LAW COMMISSION OF ONTARIO
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IMPROVING END-OF-LIFE CARE SETTING TRANSITIONS: A MIXED-METHODS RESEARCH REPORT

Improving the Last Stages of Life

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I. OVERVIEW

A. Introduction

End-of-life (EoL) care is different from other types of health care in terms of both its goals and practices. While mainstream health care is primarily oriented to the effective diagnosis and treatment of illnesses, EoL care, which includes palliative care and hospice care, is designed to maintain or improve the quality of life remaining.[1] EoL care recognizes and supports persons with life-threatening illness and their family members through the effective prevention and treatment of symptoms and the reduction or elimination of emotional, social, and physical distress.[2] The ultimate aim of all EoL care efforts is a "good" death through a good dying process.[3] Good deaths and good dying processes are extremely important to the dying person, their loved ones, their family and other caregivers, and society as a whole.[4]

Most people approaching the end of life develop care needs that can be addressed in one or more care settings; often homes, hospitals, and long-term care facilities.[5] EoL care needs typically exist over a longer period of time than just the few days immediately prior to death, and these needs often change over time.[6] Increasing dependency on others for assistance with instrumental activities of daily living (such as banking, housework, and shopping) and then basic activities of daily living (such as bathing, eating, and dressing) is common as terminal illnesses or life-limiting conditions progress.[7] Moves, from one care setting to another and moves within care settings, may be required with changing care needs and circumstances.[8]

Moving from one care setting to another when terminally-ill or actively dying has unique considerations though, as compared to relocations at other points in the life course. Of prime importance to a good death and a good dying process is appropriate and high quality care setting transitions.[9] Mishap-free and mistake-free care setting transitions are essential when moving from one care setting to another. Rapidly accomplished moves are also important when moving is required. It is also critical that few, if any, EoL care setting transitions occur as death nears. Every move has considerable personal, family, healthcare team, healthcare system, economic, and other costs.

The matter of appropriate and high quality care setting transitions is particularly relevant today. Few deaths are sudden and unexpected now, as chronic progressive incurable diseases have become the leading causes of death in Canada.[10] Moreover, as half of all deaths in Canada take place after the age of 80 has been reached or exceeded, age-related disabilities are commonly present.[11] Consequently, as death nears, often over a course of months or years during which illness progression coupled with advanced aging become apparent, a decline in health and well-being occurs and EoL care needs emerge.[12]

Good deaths and good dying processes require appropriate, high quality, and rapidly accomplished necessary care setting transitions, both within institutions (e.g., intensive care units to palliative care units) and across care settings (e.g., hospitals to home). Once a person is identified as having EoL care needs, the quantity, nature, and timing of care setting transitions should be determined by the needs and preferences of the person, and the number of transitions should respond to and be determined by changes in those needs and preferences, as opposed to the availability and configuration of existing services and settings.

At this point in time, however, little is known about the timing of EoL care setting transitions, the frequency of EoL care setting transitions, the frequency and seriousness of the issues that occur with care setting transition issues, and the solutions needed to prevent or mitigate these issues. This gap in knowledge is not surprising in light of the Auditor General of Ontario's 2014 statement highlighting a major lack of information on EoL care in general:

There is little province-wide or LHIN-level information on the supply of or demand for palliative and end-of-life care. For example, the Ministry does not have accurate information on the number of palliative-care beds in hospitals across the province, nor is the number of patients served tracked consistently. Consistent and comparable information is needed to make good decisions regarding current and future palliative-care services, and to ensure that patients get the services they need in the most cost-effective manner. This will be even more important in coming years because demand for palliative care is expected to increase as baby boomers approach the end of their lives.[13]

B. Purpose and Scale of Research Project

A mixed-methods research investigation focusing on EoL care setting transitions was undertaken in 2016. The purpose of this research project was to inform the Law Commission of Ontario about the number, nature, and timing of EoL care setting transitions and to explore opportunities for improving the management of patient transitions between and within care settings. The research scope is focused on EoL care in Ontario. However, this scope included other jurisdictions both nationally and internationally to identify lessons for Ontario.

This research contributes to the Law Commission of Ontario's aim to improve the last stages of life for people living in Ontario through a review of Ontario's law and policy framework for providing care to persons approaching death and services for those who support them, including caregivers, family members, friends, and health care providers. The research investigation consisted of three interrelated and complementary components:

1. A comprehensive grey literature review and research literature review to gather existing information and identify current evidence related to EoL care setting transitions,

2. An analysis of hospital data for the province of Ontario (as compared to Canada as a whole) to quantify and describe EoL care setting transitions in the last year of life and explore the last hospitalization before dying in hospital, and

3. Qualitative interviews to gain needed insights, knowledge, and advice from key informants across Ontario on EoL care setting transition issues and solutions.

Each of these components is described in the subsequent chapters.

As these three components were being conducted, the findings were used by the research team to develop conclusions and recommendations. The focus was on:

1. core transitions within and across care settings,

2. existing law and policy barriers to and supports for seamless transitions,

3. the respective roles of health care and service providers in facilitating seamless transitions, and

4. a range of options for improving transitions, possibly including simplification of the law, policies or processes; clear assignment of responsibility to providers; provision of additional supports; barrier removal and other options; and other issues considered to be of significant relevance to this topic; such as practical considerations needed to reduce the number of care setting transitions taking place in the last year of life and also those needed to improve and speed EoL care setting transitions when these moves are required.

C. Report Structure

This report consists of five chapters. This first chapter provides an outline of the study goals and methods.

Chapter 2 presents a review of existing literature to identify existing evidence on the quantity, type, frequency, timing, and outcomes of care setting transitions in EoL care as well as factors that explain variations in care setting transitions and outcomes. The review covers both the published scientific peer-reviewed literature and the grey literature (primarily unpublished policy documents and reports) to identify themes related to EoL care setting transitions in Ontario and other jurisdictions.

Chapter 3 reports on an analysis of Canadian hospital data with particular attention paid to Ontario to quantify and describe care setting transitions that involve admissions to and separations from a hospital in the last year of life and the use of hospitals for end-stage EoL care.

Chapter 4 provides information gained from interviewing key Ontario informants to gain their insights, knowledge, and advice about EoL care setting transition issues and solutions to achieving appropriate, high quality, and timely necessary EoL care setting transitions.

Chapter 5 concludes this report by summarizing and discussing the findings and presenting recommendations.

II. LITERATURE REVIEWS

A. A Scoping Literature Review of Research on End-Of-Life Care Setting Transitions

1. Background

i. Introduction

This literature review was founded on the knowledge that most people approaching the end of life develop care needs.[14] These EoL care needs typically change over time.[15] Increasing dependency on others for assistance with instrumental activities of daily living (such as banking, housework, and shopping) and then basic activities of daily living (such as bathing, eating, and dressing) is common as terminal illnesses and other life-limiting conditions progress.[16] Moves from one care setting to another and moves within care settings may be required as care needs and circumstances change.[17]

Moving from one care setting to another when terminally-ill or actively dying has unique considerations as compared to moves at other points in time. Effective, appropriate, and high quality EoL care setting transitions have been a concern for some time, but this concern is increasingly relevant today as most deaths now are not sudden or unexpected.[18] Chronic progressive incurable diseases, such as cancer, are leading causes of death.[19] Moreover, as half of all deaths in Canada take place after the age of 80 has been reached, many dying people have dependency care needs from advanced aging.[20] As death draws nears, typically over a period of weeks, months or years, a decline in health usually occurs and EoL care needs become apparent.[21] Anticipating and meeting those needs is of critical importance.

Definitions of palliative and EoL care often focus on an optimal shift of focus to quality-of-life care as death approaches.[22] A timeframe of one year is often used for EoL care planning in keeping with the "surprise" question – Would you be surprised if this person were alive a year from now?[23] For instance, the Medicare Hospice Benefit, which was designed in 1986 to ensure dying people in the United States receive EoL care, permits 12 months of publicly-funded hospice care.[24]

ii. Purpose of Literature Review

Given the importance of effective, appropriate, and high quality EoL care setting transitions, a review of the research literature was undertaken on the subject of EoL care setting transitions.

This body of literature was searched for evidence on: (a) the frequency and types of EoL care setting transitions, (b) EoL care setting transition issues, and (c) solutions to transition issues.

2. Literature Search And Information Analysis Method

i. Scoping Literature Review Overview

A scoping literature review was undertaken. Scoping reviews are comprehensive research literature explorations that are done to create knowledge on topics that have either had few research studies performed on them or no consolidation yet of the existing research evidence.[25] As such, scoping reviews “map” the research on new or emerging fields of interest.[26] Like systematic literature reviews, scoping reviews are conducted to collect and organize research information to gain an understanding of the current evidence and any evidence gaps.[27] Scoping reviews are broader than systematic reviews, however, as scoping reviews retain all identified research articles for review.

ii. EoL Care Setting Transitions Research Literature Gathering Methods

A number of strategies were used to identify relevant research literature for review. The goal was to find and examine all English-language research reports published in peer-review journals starting with the 2000 year for current research evidence on EoL care setting transitions. The inclusion criteria were: English-language, had an abstract, was published in a peer-review journal dated 2000 or more recently, was a report of a research study on one or more aspects of EoL care setting transitions, and information on the methods used to gather and analyse the research data was provided. A total of 105 research articles were found, with all retained for review.

iii. Research Evidence Consolidation

To organize the information contained in such a large number of articles, key points from each were summarized in a table (see Appendix A, Table 1). The information in this table is organized in 5 columns: (a) author(s), year published, and country, (b) research focus, (c) research methods, (d) findings, and (e) notes. This table is helpful for providing an overview of each study, and for identifying and collating information on the frequency and types of EoL care setting transitions.

At the same time as Table 1 was being created, a second table was created to highlight EoL care setting transitions issues and solutions (see Appendix A, Table 2). For this table, care setting transitions issues were listed as they were identified in each article, and tested or suggested solutions were also correspondingly listed as they were identified in each article. A total of 49 issues were identified, each with tested or suggested solutions. The information in Table 2 is organized in 4 columns: (a) issues, (b) articles relevant to each issue, (c) tested or suggested solutions, and (d) articles with tested or suggested solutions for each issue.

3. Findings and Discussion of Findings

i. Overview of Research Literature

As indicated, 105 research articles published in 2000 or more recently were identified for review. Although this large number of articles would suggest much researcher awareness and considerable practice or policy interest in EoL care setting transitions, the studies outlined in Table 1 are extremely diverse, with minimal consolidation of findings therefore possible. This diversity could be a result of EoL care setting transitions being a relatively new focus of research. Only 25 (23.8%) of the reviewed articles were published prior to 2010; three quarters were published in 2010 or more recently. This helps explains why no library search terms (or Medical Subject Headings, called "MeSH") exist yet to distinguish EoL care setting transitions as a focus of research or policy and practice interest. Care setting transitions is a growing topic of focus, however. Ten articles (9.5%) had been published in 2016 as of April 20th.

Most of the 105 articles reported quantitative studies (n=92 or 87.6%). These studies typically analyzed administrative data. Administrative data is information collected routinely on hospital patients, hospital use, long-term care facility use, long-term care residents, and other types of people or entire populations such as through census undertakings and death certificates. In addition, 6 qualitative studies, 4 mixed-methods studies, 2 case studies, and 1 qualitative, structured expert study (Delphi survey) were done. These studies also helped to show EoL care setting transitions is a diverse and multi-faceted subject, with many topics of relevance to consider when trying to determine how best to support terminally-ill and dying persons.

The 105 research studies had been conducted in 16 countries, with 3 using data collected from multiple European countries. The most common country of study was Canada, with 35 publications (33.3% of the total), followed by the United States of America (n=27), England (n=13), Finland (n=6), Spain (n=4), Taiwan (n=3), Australia (n=2), Belgium (n=2), the Netherlands (n=2), and with 1 study in each of nine other North American, Asian, African, European, and middle Eastern countries. As such, it is evident that Canadian researchers are not alone in having an interest in or concerns about EoL care setting transitions. However, it is important to realize that research evidence from other countries may not be relevant to Canada. Moreover, research evidence from other Canadian provinces may not be relevant to Ontario as cross-border health system and other differences exist. Of the 35 Canadian studies, 16 were fully or partly done in Ontario (45.7%).

ii. Frequency and Types of EoL Care Setting Transitions

Many of the studies focused on the last EoL care setting transition that preceded death. The studied transition was often a move from a home or long-term care facility to a hospital where death occurred. Only a small number focused on other moves, such as a move from hospital to home, home to a long-term care facility, or home to hospice. None reported hospital to hospital transfers and none focused on home to home moves, although one study counted all care setting transitions that took place in the last year of life including moves from one home to another.[28] Only one study reported on the move out of hospital to die at home, with death typically occurring soon after arrival there.[29]

One Ontario study is notable. A study by Bainbridge et al. found 61% of long-term care residents in Ontario visited an emergency department in the last 6 months of life and 20% died in hospital.[30] Younger long-term care residents were more likely to die in hospital, but considerable differences in hospitalization rates across the province were also found.[31]

Although the reason or reasons for EoL care transitions was not the focus of any investigation, many reasons were apparent in the articles. These reasons could be grouped into three themes. Often, moves were made because dependency care needs emerged. Moves also occurred because of a serious reduction in health. Finally, moves occurred after a problem had arisen, commonly this was worsening or severe and unrelieved pain or family caregiver overburden. As such, most of the studied moves were reactive.

