the primary author.

A good level of internal consistency reliability (α = .90 and α = .83) has been reported for the SWC EOLD questionnaire (Volicer et al., 2001; Kiely et al., 2006), and it’s appropriate to be used as an outcome measure in “studies investigating effectiveness of interventions aimed to improve end-of-life care for individuals with dementia” (Volicer et al., 2001, p. 194). Although the questionnaire was designed for and tested with caregivers of persons with dementia, it is proposed that given the general nature of the items, it could be used with any family caregivers involved with end-of-life care decision making. The questionnaire is composed of ten items to measure satisfaction with end-of-life care during the last 90 days of a person’s life (Volicer et al.). The respondents specify their level of satisfaction for each item and a total score is determined; with a higher score indicating more satisfaction (possible range: 10-40).

Volicer et al. (2001) recognized that participants tend to respond positively to satisfaction questionnaires. Therefore, participants were given the option of participating in a follow-up interview to increase the understanding of any factors or experiences that influenced their level of satisfaction with end-of-life care. All of the interviews were digitally recorded and took between 30 minutes to one hour to complete.

**Staff interviews.** A dedicated staff member helped to recruit participants through talking about the study at meetings and sending out memos. Semi-structured individual interviews were conducted with (n=4) interdisciplinary staff members and (n=2) medical directors, and one focus group was held with (n=5) nurse managers. The interview questions focused on exploring or understanding the experiences of staff who participated in the PATH training and implementation (guide is available upon request). Since the medical directors did not participate in the initial training, they were not asked to talk about this aspect. The individual and focus group interviews took between 30 and 75 minutes to complete. The variation in length depended on the interview format (e.g. the focus group took longer than most individual interviews) and the participant’s level of involvement with implementation.

**Data Analysis**

**SWC EOLD questionnaire.**The mean total score was calculated for all participants and a mean score for each item was determined.

**Interviews.** Burnard’s (1991) approach to thematic content analysis was used to develop the main themes for this study. The authors engaged in a similar approach for both individual and focus group interview data sets (bereaved family caregivers and staff members). Therefore, each set of the interviews, (n=7, staff members; n=6, bereaved family caregivers) were transcribed by the primary author (AWG) and read in their entirety to get a sense of each. During this time, general notes about the content were recorded. Subsequently, each transcript was re-read and the primary author (AWG) engaged in a process of open-coding, and a preliminary coding list was established for each dataset. Next, for the staff member interviews, co-authors (SK, CM, JP) reviewed and coded (n=2) transcripts to help refine the coding list. To help establish the trustworthiness of the coding list, staff member participants were asked to engage in member checking by reviewing and commenting on it. Based on the feedback provided by the participants, the coding list was further refined and main themes were identified. For the family caregiver interviews, co-author (SK) reviewed and coded the data set to help refine the coding list. To help establish trustworthiness of the overall data, the primary author took opportunities to ask clarifying questions throughout the interviews.

**Ethical Considerations**

The study proposal, data collection tools and consent forms were reviewed and approved by appropriate institutional review boards. Although staff participants had prior knowledge of the study, they understood the voluntary nature of their participation. Immediately prior to the interviews, written and verbal consent were obtained. For bereaved family caregivers, completion and return of the questionnaire was understood as consent. The primary author obtained verbal and written consent prior to the follow-up interviews. In appreciation of their time to complete the questionnaire, potential participants received a $5 gift card by mail; and all interview participants each received a $15 gift card.

**Findings**

**Characteristics of the Sample**

**Bereaved family caregivers.** A total sample of 18 bereaved family caregivers agreed to receive the SWC EOLD questionnaires and interview invitations by mail and 11 were returned (61% response rate). Participants identified themselves as an adult child (64%), spouse (18%), or other relative (18%). Sixty-three percent (7/11) of family caregivers who returned the questionnaire, and 66% (4/6) of the interview participants were female. All were either Power of Attorney(s) for Care and/or Finance. All of these participants had been active caregivers and involved with the care decisions and/or communication with LTC home personnel.

**Staff interviews.** Eighty-two percent (9/11) of the interdisciplinary staff participants were female. The participants had at least two years of LTC home working experience. All but one participant had previous dementia care training, while fewer indicated having palliative or end-of-life care educational training.

**Perceived Need for PATH Program- Bereaved Family Caregiver Perspectives**

**Bereaved family caregiver survey.**Generally, participants were satisfied with the care provided to their relative as well as their involvement (e.g. decision-making, communication with staff) during the end-of-life care period. The SWC EOLD questionnaire revealed a mean total score of 33.64 (SD=6.8). The respondents were most satisfied that “all measures were taken to keep my care recipient comfortable” (M=3.73, SD=.47), a little less that “I did not really understand my care recipient’s condition” (M=3.45, SD=.69) and least that “I always knew which doctor or nurse was in charge of my care recipient’s care” (M=3.00, SD=.89). See Table 1 for a summary.

**Bereaved family caregiver interviews.** The analysis of the interviews revealed four main themes: perceived involvement with decision-making, overall good knowledge of their relative’s health status, good knowledge of medication and treatments and resident comfort, and a generally positive impression of their communication and relationship with staff.

***Decision-making.*** Some participants shared that they were not involved in decision making, but rather guided by staff who would communicate changes to their relatives’ health status, treatments, medications and test results. The LTC home staff provided guidance and the participants trusted them to make the right treatment and care decisions on behalf of their relative. For example, one participant shared that, “We always took for granted that they were the experts. They would make the recommendations and we would just go along with it.”(FC #2) Other participants expressed that the advance care discussions they had with their relatives directed the decisions that they made and/or expressed to LTC home staff on their behalf.

***Knowledge of relatives’ health status.*** For the most part, participants agreed that the staff let them know about changes to their relatives’ health status and/or care, and that they had a good understanding of it. In some cases, staff directly told participants that their relative’s death was imminent by letting them know to come to the home. Most participants acknowledged that their relative’s refusal or inability to eat was a sign that their end-of-life was near. However, one participant was initially unaware of this sign and commented that, “I look back now, and no one came to me to say, and I am assuming, that is the way the mind and the body start to shut down. I look back at it now, and ‘oh, yah- I guess it does kind of make sense.’ But no one sat down and said that to us.” (FC#1)

***Knowledge of medication and treatments* *& resident comfort.*** Most of the participants expressed that they knew about and were confident that their relative received all of the medications and treatments they could have benefitted from during their end-of-life period. They also felt that their relatives were comfortable during this time. However, some participants questioned and/or felt that more could have been done to promote their relative’s comfort or prolong their life.

***Communication and relationship with staff*.** For the most part,participants felt that they could share concerns or ask questions about their relatives’ care. One participant commented that, “overall, the care she received was excellent. The communication was just great.” (FC #4) In general, the participants trusted in the information they received about their relatives and the care that was advised and provided.

**Staff Perspectives**

The analysis of staff interviews revealed three main themes: perceived need for PATH, reaction to PATH training, and reaction to PATH implementation and perceived barriers. See Table 2 for a summary of these themes as well as sub-themes.

**Perceived need for PATH.** Prior to learning about PATH, the three LTC homes had been using the Plan of Treatment for CPR Program (CPR Program) (South West Hospice Palliative Care Network, 2013). In implementing the CPR program, staff sought to find an alternative to the *levels of care* advance directive documentation, which had long been used.[[1]](#footnote-1) With the CPR program, it was intended that at six-week post admission, the registered nursing staff would discuss the resident’s life-limiting health condition(s); the benefits, risks, side effects (if any) of CPR; and alternatives (if any) to CPR, with the family caregivers and resident (where able). The goal of the conversation and subsequent documentation was to engage the family caregivers and residents in informed decision making for CPR. Clinical leaders including the NP, medical directors and administrative staff supported an enhancement to their practice.

**Addressing the gap.** After reflecting on the introduction and use of the CPR program, some participants felt that they were still neither adequately nor comfortably discussing and documenting the residents’ and family caregivers’ goals for future care. They realized that there was a disconnection between knowing how to have and actually having a conversation about the residents’ health conditions and progression. The NP explained that,

We were not having our six week conversations because no one knew how to do that. So, we were not having those basic, information gathering, share this, conversations that we had intended to have with our CPR [program]. From which we would then proceed to have further conversations and have people onboard with changes in their residents.

A social worker described that it could be difficult to have a conversation with family caregivers if they felt the content would not be well received: “so, it’s not that we ever did it purposefully, it’s the same in the hospital setting, we never did it purposefully but we aren’t always terribly open because we are not sure if they can handle the information they are going to get.”

**PATH program description resonates with the palliative approach in LTC.** There was also the recognition among staff that the LTC home environment was an appropriate place for a palliative approach to care. The social worker explained that, “the reality in LTC is, is comfort and care without cure.” Therefore, a new program or structure was needed to help staff members talk to residents and their family caregivers about options for health care treatments.

**Empowering staff to have discussions/relationships.** Staff also noted that more effort was needed to create trusting relationships between the staff, and residents and their family caregivers, in order to engage in information sharing, care planning and decision-making conversations. Again, a new structure or process was needed to help staff establish these relationships, which is explained by the NP,

The conversations were what I felt were so important, that lead to relationships. Honest relationships. We needed to establish more confidence in, myself as a NP, talking to families and the [registered nurses] and eventually the [registered practical nurses] talking to families because we were still at the point where they always wanted to talk to the doctor.

**Initial Reactions to the PATH Training**

The analysis of the staff interviews revealed four main sub-themes related to their initial reactions to the PATH training: impression of the training, resonance with approach to caring for residents in LTC homes, new learning, and helping them to achieve resident, family caregiver and organizational goals.

**Impression of the training**. Overall, the staff reacted positively to the training they received, and mostly described it as “great” or “wonderful.” They appreciated the facilitation style used by the two PATH developers to communicate the material. However, most participants agreed that they could have benefitted from more training days to help practice the PATH approach, or additional preparation on the key concepts ahead of the training.

**Resonance with approach to caring for residents in LTC homes***.* For some participants, the program was well received because they embraced the palliative and therapeutic approach for residents in their care. Recognizing resident decline and providing appropriate care were already important to these participants. The NP described that, “I have to say that maybe they were preaching to the converted, too. Because we had already had a lot of discussion around advance directives and how they do not fit in our facility, and we had already completed our CPR project.”

The PATH program resonated with the participants as some stated that they were already completing parts of the CGA in their practice, such as cognitive testing. However, they felt they were not doing it in a structured or uniform way. One nurse manager explained that,

I found those sections of the PATH training; we have been doing some of them. But, it wasn’t formalized in a program... The cognitive testing, we did that. We looked at functional abilities. We looked at their histories- maybe not as in depth. But a lot of it I think we were doing, just not the whole [PATH] program.

**New learning.**Participants also recognized that the PATH training provided them with new learning including best practices for medication, process and language for communicating with residents and families, and reflecting on how care can be provided in the LTC home setting. As an example, one method of providing training on the PATH process was to have residents and their family caregivers participate as ‘case scenario’ subjects. This provided the participants with the opportunity to work through the CGA and have conversations with actual care recipients. In these case scenarios, the participants had access to the resident’s chart, assessed their level of frailty and cognition, and reviewed their history and CGA findings with the family caregiver. This case scenario exercise not only helped participants engage in the PATH process, but enabled them to reflect on the resident’s ongoing health issues, the family-preferred course of action in an emergency, and newly learned information about their health history. A nurse manager offered the following,

Because I think for [other participant] and I, when we were working with our resident who had ongoing cardiac issues, we never really once thought of in the conversation saying to the family, ‘Well next time it happens, what are we going to do, are we going to send her back to the hospital?’ We just assumed that I guess that is what we would do.... I think when they, I don’t know what the one [PATH] physician said... ‘Yah- we can manage that here, and what would that look like?’- I think. I never really thought like that, I guess.

**Help them achieve resident, family caregiver and organizational goals.** As a result of engaging in PATH, the participants felt it would create an environment where the staff would be able to inform family caregivers of residents’ diagnosis(es). They envisioned that this, in turn, would lead to: more knowledgeable residents and family caregivers being able to make better informed health care decisions, increased satisfaction with the care provided, and increased positive end-of-life experiences or “good deaths”. The physiotherapist explained that, “I hope the best outcome that we could have is that family members, ultimately, are so well informed that they just make the best decisions for their family members. And they are happy with how their care is. I think that is just the best outcome you can see.” They also envisioned that engaging in PATH program would allow them to know each resident, and provide resident-centered information and care. They pictured that they would gain a reputation in the community for providing excellent palliative and end-of-life care. The NP said,

I would like to see as a whole organization that we have a reputation as a place that is going to take care of your loved one to the best of their ability; and are going to be communicative and want to hear your side; and are open and receptive yet honest about what the future looks like.

**Reaction to PATH Program Implementation and Perceived Barriers**

Finally, the analysis of the interviews revealed three main sub-themes related to the implementation of the PATH program and perceived barriers: managing multiple priorities, need for education for the frontline staff, and perceived barriers in implementing the PATH program.

**Managing multiple priorities.**As the participants began to implement and use the PATH process in their practice, they described several instances of challenges with priority setting. First, many staff commented on the time commitment needed to complete the PATH process with all residents and family caregivers – those newly admitted and those already living at the LTC homes. Second, as the staff began to engage in the PATH program, they also experienced challenges in prioritizing which residents to assess first, as some residents already living at the LTC homes may have been in greater need than some of the more newly admitted residents. Third, the staff recognized that while they valued the PATH approach, they had to balance their existing workload with the demands of the new initiative.

**Education for the frontline staff.** Only a few clinical leaders received the PATH training and were therefore, responsible for using it with the residents and family caregivers. Given this situation, the participants recognized that additional education would be needed for all frontline and administrative staff as well as department managers, so that all team members would be knowledgeable about the PATH process. Some study participants recognized that there were instances where PATH trained and non-PATH trained staff members were providing family caregivers with conflicting messages about the direction for resident care. In addition, as a relatively small number of staff members were trained to engage in the PATH program, this meant that they could not share the workload of assessments and conversations with other colleagues.

**Perceived barriers in the PATH program implementation.** Participants noted perceived difficulties in implementing and using PATH. While the PATH approach resonated with the participants, one noted that they might experience difficulty in helping the frontline staff members to accept when a resident’s goal of care changes from a curative to comfort approach. Also, there was perceived difficulty in establishing good lines of communication and trust with some residents and family caregivers. One participant recognized that there did not seem to be a structure for conflict resolution when the goals of care differed between health care providers and resident and/or family caregivers. Finally, participants recognized that any documentation that resulted from PATH assessments and conversations should not be read as advance directives, which would have to be understood by the larger health care team. The participants stated that they were still in the process of refining their documentation structure.

**Discussion**

This mixed-methods study contributes to the literature by offering the perspectives of bereaved family caregivers and interdisciplinary staff members for the need for programs like PATH in LTC homes. As this was the first time the PATH program had been introduced and implemented in the LTC setting, this paper highlights the initial reactions of staff to the program’s training as well as initial barriers that they have encountered during its implementation.

We found that the PATH program was well received by the staff participants who were involved in the training and initial implementation across the three LTC homes. Not only did they report that the PATH process resonated with how they envisioned providing care to older adults but it gave them a structured approach to engage in advance care planning conversations with residents and their family caregivers. We view this as a promising reaction. Internationally, there has been a greater awareness of the palliative care needs of residents dying in LTC homes (Canadian Hospice Palliative Care Association & Quality End-of-Life Care Coalition of Canada, 2014; Frogatt et al., 2013); however, introducing new practices that change from a curative to a comfort approach requires a substantive culture shift (Abbey, Froggatt, Parker, & Abbey, 2006). It is encouraging that staff participants in our study identified with providing palliative care to residents, and therefore may be more inclined to regularly use the PATH approach, and make it a priority for sustained change. Second, it is also promising, that the introduction of the program was supported by persons in clinical and administrative leadership positions, which is important for sustained change in improving end-of-life and palliative care (Abbey et al., 2006). These persons will be in key positions for helping other staff members to embrace and use this approach.

As with any implementation of a new innovation, it is important to identify barriers, which may prevent its success and sustainability (Graham & Logan, 2004). The Revised Ottawa Model of Research Use, is one such model that recognizes the importance of identifying barriers (Graham & Logan, 2004). As the staff participants implemented the PATH program, they identified barriers and potential barriers with its use, which included: providing education about the program to other staff, making the program a priority in heavy work demands and anticipated problems. Not surprisingly, others have identified barriers similar to the ones identified in our study, such as lack of trained staff and time in implementing other initiatives in LTC homes such as P.I.E.C.E.S. (Stolee et al., 2009) and pain management improvement (Kaasalainen et al., 2012). As the PATH program moves past initial implementation, it will be important for staff to address these barriers to ensure sustained use of the program and warrants further investigation.

Finally, Volicer et al. (2001) noted that high levels of satisfaction are commonly found in satisfaction surveys, which was the case in our study. Given the staff participants’ noted desire to improve relationships and communication with family caregivers, and achieve “good deaths” for residents, we were surprised at the bereaved participants’ high level of satisfaction. By following up with bereaved family caregivers through interviews, we found that they were mostly satisfied that: their relatives received necessary medications and were comfortable at the end of life; they were knowledgeable about their relative’s heath status; and that they engaged in communication with staff. However, the survey findings could be biased given our small sample size, and our exclusion of family caregivers thought to be experiencing complicated grief (as determined by personnel at the LTC home study sites).

To further  help us understand this finding, we note that international researchers have also used the SWC EOLD to measure family caregivers’ satisfaction with care provided to their dying relatives in the LTC home (Engel, Kiely, & Mitchell, 2006; van Uden et al., 2013). Engel et al. conducted a study in the United States, and found that 148 family caregivers of persons with advanced dementia had a total mean SWC EOLD satisfaction score of 31 ± 4.2,slightly lower than what we found in our study (mean=33.63; SD=6.8 ). Family members in our study stated they were satisfied with resident care if they felt that residents were comfortable, which was similar to Engel et al.’s findings. However, using other quantitative measures, Engel et al. also found that talking about advance directives for more than 15 minutes upon resident admission, care provided in a specialized dementia unit and no tube feeds for the resident were associated with higher family caregiver satisfaction.In addition, a study conducted by van Uden et al. (2013), found a high level of satisfaction for (n=353) Dutch and Belgian bereaved family caregivers during the last week of their relatives’ lives (mean SWC EOLD=32.4; SD=5.5). Despite our sample size, we found similarly high levels of satisfaction, which makes it likely that our participants may have had similar end-of-life care experiences.

Even with these reports of satisfaction, it is commonly noted that palliative and end-of-life care needs to improve in the LTC home setting. Interestingly, Vohra et al. (2004) also found high levels of bereaved family member satisfaction using the Family Perception of Care scale. These authors questioned whether their results reflected high-quality end-of-life care, or if participants defaulted to remembering events in a more positive light to avoid psychological distress, as suggested by Sinding (2003). Also, we question whether given the bereaved family caregivers’ generally positive opinion of staff and their relationships with them, they would be reluctant to report negative experiences or dissatisfaction. Perhaps a larger more representative sample might provide a clearer picture of their satisfaction.

**Study Limitations**

We recognize a few limitations with this study. First, compared to others that surveyed bereaved family caregivers’ satisfaction with the end-of-life care using the SWC EOLD (Engel et al., 2006; van Uden et al., 2013) we had a very low sample size. Although our results were consistent with these studies, we could have achieved more representative findings with a larger sample of bereaved family caregivers. Second, we did not learn the perspectives of the frontline staff (e.g. personal care aides, licensed nursing staff) on the need to improve on end-of-life care or implement the PATH program. These perspectives would have been helpful in knowing how the PATH program may be received by the larger LTC home staff community during implementation, and anticipate possible barriers and facilitators. Third, the LTC homes in our study were keen to implement the PATH program, which was supported by the medical directors, administrators and clinical leaders. This may have influenced their positive response to the training. Finally, our study results may not be transferable to other LTC home settings with different characteristics (e.g. urban setting, larger bed size, for-profit).

In summary, clinical leaders at three LTC homes received training and implemented the PATH approach. While bereaved family caregivers generally reported a high level of satisfaction through the SWC EOLD questionnaire and follow-up interviews, staff participants felt the need to address gaps in improving communication with residents and their family caregivers. They reacted positively to the PATH training, and highly valued the approach they learned for communicating with residents and their family caregivers. As the staff implemented the PATH program, they recognized initial barriers, which need to be addressed as the program is introduced in the LTC home setting. Addressing these barriers will also be important as this promising program continues to be implemented in other LTC homes.

Word Count: 5928 (including in-text citations)

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Table 1.