Just over half of the 105 articles (n=58, 55.2%) studied the EoL care setting transitions that occurred in a defined timeframe. The most common timeframe was the last year of life (n=12), followed by the last 6 months of life (n=11) or 1 month of life (n=11), 3 months of life (n=9), 2 years of life (n=5), 2 months of life (n=3), 2 weeks of life (n=2), 4 months of life (n=2), 1 day of life (n=1), 1 week of life (n=1), and 5 years of life (n=1). As such, the last year of life was the most commonly studied time period, but many shorter and longer timeframes were also used in the tabulation of transitions or for determining the timing and circumstances of the last EoL care transition. Regardless of the timeframe, these studies collectively show terminally-ill or dying people are often moved once if not more often as death approaches. Moreover, the final move before death occurs is often in the last week or few days of life. As such, these studies indicate that the risk of moving from one care setting to another increases as death nears.

However, few studies provided information on the total number of moves made by terminally-ill or dying people in a defined time period. Specifically, Wilson et al.'s population-based Alberta study found younger (<65 age) persons were moved 3.9 times to access emergency department, outpatient clinic, day surgery, and hospital-based healthcare services in the last year of life as compared to older (age 65+) persons who were moved 3.4 times on average.[32] This study also found rural residents of Alberta were moved 4.2 times on average for healthcare purposes in the last year of life as compared to urban residents who were moved 3.3 times on average.[33]

Nearly half of the studies (n=47, 44.8%) focused on other time periods. Some focused on the care setting transitions that occurring following a terminal diagnosis. Others focused on the care setting transitions occurring after entry into a home care program or a palliative care program. The findings from these studies varied widely.

As such, it is not clear from this body of research how often terminally-ill and dying people are moved and so how often they experience EoL care setting transitions of one form or another. Although a large number of studies showed people are moved at least once from one care setting to another, with this move often made as death drew near or as impending death became apparent, no studies identified which moves of the person are more common. For instance, a move from home to home or a move from home to hospital could be the most common EoL care setting transition. Future research needs to establish an overall rate of EoL care setting transitions, identify and categorize all types of EoL moves, and determine the reasons for moving from each place to place.

iii. EoL Care Setting Transition Issues

Despite the 105 studies having been done largely out of concern over EoL care setting transitions, only two studies identified the proportion that were "burdensome." These proportions ranged from 9.5% in the last 2 years of life as found in a study in Finland by Aaltonen et al. to 19% in the last 120 days of life as found in an American study by Gozalo et al.[34] Of note, Aaltonen et al. used three burdensome definitions in their study: (a) any transition or move to another care facility in the last 3 days of life, (b) a lack of continuity between hospitals and care facilities in the last 120 days of life, and (c) more than 2 hospitalizations in the last 90 days of life. This Finnish study found repeated hospitalizations in the last 3 months of life were the most common burdensome issue, followed by moves in the last 3 days of life.

As such, it cannot be concluded from these two non-Canadian studies what percentage of transitions are problematic. The findings of these two studies, however, indicate that a good proportion of care setting transitions are problematic, and therefore warrant policy and practice attention.

No research studies in Ontario or elsewhere in Canada could be found that identified and classified issues arising from or with EoL care setting transitions. As a result, it is not clear which transition issues are more common and which issues are more problematic. Future research must address these knowledge gaps. It is particularly important to establish how common EoL care setting transitions issues are as a seminal Canadian safety study that found 7.5% of hospital patients experience an adverse event such as an unintended injury or complications resulting in death, disability or prolonged hospital stay, led to many positive changes after it was published in 2004.[35]

Regardless, most of the studies focused on issues arising from or associated with a move to hospital from another location. Many of the reviewed studies found or suggested that these admissions to hospital were almost always through the emergency department; they were not planned and booked admissions to hospital. As such, emergency departments and ambulance teams are of prime importance for preventing or addressing hospital admission-related care setting transition issues. This is a compelling consideration, as the respective studies showed that emergency department visits often led to admissions to hospital and to long hospital stays as these hospitalizations continued until death occurred or until a transfer to a long-term care facility could be arranged.

The 105 articles revealed a total of 49 different EoL care setting transition issues. These issues could be grouped into four distinct but often overlapping categories: (a) patient issues, (b) family issues, (c) healthcare provider issues, and (d) system issues. Of these, health system issues were the most common (27 issues), followed by patient issues (11 issues), healthcare provider issues (7 issues), and family issues (4 issues). Although health system issues were more common, all issues regardless of category are concerning. We summarize the issues identified in the literature below.

Health System Issues

As indicated, health system issues were the most numerous, with many different health systems issues identified. These included the observation that no person has overall responsibility for EOL care in systems that allow or permit many care providers such as family physicians and specialist physicians to actively provide care to one individual person, along with many other care providers such as nurses and junior physicians. Another system issue is not having enough long-term care facility beds to provide 24/7 nursing care; an issue which is thought to be in part a result of the shift of seniors' care from long-term care facilities to assisted living facilities and the home. Other issues are listed below to illustrate and catalogue the wide range of system issues. We have categorized these issues under several broad headings; however, there is considerable overlap among them and they should not be viewed as entirely separate.

i. Level of services

- Many dying persons do not have a family physician or an accessible primary care or other healthcare clinic, or have other healthcare access issues such as a lack of healthcare services in rural and remote areas.
- There is much awareness of the need to keep terminally-ill or dying persons adequately supported and cared for at home, but this requires home care services and other supports to be provided there.
- There is a need to provide enough home care services to meet the needs of terminally-ill people and thus be able to keep dying persons at home, with the concern that there is not enough home care services provided now to prevent the need for emergency department and hospital EoL care.
- Palliative care specialists typically only provide care for cancer patients and with palliative care services mainly designed for cancer patients or thought to be reserved for cancer patients.
- Hospital beds are much more available than hospice beds, and hospitals are much more available than hospices.
- Long-term care facilities do not have enough onsite services to keep ill, terminally-ill, and dying persons there.

ii. Coordination of services and supports

- Sending a dying person home from hospital requires a great deal of planning, as this planning often involves two or more sets of care providers such as family members and home care agencies.
- The emergency department is a gateway to inpatient hospital care; with ambulances routinely taking ill people from homes and long-term care facilities there after an ambulance call.
- There is limited access to and little or no referral of people to specialist

palliative care services, including those services in hospital such as palliative care units and palliative care teams.

- Territorial issues exist in relation to the terminally-ill and dying person, as one physician alone is able to refer "their" patient to palliative care services in the hospital, admit their patient to hospital, and discharge their patient from hospital.
- Available open long-term care facility beds, as well as hospice beds and other beds such as chronic care or aged care beds are needed for a rapid discharge from hospital.
- There is a need to discharge people from hospital to the right care setting, not just any care setting, after a terminal diagnosis and/or stabilization in health has occurred.

iii. Knowledge and education

- There is a lack of advanced support such as specialized palliative healthcare services including pain assessment and pain management in the home to keep people with EoL care needs at home, particularly those having pain emerge and worsen and those experiencing other sudden or worsening health issues.
- There is a lack of EoL care knowledge among long-term care staff and not enough supportive care available onsite to keep dying residents from being transferred to hospital for EoL care as a result of low staffing levels in long-term care facilities.
- Hospitals are well established while hospices are new, with the public typically only aware of hospitals.
- No professional or public education programs exist to draw attention to death and dying, including those that raise awareness of alternatives to hospital-based EoL care.

iv. Decision-making and care planning

- Considerable uncertainty exists among care providers in all sectors about the existence of patients' advance care planning or other EoL goals, such as and most notably the preferred place of death.
- There is a need for long-term care planning for all persons diagnosed with dementia and other chronic illnesses, with this EoL care planning not routinely being done now.

v. Policy vision, standards and measurement

- Vague policy and care standards documents exist; with these not directing EoL care efforts and care planning, or indicating the preferred vision of EoL care now and in the future.
- No standards or routine guidelines are available for use as a checklist to determine if all needed or possible EoL care planning has been done.
- Statistics are not kept on the use of palliative care services, referrals to specialist palliative care services, nor the use of hospices.
- No EoL quality indicators exist for benchmarking purposes and for use in quality improvement efforts.
- Existing EoL policy and EoL care standards from other countries, where EoL care is well planned and established, are not in use.
- There is a lack of information collected and available about the quality of dying or quality of EoL care in hospitals, long-term care facilities, and homes.

vi. Socioeconomic factors

- For-profit agencies can provide minimal care to maximized profits, and can shift the person to hospital to reduce their agency costs.
- High out-of-pocket costs for non-hospital EoL care and for other uninsured or partly insured services exist.

Although the above system issues were identified from the 105 articles, a number of Ontario studies illustrate some of these issues. A research report by Seow et al. reported no change in access to home care services in the last 12 weeks of life had occurred despite the Province of Ontario having had their End-of-life Care Strategy in place for one year; moreover, for those care recipients studied in the 2005-2007 timeframe, their care hours remained at the same 3.8 hours of nursing care and 3.8 hours of personal support care hours per week, and with 38% of deaths continuing to take place in hospital.[36] A study by Bainbridge et al. using 2006 data found 25% of the people who died of cancer in the province never received any home care services in the last 6 months of life.[37] A study by Barbera et al. using data from 4 provinces (BC, Alberta, Ontario, and Nova Scotia) revealed significant variation in EoL quality indicators for cancer patients.[38]

Moreover, few provinces were meeting their own care benchmarks, for instance, in relation to emergency department use or intensive care unit (ICU) use. Guerriere et al.’s Ontario study found caregiver burden increased over time in a non-linear fashion until death occurred, with increasing unpaid care-giving time a key factor for caregiver burden and the use of emergency departments.[39]

Patient Related Issues

Patient-related issues were also common. The following issues were identified from the 105 studies.

- Some hospitalized patients and families do not ask about and some do not want to be told they are seriously ill, terminally ill, or dying.
- Some terminally-ill or dying persons require frequent healthcare services and often also a large amount of EoL care, including medical care, other healthcare services, and supportive care, notably community-based people who are advanced in age, those diagnosed with cancer, those diagnosed with dementia, and others.
- Some people have cognitive and/or physical disabilities, which often worsen over the course of their illness.
- A very long illness can occur, such as one lasting years if not decades.
- EoL care needs often emerge typically in the last 6-12 months of life and often change as death nears.
- A rapid deterioration in health, with EoL dependency care needs suddenly emerging, is common.
- Pain and other symptoms suddenly appear, with these not easily managed at home or in a long-term care facility.
- The person who needs considerable EoL care wants to die at home, or to have most or all of their EoL care take place at home.
- The terminally-ill or dying person lives at home alone, with no onsite family member to provide 24/7 EoL care there.
- The terminally-ill or dying person has no able-bodied family caregivers living with or near them to provide 24/7 EoL care there.
- Many people have unpredictable dying processes, often those with organ failure such as heart failure or lung failure.
- People who are hospitalized get settled into the hospital and it is difficult to move them home for EoL care; while people accustomed to outpatient and community-based care are more likely to stay at home for their EoL care.

Only one Ontario study illustrated patient reasons for some care setting transitions. This study by Barbera et al. found the most common reasons for emergency department use in 2002-2005 over the last 2 weeks and also the last 6 months of life among persons dying of cancer were abdominal pain, lung cancer, breathing problems (dyspnea), pneumonia, malaise and fatigue, and the appearance of fluid in the chest (pleural effusion).[40]

Healthcare Provider Issues

Healthcare provider issues were also apparent in the 105 studies. These often were related to the inability or unwillingness of healthcare providers to recognize a terminal illness or dying state and thus realize and act upon the need for EoL care, as well as their reluctance to abandon or stop diagnostic and treatment-oriented curative care. Hospital patients and other persons are therefore not told that they are terminal or dying, and some are given false hope. Many do not then have open and timely conversations about their illnesses so they can begin to plan for the end of life. Also as a result of the avoidance, healthcare providers continue to provide "regular" health care, since there are no frank discussions and planning for their care to be shifted from curative care to EoL care services. Aggressive curative care is often provided, such as chemotherapy and ICU services in the last days, weeks, or even months of life.