Summary of SWC EOLD\* Total and Item Mean Scores for (n=11) Bereaved Family Caregivers

|  |  |  |  |
| --- | --- | --- | --- |
| Item | | Mean Score\*\* | SD |
| 1 | I felt fully involved in all decision making | 3.45 | .82 |
| 2 | I would probably have made different decisions if I had had more information | 3.09 | 1.04 |
| 3 | All measures were taken to keep my care recipient comfortable | 3.73 | .47 |
| 4 | The health care team was sensitive to my needs and feelings | 3.55 | .69 |
| 5 | I did not really understand my care recipient’s condition | 3.45 | .69 |
| 6 | I always knew which doctor or nurse was in charge of my care recipient’s care | 3.00 | .89 |
| 7 | I feel that my care recipient got all necessary nursing assistance | 3.45 | .69 |
| 8 | I felt that all medication issues were clearly explained to me | 3.55 | .69 |
| 9 | My care recipient received all treatments or interventions that he or she could have benefited from | 3.27 | 1.19 |
| 10 | I feel that my care recipient needed better medical care at the end of his or her life | 3.09 | 1.22 |
|  | Total mean score for all items | 33.64 | 6.8 |

\* Note. From “Scales for Evaluation of End-of-Life-Care in Dementia,” by L. Volicer, A.C. Hurley, and Z.V. Blasi, 2001, *Alzheimer Disease and Associated Disorders*, 15, p. 196. Copyright by Lippincott Williams & Wilkins, Inc.

\*\*The 11 respondents rated each item from 1=Strongly Disagree to 4=Strongly Agree. A higher score indicates more satisfaction. The scores for items 2, 5, and 10 were reversed because of the negatively worded statements. The possible range of scores is 10-40. The mean and standard deviation (SD) is reported for each item.

Table 2.

Summary of Main Themes and Sub-Themes

|  |  |
| --- | --- |
| Main Theme | Sub-themes |
| Perceived Need for & Description of the PATH Training | * Addressing the Gap * Reaction to PATH training * Resonance with Approach to Caring for Residents in LTC homes |
| Perception of PATH Program & Training | * Impressions of PATH * Resonance with Approach to Caring for Residents in LTC homes * New Learning * Helps the Achieve Resident, Family Caregiver and Organizational Goals |
| Barriers to PATH Program Implementation | * Managing Multiple Priorities * Need for Education for Frontline Staff * Perceived Difficulty of Implementing PATH |

**Chapter 3: Introduction**

The previous chapter highlighted that when residents have health conditions that prevent them from engaging in end-of-life care decision making, family members become responsible for this process (Shalowitz, Garrett-Mayer, & Wendler, 2006). Therefore, it is important to encourage family members to be involved in discussing and planning for end-of-life care with and/or on behalf of their relative (Moorhouse & Mallery, 2012).

The PATH program, which was newly implemented in the LTC home setting, recognizes the importance of family member involvement in care planning and decision-making on behalf of their relative with cognitive impairments. Being newly implemented in this setting, it was important to understand the experiences of family members participating in the PATH discussion and in identifying the perceived impacts of their participation in the process.

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**Chapter 3**

**Family Members’ Experiences with and Perceived Outcomes of the Palliative and Therapeutic Harmonization Program in the Long-Term Care Home Setting**

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**Abstract**

This is the first qualitative descriptive study that describes the experiences and perceived outcomes of family members of residents living in three long-term care homes, who participated in the Palliative and Therapeutic Harmonization (PATH) program. Thematic content analysis of interviews revealed that prior to their PATH discussion with staff members, participants were involved in making decisions on their relative’s behalf. However, they described varying levels of comfort with decision-making, knowledge about their relative’s health status, and wishes for future medical care. All participants had a positive impression of the PATH discussion process. Their perceived outcomes of the PATH discussion were: opportunities to share and learn about their relative’s health status and trajectory, creating a mutual understanding of directions for care, and receiving support and reassurance for health care decision making. These findings suggest the PATH program is a helpful and well-received strategy for engaging family members in informed decision making.

**Introduction**

Older adults living in long-term care (LTC) homes are often affected by frailty and dementia (Alzheimer Society, 2010; Gillick 2004), and are therefore likely to have multifaceted illness trajectories, a limited survival time and eventual loss of decision-making capacity for directing their own care (Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007). Thus, family members in this setting regularly become involved in their relative’s care and eventually take on the role of decision-maker on their behalf (Bern-Klug, 2014). Family members of residents with cognitive impairments require assistance from health care providers in understanding their health condition and trajectory, options for palliative care, and interventions that may prolong death (Forbes et al., 2000). Internationally, initiatives have been implemented in LTC home settings to help improve advance and end-of-life care planning and decision making for residents and their family members, such as *Let Me Decide* (Molloy et al., 2000), *Physician Orders for Life-Sustaining Treatments* (Hickman et al., 2010), and the *Gold Standards Framework for Care Homes* (Badger, Clifford, Hewison, & Thomas, 2009; Watson, Hockley, & Murray, 2010).

More recently, the *Palliative and Therapeutic Harmonization* (PATH) program was developed to improve older adults’ (and their family members’) knowledge about their health conditions, and help to empower them in health care decision making (Mallery & Moorhouse, 2010). The PATH program is especially suited for the LTC home setting because it recognizes the important role of family members in engaging in a process of mutual understanding with health care providers related to their relative’s life-limiting health conditions. This understanding will help family members make future health care decisions on their relative’s behalf. Moreover, with the focus of the PATH program on understanding and making decisions within a frail population, which is the case in LTC, the PATH program is clearly well suited for the LTC setting. Although the impacts in the LTC home setting have not been evaluated, the PATH program has strong potential for improving both (a) family members’ understanding of their relative’s health conditions in the context of frailty and dementia, and (b) their confidence in palliative and end-of-life care decision making based on this understanding. Since it has just been implemented in the LTC home setting, this is the first study that seeks to understand the experiences of family members in going through the PATH discussion and in identifying the perceived impacts of their participation in the process. Hence, the purpose of this study is to *describe family members’ experiences and perceived outcomes of the PATH program.*

**Context**

As previously reported by the authors, clinical leaders at three LTC homes received PATH program training and implemented the process in their practice (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014a). The PATH process is an approach to help frail older adults and their family members (or substitute decision makers) in making medical decisions (Mallery & Moorhouse, 2010). The distinctive feature of PATH is that the frail older adult and their family member caregiver are able make informed health care decisions after first understanding the progression of their illness(es) in the context of frailty (Moorhouse & Mallery, 2010). The informed decision making results from three main encounters that the health care provider, resident and family caregiver engage in, which include the processes of: *understanding* (the older adult’s health condition in the context of frailty)*, communicating* (the results of the older adult’s physical and cognitive assessment) and *empowering* (the older adult and family member to make medical decisions)(Moorhouse & Mallery, 2010).For a more detailed description of PATH program and the evaluative work completed in the community, please refer to the PATH clinic website (PATH Clinic, 2013).

**Methods**

**Design**

A qualitative descriptive design as described by Sandelowski (2000; 2010) was used. This approach was selected to guide the study because it allows researchers to stay close to the data,and describe events as they happened (Sandelowski, 2000).Therefore, this approach was congruent with the authors’ purpose oflearning about and describing the participants’ experiences and perceived outcomes of participating in the PATH program.

**Setting and Sample**

Data were collected at three not-for-profit LTC homes, which were selected because staff at these sites had recently received PATH program training, and were implementing the PATH process with family members. The LTC homes were under the same management structure and ranged in bed size from less than 50 to more than 150. The three homes were located in Ontario, Canada, in (n=1) suburban and (n=2) rural settings. Using criterion-based purposive sampling, interview data were collected from family members who: had participated in the PATH process, were responsible or shared decision-making responsibilities for their relative, were able to speak and understand English, and were over 18 years old.

**Data Collection**

The primary author was responsible for the data collection, and has previous experience conducting qualitative interviews with family members in the LTC home setting about their experiences with palliative and end-of-life care. Following the PATH discussion with a staff member(s), the family members were informed about the study and asked if they would be willing to be contacted by the primary author. If agreeable, the primary author contacted them by phone to explain the study and invite them to participate in an interview. From February to September, 2013, semi-structured interviews were conducted with (n=22) study participants about their PATH program experiences. The interview questions were collaboratively developed by the research team with the guidance of the advance care planning program evaluation literature. The questions focused on the participants’ experiences with the PATH program, specifically, the format and content of PATH discussion, any perceived benefits or outcomes of participating, areas for improvement or recommendations, and the program’s influences on care planning and medical decision making on behalf of their relative.The primary author took opportunities to ask clarifying questions throughout the interviews. With the participants’ permission, the interviews were audio-recorded and took an average of 35 minutes to complete.

**Data Analysis**

A modified version of Burnard’s (1991) approach to thematic content analysis was used to analyze the interview data. This approach was selected because it is appropriate for analysis of qualitative descriptive studies (Sandelowski, 2000; 2010). That is, it is suited to guide the analysis of transcribed interviews, which were semi-structured and included open-ended questions (Burnard, 1991). To help gain a holistic sense of the entire data set, digital copies of the interviews were transcribed by the primary author. All co-authors read and engaged in a process of open-coding for one transcript to establish an initial coding framework**.** Subsequently, co-authors (AWG, SK) read and independently open-coded eight additional transcripts, and then engaged in a process of collapsing the redundant codes to further refine the coding list and gain a sense of the main themes.Co-authors (AWG, SK) read and coded the remaining transcripts according to the master coding list to develop the final themes and sub-themes. All authors engaged in reviewing the final themes, and agreed on quotes from the participants’ transcripts that helped to illustrate the main theme and sub-theme descriptions.

**Ethical Considerations**

The study proposal was reviewed and approved by the institutional review board at McMaster University [REB #09-271], and at the community-level. During the initial phone contact with the participants, the purpose of the study was explained, with the voluntary nature of their involvement emphasized. Immediately prior to the interviews, written consent was obtained. In appreciation of their time, participants received a $15 gift card from a national coffee shop. To help reduce caregiver burden, effort was made to schedule the interviews around a time that the participants would usually visit their relative, or at a mutually convenient time.

**Findings**

**Characteristics of the Family Members (interviewees)**

Participants identified themselves as adult children (72.7%), spouses (22.7%), and other relatives (4.5%). Eighty-six percent were female, with an average age of 63.4 (SD=11.6)years.All participants were involved in decision making on behalf of their relative. They shared that along with other family members, they regularly visited their relatives in the LTC homes, which ranged from monthly to every day.

**Description of Residents**

About one third of the participants indicated their relatives were newly admitted (within six months of PATH discussion) to their LTC home. Almost two thirds of their relatives came to live at their LTC home from either their family homes or retirement homes, and the remaining from either hospital or another LTC home. All of the participants reported that their relative was affected by some level of cognitive impairment, ranging from “not being as cognizant as he used to be” to “severe dementia.” They also reported other past (e.g., stroke, fracture from falls) and ongoing (e.g. frailty, risk for falls, cardiac and respiratory disease, blindness/deafness, difficulty or unable to ambulate or have mobility) health or well-being issues.

**Main Themes**

Through the analysis of interviews with the family members, three main themes were developed and included descriptions of: (a) the PATH process, (b) the perceived PATH outcomes, and (c) participant recommendations related to PATH. Table 1 provides a summary of the main and sub-themes.

**The PATH Process**

The participants described the general process of the PATH discussion that they had with staff member(s). They described: (a) learning about the PATH program, and (b) discussing PATH.

**Learning about PATH.** For the most part, participants stated that either the nurse practitioner or the nurse manager contacted them by phone, in-person or by email to let them know about the PATH program and invited them to have a discussion. A participant [#2] shared that, “[nurse manager] just sent me an email to explain to me that they have this PATH program now.” A few participants also shared that they first learned about the PATH program from either the LTC home newsletter or direct communication with the primary author. Generally, the PATH discussion was scheduled around the time of the six-week admission conference for newly admitted residents, and the annual care conference for others.

**Discussing PATH.** In terms of the PATH discussion format, the number and composition of family members present, and staff member(s) who led the discussion, varied. For example, some PATH discussions included two or more family members with one or two staff members (e.g., a combination of the nurse practitioner, nurse manager, or medical director). Others included a single family member and staff member (i.e. either the nurse manager or nurse practitioner). All participants commented that they had one PATH discussion. Some offered that they welcomed the opportunity for follow-up discussion, or would be participating in an annual care conference with the larger multidisciplinary team.

While the specifics of each discussion may have varied somewhat, the participants stated that the main aspects of the PATH discussions included opportunities for: information sharing, reviewing the residents’ health status and trajectory, discussion of quality of life issues and planning for end-of-life or emergency care. In some discussions, participants shared information about their relative’s past medical and social history, which they felt helped the staff member(s) to better know their relative. Some participants also shared that staff member(s) reviewed their relative’s current health condition, including their current diagnosis/es (and how that/they might progress), level of cognition (and anticipated decline), weight (and expected weight loss), nutritional intake (and anticipated changes), and mobility. A participant [#14] described that,

And so she [nurse manager] had done some of her own evaluations, trying to get the level of dementia that was going on. So she called me in at that point and basically went over my Mom’s file as far as her physical health, her mental health, her depression.

In discussing issues around quality of life, some participants also took the opportunity to ask about their relatives’ care or care plan in general, or specifically, current treatments and medication regimens. For example, a few expressed concerns over medications, which were discussed until a mutual decision was reached between themselves and the staff member(s). Others talked about changes to their relatives’ daily routines and mobility issues to help enhance their quality of life. Finally, most family members talked with the staff members about planning for future care including: options for place of care during an emergency or health crisis, hypothetical options for level of intervention or treatment in specific situations (e.g. fractures, stroke, pneumonia), and wishes for resuscitation and life-sustaining treatments. For example, a participant [#7] summarized that the PATH discussion mostly focused on quality of life issues and plans for future care. When asked about the content of the PATH discussion, she responded that,

Her ongoing dementia- what can we do to make it better? You know, treat her pain, and get her, things that we could do because we think she is having a fair bit of pain. And, she is difficult to take pills. So we talked a lot about things we could do to improve her life about- and then what are we going to do if the time comes, that, you know she can’t eat. Or what they can do and what we can do- that was the essence of the discussion.

**Perceived PATH Outcomes**

Participants also shared their perceptions of the outcomes or benefits from participating in the PATH discussion. They talked about: (a) their impression of the process, (b) learning about their relative’s health condition and trajectory, (c) creating a mutual understanding for the direction of their relative’s care, and (d) their decision-making context and receiving support for current and future medical decision-making on behalf of their relative.

**Impression of PATH.** All participants reacted positively to participating in the PATH discussion with the staff member(s), using descriptors such as “good,” “wonderful,” “impressed,” “helpful,” “great idea,” “informative,” “enlightening,” “appreciate,” and “good for anybody”. When asked about her impression of the PATH discussion, one participant [#6] stated,

Oh, she [nurse manager] is very, very good. She answered any questions that I [had]. And she gave me more information than I knew. She went through all the files and explained everything to me. And if I didn’t understand, she explained.

As reflected in the content of the PATH discussions and perceived outcomes, family members felt that overall, the PATH program provided an opportunity for them to have input and communicate with the staff about their relative’s health status and direction for future care. One participant [#3] stated, “Oh yes, I was very impressed. And, it was very helpful to us just to know a few things that were happening, or a few things that he had that we didn’t know...” Another [#9] summarized that, “I think it will help me in the future. I think it will help me understand, you know, when he does decline it is expected at some point in time. Probably I wouldn’t have been so well prepared.” A few participants commented that it was reassuring that there was time dedicated for this discussion. They didn’t feel guilty for taking up staff’s time or didn’t feel rushed to get through the conversation:

So when there is actual time set aside for this, I think that makes a big difference for people feeling comfortable, for people getting their questions answered and to ask those questions. Because, they know, no I am not bothering anybody, this is what I am supposed to be doing at this time, is asking these questions. [#2]

**New learning.** Participants also shared how the PATH discussion provided them with the opportunity to learn about their relative’s health condition or trajectory. While some participants described that they either already had a “good idea” about their relative’s health condition or didn’t learn anything new, others felt that the PATH discussion provided an opportunity to learn or share information about their relative. These participants learned more about their relative’s general health condition and trajectory. Participants shared that they gained a better understanding of their relatives’ overall health picture, or how a specific diagnosis could affect their overall functioning and/or eventual decline. One participant [#3] described that, “for me, the PATH program helped a lot because we were able to bring it out and understand it, and know what actually is wrong, or not wrong, or whatever you know?” In another example, a family member [#2] shared that learning about frailty helped her to know how the staff understood her relative’s level of function, but that she had never thought of him as being “frail.” In another instance, a participant [#17] described that she knew about her relative’s declining health condition but hadn’t emotionally connected with the eventual outcome. She shared that,

And I did learn that, yeah it kind of touched me a bit because [staff member] said, “you know the kidneys are starting to not work like they used to.” And you know, as she listed things very gently that were occurring, in general it’s like a slow motion the body is starting to shut down *and even though the head knew it the heart hadn’t heard it until she put it in words* [emphasis added]. And it was like, “yeah I guess.” And then she very kindly said, “barring a stroke or heart attack you know this will be a gradual thing and she’ll just go on up,” which is perfectly okay.

As for learning about specific conditions, while some participants were aware that their relative had dementia, they were provided with more details around staging, progression and behavioural changes. One participant [#6] shared that she learned more about dementia, and that her relative would decline and “get worse.”

**Creating a mutual understanding.** Participants discussed their relative’s plans for current and future medical care. As a result, some shared that they were able to come to a mutual understanding or decision for current or future care with the staff member(s). An excerpt from an interview with one participant [#15] illustrates this mutual understanding:

Interviewer: And it does sound like you had a good idea of your husband’s advance care plan, kind of what

Family Member: What would happen when the time comes, what they do with him, yes they know. She [nurse manager] will go with what he wants.

For some participants, it was their first opportunity to share the relative’s wishes for future medical care with the staff. Also, in cases where two or more family members participated in the PATH discussion, a few felt that it provided them with their first opportunity to openly share their thoughts with each other around their relative’s direction of care. For example, a participant [#7] shared her and her sibling’s experience around creating mutual understanding:

Because we never really say out loud- “well, if Mom gets sick, we are not going to do anything,” we have never come out and said that. But we would certainly want her treated if it was something minor- but we are not going to go and give her an MRI or anything. You know? And I think just having the open conversation, even between her and I, and [the staff], at least we are all thinking the same way.

**Decision making.**Participants also shared the context in which they made decisions on behalf of their relative prior to the PATH discussion. Some participants also described how they gained support for ongoing or future health care decisions through the PATH.

***Decision making context.*** Prior to the PATH discussion, the participants were responsible, or shared medical decision-making responsibilities on behalf of their relatives living in the LTC home. However, as a group, they had varying levels of decision-making experience, comfort, and support from their larger family. In general, participants who expressed a greater comfort level in making decisions on behalf of their relative usually had the support of other family members, knew their relative’s wishes for future medical care, and had been responsible for making decisions for some time. For example, a participant [#5] matter-of-factly explained, “I have been making decisions- that’s my job.” Participants who shared that they were not as comfortable with making decisions, usually described reasons such as feeling guilty, ill-prepared (i.e., not knowing their relative’s wishes or health conditions), inexperienced, or unsupported by their larger family. For example, a participant [#11] explained how her family was not supportive of her decision-making role, “And as being a power of attorney, I have a hard time with the family because they don’t agree with everything.” Overall, it was clear that participants entered into the PATH discussion with varying family dynamics, and levels of comfort for decision making on behalf of their relative.

***Decision-making support.*** Participants also shared that the PATH discussion helped them to (a) feel prepared to make future decisions about care and interventions for their relative, (b) make actual decisions, and (c) feel reassured about thoughts on/decisions for future care. In part, this was achieved by discussion of their relative’s health status with the staff member, and learning about (or reviewing) the expected illness trajectory of the resident. By doing this, they were more comfortable or more prepared to make current and future medical decisions. Even in cases where the PATH discussion provided more of a chance to review or confirm information about their relative and plans for the future, family members felt it was good, or made them feel reassured. For example, a participant [#1] shared that she and her family members were able to think back to the PATH discussion when making decisions about whether or not to proceed with a chest X-ray and invasive dental work for their relative with advanced dementia. These experiences were summarized by the following:

So, I think it is times like those where I think back to the [PATH] program and I think, it reinforces for me anyway that we are trying to make proper decisions for [relative] that she would accept as okay.

In other instances, participants felt that they would be “prepared for the phone call” or “better prepared” in the event of their relative’s health decline or imminent death. Some participants also gained a sense of reassurance, because their thought processes or decisions for current or future medical care were validated or supported by the staff members. A participant [#12] shared that,

Family Member: I wasn’t sure how other people thought about that. You know, about me making those decisions. “Okay, don’t give him meds that’s going to keep his heart going,” and stuff you know that is just going to prolong his life in a chair. It’s okay for me to say “no” to things like that, because nobody’s going to look bad on me.

Interviewer: And just to clarify, is that the staff won’t look...

Family Member: Yah, the staff. ... It’s okay to make those decisions. It’s okay to say, “we don’t want to prolong Dad’s life.”