Other healthcare provider issues were also identified however:

- Healthcare providers do not question established or historical cure-oriented care practice patterns, with these not changed to accommodate EoL care.
- Physicians, nurses, and other care providers are not familiar with specialist palliative/hospice care or home care services, and so do not refer patients there.
- A high level of clinical monitoring is done, or believed to be needed and useful in hospital, including the ordering of daily and other diagnostic tests in the last weeks or months of life.

Family Issues

Family issues were the least commonly identified issues, although many of the above issues relate to or involve family members. Four specific family issues were identified in the literature:

- The family as a whole or the primary family caregiver requires support to prevent caregiver burden and burnout.

- Family members of terminally-ill and dying people do not have much, if any, experience with providing EoL care, and they have a low level of knowledge of EoL care. Some of these resist to provide home-based care as a result and others need considerable support in providing EoL care.
- Some families insist that their family member who resides in a long-term care facility be sent to a hospital when dying.
- Considerable uncertainty exists among families, and also among dying persons, about if there will be enough EoL care or support provided to them at home to permit their dying at home. This uncertainty also exists about long-term care facilities and other non-hospital places, with the exception of hospices.

iv. Solutions for End-of-life Care Setting Transition Issues

Few of the 105 studies were designed to research one or more solutions to EoL care setting transition issues, with few providing evidence then for action or action planning. Many suggestions from the authors of the reviewed 105 research publications instead were provided to reduce, ameliorate, or prevent EoL care setting transition issues. As such, with few exceptions, evidence was limited in relation to solving or preventing many of the identified EoL care setting transition issues.

However, home care was the most frequently studied solution (34 studies), with EoL home care services provided either by specialist palliative care teams or generalist home care providers. These home care studies showed, often through a comparison of home care recipients and non-recipients that the people with EoL care needs who received home care services or home hospice care were more likely to stay out of hospital. These studies collectively demonstrated that home care was effective for reducing emergency department visits, hospital admissions, or delayed admissions so the length of hospital stays was shorter. For instance, a study by Guerriere et al. of a well-established home care program in Ontario found home care clients with higher home nursing care costs and higher personal care worker costs were more likely to die at home than those with minimal services and so lower costs.[41] In addition, those wanting to die at home and those who were co-habiting were more likely to die at home with home care services.[42]

Home-based nursing care was the most frequently studied home care solution, with this care provided by licensed nurses and unlicensed home care providers, all of whom are generalist care providers and not specialists in palliative or EoL care. These studies collectively illustrate the value of this home-based nursing care for reducing the need for hospital-based EoL care and also the need to visit an emergency department. However, it is not clearly evident from these studies and the other home care studies how much home care is needed for these results. Some evidence was presented for the provision of daily home care services and for starting home care services early in the course of a terminal illness.

In addition to home care, some evidence was also apparent for other solutions. For example, the literature identified the following possible solutions to address transitions in the last stages of life:

- Onsite EoL care in long-term care facilities to reduce the need for emergency department visits and hospitalizations.
- Home visits by nurse practitioners to reduce the need for emergency department visits and hospitalizations.
- Nurse practitioners employed by long-term care facilities to reduce the need for emergency department visits and hospitalizations.
- Hospital-based transition nurses who educate patients and families about EoL care and EoL care services in the pre-hospital discharge phase and then provide post-hospital follow-up to enable successful transfers home and then retention at home.
- Telehealth services to support family caregivers who are providing home-based care (these are 24 hour telephone services with advance practice nurses or palliative care nurses providing information, advice, and support).
- Hospital-based palliative care teams who assess terminally-ill or dying patients and plan their post-discharge care.
- Early EoL care planning that determines the preferred place of death and ensures arrangements are in place to support that preference.
- Do-not-resuscitate planning and posted plans to clarify and consolidate viewpoints and actions among all involved persons.
- Family physician or primary care clinic continuity to ensure one medical care provider is informed and involved in the EoL care through to death.
- Home visits by family physicians to reduce the need for emergency department visits and subsequent hospitalizations.
- Community-based aged care teams who do assessments of care needs at repeated regular home visits.

Some Ontario research studies highlight these solutions. For instance, an Ontario study by Seow et al. found early admission of terminally-ill persons to a home care program and more home care services help to reduce emergency department and hospital use.[43] Specifically, those admitted to a home care program 6 months before death were more likely to not use emergency departments and hospitals, and those using more than 7 hours of nursing care and more than 7 personal support hours per week were also more likely to avoid emergency departments and hospital admissions. Another Ontario study by Seow et al. revealed that people dying in 2009-2011 who received care in the home from a specialist palliative care team in their last 2 weeks of life were less likely to use an emergency department and die in hospital.[44] This study by Seow et al. also revealed that compared with a matched group of patients, the people who received specialist palliative care services in the home were more able to stay out of hospital in the last 30 days of life.[45]

In contrast, an Ontario study by Almaawiy et al. found an increased continuity between family physicians and dying patients reduced their odds of dying in hospital, although people with 4 or more family physician visits per week were the most likely to be admitted to hospital in the last 2 weeks of life and die in hospital.[46] A research article by Tam et al. found a hospital in Ontario that had a rapid in-hospital response team to crises could prevent many of their hospital patients from unnecessary admissions to the ICU, as this team quickly assessed the patient and could determine their care needs and plan for those care needs outside the ICU.[47]

A more recent study by Seow et al. involving home care data from three provinces (BC, Ontario and Nova Scotia) revealed those home care clients who received care from nurses with palliative or EoL care expertise were less often hospitalized as compare to home care clients receiving care from generalist home care nurses.[48] Moreover, the clients who received more than 5 hours of home care per week in the last month of life were more likely to stay home. Similarly, this study by Seow et al. revealed increased home care nursing costs in the last month of life were associated with lower hospital costs.[49] This study, by Seow et al., also revealed that patients who had nursing care were much less likely to use emergency departments in the last week of life as compared to those receiving none or less than one hour of home care per week.[50] Another article by Seow et al. reported that people dying of cancer in Ontario were more likely to not use emergency departments if they were receiving home care in the last 6 months of life.[51]

4. Implications

Although it could be said that a considerable body of research literature exists on the topic of EoL care setting transitions, as 105 research articles were reviewed, only a few studies quantified the number of moves occurring in the last year of life or over other timeframes. It was also not evident which moves are more common. It is possible, for instance, that moving from one home to another occurs more often than moves into a hospital. It would appear however that the risk of moving increases as death draws near, with care needs emerging and often changing.

The diverse research findings in the 105 studies collectively indicate that many different EoL care setting issues exist. As much of the focus of research conducted to date was on the move from home or long-term care facility to hospital, it is not evident that all transition issues have been identified however. The identified issues were grouped into health system issues, patient issues, healthcare provider issues, and family issues. Although health system issues were more commonly noted, it is not evident which issues are more problematic.

Similarly, although many possible solutions were noted in this literature base, little evidence exists to indicate how to improve the quality of transitional care or ensure high quality moves occur. Moreover, minimal evidence exists to speed necessary moves when moves are required. However, sufficient evidence exists on home care services reducing the number of moves occurring in the last year of life or over other time periods. Clearly, home-based nursing care provided by generalist nurses or perhaps for select clients by specialist palliative care teams has the potential to reduce or eliminate the need for terminally-ill or dying people to move to the hospital through the emergency department for EoL care.

However, only 1/3 of all reviewed studies were conducted in Canada, and less than half of the Canadian studies were conducted in Ontario. Ontario research is needed to ensure a solid understanding of EoL care setting transitions. It is important to know how often people are moved in the last year of life in Ontario, and what the most common and problematic moves are. Issues and solutions also need to be researched in Ontario to provide a solid foundation for action. Although past research attention has focused more often on transfers to hospital, all possible transfers need to be studied, as issues and solutions for one type of move may not be relevant to other types.

Finally, it is important to note that this body of literature clearly documents considerable concern exists over EoL care setting transitions. Much should be done and can be done to improve EoL care setting transition issues. System responses to persons requiring EoL care need to reflect the underlying compassionate aim of EoL care, and the challenges provided by the unique and at times conflicting needs of each individual person and their caregivers or caregiver teams. At this point in time, terminally-ill and dying persons appear to be moved between different types of care settings and moved within each particular care setting in accordance with system priorities and constraints as opposed to their own needs and preferences. It is therefore important for targeted research to be done, and for healthcare professional and health policy attention to become focused on EoL care setting transitions as these are occurring because terminally-ill and dying people have increased care needs as death nears. Solutions are needed to reduce and improve transitions, ones that address the best interests and needs of the person, as well as the best use of the healthcare system and other resources such as the family and community.

B. A Review of the Grey Literature on End-Of-Life Care Setting Transitions

1. Introduction

i. Purpose and Scope

This section reviews the non-scientific or “grey” literature on the topic of EoL care setting transitions or moves from place to place as death draws near, often over the last year of life. Grey literature consists of documents, reports, and other print materials prepared by governments and other organizations. These are not scientific peer-reviewed articles or books but instead self-published or commissioned organizational documents. Many however use research evidence or summarize research evidence as a basis for policies and program or service strategies. Moreover, they may be drafted by authors with extensive practical or academic knowledge.

This search for and analysis of the grey literature was performed to identify and assess policy and other information about EoL care setting transitions that is not reported in the scientific (peer-reviewed) research and theory literature. Government and other organizational perspectives, program or service strategies, and policy recommendations for EoL care are of a critical importance to improving EoL care setting transitions.

ii. Search and Analysis Method

A pragmatic approach was used to find relevant grey literature for review. This search included:

- web-based searches for reports and policy documents of government ministries and healthcare agencies in Ontario, elsewhere in Canada, and in other English speaking countries,
- discussions with key informants and colleagues in Canada and other countries, and
- a review of the reference lists of scientific papers for appropriate grey literature.

An analysis of each document was conducted to determine if EoL care setting transitions was addressed directly or it there was any information of relevance to EoL care setting transitions. The following is a report of what was found in the grey literature, starting with Ontario. Following this, we identify relevant information from other jurisdictions. In the final section, we consider barriers to and opportunities for improving patient care management with respect to EoL care setting transitions, as identified in the reviewed documents on strategies and policy recommendations for EoL care.

2. Findings

i. Ontario

Although a substantial body of Ontario-based grey literature exists on the topic of palliative, hospice, or EoL care, few of these sources include a focus on EoL care setting transitions. Even where a report mentions transitions, the focus is on the transition to palliative or EoL care as opposed to care setting transitions after EoL care has begun.

The few reports that have care-setting transitions as a focus are general in relation to the patient populations covered, with no specific attention paid to the particular needs or challenges faced by people as they near the end of life, and those of their families and healthcare providers.

Three main themes emerged from a review of the grey literature in Ontario for the planning, management and delivery of EoL care: (a) communication, both among providers and between providers and patients, (b) capacity to provide EoL care, and (c) collaboration and coordination of services and support (including the use of team-based care).

ii. Communication

Communication was identified as a critical aspect for EoL care setting transitions. Where EoL discussions between care providers and patients take place, the patients are then observed to have fewer hospital admissions, fewer days in hospital, lower probabilities of being admitted to intensive care units and fewer hospital outpatient visits.[52] Such discussions increase the chances of advance care planning and hospice care being received. Timing is also important with earlier advance care planning being associated with less hospital care and more hospice care.[53]

iii. Capacity to provide EoL care

Capacity to provide EoL care was another major factor for care setting transitions. Capacity to provide EoL care relates to both the physical infrastructure and the skills, education, and training of providers. The hospital patients who are served by providers with EoL care education are less likely to transition to an intensive care unit once admitted to hospital and the length of stay there when admitted is lower compared to those served by providers with no palliative or EoL education.[54]

A recent report on palliative care in Ontario by Health Quality Ontario identified the size and scope of the current problem of delivering effective EoL care to terminally-ill and dying people in Ontario.[55] It noted that during the last month of life', for every 100 patients who received palliative care in the year ending March 31, 2015:

- 66 had unplanned visits to a hospital emergency room,
- 61 were admitted to hospital,
- 25 spent 15 days or more in hospital,
- 66 died in hospital,
- 43 received palliative home care services, and
- 33 received a home visit from a doctor.

These findings indicate that EoL care is concentrated in and around acute care hospitals. Yet there is considerable evidence that non-hospital palliative care, where available, is an effective alternative care setting.[56]

In terms of physical infrastructure, a Quality Hospice Palliative Care Coalition of Ontario report states that 137 hospital inpatients in Ontario were awaiting discharge or transfer to an alternate palliative care setting (either home, long-term care facility, or hospice), and these patients accounted for 10% of all hospital days for patients awaiting discharge or transfer.[57] Moreover, those receiving hospice palliative care, whether in a residential hospice or through home visits, were said to have less hospital admissions and fewer inpatient hospital days of care.[58] The timing of admission to hospice care was also identified as important, with patients admitted to a hospice more than 6 months prior to death being less likely to have a hospital admission than patients admitted to a hospice 4 weeks or less prior to death.[59]

In 2007-08, there were 20,000 admissions of palliative care patients to acute care hospital beds in Ontario, with 80% of these patients being admitted through a hospital emergency department.[60] However, those receiving palliative home care services were less likely to have an emergency department visit and had fewer emergency department visits overall than those not receiving palliative home care, and hence were at less risk of being admitted to an acute care hospital. The majority of palliative home care clients were cited as not having any emergency department visits or hospital admissions during the last month of life.[61]

More hours of home nursing care and personal support care were also associated with a reduced probability of hospital admission.[62] Moreover, the Quality Hospice Palliative Care Coalition of Ontario report states that home deaths in Ontario are significantly more likely to occur and hospital admission less likely to occur if the terminally-ill or dying person receives nurse or family physician home visits, and if they are cared for by a multi-disciplinary home care team.[63]

iv. Collaboration and coordination of services and support

Coordination of services and support includes, but is not limited to collaboration between different providers or professions in delivering care. The reviewed documents demonstrated that inter-professional and inter-sectorial collaboration and coordination are important features of effective EoL care provision which reduces the need for EoL care setting transitions. People who receive team-based EoL home care services have fewer hospital admissions, lower probability of intensive care unit admission, and a higher probability of home EoL care and death. Similarly, team-based EoL comprehensive care (care provided across the hospital and home) is linked with a higher probability of a home death and a lower probability of a long-term care facility death.

For instance, terminally-ill and dying persons are less likely to be admitted to an intensive care unit when hospital-based palliative care is provided by multidisciplinary teams.[64] In addition, adding nurse practitioners to community-based palliative care teams was associated with lower probability of hospital admission.[65]

A recent report based on round table discussions with stakeholders also identified collaboration and coordination as important elements in the design of a comprehensive EoL care system.[66] In this report, local program collaboration between hospice and housing programs was associated with more home deaths. Other suggestions emerging from the roundtables included collaboration to support smooth care transitions, with long-term care facilities to identify their place in the care continuum. Moreover, gaps in EoL care were often found in long-term care facilities as needing to be addressed. Other issues that were raised included the need for coordination with caregivers for enhanced timing of support, such as respite care which is often restricted to 'office hours'.[67]

Before moving to other jurisdictions, it is worth noting that the Quality Hospice Palliative Care Coalition of Ontario's strategy for creating an integrated hospice palliative care system in Ontario presents a blueprint for quality EoL care, including improved care setting transitions.[68] For instance, an Integrated Client Care Project initiative for hospice palliative care is outlined with this designed to ensure the following:

> …everyone across the continuum of care is working together to build the future hospice palliative care system and that we continue moving from our current system of sector specific service provision to a cross-sector system that requires:
>
> 1. A full continuum of care settings and services is in place;
> 2. In each care setting where patients die, there is a clearly defined hospice palliative care program;
> 3. Sectors and services are linked by common practice, processes, structures and education;
> 4. Adequate numbers of trained professionals are available;
> 5. System-level accountability is clearly defined and communicated; and
> 6. Funding models, guidelines and policy directions support an integrated system.[69]

v. Other Jurisdictions

Information on EoL care setting transitions in other jurisdictions is present, as well as a number of comprehensive EoL care strategies developed and in use in these jurisdictions. In general, these documents envision and report much more use of non-hospital settings at the end of life. For instance, a review of United Kingdom evidence on the provision of palliative care found that patients receiving home-based specialist palliative care had double the odds of dying at home as compared to those who did not receive this care, and patients receiving specialist palliative care were less likely to be admitted to hospital as compared to those who did not receive this care, with this resulting in an estimated average saving of 958 pounds per hospital death averted.[70]

A report by Chitnis et al. on Marie Currie Nursing services in the United Kingdom focused on the period of 2009-2011 for those who received their home-based palliative nursing care services and those who did not.[71] Those receiving their services were significantly less likely to die in hospital, to be admitted to hospital through the emergency department, to have an elective admission to hospital, and to have an outpatient hospital visit or an emergency department visit. The additional costs associated with the higher level of transitions among those not receiving the palliative home care services amounted to 1,100 British pounds per person. The differences in number of transitions were greatest for those receiving pre-planned overnight nursing care in the home of 9 hours.

In Ireland, EoL care patients in areas where palliative care services (specifically home-based and inpatient hospice care) were more developed have lower utilization of services from other health and social care programs as compared to areas were palliative care services are less developed and less available.[72] In addition, hospital admissions were said to be reduced over the last year of life in the areas with well-developed palliative care services and higher in other areas. When a hospice bed is not available, the chance of an admission to hospital increases.[73]

A report by the Palliative Care Council of New Zealand that reported a study of a large public hospital in New Zealand found that 1 in every 5 admissions were patients with palliative care needs.[74] Half of these palliative care patients were admitted through the emergency department. This report also indicated that the aged residential care (or long-term care) sector was taking responsibility for a rapidly increasing number of EoL care patients without the need for care setting transitions in the vast majority of cases. For example, less than 1 in 10 of the long-term care residents were transferred to hospital for urgent of emergency care during the last year.

The report by the Palliative Care Council of New Zealand also provided information from a survey of hospital-based palliative care services that found patients admitted to dedicated palliative care hospital beds had an average length of stay of 6 days compared to over 12 days for palliative inpatients not admitted to palliative care beds.[75] Moreover, one in four palliative care patient admissions ended in a hospital death, one third the rate of death among those admitted to a hospice. However, 71% of patients admitted to hospice care had multiple admissions over a 12 month period indicating that in New Zealand hospices are used as an ongoing and final place for care for many people with EoL care needs.

Similar differences in the location of death were reported for Australia, with around half of hospital admissions among palliative care patients in 2009-10 ending in death compared to 97 in every 100 admissions for palliative care in long-term care homes in the same period.[76]

Almost half of the long-term care home palliative patients had a hospital admission at some point during the year but most returned to their long-term care home prior to dying there.[77]

An American paper is of particular note as it reports an evaluation of the Community-based Care Transitions Program that was initiated by the Centers for Medicare & Medicaid Services in April 2011 to improve transitions of Medicare beneficiaries from inpatient hospitals to home or other care settings.[78] These "care transition services are designed to improve quality of care, reduce readmissions to hospitals by high-risk beneficiaries, and achieve cost savings for the Medicare program".[79] A total of 101 community-based organizations were in existence, with some positive results at this early implementation stage. Specifically, there was some positive action in relation to reducing 30-day readmission to hospital rates and 30-day emergency department readmission rates.

Finally, it is worth mentioning the various strategies identified in policy documents for other international and Canadian jurisdictions for improving EoL care.[80]

The strategies in these documents represent three main themes of relevance to EoL care setting transitions:

1. Communication and information, largely through the adoption of systematic collection of information and the development of infrastructure to support information transfer between settings and providers. This includes an early identification of persons likely to benefit from EoL or palliative care, and the greater use of advance care plans.
2. The development of dedicated inter-sectoral palliative or EoL care programs based on the use of and widespread availability of multi-disciplinary teams. The Government of Nova Scotia's strategy, for instance, focuses on continuity of care across care settings, with case coordinators to be involved for continuity of care.81
3. Training and education in palliative or EoL care to provide enhanced knowledge and skills for caring for terminally-ill and dying persons, as well as reviews of professional scopes of practice to remove unnecessary barriers to appropriate and timely care setting transitions.

C. Conclusion

This research and grey literature review, which gathered existing contemporary information on EoL care setting transitions, was done to identify what is known about EoL care setting transitions. Much was learned, but it is clear that EoL care setting transitions has not been a major focus of policy or research. Much more research is needed to identify and examine EoL care setting transitions of all kinds, as well as transition issues and solutions to prevent these issues or reduce the impact of these issues. To this end, a quantitative study of current hospital data to provide information on hospital utilization in the last year of life was undertaken and will be reported in a chapter below. In addition, a qualitative study of care setting transition issues and solutions was undertaken and will be reported in another chapter below.

In closing, through this literature review, many care setting transition issues became apparent, although these were mainly associated with the transfer to hospital through the emergency department. The imperative to provide safe and effective care to terminally-ill and dying persons in all settings and across settings requires new policy, law, and practice efforts. Many different solutions, including increased access to home care services and enhanced or more plentiful home care services, were identified as potentially viable and many more could be devised to ensure fewer EoL moves, higher quality moves, and more rapid moves when these are needed.

III. NEW EVIDENCE ON END-OF-LIFE HOSPITAL UTILIZATION IN ONTARIO

A. Background

1. Introduction: Purpose and Scope

This chapter outlines a research study that was conducted to provide new evidence on the topic of effective, appropriate, and high quality end-of-life (EoL) care setting transitions. This study identified and described EoL care setting transitions in the last year of life that involved the use of inpatient hospital beds in Ontario, with cross-Canada findings provided for comparative purposes.

This study was done because many concerns exist in relation to EoL care setting transitions. These concerns are often related to low quality transitions, as mistakes and other mishaps during or around the time of transitioning are possible. Frequent and inappropriate moves from one care setting are also possible, as are delayed and denied necessary moves. The scoping research literature review undertaken for this mixed-methods project revealed limited information exists on how often EoL care setting transitions occur in the last year of life or any other timeframe. Few studies have reported on the frequency of use of hospitals as death nears.

Focusing on inpatient hospital utilization in the last year of life is important. Although EoL care may be very effective in hospitals, large and small, hospital bed shortages can result in dying people waiting in emergency departments for hours or days for an inpatient bed. Another concern is that hospitals are designed for acute treatment-oriented curative care and so may deliberately or without consideration of alternatives provide unnecessary tests and inappropriate treatments to dying persons. Another concern is that hospitals are the most expensive care setting. The high cost of providing EoL care in acute care hospitals results in less community resources being available for the provision of accessible and high quality EoL care in long-term care facilities, hospices, homes, and other places.

In summary, given the importance of effective, appropriate, and high quality care setting transitions in the last year of life, the current gaps in research evidence suggest a research study using hospital data for the province of Ontario and Canada as a whole (excluding Quebec) will provide helpful new information on EoL care setting transitions. This evidentiary insight will help to prevent or address hospital-related EoL care setting transition issues.

B. Quantitative Research Data And Analysis Method

1. Canadian Institute for Health Information Data Sourcing

For this study, inpatient hospital data were obtained for analysis from the Canadian Institute for Health Information (CIHI). CIHI was established in 1994 to develop and maintain comprehensive Canadian health information for improved health care and health.[82] Since then, CIHI has worked with stakeholders across Canada to create and maintain 27 health databases. The data in these databases is analyzed by CIHI, with this evidence-based information released on their website for use across and outside of Canada. CIHI also shares data for research purposes upon request.

One of the 27 CIHI databases is a Discharge Abstracts Database containing information on inpatients and inpatient hospital services. More specifically, this hospital database contains socio-demographic, administrative, and clinical data on all separations from acute care hospitals (with the exception of stillbirths and cadaveric donors) in all Canadian provinces and territories except Quebec.[83] CIHI receives this data directly from all acute care hospitals across Canada or from their respective health or regional authority, or ministry or department of health. All hospitals in all provinces and territories except Quebec are required to provide data, with CIHI information standards ensuring complete high quality data.

2. Data Obtained for Analysis

For this 2016 study, 2 years of comprehensive individual-anonymous Canadian (with the exception of Quebec) inpatient hospital data were obtained upon request from CIHI. The data years were 2013-14 and 2014 and15, the two most recent years of complete Canada-wide (excluding Quebec) data, with each year containing all inpatient hospital and patient data gathered routinely from April 1 through March 31. As each individual patient had been assigned a consistent unique number, since no patient names or other identifying information were released, this number was used to create a third dataset from the two annual datasets. This third dataset contained all of the information collected over the last 365 days of life for inpatients who died in Ontario hospitals in the 2014-15 year.

This study was undertaken after research ethics approval for it was obtained on March 23, 2016 from the University of Alberta's Health Research Ethics Board (#Pro00063626).

3. Data Analysis

After the data were received from CIHI, they was loaded onto a secure password-protected computer and checked for issues such as missing or incorrect data. No major issues were found, although a small amount of missing data for some variables was noted, as is common with large administrative healthcare databases.