In the same vein, some participants expressed guilt or uncertainty in decision making on behalf of their relative. They shared that the PATH discussion provided them with the reassurance to be at peace or feel relief with the decisions they were making on behalf of their relative and, as one family member [#1] said, “not beating” themselves up afterward. In another example, a participant [#5] shared,

If that’s what it is, these talks would be very beneficial to me at least because I would be able to come and say what’s going on and how I feel about it and get some reassurance that we are not doing something wrong, we’re doing what’s best for Mom.

**Participant Recommendations Related to PATH**

Participants made recommendations around helping families to prepare for the PATH discussion, its timing, and perceived benefits for families. One participant suggested that it would have been better to have more background knowledge about PATH and what would be discussed prior to the meeting. Also, there were mixed recommendations around the timing of the PATH discussions, with some in favour of having it in place during the admission process. Others felt that the PATH discussion could or should wait some time (e.g, weeks to months after admission) so that the resident and family could adjust to living in LTC, health conditions could stabilize (if needed), and staff could have time to get to know them as well. One participant [#4] shared that, “I think they would have to wait a little while so they can see how they are doing, and so the nurses and everybody can understand how they are doing, so that they can come and tell you.” Finally, a few participants shared that PATH discussion would be beneficial for all families in the LTC home, especially where there are multiple family members with different viewpoints, needing to understand their relative’s health condition. They also shared that the PATH discussion would be beneficial in cases where family members are not as involved with their relative’s care, as a way of establishing formal lines of communication with the staff.

**Discussion of Findings**

Results from this qualitative descriptive study are important because they are the first that advance the understanding of what family members experience (PATH process) and take away (perceived outcomes of PATH) from a PATH discussion with staff members in the LTC home setting. Since the PATH program has been recently implemented in the LTC home setting, it is critical to examine family members’ reaction to this initiative and to contemplate how future refinement of the program and subsequent research may enhance our understanding of family member outcomes.

Authors have summarized the impacts of initiatives (quantitatively evaluated) used to enhance or increase advance or end-of-life care planning and decision making for residents living in LTC homes and their family members (Robinson et al., 2012; Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). While these authors collectively identified resident and organizational-related impacts from the initiatives, the family member-related impacts of satisfaction with health care and greater knowledge of resident wishes were also recognized. This study’s findings add to this growing body of literature by identifying the family members’ experience with the PATH discussion, including how they learned about the program and the discussion format. The perceived outcomes from participating in the PATH discussion also included, learning more about their relative’s health conditions, creating a mutual understanding for their relative’s direction of care, and support for current and ongoing decision making.

In addition, it was found that the PATH discussion was positively received by all of the family member participants across the three LTC homes. This as an encouraging finding, given that participants had varying knowledge levels of their relative’s health conditions and illness, and comfort and experience with decision making on their behalf. Literature indicates that surrogate decision making for relatives with dementia can be difficult and made in the context of overwhelming burden, guilt and uncertainty (Givens, Lopez, Mazor, & Mitchell, 2012). However, the participants’ encouraging reaction to it in our study is consistent with positive reports from those who completed the PATH program in the community setting (Moorhouse & Mallery, 2012). According to satisfaction surveys completed by (n=50) program participants in the community, although the experience could be emotionally charged or difficult, nearly all found the information in the PATH discussion helpful, and all found the process very beneficial for care planning (Moorhouse & Mallery, 2012). Together these positive reactions have implications for the larger population of older adults and their family members in planning for and making decisions around end-of-life care.

In addition, when participants were asked to describe their experience with the PATH discussion, they revealed interesting points to consider for future work and refinement to the program. Some participants shared that multiple family members were involved in the PATH discussion, which provided opportunities for them to simultaneously share and receive information about their relative, and create mutual understandings for the direction of care for their relative. A recent systematic review identifying factors associated with the initiation of advance care planning in dementia revealed that family conflicts can be a barrier or complicate initiating decision making (van der Steen et al., 2014). In recognizing the important finding of creating a mutual understanding for the direction of care, further refinement to the program could address a process for identifying and helping families in need of conflict resolution.

Also, family members were invited to participate in the PATH discussion at different points of their relative’s stay in the LTC home (i.e., some were new to this setting; others’ relatives had lived in this setting for years). They also provided different recommendations for the timing of the PATH discussion with staff members. Due to the emotional stress of admission to the LTC home setting, other research has found that family members have expressed that this was not an optimal time for advance care planning discussions (Givens et al., 2012). Therefore, further refinement to the program around establishing an optimal time for the initial and any follow-up discussions will be helpful. Overall, while it is encouraging that a variety of PATH discussion formats, contents and timing produced positive perceived outcomes for the participants, ongoing refinements and subsequent evaluation may reveal consistent family member-related outcomes or identify new ones.

**Limitations**

We recognize a few limitations with this study. The three data collection sites are not necessarily representative of all types of LTC homes (e.g. geographic setting, size, funding model, staff mix). It also follows that the participants may not be representative of all family members making decisions on behalf of their relatives living in LTC, as they identified themselves as being regularly involved with their relative’s care and social life. It is possible that those who were less involved with their relative’s care may have identified different experiences and outcomes or recommendations related to the PATH process. Also, the majority of the sample were women. The sample would have been more representative by including more men, and perhaps exploring their different experiences. Together, the setting and sample obtained for this study may limit the transferability of the findings to other LTC home settings and family members.

**Conclusion**

In summary, family members participated in PATH discussions with staff members at three LTC homes and reacted positively to this experience. During the PATH discussion, they were able to share information and discuss their relative’s quality of life, health conditions and anticipated health trajectory, and plan for and discuss options for future health care and interventions. Participants identified several perceived outcomes by participating in the PATH discussion, including learning about their relative’s health conditions, creating a mutual understanding for their relative’s direction for care, and receiving support for decision making. These findings suggest the PATH program is a helpful and well-received strategy for engaging family members in decision making for their relatives in the context of frailty and dementia. However, ongoing refinement of the program and evaluation in this setting may help to determine an optimal staff and family member mix for participation in the PATH discussion.

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Table 1.

Main Themes and Sub-Themes from Family Member Interviews

|  |  |
| --- | --- |
| Main Themes | Sub-Themes |
| PATH Process | * Learning about PATH * Discussing PATH   + - Discussion Format     - Content of Discussion     - Following- Up |
| Perceived PATH Outcomes | * Impression of PATH * New Learning * Creating a Mutual Understanding * Decision Making   + - Context     - Support |
| Participant Recommendations Related to PATH | * Preparing for the discussion * Timing of the discussion * Benefits for families with relatives in LTC homes |

**Chapter 4 Introduction**

This chapter extends the previous chapters by describing the study findings related to the perceived outcomes of staff and residents. After the PATH program had been used in practice for approximately one year, it was important to understand further outcomes related to the program’s implementation. Therefore, the purpose of this sub study was to evaluate the PATH program outcomes in the LTC home setting. The main objectives were to:

* describe the perceived outcomes and experiences of LTC home staff members using the PATH program; and
* describe the differences in the documentation related to resident health status, advance care planning discussion and decisions between the charts of residents at the intervention (PATH and non PATH participants) and comparison sites

**Chapter 4**

**Exploring Staff and Resident Outcomes from the Implementation of the Palliative and Therapeutic Harmonization (PATH) Program in the Long-Term Care Home**

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**Abstract**

The primary purpose of this mixed-methods study was to describe the perceived outcomes of staff who used the Palliative and Therapeutic Harmonization (PATH) program in their LTC home practice. A secondary purpose was to describe the differences in documenting residents’ advance care plans and discussions. Clinical leaders, who had been using the PATH program in their practice, participated in semi-structured, qualitative interviews at two points in time. Thematic content analysis revealed main themes around perceived outcomes that were both practice oriented as well as personal. Perceived practice outcomes included: using the PATH program in LTC home setting, having a structure to discuss current and future care, engaging in proactive care planning, and making a difference for residents and families. Perceived personal outcomes included: improving work satisfaction, establishing relationships, and growing comfort and confidence in discussions. In addition, retrospective chart reviews were used to determine that documentation around advance care planning changed in the intervention homes with the implementation of the PATH program. Overall, the PATH program offers a promising approach for enhancing LTC home staff’s practice.

Residents living in long-term care (LTC) homes are often affected by co-morbid, life-limiting conditions (Canadian Healthcare Association, 2009). However, palliative and end-of-life care delivery remains a challenge in this setting (Brazil et al., 2006). There is a general consensus that a palliative approach can be offered in a plan of care for individuals who are diagnosed with a life-limiting illness; where cure is not possible (Whitaker, Kernohan, Hasson, Howard, & McLaughlin, 2006; Canadian Hospice Palliative Care Association, 2012). Internationally, many programs and strategies have been implemented in LTC homes to improve palliative and end-of-life care by addressing the need for advance care planning and directives (Wickson-Griffiths, Kaasalainen, Ploeg, McAiney, 2014a). A valuable addition to these programs is the Palliative and Therapeutic Harmonization (PATH) program, which was recently introduced in the LTC home setting. This program is well suited for use in the LTC home setting because it focuses on residents (and their family members’) understanding of their health conditions and trajectories in the context of frailty and dementia, two common conditions in this setting (Alzheimer Society, 2010; Gillick, 2004).

Recently, the PATH program was implemented in the LTC home setting (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). The need for the PATH program in the LTC home setting was clearly described by staff members and bereaved family caregivers, highlighting that the program would help them to address gaps in care around improving palliative and end-of-life care planning and communication with residents and families (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). Staff’s initial perceptions of the PATH program training as well as identification of initial implementation barriers were also described (Wickson-Griffiths, Kaasalainen, McAiney, & Ploeg, 2014b). Secondly, family members’ experiences and perceived outcomes of participating in the PATH program were identified (Wickson-Griffiths, Kaasalainen, McAiney, & Ploeg, 2014). In addition to the studies conducted in the LTC home, an additional study reported by the PATH program developers described outcomes related to health care decision making for older adults in the geriatric clinic setting (Moorhouse & Mallery, 2012). However, this is the first paper that reports the perceived personal and practice outcomes identified by interdisciplinary LTC home staff members using the PATH program. It is also the first to describe resident outcomes through changes in documentation practices in the LTC home setting. As palliative care delivery has been identified as a challenge in this setting (Brazil et al., 2006), examining these important outcomes advances knowledge around the possible implications the PATH program has for improving care in LTC homes.

**Context**

As previously described by the authors, interdisciplinary staff at three LTC homes received PATH program training and subsequently implemented it in their practice (Wickson-Griffiths, Kaasalainen, Ploeg & McAiney, 2014b). A hallmark feature of the PATH approach is that the frail older adult (and their family member) are able to first understand the progression of their illness(es) in the context of frailty, which is intended to empower them to make informed health care decisions (Mallery & Moorhouse, 2010). A full description of the PATH process is described by the program developers and is available on the PATH Clinic website (PATH Clinic, 2013).

**Purpose**

The purpose of this study was to evaluate staff and resident outcomes related to the PATH program implementation in the LTC home setting. The two research questions addressed in this study are: What are the perceived outcomes and experiences of LTC home staff members using the PATH program? What are the differences in the documentation related to resident health status, advance care planning discussions and decisions between the charts of residents at the intervention (PATH and non PATH participants) and comparison sites?

**Methods**

**Design**

This study used an embedded mixed-method design (Creswell & Plano Clark, 2011). The embedded design was selected to answer both the qualitative and quantitative research questions. However, because this was an embedded design, the quantitative data was secondary (i.e. embedded) to the qualitative data, which is noted as QUAL(quan) (Creswell & Plano Clark, 2011). Qualitative interviews were used to learn about the staff members’ experiences with and perceived outcomes of using the PATH program. Quantitative methods (retrospective chart reviews) were used to learn about resident outcomes and changes in advance care planning or health care decision-making documentation.

**Setting and Sample**

**Staff interviews.** Interview data were collected at three intervention sites that were located in (n=1) suburban and (n=2) rural settings, had a range in bed size from <50 to >150, operated under a not-for-profit funding model, and had the same management. A criterion-based purposive sampling strategy was used to select interdisciplinary staff member participants at the three intervention sites at the mid-point and end of the intervention period. The intervention period began in May, 2012 and concluded in August, 2013. To be included in the study, all participants had to be involved in the PATH program implementation, and speak and understand English. The interdisciplinary participants included a nurse practitioner, social worker, pharmacist, physiotherapist, and medical directors and nurse managers.

**Chart reviews.** Data were collected from residents’ charts at the three LTC home intervention sites that implemented the PATH program (described above), and one LTC home comparison site, where care continued as usual. It is important to note, however, that not all residents at the intervention sites were involved in the PATH program. All sites were located in southwestern Ontario, Canada. The comparison site was located in an urban setting, had >150 beds, and operated under a for-profit funding model with a corporate management structure. Using criterion-based sampling, the charts of residents receiving care from the medical directors (and one attending physician at the comparison site) were eligible to be included in the sample. To participate in the study, residents or their substitute decision maker had to understand English, be at least 18 years old and provide written consent to have the chart reviewed,.

**Data Collection Procedures**

**Staff interviews.** A dedicated staff member sent out memos through email to help recruit staff members for individual interviews. Semi-structured individual interviews were conducted in the Winter of 2013 (i.e., midpoint of the study) with (n=4) nurse managers, (n=3) allied health professionals, (n=2) medical directors, and a (n=1) nurse practitioner. In the Fall of 2013, a second and final set of interviews were conducted with (n=5) nurse managers, (n=2) allied health professionals, (n=2) medical directors, and a (n=1) nurse practitioner. At both times the same practitioners were invited to participate in the interviews. However, one nurse manager and one allied health professional were not available during the midpoint and final interview times, respectively. The interview guide (available upon request) was previously developed in collaboration with the research team and literature related to advance care planning program evaluation. The interview questions focused on the participants’ ongoing experiences of using the PATH program in practice, facilitators and barriers to implementing the program, and perceived outcomes of the program. The length of the interviews varied between the two data collection points; taking between 20 and 65 minutes for the midpoint interviews, and between 20 and 80 minutes for the final interviews. The variation in length depended on the participant’s level of involvement with using the PATH program in practice (i.e., interviews for staff members who were more involved in PATH discussions with family members took longer to complete, versus those who played more of a supportive role). Also, the final interviews tended to take longer to complete, as the staff participants were asked to complete a member-checking exercise, which is addressed later in this paper.

**Chart reviews.** Personnel from the intervention and comparison sites identified a) residents receiving care from the participating medical directors and attending physician, and b) residents who were capable of deciding if they wanted to participate in the study. All potential participants received information about the study, and if agreeable, provided permission to be contacted by the primary author. A staff member introduced the primary author to the residents who were deemed to have decision-making capacity, the study was explained to them in-person, and written consent obtained. In cases where the resident was not deemed to have decision-making capacity, the primary author contacted their substitute decision maker for healthcare by phone to explain the study, and written consent was obtained by mail.

An electronic chart review tool was collaboratively designed by the research team in consultation with the PATH program developers who had previously designed a tool to retrospectively collect resident data (Moorhouse & Mallery, 2012). The data collection tool in this study contained groups of key variables including: resident characteristics (e.g., age, gender, time living in long-term care, medical diagnosis, number and types of medications), evidence of care planning and discussion (e.g., presence of advance directive, documented discussion with healthcare providers, and preferences for setting for end-of-life care, level of intervention, comfort care options), and location of death for deceased residents. Chart data were collected retrospectively up to one year prior to the PATH program implementation (May, 2012) for baseline data, and after the evaluation period concluded (August, 2013) for final data.

**Analysis**

**Interviews.** The data analysis was guided by a modified approach to thematic content analysis (Burnard, 1991). The primary author (AWG) conducted and transcribed all of the midpoint interviews. The primary author (AWG) coded all of the transcripts to develop a coding list. To help refine the coding list, co-author (SK) independently read and coded all of the transcripts. The co-authors (SK, AWG) collapsed redundant codes and discussed the emerging themes. After the final interviews were conducted and transcribed, the coding list developed from the midpoint interviews was used to guide the coding of all of the final data. Again, to help establish trustworthiness of the data, co-author (SK) read and coded all final interview transcripts, and discussed the developing themes with the primary author (AWG) to help build consensus. All co-authors reviewed the final themes and agreed upon participants' quotes that would best describe their perceived outcomes of the PATH program.

**Chart reviews.** Descriptive statistics were used to analyze all data collected from residents’ charts. Means and standard deviations were calculated for all residents’ basic demographics including mean age, length of time in LTC, and number of scheduled and as needed medications; and frequencies and percentages were calculated for gender and major diagnosis, as well as for residents with documented advance directives, and their indicated level of care (i.e., full intervention to palliative care) at the comparison site. Frequencies and percentages were also used to describe the number of residents with a signed Plan of Treatment for CPR (South West Hospice Palliative Care Network, 2013) and their indicated treatment (i.e., CPR, no CPR) at the intervention sites for all residents. Finally, frequencies and percentages were calculated to describe the family members and practitioners who attended the PATH discussion; reviewed diagnosis or issues, immediate decisions or action for medical care, and summary of PATH discussion for residents at the intervention sites with a documented PATH discussion. For residents who had died during the intervention period, the PATH summary (intervention site) and progress notes as well as practitioner’s orders were examined to determine if they had died in their preferred location.

**Rigor**

**Qualitative interviews.** To help establish trustworthiness of the data, the primary author took the opportunity to ask clarifying questions throughout both sets of interviews with staff members (Milne & Oberle, 2005). Also, the primary author engaged in a process of member-checking previously identified themes during the staff members’ final interviews (Milne & Oberle, 2005). All staff member participants (n=11) were asked to review the list of main themes and examples, as well as to identify any new experiences related to the themes during the final interview. While collecting the final interview data, the primary author participated in a PATH team staff meeting attended in-person or by phone by (n=2) allied health professionals, (n=4) nurse managers and the nurse practitioner. During this time, the staff shared their overall impressions of the PATH process and notes were taken and compared to the interview data.

**Chart reviews.** Several issues have been identified with conducting retrospective chart reviews such as the medical chart itself (e.g., illegible, incomplete or inaccurate documentation), and the review process (e.g., lack of clear procedures, inconsistency of coding data) (Engel, Henderson, Fergenbaum & Colantonio, 2009; Gilbert, Lowenstein, Koziol-McLain, Barta, & Steiner, 1996; Hess, 2004; Gearing, Mian, Barber, & Ickowicz, 2006; Jennett & Affleck, 1998; Yawn & Wollan, 2005). Therefore, findings from published guidelines and methodological standards for conducting retrospective medical record reviews were incorporated into the tool design and data collection process to help ensure the validity and reliability of the data (Engel, Henderson, & Colantonio, 2008; Gilbert et al., 1996). Also, to prepare the primary author for data collection, the quality of articles using retrospective chart review as the method of data collection were reviewed and summarized for the palliative/end-of-life care-based literature (See Appendix B).

To help ensure a rigorous data collection process, the following steps were used. First, the previously stated research question (eg, understanding any changes in documentation related to resident health status, advance care planning discussion and decisions from the PATH program) was defined to justify the purpose of and guide the data collection (Engel et al., 2008). Second, to better help understand the resident charts, LTC home personnel from the intervention and comparison sites helped to familiarize the primary author with the charts and the information typically collected related to advance care planning discussions and activities (Engel et al., 2008). Third, based on the research question and a data collection tool previously created and used by the PATH program developers (Moorhouse & Mallery, 2012), a chart review tool was designed for this study. Fourth, to help establish content validity, the chart review tool was reviewed by the PATH program developers and LTC home personnel at the intervention and comparison sites (content experts) (Streiner & Norman, 2003). Fifth, prior to the data collection, the tool was reviewed with LTC home personnel to ascertain the best location of data for each variable. Personnel were also consulted about the best location for data when a variable was documented in several ways or places (e.g., resident diagnosis listed on the medication administration record, annual physical notes, problem list). Sixth, the location of data for each variable was incorporated into a chart review guide, created for each site. Seventh, to test the usability and reliability of the tool, data were extracted for 10% of the baseline sample by the primary author and a research assistant. Finally, in addition to creating and following a data abstraction protocol, the research team discussed the chart review data collection process throughout the study (Engel et al., 2008; Gilbert et al., 1996).

**Ethical Considerations**

The study was reviewed and approved by the respective University and community-level institutional review and quality assurance boards [McMaster University REB# 09-271]. All staff member participants had prior knowledge of the study, and had previously consented to participate in other interviews related to their PATH program experiences. The ongoing voluntary nature of their participation was emphasized prior to their midpoint and final interviews, and written consents were obtained. In appreciation of their time, all interview participants received a $15 gift card for each interview. Residents or their substitute decision makers provided written consent for the chart reviews.

**Qualitative Findings**

**Characteristics of the Sample**

Eight-two percent (9/11) of the interdisciplinary staff participants were female. They had been working in the LTC home setting for at least two years.

**Main Themes**

The analysis of staff interviews revealed two main themes related to perceived outcomes: practice and personal. Perceived outcomes related to practice included descriptions of how staff used the PATH program and how it enhanced or changed their practice. Perceived personal outcomes included descriptions of satisfaction and individual growth from the PATH program. See Table 1 for a summary of these themes and sub-themes.