The computer programs of SAS and SPSS were used to analyze the data. This quantitative data analysis was guided by six research questions:

1. What proportion of hospital admissions in the 2014-15 year ended in death?
2. What is the average length of final hospital stay for persons who died in the 2014-15 year and how does that compare with stays that did not end in death?
3. How do the people who died in hospital in the 2014-15 year differ from those discharged alive? This question takes into consideration all of the relevant variables for analysis that were contained in the 2014-15 CIHI dataset: age, gender/sex, rate of admission through the emergency department or through the admitting department, the rate of use of ambulance to reach the hospital, the procedures and other interventions performed in hospital, and the use of special care units such as intensive care units and coronary care units.
4. How many times were people admitted to an Ontario hospital in their last 365 days of life prior to dying in hospital in the 2014-15 year?
5. For people who died in an Ontario hospital in the 2014-15 year, what locations were they transferred from and what locations were they transferred to in their last 365 days of life?
6. For people who died in an Ontario hospital in the 2014-15 year, what proportion of their admissions to hospital in the last year of life were through the emergency department and/or involved an ambulance?

C. Research Findings

The following are answers to the 6 research questions. The first 3 questions were answered using the 2014-15 Canadian (excluding Quebec) hospital data. The last 3 questions were answered using the created dataset containing information on the last 365 days of life before death in an Ontario hospital.

1. What proportion of hospital admissions in the 2014-15 year ended in death?

There were 1,136,502 admissions to Ontario hospitals in the 2014-15 year, with 41,370 (3.6%) of these ending in death. In comparison, there were 2,525,987 admissions to Canadian hospitals (excluding Quebec) in the 2014-15 year, with 88,662 (3.5%) of these admissions ending in death. Of those 88,662 persons who died, 41,370 (45.0%) were residents of Ontario.

Statistics Canada reports, for the 2014-15 year, a total of 100,327 Ontario deaths and 202,706 Canadian (excluding Quebec) deaths.[84] As such, 41.2% of Ontario deaths and 43.7% of Canadian (excluding Quebec) deaths took place in an inpatient hospital bed.

2. What is the average length of final hospital stay for persons who died in the 2014- 15 year and how does that compare with hospital stays that did not end in death?

In Ontario, the average length of hospital stay for hospital stays that ended in death was 13.9 days as compared to 5.6 days for all other hospital stays. Across Canada (excluding Quebec), the average hospital stay ending in death was 16.4 days in length versus 6.4 days for all other hospital stays.

3. How do the people who died in hospital in the 2014-15 year differ from those discharged alive?

This question takes into consideration all of the relevant variables for analysis that were contained in the 2014-15 CIHI dataset: their age, gender/sex, rate of admission through the emergency department or through the admitting department, the rate of use of ambulance to reach the hospital, the procedures and other interventions performed in hospital, and the use of special care units such as intensive care units and coronary care units.

The people who died in Ontario hospitals were much older on average as compared to those discharged alive from Ontario hospitals (75.5 versus 48.2 years of age respectively). Similarly, the people who died in a Canadian (excluding Quebec) hospital were much older on average at the time of death than the other persons admitted to and discharged alive from hospital (75.0 versus 47.5 years of age respectively).

Of all 41,370 persons who died in an Ontario hospital in the 2014-15 year, 52.7% were male and 47.3% were female. This composition differs from that of all other admissions to Ontario hospitals, which was 43.1% male and 56.9% female. Similarly, of all 88,662 people who died in Canadian hospitals (excluding Quebec), 53.0% were male and 47.0% were female, and for those discharged alive from hospital, 43.3% were male and 56.7% were female.

Most (75.4%) of the 41,370 people who died in Ontario hospitals in 2014-15 were admitted to hospital from a home, with 24.6% admitted from all other places. Among these other places were homes for aged care such as lodges and assisted living or other facilities that are not designated as long-term care facilities (8.5% of all 41,370 who died), long-term care facilities (6.9%), or another acute care hospital (6.9%). Similarly, most (76.2%) people who died in hospitals across Canada (excluding Quebec) were admitted from home, with 23.8% admitted from another place, such as a long-term care facility or another hospital.

Most (81.6%) people dying in an Ontario hospital were admitted through the emergency department, with this a much higher rate than the 48.0% rate for all other admissions not ending in death. Similarly, 78.9% of all 88,662 people who died in a Canadian hospital (excluding Quebec) were admitted through the emergency department as compared to the 48.3% rate for all admissions not ending in death. As such, 18.4% of Ontario hospitalizations ending in death and 21.1% of Canadian (excluding Quebec) hospitalizations ending in death occurred after a planned and booked admission to hospital.

Most people who died in an Ontario hospital arrived by ambulance (71.2%), with this a much higher rate than the 26.2% rate for all other admissions not ending in death. Similarly, most (70.4%) of the 88,662 people who died in a Canadian (excluding Quebec) hospital arrived by ambulance; only 26.9% of admissions ending in a live discharge from hospital involved an ambulance.

Only 381 of all 41,370 deaths (0.9%) in Ontario hospitals occurred during an intervention, such as cardio-pulmonary resuscitation or an operation. Similarly, only 7,093 of all 88,662 deaths (0.8%) in Canadian hospitals (excluding Quebec) occurred during an intervention.

Special care units such as intensive care units and coronary care units were the recorded death place for 10,158 of the 41,370 people (24.6%) who died in an Ontario hospital. In contrast, only

17,336 of all 88,662 deaths (19.6%) that took place in hospitals across Canada (excluding Quebec) in the 2014-15 year occurred in a special care unit.

The average length of stay in a special care unit in Ontario hospitals was nearly twice as long for people who died in hospital than for those who did not die in hospital (8 days versus 4.8 days respectively). Similarly, the average length of stay in special care units across Canada (excluding Quebec) was longer for people who died than for the all other admissions not ending in death (7.5 days versus 5 days respectively).

4. How many times were people admitted to an Ontario hospital in their last 365 days of life prior to dying in hospital in the 2014-15 year?

Ontario residents who died in hospital in the 2014-15 year were admitted to hospital a total of 1 to 26 times in the last 365 days of life. The most common number of admissions was 1, with this number demonstrating that no other admissions occurred other than the one ending in death. The average number and the median number of admissions (the middle number where one half of all cases are above this number and one half are below this number) in the last 365 days before dying in hospital was 2.

More specifically, 47.7% of Ontario residents who died in hospital in the 2014-15 year were only admitted once to hospital in the last 365 days of life, with this admission ending in death. Another 27.3% were admitted a total of 2 times to hospital in the last 365 days of life. Consequently, 75.0% of Ontario residents who died in hospital were admitted only 1 or 2 times to hospital in the last 365 days of life. The remaining 25.0% were admitted more often to hospital. However, only 40 out of all 41,370 cases (0.1% of the total or 1 in every 10,000 cases) were admitted 12 or more times, the equivalent of once a month or more often.

5. For people who died in an Ontario hospital in the 2014-15 year, what locations were they transferred from and what locations were they transferred to in their last 365 days of life?

Of all admissions to Ontario hospitals that ended in death, 70.3% were from a home. Another 1.3% of admissions ending in death was from a home receiving home care services. As such, 71.6% of all admissions to hospital ending in death were from a home. Other places admitted from included a home for the aged (7.3%), another acute care hospital (7.3%), an ambulatory care clinic (5.9%), a long-term care facility (5.4%), and other less common places such as an outpatient department, a psychiatric facility, a private clinic, and a rehabilitation facility.

Of all discharges from hospital over the last 365 days of life before dying in hospital, 66.3% of these discharges were to a home not receiving home care services. Another 17.7% of discharges were to a home receiving home care services. As such, 84.3% of all discharges from hospital in the last year of life were to a home. In addition, 6.7% of discharges from hospital in the last 365 days of life were to another acute care hospital, 2.6% to a long-term care facility, 2.2% to a rehabilitation facility, 2.2% to a home for the aged, 1.4% to a chronic care facility, and other less common places such as a psychiatric facility.

6. *For people who died in an Ontario hospital in the 2014-15 year, what proportion of admissions to hospital in their last year of life were through the emergency department and/or involved an ambulance?*

Of all admissions to Ontario hospitals in the last 365 days of life, 79.6% were through the emergency department. In addition, 61.9% of all admissions to Ontario hospitals in the last 365 days of life involved the use of an ambulance.

Only 17.7% of Ontario residents who died in hospital were admitted directly to an inpatient hospital bed, with the emergency department bypassed. In contrast, 34.4% of all admissions that did not end in death involved a direct admission to an inpatient hospital bed.

D. Discussion of Findings

The findings of this analysis of CIHI hospital Discharge Abstracts Database data illustrate the use of hospitals by terminally-ill and dying persons (those in the last year of life) in Ontario and across Canada (excluding Quebec). One notable finding was 3.6% of all hospital admissions in Ontario ended in death, a figure slightly higher than the 3.5% national rate. These findings suggest dying persons in Ontario are admitted more often for EoL care purposes than in other parts of Canada (excluding Quebec). Attention is drawn then to the availability of community alternatives such as home care services, hospices, and long-term care facilities. Other issues are also relevant to consider, including the possibility that less EoL care planning is being done in Ontario than elsewhere to enable deaths and the EoL care preceding death outside of hospital.

The finding that only 1.3% of admissions to Ontario hospitals in the last year of life were from homes marked as receiving home care services while 70.3% of all admissions to hospital in the last year of life were from homes not receiving home care services is highly suggestive of a need to increase access to home care services for terminally-ill and dying people. Moreover, only

17.7% of hospital discharges were to a home receiving home care services, while another 66.3% of hospital discharges were to a home not receiving home care services. The reliance on hospitals for necessary EoL care will remain high unless home support is increased, or alternatives such as hospice beds and long-term care beds become more available.

The finding that 84.3% of discharges from an Ontario hospital in the last year of life were to homes underscores the point that homes are a common site of EoL care. Supporting that site to ensure it is a viable place for more people needing EoL care is a major but necessary challenge to reduce hospital admissions in the last year of life. More available home support would also enable additional transfers out of hospital for EoL care and death at home, with hospital stays shortened as a result. This home support is critical, as most adults prefer to die at home.[85]

It is important to point out that hospitals are entirely appropriate places for EoL care and death at times, such as when emergency care has been attempted for injured individuals and those suffering from sudden serious health problems. However, unnecessary and inappropriate care in hospital prior to death in hospital is a long-standing concern.[86] The use of special care units, with 24.6% of all deaths in Ontario hospitals occurring in intensive care or coronary care units, as compared to a 19.6% national rate, underscores this concern.

The much longer average length of stay for terminal hospitalizations involving special care units (i.e. 8 days versus 4.8 days), and the much longer average length of stay for all hospitalizations ending in death as compared to other hospital stays (i.e. 13.9 versus 5.6 days) indicates that much more needs to be done to identify terminally-ill and dying persons in hospital and elsewhere. Transfers out of special care units, transfers out of hospital, and a reduction in hospital admissions would be increasingly possible then for quality EoL care purposes.

High quality EoL care outside of hospital is particularly important for reducing the need for hospital care. If EoL care needs were more successfully met outside of hospital, hospital admissions could be avoided. This point is particularly relevant for the 24.6% of people who died in Ontario hospitals after being admitted from places other than the home, often long-term care facilities and other facilities designed for aged care. This finding indicates that all types of aged care facilities should be encouraged, to set up and provide onsite palliative care services to ensure residents can remain comfortably in place and die in place. Funding could be designated, for instance, for hiring nurse practitioners since they can assess sudden illnesses or symptoms and can prescribe pain and other medications to negate the need for transfers to hospital. Funding could also be used for extra staffing to ensure dying persons can receive more hours of care onsite in the last days of life. Consequently, these care facilities could be recognized for providing high quality palliative care, a recognition important for reducing the public's reliance on hospitals for EoL care purposes.

Currently, hospices alone are recognized as places where high quality EoL care is provided. However, hospices are not numerous in Ontario nor anywhere else in Canada, and they are often limited in bed numbers and services as most rely in part or in whole on private donations for operational funding.[87] Another issue is that no CIHI or other database has been set up to capture hospice data. It is not known then how often death takes place in hospices, nor who uses hospices and what care is provided to dying persons in hospices. Unless hospice data begins to be collected routinely, hospices will continue to be overlooked as a viable place for EoL care. Hospices will likely require public funding for expansion, so as to gain capacity for providing the EoL care that is otherwise often provided now in hospital.