**Practice Outcomes**

**Using the PATH program in the LTC home setting.** After the PATH program training was completed, an important outcome was that staff used the process in practice. The nurse managers were primarily responsible for assessing the resident, and engaging in the PATH discussions with residents and family members. The nurse practitioner and one medical director often supported the nurse managers by reviewing their resident assessments and planned discussion points, and/or by directly participating in the PATH discussion with family members. One participant [nursing #3] shared how her comfort level with the planned discussion helped her to decide on whether additional support from the nurse practitioner or medical director was needed for the PATH discussions with families:

I make arrangements to set up a meeting with myself [and family member] if I feel comfortable doing it on my own. If I don’t feel comfortable doing it on my own and I think, depending on the family, depending on what the issues are sometimes I get [MD] and [NP] involved with the meetings too, especially depending on what they have [resident diagnosis]. Or I get them to review it [planned PATH discussion] before I would actually meet with them.

The social worker, pharmacist and physiotherapist played more supportive roles, by incorporating the PATH principles into their own practice. Staff members identified three main ways they applied the PATH program or its principles in practice, including the comprehensive geriatric assessment for LTC (CGA-LTC), and formal as well as informal PATH discussions.

***Comprehensive Geriatric Assessment for LTC.*** The staff shared that they primarily used the CGA-LTC form provided by the PATH program developers to assess newly admitted residents or residents who were already living at the LTC home but where more health and/or social history information was needed. A participant [nursing #3] explained how she used the CGA for newly admitted residents, “I would use this CGA-LTC form, and I have started on all my new admissions, and I write down all their current diagnoses, and what I do is I try to do the assessments.” In cases where the staff felt they already knew the resident, they streamlined the assessment to focus on identifying the health conditions that most affected their quality of life to further discuss with the family. One participant [nursing #4] explained how she modified the approach:

So I thought the background information [CGA-LTC] we might not use as much with some people because we already have a pretty good picture of who that person is and how their medical health has progressed. What I like to focus on are what are the key issues of this person’s quality of life right now and what are some interventions we can put in place to work on those so that they can have some meaningful purpose and improve their quality of life for the remainder.

***Formal PATH discussion.*** Staff formally invited family members to participate in a PATH discussion to share the findings of the CGA-LTC, or discuss the issues and conditions affecting their relative. The main focus of the discussion was on the resident’s diagnosis and prognosis, reviewing the care plan and goals of care, and establishing or reaffirming their relationship or rapport with family members. One participant [nursing #6] explained how she approached the PATH formal discussion:

So I look at the diagnoses, anything that happened to them medically since they came, and then discuss that with the family, talk about the frailty or if they had any mini-mentals done and then try and develop the PATH summary [issues discussed and directions for future care] with the family, that’s how I do that.

***Informal PATH discussion.*** Staff informally used PATH principles (e.g., being open, honest, and direct in communicating with family members, or preparing family members to make an informed decision in the context of resident’s frailty) in everyday practice. They used it when communicating with family members around changes in the resident’s status, new palliative or end-of-life care needs, or the potential resident outcomes during an outbreak.

**Having a structure and permission to discuss current and future care.** All participants agreed that the PATH program provided them with a structure or process for gathering information about the resident, and then having a conversation with the family members and/or resident around the health status and current and future goals of care. One participant [allied health #2] shared how the PATH program training provided staff with learning a new way to communicate with residents and family members, which in turn meant they were helping them to make medical decisions and build a better relationship. This participant shared that:

Giving the staff the language and the structure was probably the best thing that happened I think. Because now they have a way of approaching the family and saying this is where your family member is and then helping them to do all these other things. You know, to make decisions, to build a better relationship with the staff and more trust. All those things just come out of that improved way of communicating. So I think that’s the best outcome.

Staff also shared that by using PATH program they had a new sense of “permission” or justification to engage in discussing a resident’s health condition(s) and prognosis(es). For example one participant [nursing #1] shared how the PATH program provided her with the permission to engage in an honest discussion about prognosis, where her educational preparation did not:

Imagine being a nurse, even a nurse practitioner and being given that permission to say, ‘you have congestive heart failure and that's a progressive disease and can take your life.’ We're just not given permission to say things like this in our training at school. It was still so much, ‘well that's something the doctor would say.’

Another participant [nursing #5] shared a similar new sense of permission for being able to share health information, and highlighted how the PATH program had changed her thinking in how she communicated with family members and residents. She shared that:

I think culturally we don’t tend to look at... we want to sugar coat things for people because obviously they are going through a rough time... And, in a sense we almost need to desensitize that to give them the information they need to make the important decisions about why, what our next steps or treatments are going to be. Which I don’t think, from my experience, up until I got the PATH training, I was under the same influence... So, once I took the PATH training, ‘well, why not? Why can’t we be honest? Why can’t we say, ‘your mom has dementia. It is going to get worse?’

**Engaging in proactive care planning.** Engaging in informal and formal PATH discussions with family members meant that staff were focused on being more proactive with care planning discussions. The staff shared that a main goal was trying to prepare residents and family members for eventual outcomes related to their (co-morbid) disease process, and as one participant [nursing #4] shared, “before we get to the palliative and end-of-life stages.” Incorporating a proactive approach was important to one participant [nursing #2] who explained that, “I think to me, the most important goal is that they [family members] understand or they are beginning to get an understanding of where the resident is at, what the expectations are. Because I think the most important thing is that there are no real surprises, no panic at a critical time.” The PATH discussions in turn helped the staff members to have a better sense of the future direction for care.

For staff in more of a supportive role, the PATH program generally helped them to be more proactive in care planning or thinking about interventions to support residents’ quality of life. One participant [allied health #2] explained that reviewing the contents of documented PATH discussions “helps me to be maybe a little more proactive in looking at the medication and what they [residents] need and what maybe we can dispense with based on frailty and dementia and co-morbidities and all the things we look at with PATH.” In addition, another participant [allied health #1] shared that the PATH discussions helped her to be more proactive in following up with residents or family members who were struggling with the realities of the health conditions and trajectories. She explained how the implementation of the PATH program helped to facilitate this proactive approach:

The [allied health team member] is being invited in to continue care. So that [PATH] discussion happens, they realize the family is having great difficulty with the fact that Mom and Dad are sicker than they thought and they are dying. So being invited in to continue on with some care and counselling with that family and the resident. So that’s been a positive outcome.

**Making a difference for residents and families.** The staff also recognized perceived outcomes that they were seeing for residents and family members. Perceived resident outcomes resulting from PATH implementation included: decrease in unnecessary tests and medications, fewer transfers to hospital, and care planning leading to a better quality of life. One participant [nursing #3] recalled that for “one particular resident we don’t do any blood work, we don’t do x-rays even, we do no unnecessary testing. It’s just a comfort approach. So those types of decisions have been made through the PATH discussions.” Staff members also expressed that family members seemed better informed and more knowledgeable about their relative’s health conditions and trajectories. They also thought that the PATH discussions offered family members a chance to think ahead for the types of health care decisions they would make on their relative’s behalf, and that family members seemed better prepared or empowered, and more comfortable with the medical decisions they were making. The staff also shared that family members appreciated the time spent discussing their relative. A participant [nursing #6] stated her thoughts on one of the most important outcomes from the PATH program around family members being better informed and more comfortable with decision making:

For me is that the family understand what the PATH is all about and why we do it and that when they walk away, they feel better knowing that they come up with some kind of plan. I call it a plan because going forward this is what they would like to see and that they feel good that we’ve educated them on diagnoses and medications and why they get this, and that I think really helps them and it makes them feel better.

**Personal Outcomes**

**Improving work satisfaction.** In general, all of the staff participants expressed that they had a positive impression or were satisfied with applying the PATH program training in their practice. This overall impression is summed up by one participant [nursing #6] when she explained that, “Well I’m really satisfied because I really do like the program and I’m really excited about it.” However, participants offered more specific examples of how using the PATH program created their positive impression or satisfaction. Some participants explained that it was satisfying to be able to use PATH program principles when communicating with residents and family members in everyday practice. This meant that they could extend the use of the program principles beyond the formal meetings with family members. For example, a participant [nursing #1] stated that, “I am really satisfied because we have been able to transfer those skills [applying PATH program principles] to day-to-day functioning.” Others expressed satisfaction or a sense of accomplishment when completing the more formal PATH program discussion with family members. This personal satisfaction seemed to stem from helping family members to understand their relative’s health conditions and trajectory through the PATH discussion. For example, one participant [nursing #5] recalled, “Those days I leave feeling more satisfied because I feel like I have informed the families with what they need and it’s a huge satisfaction for me in terms of my role, my job.” Another participant [nursing #3] explained that, “It’s really a reward. You really feel good about it after you have done it, right? Because you know that they [family members] really trust you and you took the time to go over all this and explain what’s happening.”

**Establishing relationships.** An important goal for staff members in implementing and using the PATH program was to establish good relationships and rapport with residents and family members. Staff expressed that using the PATH discussion provided opportunities for, and helped them to establish these desired relationships with family members. Establishing trust was important, as this in turn made for better care planning and communication between themselves and the family members. In addition, the staff engaging in the PATH discussion wanted family members to be comfortable with them as their main contact. One participant [nursing #6] who was particularly dedicated to developing relationships and rapport with families, explained that:

I like to be able to spend the time with them as soon as they are admitted because they have a lot of questions. And then I find once I go through the PATH and then if they have other questions they will always call or they will stop by and that just makes it easier.

Another participant [nursing #1] recognized the nurse managers’ success with establishing relationships or rapport with family members, and highlighted the importance of family members feeling comfortable with the professional relationship established through the PATH discussion. She explained that:

We want to be seen as part of their [family member’s] team, part of the team surrounding the resident or with the resident. We don’t want to be seen as in any way an adversary, we want to establish that relationship of trust and conversation. That relationship says at any time you can call me and ask me when you see your mother deteriorating or you have concern. And I really believe the [nurse managers] have become very successful with doing that.

**Growing comfort and confidence in discussions.** Building or growing comfort and confidence with difficult discussions was another noted outcome. The staff who were primarily responsible for engaging in the PATH discussions with family members commented that over time, they became more comfortable or confident with them. A participant [nursing #4] offered that, “I think it’s important to continue to do these PATH assessments consistently. I find that I was really comfortable, maybe not the first one, the first few that I did, but then I became pretty comfortable having these discussions.” Another participant [nursing #2] shared this sense of growing confidence, which to her meant that she could engage in the discussion more frequently. She shared that,

I am definitely more comfortable because I know it has to work and that discussion has to happen, so I think I’m more comfortable with it and I feel I am more comfortable having those discussions. And I think they are happening more than they were for that very reason.

The growing confidence of the staff in primary PATH roles was also noted by those in the supportive roles. A participant [allied health #1] explained how the PATH program has helped staff become more comfortable with difficult end-of-life care discussions, which has improved communication around providing comfort care.

From my perspective, too, the [nurse managers] are becoming far more comfortable in having those difficult conversations- far more confident. And there are always those difficult ones, we have one darling lady who has end-stage cancer, that one has been really, really hard, but I think we are all just far more comfortable just talking about it. Because everybody is on board and we just want her to be pain free and be comfortable and everybody is on the same page, I don’t know if that would have been as easy for all of us to get to without PATH, I think that has helped us.

**Quantitative Findings**

**Characteristics of the Sample**

Using the chart review method, demographic data were collected for residents at the intervention and comparison sites. See Table 2 for a summary of the residents’ characteristics. In both sites the majority (65%) of the sample was composed of women, who were diagnosed with multiple conditions including cardiac/vascular or circulatory diseases, cognitive impairment, and ailments affecting bones and joints.

**Comparing standard advance directive documentation over time.** *Intervention group:*Ninety-eight percent (62/63) of the residents living at the intervention site had a signed Plan of Treatment for CPR included in their chart at baseline. Ninety-two percent (58/63) did not include CPR in their plan of treatment. For all residents, this decision remained unchanged at the final evaluation or time of their death during the intervention period.

*Comparison group.* All residents had a documented Levels of Care document included in their baseline chart review. The majority (20/25) of residents indicated a supportive level of care (i.e., provide treatment at the LTC home). Sixteen percent (4/25) of residents indicated a palliative level of care (i.e. do not provide treatment to prolong life). Four percent (1/25) indicated an extensive level (full treatment) of care (i.e., provide treatments as necessary). During the intervention period 4% (1/25) of the sample changed their directive from a supportive level to a palliative one, and 4 documents were not able to be located.

**Comparing directions for care.** Thirty-eight percent (24/63) of residents in the *intervention site* had one documented PATH discussion summary. Table 3 provides a summation of the content of the PATH discussions, including persons in attendance, reviewed conditions, immediate decisions and a synopsis of discussion points. About 47% (10/19) of residents with a PATH summary had specific documented preferences for transfers to the hospital, whereas 100% of residents in the *comparison site* had this information included in their advance directive. Also, about 17% (4) of residents in the intervention site had specific documented preferences for treatment options, where as 100% residents in the *comparison site* had this included in their advance directive.

**Deceased Resident’s Location of Death and Congruence with Preference.** For residents who had died, the place of death and congruence with preferred location were determined. Of the total residents who consented to have their chart reviewed during the intervention period, 30.2% (19/63) died in the intervention homes, and 28% (7/25) in the comparison site. In the intervention sites, all but one resident (18/19) died in the LTC home, which was known to be the desired location for 88.8% (16/18) of this sample. One resident died in the hospital, which was known to be the preferred location for death. One hundred percent (7/7) of the residents at the comparison site died in the LTC home, which was their preferred location.

**Discussion**

This mixed-methods study adds important information about the outcomes of the PATH program and supports its use in LTC. Specifically, this study highlights the personal and practice outcomes identified by interdisciplinary staff members using the PATH program in the LTC home setting. The results demonstrate that the implementation and use of the PATH program not only have positive outcomes for building on care planning processes and documentation, but builds staff’s capacity and comfort with end-of-life care planning and discussion. Secondly, this study shows improvements in advance care planning discussion documentation in the intervention group; all of which support the use of the PATH program in LTC.

The findings of this study build on the previously described perceptions of staff around the need for the PATH program in the LTC home (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). Initially staff expressed that they needed a structure or process to help establish good relationships and rapport with residents and family members. They felt that this relationship would set the foundation for better communication around care planning and decision making with residents and family members (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). Findings in this study demonstrated that staff perceived that they were establishing these important relationships. In the context of dementia, literature has shown that family members would benefit from a consistent health care provider to give informational and emotional support for end-of-life decision making (Forbes, Bern-Klug, Gessert, 2000). The perceived outcome of establishing relationships through the PATH discussions is one way to address this important gap in care for the family.

Another important goal for staff was learning how to engage in discussions around explaining residents’ progressive health conditions and goals for future care (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014b). In this study, staff shared that an outcome of using the PATH approach was that their confidence and comfort was growing in having these discussions with residents and family members. Improving their capacity to have these discussions is an important finding, given that healthcare professionals have generally recognized their lack of competence around end-of-life care delivery (Canadian Healthcare Association, 2009).

A new outcome identified in this study is that staff were able to engage in PATH discussions both formally (i.e., formal PATH discussion) and informally (i.e., applying PATH principles to everyday communication). The informal PATH approach to communication may have important implications for implementing the program in this setting. Nurses have recognized that there is too little, or limited time to complete required tasks in LTC homes (Bowers, Lauring, & Jacobson, 2001). In fact, a limited or lack of time is a commonly perceived barrier in implementing changes in practice or interventions in the LTC home setting (Wickson-Griffiths et al., 2014). It has also been found that a lack of integration of best practice guidelines into existing policy, procedures and documentation creates barriers to implementation (Ploeg, Davies, Edwards, Gifford, & Miller, 2007). However, with staff being able to informally apply PATH principles or integrate them into already occurring communication with residents and families, this important change in practice may be better accepted, and therefore, successfully implemented.

In terms of the quantitative data, the chart reviews revealed that there were different mixes of the number and types of staff and family members involved in the formal PATH discussions. The inclusion of interdisciplinary health care providers is congruent with the approach taken in the PATH clinic, where different health care practitioners (i.e., geriatricians, a nurse practitioner, nurse, and consultative social worker) are responsible for: assessing residents, discussing results with the participants, developing a plan for care, and empowering participants to make decisions (Moorhouse & Mallery, 2012). An important implication for future research will be to determine any differences in communication styles or resident outcomes from various professionals facilitating the discussion.

In reviewing the reported impacts of implementing advance care planning programs in the LTC home setting, an increase in advance care planning discussion and documentation was found (Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014a). Similarly in this study, the implementation of PATH program meant that staff enhanced documentation by completing PATH summary notes, to help communicate the content and synopsis of the PATH discussions. They were able to document the resident conditions that were reviewed as well as places for care, and being contacted in emergency. The comparison site continued with their approach to care as usual with little changes in the levels of care advance directive documentation. It is noted that these directives would only be used in urgent care situations where residents and/or family members could not be contacted to discuss treatment options. The convenience of having documented discussion content and directives may help healthcare providers in knowing about residents’ and/or family members wishes when reengaging in care planning conversations later on when end-of-life is near. However, there is recognition that healthcare providers should help residents and family members prepare to make “the best possible in-the-moment medical decisions” through care planning discussions (Sudore & Fried, 2010, pg. 259). The implementation of PATH program contributed to both outcomes, where residents and family members could discuss advance treatment options, and also prepare to make future decisions.

**Study Limitations**

First, the sample of charts was much greater in the intervention site. Despite assistance from LTC home personnel to recruit potential participants, difficulty in obtaining a similar sample size remained in the comparison site. Perhaps there was less enthusiasm to participate in the chart reviews, given that the residents were not receiving the intervention. Second, it was difficult to assess resident outcomes from the chart review. The intervention and comparison sites used different approaches to documentation of advance care plans, namely levels of care advance directives in the comparison site, and CPR only in the intervention sites. Third, although it is encouraging that most residents’ preference for place of end-of-life care was known and honored at the time of their death, it is difficult to determine whether that outcome resulted from standard communication, or perhaps informal or formal PATH discussions as this was not consistently documented. Finally, the results of the study may not be transferable or generalizable to other LTC home due to their unique characteristics (e.g., advance care plan documentation method, size, management structure, funding model).

**Conclusion**

In summary, outcomes for staff and residents related to the implementation of the PATH program were examined in this study. Through qualitative interviews, staff revealed both personal and practice outcomes from receiving PATH program training and using it in their practice. In addition, through retrospective chart reviews, resident outcomes related to a change in documenting advance care planning discussions were also noted. These positive outcomes from both staff and residents suggest that PATH is a well suited for implementation and continued use in the LTC home setting.

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Table 1.

Main and Sub-Themes

|  |  |
| --- | --- |
| Main Themes | Sub-Themes |
| Practice Outcomes | Using the PATH Program in the LTC Home Setting  Having a Structure and Permission to Discuss Current and Future Care  Engaging in Proactive Care Planning  Making a Difference for Residents and Families |
| Personal Outcomes | Improving Work Satisfaction  Establishing Relationships  Growing Comfort and Confidence in Discussions |

Table 2.

Resident Characteristics

|  |  |  |
| --- | --- | --- |
| **Characteristics** | **Intervention Sites (n=63)**  **M(SD)** | **Comparison Site (n=25)**  **M(SD)** |
| Age in years | 86.0 (7.9) | 86.8(9.5) |
| Time Living in LTC in months | 33.5 (32.9) | 27.8(21.2) |
| Medications\* |  |  |
| Scheduled | 11.6(4.5) | 11.3(3.3) |
| As Needed/Medical  Directive | 2.9(1.6) | 3.9(2.1) |
| Mean Short Order (i.e.  antibiotics) | .2(.5) | 1.4(0.6) |
| **Characteristics** | **%(n)** | **%(n)** |
| Gender Female | 65.1(41) | 88(22) |
| Major Diagnosis |  |  |
| Cardiac/ vascular/  circulatory | 87.3(55) | 92(23) |
| Bone/joint | 69.8(44) | 80(20) |
| Cognitive impairment | 60.3(38) | 64(16) |
| Mental health | 55.5(35) | 36(9) |
| Sensory | 39.7(25) | 36(9) |
| History of fractures | 33.3(21) | 28(7) |
| Gastro/intestinal | 31.7(20) | 24(6) |
| Cancer or history of cancer | 27.0(17) | 32(8) |
| Respiratory | 23.8(15) | 20(5) |
| Endocrine | 36.5(23) | 40(10) |
| Renal/urinary | 19.0(12) | 28(7) |
| Other | 69.8(44) | 68(17) |

\*Baseline medications available for (n=54) residents in the intervention sites; and (n=23) in comparison site.

Table 3.