Developing alternative places for EoL care is particularly important, as the vast majority of people who died in Ontario hospitals were admitted through the emergency department (81.6%). Similarly, most people who died in Ontario hospitals arrived by ambulance (71.2%). These findings indicate that unmet care needs and sudden changes in health are major factors for these end-stage EoL hospitalizations. Other studies have pointed out that care needs appear and change as death nears.[88] Efforts to provide rapid and effective ongoing support for caregivers at home or elsewhere when needed are therefore indicated. This could be in the form of visits by nurse practitioners who arrive by ambulance after a call for help or a call for an ambulance has been made, daily home care services to ensure family caregivers are not overburdened when providing home-based EoL care, overnight home care services to allow family caregivers to sleep, respite services (either onsite or offsite to allow family caregivers to leave the home to do necessary activities), telehealth (a 24/7 telephone line used to reach a palliative care nurse for advice and support), or regularly scheduled and extra as needed palliative team visits over the course of a terminal illness. All of these services would reduce the need for transitioning from one care setting to another for needed care or because family members are overwhelmed or exhausted providing home-based EoL care. Family caregiver burden is a major issue in Canada.[89]

All such services would be useful for any person needing EoL care. They would be of help, for instance, to the 47.7% only admitted once to hospital in the last 365 days of life. They would also be helpful to the 53.3% who were admitted 2 or more times to hospital with recurring or worsening health and unmet care needs. All however would benefit from initial and ongoing EoL care planning through the services of a case manager or care coordinator. The identification of individuals who are near the end of life and a determination of their care needs is necessary.

It is possible, for instance, that people need to be admitted to a hospice or long-term care facility for quality EoL care.

These suggestions are in keeping with the findings that reveal the home is a very common place of EoL care, including the finding that 84.3% of all discharges from hospital in the last year of life were to the home. This means most terminally-ill people are essentially discharged from hospital in the last year of life into the care of their family or the care of themselves. Among other imperatives, education is needed before or upon discharge to ensure that this home-based EoL care is safe and effective.

It is also notable that some discharges from hospital in the last year of life were to other care facilities, such as long-term care facilities (2.6%), homes for the aged (2.2%), and chronic care facilities (1.4%). As such, these places clearly are providing EoL care and so would likely benefit from education and other mechanisms to ensure effective onsite EoL care exists. This point is reinforced by the finding that only 17.7% of the people who died in hospital were admitted directly to a hospital bed, with most needing to go through the emergency department and thus experience two care setting transitions. The transfer of a dying person from a care facility to an emergency department indicates that sudden health problems common to the dying process are not being effectively managed. Ideally, all such problems should be addressed onsite, with this being a quality indicator for compassionate high quality facility-based EoL care. All transfers of a terminally-ill or dying person to an emergency department would then be avoided.

Individualized care planning is essential for addressing the EoL needs of each person, however, the finding that only 381 of all 41,370 deaths (0.9%) in Ontario hospitals occurred during an intervention, such as cardio-pulmonary resuscitation or surgery, is highly significant. This finding demonstrates that for the vast majority (99.1%) of cases, the death was anticipated since no efforts were made to attempt to stop death from occurring. Although earlier efforts to save life may have occurred, this finding shows hospital services are not used and therefore not needed at the time of death. Hospitals could therefore be replaced by other care settings for end-stage EoL care. The transfer out of hospital to a preferred death place would be appropriate for these cases.

Avoiding hospital admission would also be appropriate for those hospital patients diagnosed with the highly non-specific most responsible diagnosis of factors influencing health status and contact with health services (24.5% of cases). In these cases, an illness is present that has led to the hospitalization but there a specific diagnosis is not possible. The remaining diagnoses are more specific to a disease noted for impacting the body, but these similarly could be end-stage.

It is also notable that of all persons who died in Ontario hospitals, 52.7% were male and 47.3% female, with this gender distribution the opposite of those discharged alive (43.1% male and 56.9% female). These findings reveal males use hospitals more often for EoL care purposes. Research should determine why this gender-based difference is occurring. Although males may suffer from different types of illnesses causing death than females and although males typically die younger than females , it is of concern that males may be less likely to get home care services or be admitted to long-term care facilities and hospices for EoL care.[90]

This study also found people who died in Ontario hospitals are much older on average than those admitted to and discharged alive from hospital (75.5 and 48.2 years of age respectively). Advanced age is often accompanied with multiple incurable chronic illnesses, and senescence or the wearing out of bodily organs and functioning.[91] For this reason, it would be advisable for older persons to be routinely monitored to identify those needing EoL home care services. This monitoring would also identify those needing care in a long-term care facility or another aged care facility.

However, before concluding, it is essential to note that 41.2% of all Ontario residents who died in 2014-15 died in a hospital bed. This 41.2% rate is considerably higher than the 32.9% Canadian (excluding Quebec) rate, which emphasizes the need for action in Ontario to reduce the use of hospitals as places of EoL care and death. However, the 41.2% rate also means nearly 60% of deaths in Ontario are already taking place outside of hospital. In 1994, nearly 80% of all deaths in Canada and thus the vast majority of end-stage EoL care took place in Canadian hospitals.[92] As such, this demonstrates that change can occur. Efforts to shift EoL care out of hospital are needed now, as every emergency department visit, every hospital admission, and every hospital discharge is a care setting transition that introduces the risk of care mishaps and other EoL quality concerns such as disrupted care teams.

E. Conclusion

This study involved an analysis of Canadian hospital utilization data, with a specific focus on Ontario residents who died in hospital in 2014-15 and their use of hospitals over the last year of life. The findings demonstrate care setting transitions involving hospitals are relatively common in the last year of life, and with many potential care setting transition issues then of concern. A qualitative study follows to gain needed insights and advice from key informants across Ontario (i.e. healthcare providers, healthcare managers, healthcare lawyers, and healthcare recipients and their family and friends) about EoL care setting transitions issues and solutions.

IV. A QUALITATIVE STUDY OF END-OF-LIFE CARE TRANSITION ISSUES AND SOLUTIONS INVOLVING CONSULTATIONS WITH ONTARIANS

A. Background

1. Purpose and Scope of this Qualitative Research Study

This chapter presents a research study that was conducted in mid-2016 to gain insights and advice from key informants across Ontario on the topic of EoL care setting transition issues and solutions. This study was undertaken to supplement current knowledge, as the existing research literature base does not provide much evidence to improve EoL care transitions. Moreover, a literature review of research reports published in the years 2000 to 2016 did not reveal any qualitative studies on EoL care setting transitions had been conducted in the province of Ontario. A qualitative study was planned, as information gained from key informants is critical for an in-depth understanding of a topic.[93] This information is also often needed for action on preventing and addressing concerns.

B. Qualitative Research Data Gathering and Analysis Method

1. Grounded Theory Overview

Grounded theory was the chosen qualitative research method. Grounded theory dates from the 1960s when Glaser and Strauss used interviews and observations in healthcare facilities to identify social processes involving dying patients and learn how these social processes influence the interaction of nurses with dying people.[94] They used the technique of constant-comparative data analysis as they gathered qualitative data to develop a theory.[95] Theories that are grounded in the data help to explain underlying social and other processes.[96]

2. Grounded Theory Research Study Plan

This study was undertaken after research ethics approval was obtained on March 23, 2016 from the University of Alberta's Health Research Ethics Board (#Pro00063626).

i. Data Collection

Data were collected through 39 interviews conducted in the months of April and May 2016. These interviews ranged from 15 to 43 minutes in length, and most were conducted by telephone. In each case, after informed consent was confirmed, the interview focused on two primary questions:

1. What do you see are issues or concerns with EoL care setting transitions, in other words the moves from one place to another that people can often make in the last year of life?
2. What solutions do you think are present or are needed to address or prevent these issues?

ii. Data Analysis

All interviews were taped and each tape transcribed verbatim to permit an ongoing analysis of data. This ongoing analysis of data as collected was useful for adapting the interviews over time to confirm or improve our understanding of the emerging themes and to probe new areas that needed to be explored. Each transcript was read through multiple times and subjected to line-by-line manual coding. Coding is the identification of key points of information. Over time, these codes were grouped together into categories, and then arranged in themes.

iii. Sample Characteristics

The majority of participants reported on work-related experiences and perspectives. The interviewed people varied considerably in their healthcare experiences and perspectives, as they included registered nurses, nurse aides or personal support workers, nurse practitioners, physicians, paramedics, and social workers (some with specialization in hospice palliative or EoL care specialization). Other perspectives were gained from interviewing owners of healthcare businesses and a broad spectrum of healthcare managers (hospitals, long-term care facilities, home care, hospices, and other community-based organizations). In addition, the perspectives of government officials and policy-makers were included, as well as lawyers and other persons such as hospice volunteers, care recipients, and family members.

C. Qualitative Research Findings

Three overarching themes emerged from this new qualitative study. Each theme revealed many areas of concern and solutions. Illustrative quotes from participants for each theme are found in Appendix B to this report. In the following sections we describe these themes, including subthemes and possible solutions:

1. Communication complexities and related solutions.
2. Care planning and coordination gaps and related solutions.
3. Health system reform needs and related solutions.

1. Communication Complexity Issues and Related Solutions

All participants commented on communication complexities and difficulties as a major contributor to or cause of EoL care setting transitions issues. These were grouped into five categories:

i. Information gaps and information technology issues,
ii. Information privacy issues,
iii. Workload issues and workplace considerations,
iv. The avoidance of difficult conversations about death and EoL care, including avoiding using words such as “palliative” and “dying,” and
v. A lack of effective communication processes and methods or tools to facilitate communication among all persons needing to be involved.

i. Information gaps and information technology issues

Participants often commented on information gaps and information technology issues that negatively impacted EoL care setting transitions. One of the most commonly reported and concerning issues was minimal EoL-care related information being provided at or near the time of transfer from one organization to another. Hospitals were most commonly cited as providing little or no information for use by the receiving organization in determining how best to provide care for the dying person. In some cases, this lack of information was considered a consequence of concerns over protecting sensitive or confidential information but more often it was thought that workload issues contributed to a lack of time for routinely provided, timely, and clear verbal and other communication between two or more care providers.

Another issue is that a common chart or common set of forms and information tools do not exist. Most organizations have their own forms and communication methods, and so a common set of information was not available to share or receive. A related issue is that electronic health records exist in some organizations, but these are not accessible to all subsequent caregivers. Moreover, there is no common electronic record system for all formal (public and private) care providers to use.

Other issues were oriented to a great deal of information being collected but meaningful information not highlighted and shared, such as if the person is aware that they have been diagnosed as terminally-ill and/or is actively dying. Information is also not always shared with the right person, such as the next caregiver or caregivers, as the information may be delayed in reaching these caregivers after it is sent formally to the receiving organization. Delays in sending information are also common, with information often arriving days after transfer. In some cases, the person has died before the information to aid their dying process in another place is received.

Another related issue is that much information is needed to provide effective EoL care. EoL care planning is always needed, sometimes because of rapid changes in care needs, but also as EoL care can be provided over a long period of time. Care plans often need to be updated, such as after the transfer, as care needs have often changed and medications and other factors have also changed. Patients and families may not be well informed about these changes and so cannot confirm needed changes, with more education of patients and families thus indicated. Patients and families often do not know where to go for the EoL information they need. A government website or another source of easily accessible information and support does not exist. Public education programs on where to access information are needed.

Another issue is that some shared or available information is inaccurate, such as the daily medications list and current care needs of the person. Gaming was also raised as an issue, as some key information is not disclosed such as information that may delay or stop a transfer out of hospital. For instance, if the dying person needs one-on-one supervision after hospital discharge because of a mental illness or high risk of falling, this information may not be shared. Regardless of these issues, current and accurate information and information systems were identified as essential for safe, effective, and timely transitions from one care setting to another.

ii. Information privacy issues

A number of information privacy issues impacting EoL care setting transitions also became apparent. One issue is that volunteers may not be able to access information that is needed to provide care out of information privacy concerns. Many other caregivers are similarly impacted, and even patients experience delays in their receiving information about themselves because of information privacy concerns.

Lengthy and complex processes to ensure information privacy exists were cited as a barrier to using information. Timely information sharing is needed for the good of the dying person and their family. The lack of a common electronic health record that is used by all caregivers was said to be a factor that caused undue concern about information privacy and information sharing. Gaming was also a concern, as the requirement for privacy was used at times to prevent the sharing of information. One example of this is when long-term care facilities will not release information to family members who do not have power of attorney.

iii. Workload issues and workplace considerations

It was often said that healthcare and other staff in all care organizations are very busy and so important information may not be shared or shared in a timely way as it takes time to communicate effectively. Rushing to get all work done was a common problem, as this reduces the time available to communicate and the time available to read care plans and check to see that they have accurate and useful up-to-date information in them. A great deal of information is collected over time to read, with another issue being that needed information is not quickly and easily found. Caregivers consequently may not seek to find this information but act without it or ask the patient and family to repeat this information. Patients and families are often required to repeat information that they have already provided.

Home care staff and long-term care facility staff were often cited as having work overload concerns, but hospital and hospice staff also had workload concerns. For instance, home care nurses can easily find additional needed care at one home, or travel issues going from one home to another, with these delays impacting the rest of their day. Another issue is that it takes time to arrange and hold meetings, and time to talk person-to-person by phone. Few helpers such as unit clerks exist to make arrangements for meetings and discussions. Moreover, many care providers work daytime hours on Monday to Friday, but others work 24/7 and so a mismatch of care providers often occurs as the right people may not be available at the same time to talk or meet.

iv. The avoidance of difficult conversations about death and EoL care, including avoiding words such as “palliative” and “dying”

Many participants commented on patients, family members, and physicians avoiding difficult conversations and even avoiding the use of specific words such as “palliative” and “dying.” As a consequence of this avoidance, and particularly when physicians do not communicate “bad” news, EoL care plans are not made. If there has been no clear communication about diagnosis and prognosis, and an EoL care plan does not exist, whenever a change in health or care needs occur, the main recourse is to use emergency departments and hospitals for EoL care. Advanced life support is often started when these difficult conversations have not taken place.

Some dying people and their families delay making important decisions, such as necessary moves to a hospice or long-term care facility as they avoid difficult conversations.

Delayed or late communication is a related issue. It was often said that early communication could prevent many problems such as those arising from not knowing where someone wants to die. Care efforts to support dying in the place of choice cannot be made. As a result, hospitals are often used for EoL care as an alternative site is not ready. For instance, family members cannot arrive in time to provide EoL care at home. EoL care plans and related documents may not be completed until late in a dying trajectory as a consequence of avoiding difficult conversations.

Another issue is that dying people and their families may not be told the reason for a transfer from one place to another, or told in a way that they can understand the reason. Treatment failure or impending death is often the reason for a transfer. Repeated meetings or opportunities to absorb and accept bad news is often needed.

It was also often said that physicians need to be more comfortable and adept at sharing bad news. Medical schools are oriented to life saving care, with dying viewed a failure. This needs to change to ensure EoL communication occurs as needed. Sharing bad news is best, however, when a relationship exists between the parties. Transfers from one care setting to another often disrupts relationships. At times though, a move is needed to restore a trusted team or trusted individual to provide or enable needed EoL care.

v. A lack of effective communication processes and methods or tools to facilitate communication among all persons or groups needing to be involved

Participants often noted there was a lack of communication processes, methods, and tools to facilitate needed communication of information between and among all relevant persons. As a result, there was an over-reliance on written materials. Limited use of team meetings and person-to-person communication to facilitate transfers or ensure transfers were successful were commonly cited as issues. This care gap also included the lack of a designated person or persons responsible for continuing or ongoing EoL care assessment, care planning, and communication purposes. Many related issues were also cited, such as working family members being unable to attend care planning or other meetings during the day.

Care setting transitions necessitate not one but a series of conversations, with this requiring time and processes, such as advance care planning that states who the substitute decision maker is. Discussions are needed around what is desired care at the EoL, including the preferred place of death. Family burden discussions are needed and their sustainability for caregiving needs to be determined.

At times communication was not effective. Some participants commented that the sole apparent goal of EoL planning in hospital is to discharge the patient as soon as possible, with this goal not openly shared but still clearly evident. Of all organizations, the hospital was considered the predominant organization, with communications not equitable or open between care provider organizations.

Some issues were also noted with existing tools and processes. One issue was related to the use by long-term care facilities of “Level of Care” forms as a form of blanket consent. Even when the patient or substitute decision-maker is capable of making decisions, these forms were said to be used to move dying people to hospital for EoL care without any discussion with the patient or substitute decision-maker and therefore, without informed consent.

A lack of province-wide forms was also noted. Some regions had forms that are considered effective for facilitating communication and moves from place to place in that region, but these are not used in other regions. Effective forms and communications are needed to avoid moves from place to place. Moves from one region to another were highly problematic as each region could have different forms and processes. Another issue is that there is no central source of information or common care database, with considerable variability then in communication processes. For instance, some organizations ask for and record the preferred place of death and others do not.

It is difficult to discharge people to different regions, as there is little consistency in services. Care delays are also problematic, as it is common not to receive discharge summaries and other completed forms for 2 to 5 or more days after the person is transferred to another facility or transferred home. These forms need to travel with the patient as they move. Another issue is not having a consistent person as a contact for communication purposes.

Finally, a tracking system to record issues, tabulate and monitor trends in issues, and provide feedback to organizations for quality improvement is needed. Process mapping for the standardization of care is needed as well. Flagging people who are at risk of needing EoL support needs to occur as well, for routine follow-up processes and better care. For instance, telehealth services should be able to know that someone calling in is receiving palliative or EoL care.

vi. Solutions to communication complexities

Many solutions were provided for the many communication issues identified.

- Set up a common accessible electronic health record.
- Do studies to learn how to move and navigate people effectively from place to place.
- Create a website with information for use by patients and families to prevent and address communication issues.
- Educate family caregivers, so they know who to call or talk to.
- Include top executives and managers in all organizations in staff orientation programs to ensure all are aware of standard EoL operating procedures.
- Prepare and give “transition” courses so healthcare staff and other people involved in planning and arranging transfers have the knowledge they need for safe, effective, appropriate, and timely transfers.
- Set up public notice boards and advertisements that advise the public on EoL services are needed for public education and self-help purposes.
- Ensure all dying and all elderly people have an EoL care plan.
- Early referral to palliative care teams or community care teams is needed to start care planning and EoL care early in the dying trajectory.
- Provide night support for family caregivers, with nurses available by phone to give advice and assistance.
- Have palliative care teams teach hospital staff and family physicians to be comfortable having difficult conversations.
- EoL discussions need to be started at the time of every diagnosis of a serious and potentially life-limiting illness, to avoid being started in the last days of life. EoL discussions also need to start routinely at the age of 80.
- EoL discussions need to be focused on if the person wants to die at home or in another place, with care planning proceeding from this point.
- Mandate the use of the LEAP program for palliative care courses.
- Host events such as Death Cafes and other death awareness for normalizing discussions and planning for the EoL.
- Sponsor a public education campaign such as “Looking Ahead” so more people start conversations about the future and their EoL wishes.

- Educate the public on hospices and palliative care so that people know about existing care options for the EoL and for actively dying persons.
- Post hospice standards of care, so members of the public and others know that they do not offer blood transfusions and other invasive treatments such as CPR to extend life when someone is dying.
- Have a case manager arranged for all EoL-designated persons.
- Have a travelling document for the patient to keep test results and other information in, including surrogacy and death wish information, and transfer documents.
- Mandate a verbal conversation between the two most responsible nurses or other care providers that is to take place at the time of transfer between two care settings; this could be designated as a Transfer of Accountability, with accreditation standards for monitoring this.
- Make the sending facility responsible for providing accurate and timely information to the receiving facility.
- Have EoL care plans available for ambulance teams to use.
- Have regular team conferences to discuss patients and their care needs.
- Start a common health care record for all dying persons, one that is used across all sectors.
- Set up a tracking system for care setting transition errors, with this monitored and used for improvement purposes.
- Use the preferred place of death as a quality indicator, and routinely monitor the provincial rate at which the preferred site is achieved.
- Identify and stop using forms and processes that are not helpful.
- Develop process maps by multi-sector teams so as to better integrate sector movement, so care setting transitions become a focus of attention.
- Flag palliative and dying patients, so that they can be noticed and given the care they need, and with this also permitting permit research and system monitoring for quality care improvements.

2. Care Planning and Coordination Issues and Solutions

Almost all participants indicated directly or indirectly that care planning and coordination gaps and issues were common. Two categories within this theme were evident:

i. most moves are not well coordinated, and
ii. some patients and families pose challenges that restrict or impede EoL care planning, care coordination, and care options.

i. Most EoL moves are not well coordinated

Many reported that EoL care in the last year of life is not well coordinated and moves therefore do not often go smoothly. None could indicate however what percentage of care setting transitions were problematic. Most indicated that moves out of hospital were more often problematic, but no records have been kept to identify the types of transitions that are more problematic nor how serious these transition problems are.

Instead, most indicated that many different problems or issues were common in relation to EoL care setting transitions, including delayed or missed moves such as the move home for those wanting to die at home. One of the most common cited issues was around patients being sent home from hospital with home care promised and yet it would be days or even weeks before home care support is provided, if at all.

Comprehensive care planning is also often not done, with patients and families not knowing what is available or advisable for them. Little, if any, remedial or immediate assistance is available to them, such as when hospital patients are sent home with a prescription for the wrong medication or without needed equipment. Most often though, patients were sent home on the understanding that they would receive home care services, and they had no recourse other than to go back to hospital when none was provided that day or more. Long-term care facilities were also cited as problematic for their lack of efforts for smoothly transferring people out and receiving people, but with this associated with low staffing levels and with staff having minimal care qualifications.

Most moves from any care setting to another were often said to be not planned or scheduled, but instead reactive to an acute symptom, a new care need, or the need to open up hospital beds. Yet, at the same time, when somebody is dying, transfers often do not happen quickly enough so the person can be in their preferred place of death. Only a few facilities or organizations have home care coordinators or patient navigators, and many of these do not go to the home for a home visit or keep in touch with the patient and family after the transfer out of their facility.

A final issue was that no meetings or any other mechanisms exist to notice, track, or help make care setting transitions more optimal. Moreover, nothing is mandated by the province or another other organization such as an accreditation body for optimal coordinated EoL care setting transitions.

ii. Some patients and families pose challenges that restrict or impede care planning, care coordination, and care options

Some patients and families pose challenges that restrict or impede care planning, care coordination, and care options. Some people require different types of services than most others, and with these special services often limited in availability. For instance, people with dementia, mental illnesses, demanding families, immigrants who do not speak the language used by those around them, and people who do not live with or near any family members pose additional challenges for care planning and coordination. In all cases, however, as death nears and care needs increase, it becomes increasingly difficult to find organizations with the skills, knowledge, and abilities to provide end-stage EoL care. Yet at the same time, few hospices exist and some existing hospices are underutilized.

It was also noted that home deaths may be a preference for most dying persons and their families, but not every person or their family wants a home death to occur. In addition, many dying persons do not have able family members living near them, and so lack the ability to call on family members for help when terminally-ill or dying. Some dying persons have no family members to call on.

Another cited issue was the unpredictability of terminal illnesses, with only a few dying processes having a relatively predictable trajectory but most not having this option which helps with advance care planning. With long dying processes, alternative care sites such as long-term care facilities may be needed. However, wait lists are problematic for transfers to a long-term care facility, particularly to preferred ones, such as those close to the family or home community for easy visitation. The last issue identified is that the considerable variability among dying persons means highly individualized care planning is required. Standard care plans may have limited usability or relevance as a result.

iii. Solutions for care planning and coordination issues

The participants provided many solutions to prevent or address care planning and coordination issues.

- Have care staff rotate through long-term care facilities, home care agencies, and hospices to ensure they have professional insight into the functions of each sector of the EoL healthcare system.
- Educate patients and families about the services available to them.
- Have a hospice nurse visit potential clients in the home or hospital prior to arrival at the hospice to answer patient or family questions, and gain insight about the patient to plan and set up care at the hospice.
- Similarly, have home care nurses visit expected clients in hospital.
- Set up a central electronic health record to increase ease of access to patient information.
- Use the U.S. National Transitions of Care Coalition initiative to increase emphasis on care setting transitions.
- Assess people at home weekly to catch issues early and notice changes and changing needs.
- Develop a standard province-wide care plan for dying people that includes common medications, equipment, and services that can ordered by any team or team member as required.
- Screen all persons 75 years of age and older prior to being discharged from hospital for EoL care and dependency care needs, such as the need of meals on wheels.
- Ensure promised services at home are present prior to discharge home.
- Have a care coordinator who presents EoL care options to patients and their families, and who determines their preferred place of death, with a back-up place in case of issues going forward.
- Have nurse practitioners in every hospital and long-term care facility to be able to assess all persons for EoL care needs, and to directly assist care setting transitions.
- Enhance the EDITH Program (Expected Death in the Home), so it is province-wide; with this set up to have a nurse work with the patient and family for an expected death in the home; with this program including someone who can pronounce a death at home, sign the death certificate, and also with the funeral home listed and prepared for arrival and thus prevent ambulance calls.