Characteristics, Content and Summary of Documented PATH Discussions (n=24)

|  |  |
| --- | --- |
| **Characteristics** | **%(n)** |
| Family members and health professionals in attendance |  |
| Nurse manager and 1 family member | 37.5(9) |
| Nurse manger and ≥2 family members | 8.3(2) |
| Nurse practitioner and 1 family member | 8.3(2) |
| Nurse practitioner and ≥2 family members | 4.2(1) |
| Nurse manager, nurse practitioner and ≥1  family member | 25.0(6) |
| Nurse manager, medical director and ≥1  family member | 4.2(1) |
| Nurse manager, nurse practitioners, nurse  manager and ≥1 family member | 12.5(3) |
| Health Conditions Reviewed |  |
| Admitting diagnosis | 20.8(5) |
| Dementia | 75.0(18) |
| Frailty | 75.0(18) |
| Other major diagnosis affecting quality of  life | 70.8(17) |
| Issues affecting quality of life (e.g.,  medications, alertness, activities of daily  living) | 29.2(7) |
| Immediate Decisions/ Actions |  |
| Discontinue unnecessary medications | 20.8(5) |
| Review medications | 25(6) |
| Discontinue unnecessary diagnostic tests | 8.3(2) |
| Summary of PATH Discussion |  |
| Goal of keeping resident comfortable | 66.7(16) |
| No CPR | 87.5(21) |
| Setting for care and future care specified  (e.g., do not send to hospital) | 41.7(10) |
| Setting for care and future care to be  discussed (e.g., notify family to discuss  options) | 33.3(8) |
| Treatment options specified (e.g., treat  treatable ailments, no antibiotics) | 16.7(4) |
| Treatment options to be discussed (e.g.  contact family to discuss treatment options  for episodic illness) | 79.2(19) |

**Chapter 5**

**Conclusions**

Using an embedded, mixed methods study design, the purpose of the overall study was to explore the implementation and perceived outcomes of the PATH program in the LTC home setting. This sandwich thesis consists of three manuscripts either prepared for or submitted to academic journals, which highlight the findings from this study. Two additional articles are appended to this thesis with the purpose of providing background information on both the content of advance care planning initiatives in the LTC home setting and methodological issues with one of the data collection methods used in this study, namely chart review. This final chapter will highlight the new contributions this study has made to the literature, as well as provide suggestions and implications to LTC home-based research, practice and policy. This chapter will also include overall strengths and limitations of the study and provide concluding thoughts.

It is important to note that this is the first study that examines the implementation of the PATH program in practice in the LTC home setting. Thus, all of the findings add valuable contributions to advancing our knowledge around how the PATH program impacts the LTC home setting, staff, family members and residents.

Findings from Chapter 2 were primarily drawn from the initial qualitative interviews with interdisciplinary clinical leaders (i.e., nursing, allied health and medical director professionals) who participated in the PATH program training and implemented it in their practice. The main findings were staff’s positive reaction to both learning about the program and program training, as well as implementation barriers that initially occurred.

Findings from Chapter 3 were drawn from qualitative interviews with family members (of residents) who participated in the PATH program with the staff members. These results are the first that describe the family members’ experience in this setting, as well as their perceived outcomes of (a) learning about their relative’s health conditions, (b) creating mutual understandings for the direction of their relative’s care, and (c) receiving support or reassurance in making medical decisions for their relative.

Findings from Chapter 4 were primarily focused on the perceived outcomes of PATH in the LTC home setting according to the interdisciplinary clinical leaders who used the PATH process and principles in their practice. This is the first study that highlights both the personal and practice outcomes for this group. In addition, resident outcomes related to documentation through retrospective chart reviews were also reported for this setting.

**Triangulation of Findings**

Throughout their qualitative interviews, staff perceived similar outcomes to those reported by family members. First, staff members perceived that family members seemed better informed and more knowledgeable about their relative’s health conditions and trajectories. This perception was confirmed by the major theme of “new learning” in the family member interviews. In addition, some family members commented on how well prepared the staff members were to discuss their relative’s health conditions. This is an important finding because residents are entering the LTC with multiple, chronic conditions- appropriate for a palliative care approach (Bacon, 2012). It is important that family members are knowledgeable about their relative’s health trajectory, as they will likely be making decisions on their behalf.

Second, staff felt that the PATH discussions provided family members with the opportunity to prepare for making decisions on their relative’s behalf. The staff also shared that family members seemed to be better prepared and more comfortable with making medical decisions. This staff perception was confirmed by the major theme of “support for decision making,” where family members shared how staff members provided them with support or reassurance for the decisions they were making during the PATH discussion. This is an important finding given that family members have been found to make end-of-life care decisions in the context of overwhelming burden and guilt (Givens, Lopez, Mazor, & Mitchell, 2012). The PATH discussion provides the opportunity for healthcare providers to help reconcile feelings of guilt for family members and provide ongoing reassurance to them for palliative and end-of-life care decisions.

Third, the staff also shared that family members seemed to appreciate the time spent discussing their relative during the PATH discussion. When speaking about their overall impression of the program, some family members provided examples of how they appreciated the time dedicated to the PATH discussion. Importantly staff also appreciated the time dedicated to the PATH discussions, as it helped them establish or reaffirm their relationship with the family members. These findings indicate that PATH contributes to relationship-based care, which is fundamental to providing quality care in LTC homes (Brown Wilson, 2009; Dupuis, McAiney, Fortune, Ploeg, & de Witt, 2014).

Fourth, the chart reviews revealed that the preference for place of care during end-of-life care were known and honoured for all but one resident in the intervention site. This is important finding given staff’s initial desire to avoid “bad deaths” for residents and family members. It has been recognized that residents prefer to stay in their LTC home until their death and that dying in a preferred location contributes to a ‘good death’ (Brazil et al., 2006; Wilson et al. 2009).

**Implications for LTC Home Practice**

An important implication for practice is that the PATH training can help nursing and allied health clinical leaders to either improve on, or learn new skills related to discussing a resident’s health status and likely trajectory, and preparing residents and family members to make health care decisions. Importantly, the acceptance of this program by LTC home administration and medical directors provided staff with the sense of “permission” to have these discussions with residents and families. Traditionally, advance care planning and end-of-life care discussions and decisions have been facilitated by the physician (Volandes et al., 2009). However, in the LTC home setting, where physicians are not always on-site, nursing and allied health professionals are more available (Resnick, Quinn, & Baxter, 2004). The PATH training and implementation meant that these professionals had the knowledge to engage in these conversations. This implication is well supported in the literature where nurses and social workers engage in care planning and health care decision making (Bomba, Morrissey, & Leven, 2011; Morrison et al., 2008, Molloy et al., 2000).

Another important implication for practice is that PATH training and continual use of the principles in practice gave staff the confidence to have difficult conversations with family members and residents. Studies have shown that nurses and social workers have deficient training in palliative care (Bomba et al., 2011; Whitaker et al., 2006). This means that practitioners are entering the workforce with very little preparation in this area, which is especially problematic in a setting where most residents have co-morbid, life-limiting illnesses, including dementia (Alzheimer Society, 2010; Canadian Institute of Health Information, 2011). While practitioners have access to information on courses to improve their palliative and end-of-life care knowledge through organizations such as the Virtual Hospice (2014) and the D’Souza Institute (2014), this education is not required. When the LTC homes in this study decided to implement the PATH program, they received intensive two-day training on the palliative and therapeutic approach to care planning for frail older adults, which resulted in better communication with residents and their family members.

The implementation of the PATH program also resulted in more of a cohesive approach to communicating care planning discussions through the PATH summary. Prior to the PATH program, decisions for CPR were noted in residents’ charts. However, more detailed conversations around family/residents understanding of condition or treatment preferences were not well documented, as they would be in the practitioner’s notes or in the electronic progress notes, which spanned the length of the residents’ stay. Therefore, proper planning helped in communication to other staff, and provided a central location for this information.

**Implications for Residents and Family Members**

The study findings show that with their relative, family members entered the LTC home setting with varying levels of decision-making comfort and experience, as well as knowledge about their loved one’s health conditions. These findings have a few important implications related to engaging in PATH in LTC home setting.

The general public (including residents and family members) may have access to sources of information around chronic disease processes and management, which are available through internet websites and/or local societies (Alzheimer Society of Canada, 2014; The Kidney Foundation of Canada, 2014; Heart & Stroke Foundation, 2014). In addition, advance care planning websites can provide the public with guidelines on how individuals and families can engage in this process e.g., Ontario Senior’s Secretariat, 2013). Together these resources may help inform the public about chronic diseases and help prepare them to make informed health care decisions. However, misconceptions around disease trajectories (e.g., unknown trajectory for dementia) or outcomes of treatment (e.g. overestimation of CPR survival) may influence how individuals and their family members discuss and plan for future care (Forbes, Bern-Klug, & Gessert, 2000; Jones, Brewer, & Garrison, 2000). The implementation of the PATH process has the important implications for residents and family members because it provides them with opportunity for dialogue with a healthcare provider. In the first case, the healthcare provider may be able to offer more resident-centred information, which could complement residents’ and family members’ previous understandings. In the second case, PATH discussions can provide the opportunity to help residents (and family members) correct misconceptions, while providing accurate, resident-specific information.

**Implications for Policy**

In recent years, national attention has focused on helping individuals and their family members become more knowledgeable about and engage in advance care planning and discussing end-of-life care. A national framework for advance care planning was released in 2012, which outlines a multi-sector strategy for engaging in advance care planning (Canadian Hospice Palliative Care Association, 2012). The national Speak Up campaign, seeks to educate Canadians about advance care planning, and provides instructional materials and work books to encourage individuals and their family members to engage in this process (Canadian Hospice Palliative Care Association, 2014). The purpose of the PATH program is well situated in the Canadian context of helping individuals and their family members prepare for end-of-life care and make palliative and therapeutic health care decisions. This finding has important implications for policy makers who may be in a position of recommending the PATH program as a strategic approach for residents and family members to engage in end-of-life care planning.

Specific to the LTC home setting, the Long-Term Care Homes Act, mandates that individuals have access to end-of-life care when needed (OMOHLTC, 2010). The findings presented in Chapters 3 and 4 help advance knowledge about the perceived benefits that PATH has to offer in preparing for end-of-life care. While PATH does not actually facilitate physical end-of-life care, it is an appropriate tool in helping to plan for it; by aiding residents (where able) and family members to proactively make or prepare to make informed decisions. It also provides education and a structure for staff to follow, which helps to facilitate planning for end-of-life care in this setting. An important implication for policy makers to consider is adding instruction or wording around “preparing” for end-of-life care, which could help LTC home staff be more proactive in this care process.

**Implications for Future Research**

As this was the first time that the PATH program was implemented in the LTC home setting, important findings relevant to this setting were discovered, mainly from staff and family member perspectives. However, reflection on the program training, as well as how the program was used in this setting, highlights the need for new research questions.

First, in Chapter 4, it was found that staff were condensing or streamlining the first part of the PATH process, the comprehensive geriatric assessment, in resident cases where they could identify the issues or conditions that were most affecting their quality of life. Streamlining of the first step of the PATH process is consistent with the approach taken in the community for older adults in palliative/end-of-life care or urgent care situations (Moorhouse & Mallery, 2012). Research that focuses on evaluating a protocol or decision tree on whether to proceed with a full comprehensive geriatric assessment or a streamlined process may be of benefit to staff engaging in this exercise in this setting. In addition, it would also be advantageous to learn if there are any differences in the experiences of PATH participants who participated in each of these approaches (full comprehensive geriatric assessment vs. streamlined approach).

Second, in Chapter 4, staff shared how they used their PATH training to engage in what they described as formal (i.e., engaging in a PATH discussion with family members) and informal (i.e., where PATH program principles were applied more casually to everyday conversations with residents and family members). Perhaps difficult to measure, it would be interesting to learn/explore if there are different resident or family member outcomes to using these two approaches. The following research question would be worthy of investigation: How does a change in communication style (i.e., informal PATH approach) affect satisfaction with care from resident and family member perspectives? A strategy for learning about satisfaction could be achieved through adding questions about communication style to LTC homes’ pre-existing satisfaction with care or feedback surveys that can be completed by residents and family members.

In Chapter 2, a main finding was that the PATH program provided the staff members with two full days of training to learn about the PATH process as well as key concepts about dementia, frailty and the effect of co-morbidities have on health and illness trajectories. Through qualitative interviews staff shared that through the training they learned a process and language for communicating with residents and families, best practices for medication, and reflected on providing palliative and end-of-life care in the LTC home setting. To help better understand the outcomes of the PATH training, using a quantitative controlled before/after approach to test knowledge would be appropriate to discover any further outcomes of the PATH training. Other quantitative scales could be used to measures staff attitudes and comfort with the palliative and therapeutic approaches to care for frail older adults and their families.

Also, as noted in Chapter 2, a limited number of clinical leaders were trained and regularly used the PATH principles or had PATH discussions with families in their practice. A noted barrier identified by staff members was the need to educate more staff at the LTC home sites about the PATH process. Further research is needed to learn about the outcomes or the experiences other allied health disciplines (e.g., dietary, recreation, occupational therapy) and frontline staff (i.e., licensed nurses and unlicensed support workers) should they receive training and implement it in their practice. Additional research could also focus on processes for providing successful follow-up education and training to other healthcare providers in this setting. Further research could also focus on how staff, family member and resident experiences and outcomes may change should the PATH program implementation be led by mixes of staff different from this study.

In addition to the perceived outcomes that family members expressed during their qualitative interviews, which were reported in Chapter 3, future research may also include quantitative measures for satisfaction with the program, such as the survey used in the community setting (Moorhouse & Mallery, 2012). Ensuring anonymity may help family members to better express their satisfaction (or dissatisfaction) with the program. Family members may also participate in quantitative pre-post PATH discussion questionnaire around knowledge and attitudes toward the palliative care approach, dementia progression and frailty.

From the perspective of the resident, thus far, only retrospective chart reviews were completed to learn about the differences in staff’s documentation around advance care planning and decision making. All of the qualitative interviews that were conducted during the study did not include the resident. However, some residents in this setting are capable of participating in a PATH discussion. Therefore, learning about their experiences and outcomes would be beneficial, as the program was designed specifically to aid older adults (and their family members) with planning and medical-decision making.

**Limitations of PATH Implementation and Related Implications**

There are a few noted limitations in the PATH program implementation. These limitations relate to cost of the program, organizational readiness, staff mix, implementing the program into an existing care structure, and presence of a research project. These limitations may limit the transferability of findings to, or ability to implement and sustain the PATH program in other LTC homes.

First it should be noted that PATH is a licensed program, and therefore should only be implemented after permission by the program developers is granted. There was a significant cost associated with the PATH program training and a subsequent five year license to use the PATH approach in the intervention sites. However, the majority of these costs were absorbed by the PATH program developers due to the inclusion of the research study. Nevertheless, cost may be an issue for other LTC homes (or other healthcare settings) to factor in, prior to considering using this program in their setting. Also, after the five year permission to use the program expires, sustainability of the program will also have to be considered for the intervention sites. In recognizing the benefits of the PATH program, an important implication for policy makers is to strategize for how the cost of the program could be covered.

Second, as noted in Chapter 2, the intervention sites had recently completed the Plan of Treatment for CPR program training and implementation. Collectively, staff had reflected on their process of care after this program’s implementation, and felt that conversations with residents and families around health status and trajectory needed improvement. There was a good deal of enthusiasm from clinical leaders following the change in practice from the implementation of the CPR program initiative. From an organizational standpoint, the LTC homes in this study were well situated to build on their existing program. An important implication for practice is the consideration that not all LTC homes may have this degree of enthusiasm or readiness for change.

Third, the LTC homes also benefited from having the nurse practitioner who championed the PATH program implementation. Nurse practitioners are registered nurses with additional education preparation and experience, which allows them to function both independently and collaboratively in their health care setting (Canadian Nurses Association, 2009). In implementing the PATH program, the nurse practitioner played key roles in: taking the lead to organize the implementation and follow-up staff meetings; supporting other clinical leaders in their use of the program; and conducting PATH assessments and discussions with family members. Currently, a small percentage (6.1%) of Canadian nurse practitioners work in LTC home setting (Canadian Nurses Association, 2013). While it is encouraging that the OMOHLTC is investing in 75 new nurse practitioner positions in LTC homes (Ontario Newsroom, 2014), not all settings will have access to this role to either champion or participate in this program. An important implication for policy makers is the support of increased numbers of on-site nurse practitioners in LTC home settings.

Fourth, in Ontario, LTC homes are regulated by the Long-Term Care Homes Act (Service Ontario, 2010). This Act outlines mandatory programs that must be developed and provided in this setting to help promote residents’ quality of life and care (Service Ontario, 2010). It is noted that PATH, or other palliative or end-of-life care programs are not mandated by the Long-Term Care Homes Act, and therefore, may not be as highly prioritized by clinical leaders. Thus, another limitation is that to incorporate the PATH program, clinical leaders and administrators will have to justify and add in another program in an already highly regulated setting. An important implication for practice could be the consideration of how the PATH program or processes could be incorporated into existing mandated programs (e.g. pain management, skin and wound care) or admission process (Service Ontario, 2010).

Last, staff expressed that the speed of implementation and continued use of the PATH program was in part facilitated and encouraged by the presence of a researcher who was eager to collect data. Therefore, the transferability of findings to other setting may be questionable without the presence of a research team to help encourage its use in an already busy environment.

**Study Strengths & Limitations**

There are a number of strengths of this study, including efforts to help establish rigor or trustworthiness of the qualitative data. That is, several measures were taken throughout the study and guided by the work of Milne and Oberle (2005). In their work, they used a number of strategies to the guide their analysis, which were organized according to four criteria for addressing rigor including credibility and authenticity, and criticality and integrity (Whittemore, Chase, & Mandle, 2001). The following provides examples of how these criteria were addressed.

To establish credibility and authenticity, measures were taken to ensure that participant’s voices were heard, and that the data was participant-driven and accurately represented (Milne & Oberle, 2005). To ensure participant’s voices were heard, the primary author took the opportunity to develop a rapport with the interview participants. Developing rapport is described as an essential component of the qualitative interview; where trust and respect for the interviewee and the stories they share is established (DiCicco & Crabtree, 2006). As a participant at the PATH program training, presence at the sites while collecting other study data, as well as being invited to attend regular PATH team planning meetings, the primary author was known to the staff members. These activities helped to establish a rapport with staff members. For family member participants, some were already familiar with the primary author through previous conversations about collecting chart review data for their relative. However, during interviews with family members, the primary author took the opportunity to ask ‘ice breaker’ questions related to the research purpose around how they were involved with their relative’s life, and how their relative came to live in the LTC home (DiCicco & Crabtree, 2006). In addition, clarifying questions were asked throughout the interviews to encourage participants to share their experiences. To ensure that the data was participant driven, semi-structured interview guides were used to encourage participants to share their experiences and be allowed to place emphasis on answering questions they found to be important. Finally, to ensure accurate representation of the interview data, the primary author transcribed the interviews.

To establish criticality and integrity, methods were employed to reflect on researcher bias, member-check findings, and seek peer review (Milne & Oberle, 2005). First, throughout the study, the primary author’s position on the importance of a proactive, palliative approach to planning care for residents with life-limiting illnesses was recognized and maintained. During the data collection and interpretation of the findings, this bias could have potentially influenced these processes. Second, staff participants engaged in member checking activities at three points (i.e. for baseline, interim and final interviews), to help ensure the integrity of the data. Finally, throughout the study members of the research team contributed to the rigor of the interpretation of the findings by reviewing transcripts, preliminary coding, and emerging themes.

There are a few noted study limitations, which may limit the transferability or generalizability of findings to other LTC homes. First, the three intervention homes in this study were aware of their need to improve communication with residents and families around health status and care planning. This awareness may not be typical of other LTC homes. Second, a consistent inclusion criterion was that participants be able to speak and understand English. Following that, there was no consideration of participants’ ethnic or cultural identity, which may have helped to describe that sample. Third, some perspectives of persons in the LTC homes’ community were missing, namely residents, and staff and administrators not directly involved in the PATH program training or implementation. Fourth, the LTC homes’ characteristics (range in bed size, management structure and staff mix) may not be representative of other LTC homes.

**Concluding Thoughts and Lasting Impression**

Engaging in advance care planning while an individual has the cognitive ability to do so is an important step in helping to achieve end-of-life care that is fitting with their preferences. However, for the majority of residents entering or residing in LTC homes, the window of opportunity to communicate their preferences for future treatment may have passed, due to progressive cognitive and physical decline. For many residents, they rely on family members to communicate their previously expressed preferences and/or make health care decisions on their behalf. A family member participant shared the following, which recognizes the importance of knowing their relative’s wishes for future care but also considers their relative’s current health condition and trajectory:

But things that you’ve said when you are seventy don’t necessarily feel the same when you are eighty. And sometimes, like in this case, a stroke took place and things have really changed. So, what you wanted when you were seventy and what path you had laid out, it can change, right? But if you haven’t a good means of communication and you don’t have a benchmark as to what was, ‘what [were] their wishes here?’ I mean you have to be aware that things change but at least you have some knowledge of what they would want, or how to do it best.

This quote may highlight the current circumstance facing many residents and family members entering or residing in LTC homes. When the PATH process is applied in the LTC setting, it can help the residents and family members to understand or better understand their current health conditions as well as palliative and therapeutics options for care. Ultimately, PATH provides these frail older adults and family members with the opportunity to make or prepare to make informed medical decisions in the context of their illness, and shape how their palliative and end-of-life care will be delivered.

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**Appendix A**

**A Review of Advance Care Planning Programs in Long-Term Care Homes: Are they Dementia Friendly?**

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**ABSTRACT**

**Background:** Persons living with dementia in the long-term care home (LTCH) setting have a number of unique needs, including those related to planning for their futures. It is therefore important to understand the advance care planning (ACP) programs that have been developed and their impact in order for LTCH settings to select a program that best suits residents’ needs.

**Methods:** Four electronic databases were searched from 1990 to 2013, for studies that evaluated the impact of advance care planning programs implemented in the LTCH setting. Studies were critically reviewed according to rigour, impact, and the consideration of the values of residents with dementia and their family members according to the Dementia Policy Lens Toolkit.

**Results & Conclusion:** Six ACP programs were included in the review, five of which could be considered more “dementia friendly.” The programs indicated a variety of positive impacts in the planning and provision of end-of-life care for residents and their family members, most notably, increased ACP discussion and documentation. In moving forward, it will be important to evaluate the incorporation of residents with dementia’s values when designing or implementing ACP interventions in the LTCH settings.

**1. Introduction**

Advanced care planning (ACP) is especially relevant for persons with dementia living in LTCHs. Over time, these persons will experience progressive cognitive decline, poor health outcomes, and ultimately lose their ability to communicate treatment preferences or wishes [1, 2]. Given the high prevalence of persons with dementia that reside in LTCHs in the United Kingdom and North America, discussing their wishes and treatment preferences is appropriate [1, 3]. Several programs that promote ACP in LTCHs have been described and evaluated in the literature. However, little work has been done to assess whether these programs include the consideration of values important to persons with dementia and their family members. Due to the nature of the disease and the unique needs of persons with dementia and their family members, it is important to understand which ACP programs are best suited for this population. Therefore, the purpose of this paper is twofold; first to determine the impact of the ACP programs implemented in LTCHs and second, to evaluate the programs’ inclusion of considering the important values of persons with dementia according to the Dementia Policy Lens Toolkit (DPLT) [4].

ACP is a process that facilitates the communication and understanding of care preferences between a person deemed to have decision-making capacity and their primary health care provider, family member(s) or substitute decision maker [5, 6]. Cantor and Pearlman [7] assert that ACP involves three components, including the consideration of health care options and expression of the person’s values, communicating their wishes, and subsequent documentation. The documentation is known as creating advance directives (ADs) or a living will. Although ACP is defined as only the communication of wishes [5, 8], ADs are commonly documented as they may be used to decisively direct care in an emergency, and typically carry more legal weight than discussion alone [9]. Importantly, whether ACP is documented or not in the long-term care home (LTCH) setting, discussions should be comprehensive. Residents, family members (or substitute decision maker) and health care providers may discuss the resident’s thoughts on reversible conditions, the intensity of desired treatments (feeding, hydration and medication), place of care, and naming of the power of attorney for health care [10, 11]. Overall, it is intended that ACP will result in future care that is provided in accordance with resident’s preferences should they lose their decision-making capacity.

Engagement in ACP is important in LTCHs for reasons such as, compliance with policy or legislation, the increasing prevalence of dying residents, and residents’ desire to communicate their wishes. It is important to note that there has been greater legislative attention given to ACP [9]. In addition, some of the oldest and frailest people reside in LTCHs [12]. Consequently, about 20% of older adults die in LTCHs in the United Kingdom and Australia, and up to 29% of older Canadians die in this setting [13-15]. Also, given LTCHs residents’ complex medical issues and disabilities, they may be less able to communicate their health care preferences [12, 16]. Thus, as summarized by Dobalian [17], residents may engage in ACP for many reasons including the acknowledgement of potential incapacity that may limit or eliminate their ability to express decisions, and the desire for future health care treatments to be congruent with their wishes. The combination of these factors makes ACP for end-of-life care critical in this setting.

Persons with dementia are particularly suitable candidates for ACP given the nature of their disease. Dementia has been described as a terminal illness, caused by neurodegeneration, and characterized by progressive cognitive impairment [18, 19]. As the disease progresses to the terminal stage, the ability to meaningfully communicate, ambulate or manipulate objects is severely impaired [20]. Although variation exists, the mean survival time of residents diagnosed with dementia is about seven to ten years [1]. Therefore, ACP is important, as it is expected that persons with dementia will lose their decision-making capacity and be unable to direct their care as their end-of-life approaches.

Despite the poor prognosis of persons with dementia coupled with their growing numbers in LTCHs, their health care preferences are not always known [12, 21, 22], which can lead to inappropriate palliative care and difficult decision-making for family members. Mitchell et al.’s [22] study found that persons with dementia were less likely than those with cancer to have AD to communicate care preferences, as dementia is not always recognized as a terminal disease. Study findings have also indicated that health care providers must default to full treatment when care limiting options are unknown, and persons with dementia have received burdensome interventions, such as, hospitalizations, restraint use, intravenous therapy, tube feedings, antibiotics or life-sustaining medications [22-24]. Another consequence of no or little ACP engagement is family members having to make uninformed decisions for residents [25]. Although a lack of congruence has been found between patients’ and their proxies’ decisions [26], family members may be able to make more informed choices if they have engaged in ACP [27]. Therefore, given the limited survival time, eventual incapacity to make health care decisions, and noted potential for poor palliative care services and interventions, it is important to address ACP in the LTCH setting for persons with dementia.

Recognizing the importance of ACP within the LTCH setting, especially for persons with dementia, it is essential to review what programs have been used in LTCHs to promote ACP. Also, given the prevalence of persons with dementia in LTCHs, it is equally important to evaluate how these programs include the consideration of values important to persons with dementia and their families. Systematic reviews have evaluated the effectiveness of interventions designed to increase AD completion rates for adults [28]; and specifically, community-dwelling older adults [29]. Robinson et al. [30] have completed a systematic review of the effectiveness of ACP interventions for people with cognitive impairment and dementia. Also, Harrison Dening et al. [31] conducted a general review of ACP for persons with dementia to determine the key themes in the literature as well as facilitators and inhibitors for affected persons. However, an extensive literature search failed to identify a review that evaluated ACP programs in LTCHs using the DPLT to ascertain whether the values of persons with dementia were considered. Therefore, to expand on existing reviews, this paper will contribute an up-to-date review of evaluation studies that a) focus on programs that promote ACP in the LTCH setting, b) employ a quantitative, comparison-group study design, and c) have an adequate description that can be critiqued using the DPLT [4]. The specific research questions addressed in this paper are what are the impacts of programs used to promote ACP in LTCHs and, do the programs include a consideration of the values that are important to persons with dementia and their family members?

This paper includes the following definitions for common terms. First, a *program* is defined as the processes that promote ACP through strategies, programs or interventions, implemented in LTCHs. Second, an *impact* is defined as the reported findings from an ACP program’s implementation. Third, *LTCHs* are residences for older adults requiring accessible 24-hour nursing care [32]. References to nursing homes, aged-care facilities, and care homes are considered to be LTCHs. For the purposes of this paper, although a LTCH provides care for adults older than 18 years, the focus is older adults aged over 65 years. Last, *family members* are also described as substitute decision makers, where appropriate.

**2. Methods**

**2.1 Search Strategy**

In consultation with a library liaison from McMaster University’s Health Sciences Library, electronic databases and key search terms for LTCHs, ACP programs and interventions were identified. Medline, Excerpta Medica Database (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Ageline were searched for literature published between 1990 and May, 2013. The publications’ titles and available abstracts were reviewed by one reviewer (Abigail Wickson-Griffiths) for relevant literature. Also, websites for the Physicians Orders for Life-Sustaining Treatment Paradigm (POLST), Gold Standards Framework in Care Homes, and Promoting Excellence in Palliative Care in Nursing Homes were accessed for further details of these programs. Subsequently, project or evaluation lists contained within the websites were reviewed to identify any further publications not yielded in the initial search.

**2.2 Study Inclusion Criteria**

The following four inclusion criteria were prerequisites for study review. First, studies had to evaluate a program focused on ACP and/or its components such as ADs or sharing goals of care. More broadly focused end-of-life or palliative care programs were included, given that a main outcome or objective was promoting ACP. Second, the program had to be evaluated within the LTCH setting. Third, an adequate description of the ACP program had to be available within the publication or obtainable through other means such as the authors’ related work or websites. Fourth, studies had to include a quantitative design with a comparison or control group. Studies that used an uncontrolled, before-after design were excluded.

**2.3 Critical Appraisal Tool Description and Rationale**

In order to evaluate the quality of the studies, criteria from an evidence-based nursing textbook that detailed methods to evaluate health care interventions was used [38]. Overall, the method was selected because of the high regard for the contributions made to evidence-based nursing by the editors [39]. In addition, a number of evaluation guides were offered in the textbook; however, the criteria for health care interventions were most congruent with ACP programs in LTCHs. Descriptions and rationales were provided for each evaluation criteria that facilitated and guided the critique of the studies.

**2.4 DPLT Description and Rationale**

There are 11 criteria in MacCourt’s [4] DPLT that are designed to collectively aid in the evaluation of policies, guidelines and/or programs that affect people with dementia and their family members. However, for the purpose of this paper, only the sixth criterion was used to evaluate ACP programs: “Does the policy, guideline, program consider values important to those affected by dementia?” (p. 4). According to MacCourt [4], the sixth criterion considers that “respect for the person with dementia, their needs, their values, and their choices” (p. 8) is important. MacCourt [4] suggests that an evaluator should score each category with a yes or no rating and review the overall results to determine the suitability of the program. This tool was specifically selected because it was comprehensively developed from the efforts of multiple stakeholders including researchers, clinicians, and persons with dementia and their caregivers [4]. In addition, it addresses key aspects of dementia-friendly care such as accessibility, and person-centred and relationship-based care [4].

**3. Results**

**3.1 Results of Literature Search**

The search returned 6145 sources. Upon completion of the title and abstract review, a total of 16 ACP programs were identified in a total of 26 articles. As indicated by DiCenso and Guyatt [38], randomized control trials (RCTs) are appropriate to evaluate intervention studies. However, only two RCTs were identified [33, 35]. Given the dearth of highly-rigorous studies in this body of literature, studies were also included that indicated the use of quantitative design with at least one comparison or control group. Subsequently, four additional studies met this inclusion criterion [5, 34, 36, 37]. For the remaining, 18studies did not meet the criteria [40-57], one involved a co-intervention [58], and one did not provide adequate detail of the ACP component of the program [59]. Therefore, six ACP programs were evaluated to identify their impacts.

The methods and context of these reviewed studies are summarized in Table 1 and 2.

**Table 1. Characteristics of the Evaluated Studies**

|  |  |  |  |
| --- | --- | --- | --- |
| Study Characteristic | Casarett et al. [33] | Chan & Pang [5] | Morrison et al. [34] |
| Study design | Randomized controlled trial | Quasi- experimental | Controlled- before and after study |
| Setting | United States  Three LTCHs | Hong Kong  Four LTCHs | United States  One LTCH |
| Sample size  Program participants  Control participants | (n=107)  (n= 98) | (n=42)  (n=36) | (n=43)  (n=96) |
| Cognitive impairment mentioned | Yes | Yes (\*Resident with cognitive impairment not included) | Yes |
|  |  |  |  |
| Program description | Identify care preferences using PRIDE assessment, and communicate to physician for referral to palliative/hospice care | Let Me Talk  (Interviews with residents exploring values and care preferences) | ACP training for two social workers using Education for Physicians on End-of-Life Care; structured discussion and documentation of ACP |
| Control/ comparison  Research staff involvement in intervention or comparison | Did not communicate PRIDE assessment to physician  Apparent | Care as usual  Apparent | Care as usual from social workers; research associate talked to participants about health care preferences but did not record them in the medical record  Apparent |

Legend: PRIDE= Promoting Residents’ Involvement in Decisions at End-of-Life; LTCH= long-term care home; LTCHs= long-term care homes; ACP= advance care planning

**Table 2. Characteristics of the Evaluated Studies**

|  |  |  |  |
| --- | --- | --- | --- |
| Study Characteristic | Molloy et al. [35] | Hanson et al. [36] | Strumpf et al. [37] |
| Study design | Randomized controlled trial | Controlled- before and after study | Prospective study with control group |
| Setting | Canada  Six LTCHs (three intervention) | United States  Nine LTCHs (seven intervention) | United States  Six LTCHs |
| Sample  Strategy participants  Control participants | (n= 527)  (n=606) | (n= 345)  (n= 112) | (n= 4 LTCHs)  (n=2 LTCHs) |
| Cognitive impairment recognized | Yes | Yes | Yes |
| Program description | Training provided to health care facilitators to implement Let Me Decide (AD) program in three LTCHs | The Improving Nursing Home Care of the Dying  (Develop palliative care teams, education for staff around palliative care) | Promoting Excellence in End-of-Life (Develop palliative care teams in two LTCHs; educational training and support provided to LTCH staff and program implemented) |
| Control/ comparison  Research staff involvement in intervention or comparison groups | Care as usual  Not apparent | Care as usual  Not apparent | Care as usual; new pain and advanced care policies introduced from corporation during the study period  Not apparent |

Legend: ACP= advance care planning; LTCH= long-term care home; LTCHs= long-term care homes; ADs: advance directives

**3.2 Impacts**

The following presents a synthesis of the reported impact(s) for each of the reviewed programs. It is important to note that any references to statistically significant or significant impacts were determined by a reported p value of ≤.05 in the respective studies. See Table 3 for a summary of the reported impacts.

**Table 3**

**Summary of the Reported Impacts of the ACP Strategies**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Impacts | Casarett et al. [33] | Chan & Pang [5] | Hanson et al. [34] | Molloy et al. [35] | Morrison et al. [34] | Strumpf et al. [37] |
| Increased ACP activities discussion | X | X | X | X | X | X\* |
| Increased ACP discussion documentation |  |  | X\* | X |  |  |
| Specific ACP documentation (e.g., hydration, antibiotics, etc) |  |  |  | X | X\* |  |
| Adherence to resident/substitute decision maker wishes | X\* |  |  |  | X\* |  |
| Greater knowledge of ACP among residents |  |  |  |  |  |  |
| Greater knowledge of ACP among family members |  | X\* |  |  |  |  |
| Greater knowledge of resident’s ACP among LTCH staff |  | X\* |  |  |  |  |
| Reduced hospitalization | X\* |  |  | X\* |  |  |
| Increased satisfaction with care | X\* |  |  |  |  |  |
| Stability of treatment preferences |  | X\* |  |  |  |  |
| Improved quality of resident life |  | X\* |  |  |  |  |
| Reduced resource use |  |  |  | X\* |  |  |

Legend: X = impact noted; X\* = statistically significant impact (p≤0.05); LTCH= long-term care home; ACP= advance care planning

**3.2.1** **Let Me Decide*.*** Let Me Decide is a specific ACP program that enables residents or their substitute decision maker to first, understand their treatment options in life-threatening, reversible and irreversible health conditions, and second, record their wishes in AD for resuscitation, feeding and level of care [10,60]. Molloy et al. [35] conducted a randomized control trial (RCT) to evaluate the systematic implementation of the Let Me Decide program in three LTCHs. The study reported significantly fewer hospitalizations as well as a less average cost per resident in the program LTCH sites when compared to the controls [35]. At the completion of the study, residents in LTCH sites implementing the program had completed more ADs (71%) than the controls (57%). Of the residents who completed ADs, 89% were the Let Me Decide directive in the LTCH sites employing the program, and 71% were the do-not-resuscitate directive in the control sites [35]. It was inferred that the Let Me Decide directive would be more comprehensive, and thus, better able to communicate specific resident wishes than a do-not-resuscitate directive. Overall, increased ACP documentation, fewer hospitalizations, and less resource were the main impacts.

**3.2.2 Let Me Talk*.*** Let Me Talk is a four-step ACP program that seeks to explore residents’ prior life experiences and values before expressing their health care preferences [5]. The focus of the program shifted from the more traditional approach of developing AD, to the exploration and sharing of residents’ values in the planning process. Four sequential individual interviews with residents were conducted exploring their life stories, illness narratives, life views and finally, end-of-life care preferences [5]. Chan and Pang’s [5], multisite, quasi-experimental study showed that over time, residents in the Let Me Talk program had significantly more stable health care preferences than those in the comparison group [5]. Better quality of life scores were found for residents that engaged in the program [5]. The participants in the Let Me Talk group were significantly more likely to share their health care preferences with family or caregivers than those in the comparison group [5]. Overall, the impact of this program was increased knowledge of residents’ ACP for staff and families, improved quality of resident life, and stability of health care choices.

**3.2.3 Social Work Strategy to Enhance ACP Documentation.**The program that was used to enhance ACP discussion and documentation in Morrison et al.’s [34] study was based on the educational material provided in module one of the Education for Physicians on End-of-Life Care (EPEC) course [61], (S. Morrison, personal communication, May 11, 2011). A controlled clinical trial was used to evaluate resident outcomes after two social workers received the EPEC training and engaged in structured methods of promoting and documenting ACP. Residents and/or their substitute decision maker were invited to share their health care preferences for life sustaining treatments and place of care in the residents’ current state of health and two hypothetical cases of moderate and severe dementia. Morrison et al. [34] found that residents in the program group were more likely to have specific instructions documented for resuscitation, intravenous antibiotics, artificial nutrition, and hospitalization than residents in the comparison group. In addition, the residents cared for by social workers in the program group were significantly more likely to receive care in adherence with their wishes than those in the comparison group [34]. In all, the reported impacts were increased documentation of specific ACP and adherence to residents’ and family members’ preferences.

**3.2.4 Improving Hospice Service.** In an effort to improve enrolment in hospice services, Casarett et al.’s [33] RCT study evaluated the communication of residents' goals of care and suitability for palliative care to physicians. The Promoting Residents’ Involvement in Decisions at End-of-Life (PRIDE) assessment tool was used to discover residents’ goals of care (for comfort care and life sustaining treatment) and suitability for palliative care (having palliative care needs) (D. Casarett, personal communication, May 11, 2011). It was reported that the residents who had their preferences and palliative care needs communicated to the physician were significantly more likely to enrol in hospice services compared to the control group, both within 30 days of the PRIDE assessment (20% vs. 1%) and during the six month follow-up period (25% vs. 6%) [36]. Also, when compared to the control group, residents who participated in the program had significantly fewer acute care admissions and days in hospital [33]. Overall, impacts of this program included appropriate palliation or end-of-life care services in accordance with ACP and healthcare preferences.

**3.2.5 Palliative Care Quality Improvement Programs.** Two studies employing LTCH-wide programs to improve the quality of palliative care were identified including, Improving Nursing Home Care of the Dying [36] and Promoting Excellence in End-of-Life Care [37]. Both of these studies focused on reporting on the training of the LTCH staff and overall impacts of the program post-implementation.

The Improving Nursing Home Care of the Dying is a multifaceted education program, which focuses on recognizing end-of-life, pain management, emotional and spiritual care, caregiver considerations and ACP [62]. Promoting Excellence in End-of-Life also provides education on relevant palliative topics including ACP, pain, and psychosocial issues, such as bereavement and spirituality [37]. Documentation of ACP discussion increased from 4% to 17% for residents receiving the program in Hanson et al.’s study [36]. Similarly, Strumpf et al. [37] reported that residents participating in the program had significantly more advanced care plans near time of death when compared to the controls. Overall, the impacts of these palliative care quality improvement strategies were increased ACP discussion documentation.

**3.3 Evaluating ACP Programs Using the Dementia Policy Lens Toolkit**

The following section provides the results of evaluating the ACP programs using the sixth criterion of the DPLT [4]. This criterion contains six main categories (with the number of subcategories indicated in the parentheses) and include: (a) respect and dignity (three), (b) self determination and independence (four), (c) social inclusiveness/ relationships/ participation (five), (d) fairness and equity (two), (e) security (six), and (f) protection and risk management (seven). Each category was scored with a yes or no rating, as per the guidance provided by MacCourt [4].In cases where a subcategory was judged to not apply to ACP programs in general, it was not included in the evaluation. The narrative section below describes where certain subcategories have been included or omitted. Please refer to the full DPLT [4] for reference.

Of note, because the Let Me Talk program evaluation did not include residents with cognitive impairment, it was not included in this component of the evaluation. The evaluation is summarized in Table 4.

**Table 4.**

**Evaluation of Advance Care Planning Programs Using the Sixth Criterion of the Dementia Policy Lens Toolkit**

| Criteria | Casarett et al.  [33] | Hanson et al.  [36]\* | Molloy et al.  [35] | Morrison et al.  [34] | Strumpf et al.  [37]\* |
| --- | --- | --- | --- | --- | --- |
| **Respect and Dignity** |  |  |  |  |  |
| Is the policy/program flexible enough to respond to the uniqueness of each individual? | Y | Y | Y | Y | Y |
| Are people with dementia and their families portrayed positively? | Y | Y | Y | Y | Y |
| **Self Determination and Independence** |  |  |  |  |  |
| Does the policy/program: |  |  |  |  |  |
| \* Provide opportunities to make choices? | Y | Y | Y | Y | Y |
| * \* Reflect knowledge of what is important to the person? | Y | Y | Y | Y | Y |
| \* Promote coping skills/ strengths? | U | U | U | U | U |
| * \* Promote and support option and informed choices for people with dementia and their caregivers at each phase of the disease/ transition point? | N | U | U | Y | Y |
| **Social Inclusiveness/ Relationships/ Participation** |  |  |  |  |  |
| Are any barriers to the participation of people with dementia and their families removed? | Y | U | Y | Y | U |
| Is spirituality supported? | N | Y | U | U | Y |
| Is a sense of mattering facilitated? | Y | Y | Y | Y | Y |
| **Fairness and Equity** |  |  |  |  |  |
| Are the procedures and criteria inherent in the policy/guideline/program fair and reasonable? | Y | Y | Y | Y | Y |
| Does it consider individual vs. collective needs? | Y | Y | Y | Y | Y |
| **Security** |  |  |  |  |  |
| Does the policy/ program: |  |  |  |  |  |
| .Provide the security of being able to plan for future (appropriate house and services, death) | Y | Y | Y | Y | Y |
| **Protection and Risk Management** |  |  |  |  |  |
| Does the policy/ program: |  |  |  |  |  |
| .Ensure the preferences of people with dementia are taken into account as much as possible? | Y | Y | Y | Y | Y |

Legend: U= Unclear; Y= Yes; N= No; \* LTC home- wide strategy; assumed that all residents eligible for participation. Criteria From: MacCourt [4]

Because the palliative care-quality improvement programs [36, 37] were implemented throughout the LTCHs, it was assumed that all residents, including those with dementia would have been affected by their implementation and impacts. This assumption is based on the prevalence of persons with dementia residing in LTCHs in general.

**3.3.1 Respect and dignity.** The respect for, and the dignity of persons with dementia were an included consideration in all of the reviewed programs. Even residents with more severe cognitive impairments could be included in the studies despite their capacity for decision-making, through their substitute decision makers. For example, when residents were assessed to lack the capacity to either make future treatment decisions and/or appoint a substitute decision maker, their next of kin (or the like) were invited to engage in the ACP programs on their behalf, in Molloy et al.’s [35], Casarett et al.’s [33] and Morrison et al.’s [34] studies. In addition, the training provided to staff in Hanson et al.’s [62] study encouraged them to include family members or substitute decision makers when engaging in ACP where residents did not have the capacity to make health care decisions. Also of note, Molloy et al. [35] indicated that residents participating in the Let Me Decide program may have been able to understand and indicate their own preferences with a Standardized Mini Mental State Exam (SMMSE) score as low as 16 out of 30. In this case, the program facilitator may have been able to help residents with cognitive impairment share their healthcare preferences. Therefore, these programs demonstrated respect and dignity, as they were designed to help include residents with dementia and their family members or substitute decision makers.

**3.3.2 Self determination and independence.**Most of the programs received an overall “yes” rating in this category, indicating that self determination and independence for persons with dementia was considered. For example, residents and/or their substitute decision makers were invited to discuss care preferences on an ongoing basis in Strumpf et al.’s [37] study, or if there was a change in health status in Morrison et al.’s [34] study. Molloy et al.’s [35] also included a follow-up with participants at the one year mark. This helps to underscore that these residents and their substitute decision makers were encouraged to re-evaluate their preferences as their health circumstances changed.

However, there were a few exceptions in this category. None of the studies explicitly included a description that promoting coping skills was facilitated; however, Strumpf et al. [37] noted that assessments for family, community, and bereavement support were included in the program. Thus, this important consideration for persons with dementia was mostly found to be lacking in description. Second, the program described in Casarett et al.’s [33] study stated that residents and family members could express their goals, and preferences for comfort care and life-sustaining treatment. However, the process around actually choosing hospice care was not clear.

**3.3.3 Social inclusiveness/ relationships/ participation.** Overall, the five subcategories in this category were more difficult to evaluate. The subcategories that included accessing social, family and community support networks were judged to not directly relate to the ACP programs, and were therefore, not included. Also, none of the studies explicitly described whether any barriers were removed for the residents’ and or family members’ participation in the ACP program. However, it is apparent in Morrison et al.’s [34] study, that attempts to identify existing but unknown substitute decision makers were made. Also, where in-person discussions with substitute decision makers were not possible, social workers engaged with this group over the telephone. Similarly, where identifiable and available, substitute decision makers were invited to participate in Molloy et al.’s [35] and Casarett et al.’s [33] studies. Additionally, the section of the PRIDE interview to determine hospice appropriateness was estimated to take between five and ten minutes to complete, making this a quick program for residents and their substitute decision maker [33].

Moreover, since all programs included persons with dementia and cognitive impairment, the subcategory of promoting a sense of mattering for persons with dementia, demonstrated the inclusion of this important value. In addition, the programs employed by Hanson et al. [36] and Strumpf et al. [37] clearly indicated that spirituality was an included component in the palliative care training programs for staff. The ACP training provided to staff in Hanson et al.’s [36] study encouraged them to talk to residents and their family members about including emotional support and spirituality into their end-of-life care plans. Therefore, overall, the value of social inclusion, relationships and participation was demonstrated through promoting a sense of mattering and supporting spirituality in the ACP programs.

**3.3.4 Fairness and equity.**All of the programs described were judged to be fair and equitable as they included residents with dementia and their family members. However, one limitation noted in Casarett et al.’s [33], Molloy et al.’s [35], and Morison et al.’s [34] studies was that residents who were assessed to lack decision-making capacity and did not have an identifiable substitute decision-maker, were excluded from participation. It is reasonable to speculate this may also be the case in Hanson et al.’s [36] and Strumpf et al.’s [37] studies. Although logistically it would be impossible for this small group of residents to participate in the respective programs, they did not have a chance of relating their goals of care through alternative means.

**3.3.5 Security.**It was judged that only the subcategory of being able to plan for the future was applicable in evaluating the ACP programs. Given the nature of all of the ACP programs, each program provided this option.

**3.3.6 Protection and risk management.** Only the subcategory of “ensuring the preferences of people with dementia are taken into account as much as possible” [4, p.8] was included in this evaluation, and all of the programs received a “yes” rating. As noted in Morrison et al.’s [34] study, in cases where residents were unable to make health care decisions but were still deemed able to appoint a substitute decision maker, they were able to do so. Social workers also tried to determine if a substitute decision maker had been named for residents no longer able to appoint one [34]. These substitute decision makers were encouraged to share any previously expressed preferences for health care on behalf of the resident. In cases where previous discussion between the substitute decision maker and resident did not occur, they were asked to answer questions based on the residents’ best interests [34]. This inclusion demonstrates considering residents preferences as much as possible, even in uncertain situations. Also of note, in Casarett et al.’s [33] study where the resident’s and substitute decision maker’s responses were not congruent, both were communicated to the physician who could consider and attempt to reconcile this. Finally, as noted above, the Let Me Decide program was designed for residents with a SMMSE score as low as 16 to be able to share their health care preferences [35].

Overall, the reviewed ACP programs demonstrated important impacts including: increased ACP discussion and documentation, adherence to resident and substitute decision maker wishes or preferences, reduced resource utilization (cost), increased staff and family knowledge about resident’s wishes, improved resident quality of life scores, and stability of health care choices over time. With the notable exception of the Let Me Talk program [5], which was not included in the DPLT evaluation, all of the remaining programs demonstrated some inclusion of values important to persons with dementia and their family members, and therefore can be considered “dementia-friendly,” by that standard.

**4. Discussion**

Others have reviewed the impacts of AD completion rates [28, 29] and the effectiveness of ACP programs for persons with dementia [30]in the older adult population. However, this review contributes the evaluation of ACP programs in LTCHs, according to the sixth criterion of the DPLT [4]. Not only does this review highlight the overall “dementia-friendliness,” of the evaluated programs, it outlines the additional impacts included in the Let Me Talk program, not previously addressed in other reviews [30, 63-65].

Although decades have passed since legislation has supported ADs, few highly rigorous studies have been published that evaluate ACP programs in LTCH setting. Similar to the observations in the reviews of end-of life care, as well as palliative care interventions in LTCHs [63-65], the research dedicated to ACP programs in this setting is largely descriptive or of a weaker evaluative quality [40-57]. Also, like Robinson et al.’s [30] review, whose included studies were all in LTCHs, this review determined the impacts of the Let Me Decide [35], Improving Nursing Home Care of the Dying [36] and the intervention involving social workers to enhance ACP [34], which included: ACP documentation, fewer hospitalizations, less resource use, and adherence to residents’ and family members’ wishes. However, in using more broad inclusion criteria, repeated and additional impacts for the LTCH setting were identified including: adherence to residents’ and family members’ wishes [33], and increased knowledge of residents’ wishes for staff and families, improved quality of resident life, and stability of health care choices [5]. In addition, while other studies have reported positive impacts for LTCHs, [40-57], more rigorous evaluations are needed to substantiate these findings. Also, with the exception of Molloy et al.’s [35] study, the cost or resource utilization of the ACP programs was not considered or evaluated in the reviewed studies, which could have serious implications for the implementation and use of these programs. Therefore, in moving forward, more rigorous testing through RCT or clinical control trial designs [30], and economic analysis of the reviewed programs are needed.

Also, in moving forward with evaluation of programs that focus on dementia care, or those that are implemented in LTCHs, the DPLT [4] may be considered. While no other published studies could be located that used the DPLT to guide program evaluation, the sixth criterion provided a helpful lens in which to evaluate the programs in terms of how they considered values important to persons with dementia. However, given the purpose of ACP program, it was difficult to use all of the categories of the sixth criterion, especially social inclusiveness/ relationships/ participation, security and risk management. Additionally, being limited to the description of the reviewed ACP programs provided in the journal articles and websites, there was difficulty in fully using the sixth criterion of the DPLT [4]. A great degree of detail would be needed to use all of the subcategories, which was beyond the scope of the description provided in the evaluation studies. In future, if LTCH personnel are trying to decide on implementing a new program, perhaps asking the authors of the potential program to complete the full DPLT would be helpful in determining if it does in fact, promote excellence in dementia care.

**4.1 Recommendations and Implications for Nursing Practice**

Overall, the review indicated a variety of positive ACP impacts from mostly “dementia-friendly” programs. However, given that a main outcome of the ACP process is creating an understanding of a person’s health care preferences, so that they may receive treatment that is congruent with their wishes; selecting a program that promotes this outcome, such as those evaluated by Casarett et al. [33] and Morrison et al. [34] seem most appropriate to consider. However, due to the varying characteristics, capacity and legislative requirements, it is recognized that no one ACP program will meet the needs of every LTCH, its residents and/or family members. Careful consideration of the most appropriate program for each LTCH or corporation is warranted. The following provides some additional points of consideration:

* It is important that the program provide direction around engaging in a comprehensive ACP discussion, and perhaps subsequent documentation [10]. The Let Me Decide [35], social workers [34] and Improving Nursing Home Care of the Dying [36] programs provide tools (available to authors) for guiding discussion and providing information around a variety of health care problems. The comprehensiveness of the discussion is important in creating an understanding of a person’s preferences, and therefore selecting a program that offers specific guidance around discussion topics is recommended.
* The palliative and end-of-life care quality improvement programs are recommended for consideration because of their multifaceted design. These quality improvement programs have demonstrated that they are not only a useful tool in improving ACP discussions and documentation but also provide the education, training and guidance to staff about how to provide high-quality palliative, end-of-life care [36, 37]. Given that a palliative approach to end-of-life care for persons with dementia has been recognized as a standard of care [1], these programs will more comprehensively and appropriately address both ACP and the provision of end-of-life care for residents, especially for those with dementia. The sustainability of the ACP program is also important to consider. In both Casarett et al.’s [33] and Chan and Pang’s [5] work, research personnel were used to engage in the ACP program with residents and families. Therefore, it is unknown whether staff members of the LTCH would be able to continue employing these programs and produce the same impacts, which is considered a limitation of these evaluations. Also, given the staff turn-over rate in LTCHs [41], a lack of attention to providing end-of-life care may result, if persons in leadership positions do not value the programs.
* Before selecting any ACP program, its evaluation using all of the applicable criteria from the DPLT [4] is recommended. This will help to ensure that the program considers all facets of dementia care, beyond the consideration of values important to persons with dementia and their families. In recognizing that persons with dementia should be included as much as possible in decision-making, it is essential to consider selecting a program that will allow the most residents with cognitive impairment to participate. Should decision-making capacity be found to be lacking, selecting programs that explicitly involve family members and substitute decision-makers involvement are encouraged [33-37].

**4.2 Review Limitations**

A few limitations of this paper are noted. First, the literature search program could have been expanded to include the reference lists of the reviewed studies. Second, due to the over 5000 sources yielded from the search strategy that were reviewed by only one person, there is a possibility that relevant articles may have been missed in the title and abstract review. Finally, the descriptions of the ACP programs provided in the reviewed studies or related websites may not have provided comprehensive details to fully appreciate every facet of their content and implementation. Therefore, the application of the DPLT was limited to the available description.

**5.** **Conclusion**

In conclusion, the implementations of ACP programs that include the consideration of values important to persons with dementia and their families are timely. While six unique programs have been identified, five of which can be considered “dementia friendly,” LTCHs should select the program that will best meet their identified needs and desired impact.

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Results of review previously presented:

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**Appendix B**

**Revisiting Retrospective Chart Review: An Evaluation of Nursing Home Palliative and End-of-Life Care Research**

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**Abstract**

**OBJECTIVE:** Retrospective chart review is a popular method of data collection in palliative and end-of-life care research. This paper provides an evaluation of the reliability and validity of this method in the long-term care home- based palliative and end-of-life care research literature.

**METHODS:** Eight criteria were used to critically evaluate the reliability and validity of the retrospective chart review data collection methods in (n=13) studies meeting inclusion criteria.

**RESULTS:** Only two criteria: defining both the important variables, and inclusion and exclusion criteria, which largely demonstrate validity, were consistently well described in this body of literature. However, the criteria used to mainly demonstrate the reliability of the method, especially data abstractors’ monitoring and blinding, and testing for inter-rater reliability, were not well addressed.

**CONCLUSION:** Overall, there was a limited description of the measures used for evaluating the validity, and especially the reliability of the retrospective chart review method included in the long-term care home-based, palliative care literature. As such, readers should proceed with caution when using this source of literature to inform palliative care research and practice, and carefully consider the inclusion of the measures of validity and reliability. Additionally, palliative care researchers should carefully consider the source of data as well as an instructional guideline when engaging in retrospective chart reviews.

*Keywords*: retrospective chart review, long-term care homes, palliative care**Revisiting Retrospective Chart Review: An Evaluation of Nursing Home Palliative and End-of-Life Care Research**

As palliative care becomes a more mainstream approach in facilitating end-of-life or terminal care in long-term care (LTC) homes[1], researchers have sought to describe and evaluate this method of care. In a variety of health care fields, including palliative care, a popular method of data collection is retrospective chart review [2,3]. Using the retrospective chart review method allows researchers to examine, record and understand past clinical events documented in persons’ medical charts [4,5].However, despite retrospective chart review’s touted feasibility, issues with the reliability and validity of this data collection method have been identified, due to both the limitations of the chart itself and the guidance in using this method provided in the literature [4,6,7]. It is important to examine the reliability and validity of retrospective chart review used in palliative care research, as the findings of such studies employing this method may ultimately shape how end-of-life care is provided in LTC homes. Therefore, the purpose of this paper is to review and evaluate the reliability and validity of the retrospective chart review method in LTC home-based palliative and end-of-life care research.

**BACKGROUND**

**Retrospective chart review**

In order to appreciate the use of retrospective chart review in health care research, it is essential to define it and understand both the advantages as well as areas for caution when using this data collection method. Retrospective chart review is a specific type of data collection method used in archival research and can be understood in two parts [5]. First, the term retrospective means to look back in time, and in this case, at clinical events [4].Second, the information in the medical chart is used as the source of data. This data collection method is commonly used in studies with retrospective designs, where research questions cannot be answered prospectively [4]. It is especially appropriate in evaluating approaches to palliative and end-of-life care, as neither the dying person nor their family member is burdened with actively participating in the research process at or near the time of death.

Although study designs and data collection methods should be based on the most rigorous way of answering research questions [8], several advantages of employing the retrospective chart review method encourage its use. It has been touted as a “quick and dirty” option because the clinical data already exist and just has to be abstracted from the medical charts [2,4]. Another advantage of retrospective chart review includes the relatively low cost when compared to prospective trials [4,9]. In addition, medical charts are generally accessible to researchers, and can be a source of clinical richness and accuracy. Due to these advantages, retrospective chart review may be suitable for pilot work in the LTC home setting, if valid and reliable methods are employed.

While it is recognized that chart reviews can be a convenient method of data collection, there are many complexities in retrieving relevant, high-quality information [10]. Importantly, authors have noted a lack of published well-established approaches to retrospective chart review, which leaves the validity and reliability of the method in question [6,7,11]. To understand how validity and reliability affect retrospective chart reviews, it is first important to explain and define each. Validity describes the degree to which a tool, protocol or process accurately represents the concept or topic it was designed to measure [12]. Reliability describes the degree that a tool, protocol or process will generate the same or similar results when it is used over time, with the assumption that what is being measured remains unchanged [12].

Several limitations of retrospective chart review have been noted around the chart itself, as well as the process of abstraction that threaten the overall validity and reliability of the method. Limitations of the medical chart itself in retrospective studies have been recognized including: inaccurate, incomplete or illegible documentation, as well as variance in the quality and location of the information recorded by medical professionals [4,13,14]. Many limitations of the chart review process have also been recognized and include: missing charts; lack of a clear procedure for data abstraction and how to handle missing or incomplete data; lack of abstractor training or blinding to the study purpose; and inconsistency or mistakes in coding chart information [11.15]. Together, these limitations may negatively impact the validity, and especially, the reliability of the retrospective chart review method, and any subsequent study findings.

**Chart review in the palliative care context**

The definitions of palliative care provided by the Canadian Hospice Palliative Care Association (CHPCA) [16] and the World Health Organization (WHO) [17] include that it is an approach to care which aims to enhance quality of living and dying for persons facing life-threatening illness, through the relief of pain and suffering, and attention to physical, psychosocial and spiritual needs. For the purposes of this paper, palliative care is considered an approach to caring for residents at the end of their life or facing a terminal diagnosis. However, no definite time period has been determined for when the palliative approach to end-of-life or terminal care is appropriate [18].

The need to improve palliative care for residents of LTC homes have been recognized in combination with continuing efforts to advance LTC home staff’s knowledge [19,20]. More high-quality studies are needed to test interventions to improve LTC home processes and resident outcomes [19]. It is postulated that a retrospective chart review method may serve as an entry point for researchers and LTC home personnel to assess the quality of current palliative care processes and outcomes. Pilot trials using this approach or accessing published studies that have used retrospective chart reviews may lead to the development of interventions or implementation of quality assurance programs aimed at improving palliative and end-of-life care. Given the possible threats to the reliability and validity of this method, it is important to examine the palliative care literature. Therefore, the following research question was explored, do palliative or end-of-life care studies, set in LTC homes, use reliable and valid methods when employing retrospective chart review as the sole approach to data collection?

**Definitions**

The following definitions will be applied throughout this paper. A *LTC home* provides accessible 24-hour nursing care for persons over 18 years of age [21]. References to nursing homes, long-term care geriatric institutions or facilities in the studies are defined as a LTC home. Any references to a *chart review* is defined as data collected from a chart review, chart audit, clinical record review, medical record audit or medical record review processes, as reported in the literature. The chart itself may contain past documented medical histories, clinical orders, test results, and assessment and care notes, specific to an individual person. The chart can be in either paper or electronic format, or a combination of both formats.

**METHODS**

**Search strategy**

In order to search for relevant literature, a library consultant helped to determine electronic databases and key search terms for LTC homes, palliative and end-of-life care, retrospective, and chart reviews. See Table 1 for an example of the search terms. The following electronic databases were searched and yielded the following results in January, 2014: Ageline (n=31), Excerpta Medica Database (EMBASE) (n=258), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (n=104), and Medline (n=179). No date restrictions were used in the search but the results were limited to the English language.

Table 1. *Example of Search Terms*

|  |  |
| --- | --- |
| Group of Search Terms | Terms |
| Long-term care home | Homes for the Aged  long-term care  long term care adj5 liv\*  long term care centre\*  long term care facilit\*  long term care home\*  long term care residence\*  long term care resident\*  nursing home\* |
| Palliative care | palliative care  end-of-life care  terminal care |
| Retrospective chart review | chart audit\*  chart review\*  medical audit\*  medical record\*  medical record review  retrospective design  retrospective stud\* |

Each grouping of search terms first combined using the OR command. The three groupings were then combined with the AND command.

**Study selection**

Three inclusion criteria were used to select the studies for evaluation. First, the study had to employ retrospective chart review as the main method of data collection. Second, the study description had to clearly indicate that the data were abstracted from LTC home residents’ charts. Therefore, studies that included data collection from multiple types of settings (e.g., hospice or hospital) were included, as long as at least one cohort of charts was obtained from a LTC home setting. Also, the data had to be abstracted and analyzed from the persons’ charts, as opposed being part of a secondary analysis. Finally, the study had to focus on the provision of palliative or end-of-life care to residents of LTC homes. As described above, terminal and end-of life care processes are relevant to the provision of palliative care in LTC homes.

Two further exclusion criteria were used. First, studies that mainly abstracted resident information from large administrative data sets such as the Resident Assessment Instrument Minimum Data Set (MDS)\*[[2]](#footnote-2) were excluded. Several issues have been raised around the consistency of the MDS’s psychometric performance in everyday use, syndrome specific scales (ie. depression and pain), its ability to accurately represent residents’ clinical status, and attitudes of home staff towards its completion [22]. In addition, DiCenso et al. [23] advocate caution in using large administrative data sets in research, due to a lack of relevant details, inaccuracy, and incompleteness of information. Second, studies using multiple data collection methods to answer the same research question or purpose were excluded. It was postulated that insufficient attention to detail in the methods section would be provided, given the possible limited space provided by academic journals [10].Therefore, if insufficient detail was provided, the evaluation of the reliability and validity of the method may not accurately reflect the actual quality of the study.

**Description of the evaluation tool and approach to synthesis**

In 1996, Gilbert et al. [11] suggested that eight methodological strategies, based on the works of Boyd et al. [24]and Horowitz et al. [25], would assess the validity, reliability and general quality of data gleaned from medical charts. The authors used these eight strategies to develop evaluation criteria, and then applied them to published emergency medicine research articles that employed chart review as the primary source of data. Of the 244 articles that were reviewed by Gilbert et al. [11] each were examined for the criteria and given a yes or no rating for the following: abstractors trained, inclusion/exclusion criteria described, important variables defined, standardized abstraction forms used, abstractors’ performance monitored, abstractors blinded to the study objective and patient assignment, inter-rater reliability discussed and inter-rater agreement tested. Gilbert et al. [11] reported on the proportion of these articles that adhered to the eight criteria, and concluded that strong chart review methods were lacking.

Others have published practice guidelines suitable for conducting retrospective chart reviews [6,7,10,15,26,27]. In their practice guidelines, these authors have included criteria used by Gilbert et al. [11] for addressing the reliability and validity of chart reviews. In addition, Panacek [5] offered Gilbert et al.’s [11]criteria as a resource for assessing chart review studies. In this evaluation, a yes or no rating was assigned to each of Gilbert et al.’s [11] criteria. The context and quality of study description helped to determine the yes or no rating. Thus, the eight criteria employed by Gilbert et al. [11] were selected to guide the evaluation of the LTC home-based, palliative care literature.

**RESULTS**

**Search results**

Without accounting for duplicates, the literature search yielded a combined total of 572 articles. The inclusion and exclusion criteria were applied to each title and abstract, which resulted in 16 articles identified for the evaluation (see Figure 1). However, it was clear that Chen et al. [28] and Lamberg et al. [29]; Hickman et al. [30] and Hickman et al. [31]; and Travis et al. [32] and Travis et al. [33] produced separate articles derived from the same retrospective chart review data collection processes. Therefore, a total of 13 unique retrospective chart review processes from 16 articles were identified for the evaluation. Herein, all references to the reviewed articles will be referred to as studies, to account for the repeated chart review processes. For a summary of the included studies see Table 2.

Figure 1.

*Flowchart of Included Studies*

Ageline

(n=31)

EMBASE

(n=258)

Medline

(n=179)

CINAHL

(n=104)

Duplicates Removed

(n=181)

Articles Meeting Inclusion and Exclusion Criteria (n=16)

Sets of Articles Describing Same Study

(n=3)

Total Studies

(n=13)

Total Articles

(n=572)

Table 2. *Description of Included Articles (n=16)*

|  |  |  |
| --- | --- | --- |
| Author & Year of Publication | Location of Study | Focus |
| Chen et al. [28] | Massachusetts, United States | Describing clinical conditions for dying residents |
| Chen et al. [38] | Massachusetts, United States | Describing medication use at end-of-life |
| Di Giulio et al. [34] | Cremona, Italy | Describing provision of end-of-life care |
| Hall et al. [1] | Ontario, Canada | Describing provision of end-of-life care |
| Hickman et al. [30] | Oregon, Wisconsin and West Virginia, United States | Describing provision of end-of-life care |
| Hickman et al. [31] | Oregon, Wisconsin and West Virginia, United States | Describing provision of end-of-life care |
| Keay et al. [40] | Maryland, United States | Describing provision of end-of-life care |
| Keay et al. [41] | Maryland, United States | Evaluating a palliative care intervention |
| Lamberg et al. [29] | Massachusetts, United States | Describing hospitalization at end-of-life |
| Osman & Becker [39] | Florida, United States | Describing provision of end-of-life care |
| Powers & Watson [18] | New York, United States | Describing provision of end-of-life care |
| Solloway et al. [35] | New Hampshire, United States | Describing the death experience according to place of death |
| Shurie et al. [36] | Pennsylvania, United States | Describing medication use at end-of-life |
| Takezako et al. [37] | Tokyo, Japan | Describing place of death |
| Travis et al. [32] | Southwestern United States | Describing hospitalization at end-of-life |
| Travis et al. [33] | Southwestern United States | Describing provision of end-of-life care |

**Evaluation criteria**

The following presents the results of the review and evaluation of the eight criteria that were applied to the 13 studies (16 articles). See Table 3 for a summary of the evaluation.

Table 3. *Summary of the Validity and Reliability Evaluation for Articles (n=16)*

|  | Abstractor trained | Inclusion/ exclusion criteria | Important variables defined | Standardized abstraction forms | Abstractor performance monitored | Abstractors blinded | Inter-rater reliability mentioned | Inter-rater agreement tested |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Chen et al. [28] | N | Y | Y | N | N | N | Y | N |
| Chen et al. [38] | N | Y | Y | N | N | N | N | N |
| Di Giulio et al. [34] | Y | Y | Y | Y | N | N | Y | N |
| Hall et al. [1] | NA | Y | Y | Y | NA | N | Y | Y |
| Hickman et al. [30] | N | Y | Y | Y | Y | N | Y | Y |
| Hickman et al. [31]\* | N | Y | Y | Y | Y | N | Y | Y |
| Keay et al. [40] | N | Y | Y | Y | N | N | N | N |
| Keay et al. [41] | N | Y | Y | Y | N | N | Y | Y |
| Lamberg et al. [29]\* | N | Y | Y | N | N | N | Y | N |
| Osman & Becker [39] | N | Y | N | N | N | N | N | N |
| Powers & Watson [18] | Y | Y | Y | Y | N | N | Y | Y |
| Solloway et al. [35] | Y | Y | Y | Y | N | N | Y | N |
| Shurie et al. [36] | NA | Y | Y | Y | N | N | Y | N |
| Takezako et al. [37] | NA | Y | Y | N | N | N | N | N |
| Travis et al. [32] | N | Y | Y | Y | N | N | Y | Y |
| Travis et al. [33]\* | N | Y | Y | Y | N | N | Y | Y |
| **Total Number of Articles Describing Criteria N(%)** | 3(23)\*\* | 16(100.0) | 15(93.8) | 11(68.8) | 2(13.3)\*\*\* | 0(0.0) | 12(75.0) | 7(43.8) |

Legend: Y=Yes; N=Not mentioned; NA= Not applicable; \*=Methods also described in related study article; \*\*3 articles not included due to Not Applicable rating; \*\*\*1 article not included due to Not Applicable rating

Evaluation criteria from “Chart Reviews in Emergency Medicine Research: Where are the Methods?, by E. Gilbert, S. R. Lowenstein, J. Koziol-McLain, D. C. Barta, and J. Steiner, 1996, *Annals of Emergency Medicine, 27*, p. 306. Copyright by the American College of Emergency Physicians.

**Abstractor trained.** Overall, the studies provided a sparse description of abstractor training and qualification, which limits the reliability of the method. Two studies reported that abstractor training or instruction was provided [34,35], and one study included that the data abstractors were highly experienced nurse data collectors [18]. Of note, it was clear by the description given in Hall et al. [1] that all of the authors were involved in the development of the data abstraction tool and completed the chart review process. Similarly, in Suhrie et al. [36] the data abstractor designed the abstraction tool, and in Takezako et al. [37] the primary author was the sole data abstractor. Therefore, in these three studies, it was assumed that training was not necessary. However, the qualifications for, and previous experience with retrospective chart review were not detailed. For the remaining studies, this criterion was not well addressed or clarified. Due to the limited description of the abstractor training, this criterion related to reliability was found to be lacking.

**Inclusion and exclusion criteria described.** This criterion was consistently well addressed, thereby giving the reader a clear understanding of the sample of charts that were included in the review processes. Inclusion criteria were described in all 13 studies. With one exception [30,31], all of the studies stated that they sampled only the charts of residents who had died within a certain time period, for example between May 2001 and 2002 [35]. Exclusion criteria were noted in five studies. Most authors listed exclusion criteria that were based on the resident either dying outside of the LTC home or unexpectedly [1,37-39], or not residing in the LTC home for a long enough period of time [29]. On the whole, the 13 studies demonstrated attention to the inclusion and exclusion criteria, which were appropriate to the topic of palliative care.

**Important variables defined.** The authors of the reviewed studies were attentive to providing detail around the important variables. However, it was more common for a list of the important variables to be provided rather than providing an operational definition. An operational definition would have better addressed the validity of the chart review processes. With one exception [39], all of the authors tended to list variables that were more objective in nature, such as resident demographic characteristics, medications, and presence or absence of clinical symptoms. However, three studies clearly defined the variables that directly related to their research questions [28,29,32,33,36]. In addition, Di Giulio et al. [34] provided an explanation of the functional assessment staging tool (FAST) used in Alzheimer’s disease diagnosis and prognostication. Also of note, studies indicated that their variables were informed by literature [1,33,40], or in combination with clinical experience [28,29,37].

**Standardized abstraction forms used.** While it was inferred that the important variables would serve to inform the abstraction tool, its design and use were overall, less clearly detailed. Nine studies included that an abstraction tool was utilized, and this was indicated in a variety of descriptions. First, four studies stated that their abstraction form drew on existing work, including the Toolkit Afterdeath Chart Review [35], Latimer’s tool to audit hospital care of the dying [1], the Medication Appropriateness Index [36], and the Physician Orders for Life-Sustaining Treatment form [30,31]. In these studies, the design of the abstraction form was more clearly explained. Second, Powers and Watson [18] as well as Keay et al. [41] provided details around addressing the validity of the variables included in their abstraction forms. Third, pre-testing of the abstraction tool was indicated in three studies [32-34, 41]. Last, Keay et al. [40] stated that their protocol had received clearance from an institutional ethics review board. While some detail was included, overall, an insufficient description of the abstraction form’s design and use was found. Therefore, the reliability and validity of the abstraction forms should be questioned.

Also, the description of the uniform handling of missing or conflicting information was lacking. Five studies commented on this aspect. Chen et al. [28], Lamberg et al. [29], and Di Giulio et al. [34] indicated that when ambiguous cases were identified, chart reviewers sought assistance from the LTC home employees to resolve issues. Similarly, Solloway et al. [35] included that the data abstractors could consult the study investigators to sort out any problems. Hickman et al. [31] also described a process of consensus building among researchers and dropping cases with insufficient information. However, Takezako et al. [37] mentioned missing charst. The inclusion of this aspect may not have been described if missing or conflicting data was not commonly encountered by the investigators.

**Abstractors’ performance monitored.** This criterion was only addressed in Hickman et al.’s [30] and Hickman et al.’s [31] study, where the inter-rater reliability of chart abstraction was assessed at regular intervals. This inclusion by only one study limits overall reliability and validity of the chart review process in this body of literature.

**Abstractors blinded to study objective and patient assignment.** Similar to the previous criterion, the blinding of the abstractors was also not well addressed in the study descriptions. In the studies where it was clear that the investigators also collected the data, abstractor blinding would not have been possible [1,36,37]. However, it was only Suhrie et al.[36] who directly indicated that the data abstractor could not be blinded. Overall, abstractor blinding was not well described, and therefore, it was inferred that this measure of reliability was not well utilized in the chart review process.

**Inter-rater reliability mentioned.** Inter-rater reliability and its related measures such as abstractor agreement and confirmation were mentioned in all but four of the reviewed studies. Like the use of a standardized abstraction form, this criterion was indicated in a variety of ways. First, Powers and Watson [18], Hickman et al. [30] and Hickman et al. [31], and Keay et al. [41] directly mentioned measuring inter-rater reliability. Second, Solloway et al. [35] stated that no processes were in place to measure inter-rater reliability. Third, Hall et al. [1], Travis et al. [32] and Travis et al. [33] commented on abstractor agreement. Also, while less conclusive, Di Giulio et al. [34] and Hall et al. [1] indicated that data collection often occurred concurrently between abstractors. In addition, the notion of reliability was implied by Suhrie et al. [36], Chen et al. [28] and Lamberg et al. [29], as they included that specific data abstracted from the chart were confirmed by a second reviewer but the term ‘inter-rater reliability’ was not mentioned.

**Inter-rater agreement tested.** An appropriate test of inter-rater agreement is the Kappa statistic because it accounts for agreement that would occur beyond chance [42]. Three studies indicated the use of this more rigorous test by reporting the inter-rater reliability of the: abstracted data [30,21], the chart abstraction tool [41], and symptoms identification [18]. In addition, the study by Travis et al. [32] and Travis et al. [33] reported a 100% agreement on the qualitative coding of all resident charts reviewed, whereas Hall et al. [1] reported 95% agreement between the abstractor and auditor on the data abstracted from 20 charts. Overall, both mentioning and testing inter-rater reliability criteria were poorly addressed.

**DISCUSSION**

**Interpretation of findings**

In revisiting the findings from Gilbert et al.’s [11] evaluation of the validity and reliability of the chart review method using emergency medicine, the LTC home-based palliative care literature produces similar results. Like in Gilbert et al., [11] the inclusion and exclusion criteria as well as defining the important variables were consistently well described in this literature. These two particular criteria relate to demonstrating the validity of retrospective chart review.

However, it was clear that the remaining six criteria provided by Gilbert et al. [11] were not as well described, especially the data abstractors’ monitoring and blinding, and testing for inter-rater reliability. These criteria related more closely to the reliability of the retrospective chart review method. Therefore, the reliability of this data collection method was not well described in this literature. Attention to these facts when both using the literature as well as conducting palliative care research should be employed.

**Suggestions: using palliative care literature**

Overall, the reliability of the chart review method in the palliative care literature was not well indicated. This fact should be considered when using research findings collected from retrospective chart review as a source of information. In the future, it is recommended that readers consider articles for use that address each of Gilbert et al.’s [11] eight criteria to ensure both the validity and reliability of the methods before using any findings to inform practice or direct research. Table 4 provides additional suggestions for critiquing a palliative care article using retrospective chart review.

Table 4.

*Using Palliative Care Literature*

|  |  |  |
| --- | --- | --- |
| **Source** | **Source Observation** | **Suggestions** |
| Keay et al. [40] | The quality of the LTC homes and staff experience can vary across sites | Carefully consider the setting and context from which the charts were sampled in the article  Due to the international perspective of the literature, the reader should take into account whether any standards or legislation that may have impacted the provision of palliative care are similar or applicable to their own geographic location |

**Suggestions: conducting retrospective chart review in palliative care, LTC home- based research**

Conducting a retrospective chart review is a useful approach to data collection to assess the quality of and provision of palliative and end-of-life care. As described above, there are several advantages to conducting retrospective chart reviews, which are applicable to the LTC home [2,4,9]. This approach may be favourable in a LTC home because the barriers to conducting research in this setting may be avoided. These barriers may include, staff time away from duties, obtaining participant consent, access to residents, as well as assessment of resident capacity [43]. However, the methodological articles and reviewed studies this paper highlight several issues that may impact retrospective chart review and should be considered before designing and implementing a study. See Table 5 for suggestions.

Table 5.

*Conducting Palliative Care Research Using Retrospective Chart Review*

|  |  |  |
| --- | --- | --- |
| **Source** | **Source Observation** | **Suggestions** |
| Aaronson and Burman [44]; Panacek [5] | Ensure that using retrospective chart review will provide the best way to answer research questions around palliative care in LTC home  \*Note: While the use of this method seemed justified in each of the reviewed studies in this evaluation, seven noted that the retrospective nature of the chart review was a limitation | Practice guidelines can be employed to guide the chart review process. While no specific source has outlined the best approach to retrospective chart review in the LTC home setting, the following may be considered:  \*Engel et al. [6], Engel et al. [7]and Liddy et al.’s [27] chart review methods could be piloted and used to help ensure greater inter-rater reliability  \*Gearing et al. [15] recommended an 11-step approach  \*Panacek [5]offered the ‘ten commandments’ for performing chart review research |
| Keay et al. [40] | LTC home sites’ overall quality may impact the quality of the documentation or end-of-life palliative care provided | Review publicly available reports on local LTC homes to help determine if the intended site(s) is suitable for chart review data collection (for example, Ontario Ministry of Health and Long-Term Care [45]) |
| Engel et al. [6]; Engel et al. [7] | To enhance the validity, access to resident charts should be planned with the LTC homes so that a representative sample of the population of interest is obtained  \*Note: In all but Hickman et al. [30] and Hickman et al. [31], the residents in the reviewed studies were deceased, and the charts obtained, easy access to chart data is not always guaranteed | Obtaining ethics clearance from the institutional review board may be necessary [46]  As the prevalence of residents with dementia continues to grow in LTC homes[47], issues with obtaining consent to access this population’s charts may be problematic. As noted, many people do not give advance directive plans about their participation in research after their decision-making capacity is lost [48] |
| Aaronson and Burman [44]; Hall et al. [1] | Assess the quality and completeness of the charts that will be used for data collection  \*Note: Authors of three studies reported that, the quality of the charts was excellent [28,29,34]. However, the quality of charts should not always be assumed | The quality of charts should not always be assumed, therefore do a pilot test before committing to data extraction  Determine whether applicable data is being recorded in alternate locations (e.g., physician offices like in Hall et al. [1])  Determine how the data is stored (e.g., paper chart and/or electronically). It is important to know which source to use, what information could be duplicated within the two sources, and on which type the staff are more likely to record information |
| Engel et al. [7] | Consider the suitability of the person that will be procuring the charts and abstracting data | LTC home personnel may be most familiar with the layout of the chart, and possibly even the content of the charts, which would enhance the reliability of the data abstraction. However, caution is warranted because these persons may not be qualified or lack experience. This may seriously affect the reliability of the findings, as noted by Engel et al. [7]  If LTC home staff will be procuring and abstracting the data, clear instruction and ongoing monitoring is recommended [49,50] |
| Hall et al. [1] | Select an appropriate period of time from which to abstract data | Select a time frame of documentation that will adequately measure variables of interest (e.g. Hickman et al. [31]). For another example, as noted in Hall et al. [1] and Solloway et al. [35], it was not reasonable to expect to abstract data around the reasons behind resident’s end-of-life care wishes, if only reviewing chart data from the final 48 hours of life |
| Hall et al. [19] | Select chart review variables that are highly representative of palliative care provided in the LTC home-based context | Selecting an existing validated tool to measure palliative care in LTC homes is limited in the chart review context [19] |

Overall, there was a limited description of the measures used for evaluating the validity, and especially the reliability of the retrospective chart review method included in the long-term care home-based, palliative care literature. As such, readers should proceed with caution when using this source of literature to inform palliative care research and practice, and carefully consider the inclusion of the measures of validity and reliability. In addition, palliative care researchers should carefully consider the source of data as well as the guideline when engaging in retrospective chart reviews. **Acknowledgements**

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Previous Related Work

Wickson-Griffiths, A., Kaasalainen, S., McAiney, C., & Ploeg, J. (2013). Assessing the quality of palliative care literature: The use of retrospective chart review as a research method. The 42nd Annual Scientific and Educational Meeting- Canadian Association on Gerontology. Halifax, CA. Poster Presentation, October 17-19.

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1. The “levels of care” is a common approach to recording advance directives for urgent care in the LTC home setting. Residents and/or their substitute decision maker are asked to determine the level of care they would like to receive from palliative care to full life-maintaining intervention. [↑](#footnote-ref-1)
2. \*1 MDS is a standardized assessment tool designed to communicate quality indicators to home and government [↑](#footnote-ref-2)