- Set up primary care teams for all EoL-designated persons that are comprised of a family physician, nurse, palliative care case manager or coordinator and others as relevant such as a social worker and spiritual care support person.
- Mandate direct admissions to inpatient hospital beds, with the emergency department bypassed, for all persons designated as EoL or palliative.
- Mandate all healthcare staff to have an appreciation of the importance of cultural diversity to ensure respect for all cultures and cultural practices.
- Ensure a translator is available, to avoid relying on family members for translation.
- On admission, check all medications for accuracy by a responsible person, such as a pharmacist or nurse practitioner or registered nurse.
- Develop or update each person's care plan on admission and at least every 2 weeks after that.
- Develop and provide palliative care education to staff and the public.
- Prior to discharge, hold a meeting, with the patient inviting anyone they wish to the meeting to discuss with their healthcare providers their care after discharge.
- Set up a community respite service out of every hospice or home care agency to visit people in the home and provide supportive and visiting services in the home.
- Expand and use the Consent and Capacity Board to be proactive about potential dispute situations.

3. Health System Reform Issues and Solutions

Health system issues were also frequently reported for their impact on EoL care setting transitions. Many different types of health system issues were reported, with these grouped into five categories:

i. a shortage of beds and services to support dying persons,
ii. fragmentation of the healthcare system, with "silos" of public and private organizations delivering only their specific package or a narrow set of services and often only in a defined geographic area,
iii. an absence of core services, ones that exist and are assured in all parts of the province,

iv. an overreliance on the family physician to assess and plan EoL care, and
v. the limited scope of practice and reduced role capacity of registered nurses, paramedics, and nurse practitioners.

i. A shortage of beds and services to support dying persons

It was quickly made apparent that hospital emergency departments and inpatient hospital beds are always available for EoL care purposes as compared to most other essential non-hospital services for terminally-ill and dying persons. These other services were either not available or not immediately available and accessible. Home care services are limited, hospices are limited in number and scale, and long-term care facilities are usually full and so cannot accept a transfer in until a death of a resident has occurred.

ii. Fragmentation of the healthcare system, with silos of public and private organizations delivering only their specific package or a narrow set of services and often only in a defined geographic area

Each organizational type (e.g. hospital, long-term care facility, community home care) and often each organization is now a separate entity within the province, with considerable separation between them based on the expected and funded function of each organization. Hospital services planning is therefore separate from home care services planning and long-term care facility planning. Moreover, different payment systems exist within or across these silos, with pay incentives creating issues such as unnecessary transfers or denied and delayed moves. One of the biggest issues however was that many EoL care sectors do not have 24/7 service provision. For instance, most family physicians do not work after five pm on Monday through Friday, with other parts of the healthcare system needing to provide EoL care outside of these hours.

iii. An absence of core services, services that are assured as available in all parts of the province

No core services to support terminally-ill persons and their families are assured in the province of Ontario. A basic package of services is therefore not available for people to expect and rely on as needed.

iv. An overreliance on the family physician to assess and plan EoL care

Family physicians have traditionally provided episodic care in the community, with hospitals and emergency departments also available for episodic care. However, the considerable amount of ongoing work associated with planning and arranging EoL care is beyond the capacity of family physicians who typically maintain busy practices with many other clients to care for. Many participants also cited the limited availability of family physicians, as calls from home care nurses for medication changes or other patient care needs, are often not returned.

Other issues involving family physicians were also cited. Many family physicians have not had additional post-graduate palliative care education and so struggle with planning and providing appropriate EoL care. Another issue is that few conversations about the EoL are originated by family physicians, despite many believing that the family physician is now the most responsible person for initiating EoL care planning.

Other issues related to family physicians were also cited. In many cases, the family doctor is not actively involved in the EoL care that is provided, with these physicians having given up their responsibility to other physicians in hospital or to other persons when the dying person is moved into a care facility or moved outside of their immediate community. As such, an informed and trusting relationship may be lost; one that may be helpful as EoL care decisions are made and the dying process enfolds.

v. The limited scope of practice and reduced role capacity of registered nurses, paramedics, and nurse practitioners

Scope of practice issues were often reported, as well as role capacity issues. Typically, these issues were related to paramedics, registered nurses, and nurse practitioners. Specifically, and as most commonly reported, registered nurses are currently not able to discharge patients from hospital and so enable needed or timely transfers. Often this issue is related to their inability to write a prescription for the same medications the patient is currently taking and which will continue after the transfer.

Other medication issues are associated with registered nurses, including home care nurses who often identify a need for a new medication or a changed medication dose or route, and all must now get a family physician to write the required prescription. Emergency department visits often occur because an order was not written by the family physician in time, if at all, to help the home care client. Similarly, long-term care residents are often sent to the emergency department because registered nurses and nurse practitioners in the long-term care facility cannot change a medication or start a new medication. No standing orders or a formula of permissible standard EoL medications exist for registered nurses to use to write prescriptions and therefore quickly ensure dying people have the medications that they need. Commonly, these are pain medications, nausea medications, constipation remedies, anti-anxiety drugs, and sleeping pills.

Ambulance calls also often result in a transfer to hospital because most ambulance staff lack the education and skills to diagnose common EoL conditions and then arrange for care in the home. Some ambulance staff with this additional education, such as paramedics, are confined like registered nurses to a traditional limited scope of practice. In addition, nurse practitioners are not used by ambulance services and so are not accessible for ambulance calls at home or by long-term care facilities. Moreover, if a completed Do-Not-Resuscitate (DNR) form is not found by ambulance staff, these staff feel compelled to start CPR and other forms of resuscitation even when the family is asking that it not be done.

vi. Solutions to Health System Issues

Many solutions were provided to address or prevent health system issues:

- Set a standard for nurse ratios and nurse staffing in long-term care facilities and home care agencies, so that people with EOL care needs can receive the additional care that they need.
- Ensure a similar educational requirement exists in relation to the care of frail-elderly persons.
- Ensure registered nurses and nurse practitioners can change medication orders and write medication orders for home care patients and long-term care residents, as well as hospital patients who could be discharged.
- Open up additional beds in hospices and fund hospices as an alternative to hospitals.
- Supplement the income of family caregivers, such as the Veteran Affairs program in the US that provides income to family members who have taken their course in home-based care.
- Develop comfort care teams in long-term care facilities to provide palliative and EoL care in designated rooms for dying residents and their family members.
- Admit all designated EoL persons directly to a hospital bed and bypass the emergency department.
- Combine hospices and home care to ensure coordinated community-based care occurs.
- Ensure all hospitals have an outreach nursing team to support patients discharged home over the first 24 hours of transfer or longer.

- Set up a hospital at home to be able to move seriously ill people out of hospital.
- Mandate the initial and continuing involvement of specialist palliative care teams for all persons dying of cancer and all persons dying with a great deal of pain and distress, with these teams responsible for the health and other care of these persons in all care settings.
- Ensure ambulance teams can take people directly to hospices to avoid hospitals.
- Ensure a 24/7 telehealth palliative crisis and support line exists, with hospices funded to set these up and maintain them.
- Ensure a rapid response nurse team exists in every city to go into homes to provide needed emergency EoL nursing care, with these nurses originating out of hospitals or hospices.
- Set up an EoL supply depot in each community, with medications and equipment needed for home use.
- Fund hospices so they can set up satellite clinics in small towns and rural areas.
- Always have an open bed in a local hospice available for immediate use.
- Encourage community groups to plan for a wide range of seniors and EoL services in the community.
- Develop a care standard that every person who wants to die at home can do so, and die there without pain and other symptoms.
- Set up standards for long-term care facilities to ensure high quality EoL care exists onsite, and that onsite deaths are not only possible but expected and welcomed.
- Ensure province-wide standards exist for palliative and EoL care in all rural and urban areas.
- Mandate clear and consistent definitions of programs, so that there is consistency in services and service expectations.
- Build palliative care expertise and frail-elderly care expertise within all primary care networks, hospitals, and community-care organizations, including ambulance teams, for mentoring of others.
- Ensure that any person can refer and that self-referral can occur to hospices, home care, and palliative care teams.
- Create centres of excellence in community EoL care.

D. Discussion of Findings

The findings from this grounded theory study involving key participants in Ontario revealed many different EoL care setting transition issues. These were clustered around the three themes of communication, care coordination and planning, and health system reform needs. Many solutions were also evident to the study participants, with these solutions outlined in this report in relation to the same themes. Although not all solutions were repeated across the themes in our presentation above, many of these solutions overlap from one theme to another, which indicates they are both necessary and possible. Each could be implemented on a province-wide basis as many solutions already exist in one or more areas of the province at the current time and as such have been trialed and found helpful. Other solutions need to be trialed or implemented immediately on a province-wide basis.

Many other solutions from other countries could be implemented as well. For instance, some UK hospitals are transferring people out of critical care units to home to die, with registered nurses who are familiar with the patient accompanying them home.[97] Another solution is the practice in some Canadian and American long-term care facilities to hire nurse practitioners to provide rapid onsite medical assessment and care, including prescription writing, with this aimed at reducing the need for hospital transfers.[98] Another solution is presented by registered nurses in Ireland, Finland and many other countries who can prescribe medications after a 6-month course in prescribing and drug management.[99] This ability of registered nurses to prescribe analgesics and other medications is expected to be very important for reducing the need for transfers and also for ensuring timely quality EoL care exists. Home-based dying persons and dying long-term care residents who develop a new symptom or concern needing medication would be benefitted, as well as hospital patients who want to die at home.

Another example of available solutions is standing orders, which are already commonly used in hospitals and elsewhere to improve access to needed medicines; for example, in New Zealand, paramedics in an emergency and registered nurses in primary healthcare settings use standing orders for palliative care patients.[100] Standing orders also ensure consistency as best-practice medications are to be used, and with standing orders also serving to reduce medication errors.[101] Standing orders in Ontario hospitals would enable registered nurses to discharge patients home with the list or a similar list of the same medications that they are currently taking in hospital. Standing orders could also be used in long-term care facilities, hospices, and homes by registered nurses, such as for EoL pain and symptom management. These and other solutions are more common in other countries and are likely to be very important for addressing EoL care setting transition issues in Ontario.

E. Conclusion

This chapter focused on EoL care setting transition issues and solutions identified by key informants across Ontario. The extensive list of issues and list of solutions clearly shows that much should be done and much can be done to prevent and address EoL care setting transition issues. Action is essential to eliminate the possibility of low quality transitions such as when mistakes and other mishaps occur with moving from one care setting to another. Frequent or repeated moves from one care setting to another should become unnecessary. Delayed and denied necessary or desirable transitions similarly should no longer occur. A move home from hospital for people who want to spend their final hours or days of life there should be a patient right and eventually a normal and supported practice.

V. FINDINGS, RECOMMENDATIONS, AND CONCLUSION

A. Overview

The purpose of this study conducted in 2016 was to inform the Law Commission of Ontario about the number, nature, and timing of EoL care setting transitions and to explore opportunities for improving the management of EoL care setting transitions between and within care settings. The research scope is focused on EoL care in Ontario. However, this scope included other jurisdictions both nationally and internationally to identify lessons for Ontario. The focus was on:

(a) core transitions within and across care settings,

(b) existing law and policy barriers to and supports for seamless transitions,

(c) the respective roles of health care and service providers in facilitating seamless transitions, and

(d) a range of options for improving transitions, possibly including simplification of the law, policies or processes; clear assignment of responsibility to providers; provision of additional supports; barrier removal and other options; and other issues considered to be of significant relevance to this topic; such as practical considerations needed to reduce the number of care setting transitions taking place in the last year of life and also those needed to improve and speed EoL care setting transitions when these moves are required.

A multi-methods information gathering and analysis approach was used that drew on reviews of existing research and grey or policy literature, a quantitative analysis of hospital utilization and patient data, and a qualitative study to gain needed insights, knowledge, and advice from key informants across Ontario on EoL care setting transition issues and solutions. This approach provided a wealth of information.

Each of these components was described in a chapter. As these three components were being conducted, the findings were used by the research team to develop conclusions and recommendations for policy and future research.

B. The Contextualization of Findings Gained from this Study

From system, social, and individual perspectives, there are shared interests in ensuring that EoL healthcare setting transitions reflect the needs of terminally-ill and dying people and respond to changes in those needs over time. Such an approach is required if the resources devoted to EoL care are to be used in ways that make the greatest impact on their well-being and that of their family and other caregivers. Ontario is not alone in this regard. All other provinces, and many countries are realizing that EoL care is a compelling, complex, and relatively new area of health and social concern.

Three major themes of findings emerged from this study. They can best be summed up as:

1. coordination,
2. communication, and
3. capacity.

1. Coordination

In terms of coordination, a fundamental problem faced is that EoL care is not planned, managed, delivered, and evaluated as a core healthcare or social program, but is instead included in care delivered under other healthcare programs (e.g., oncology or cardiology). This limits the capacity to assess, plan, and evaluate EoL care services, as do the limited information available on people with EoL care needs and no one person or organization responsible for people with EoL care needs. These concerns lead to inappropriate care setting transitions, low quality care setting transitions, and missed or delayed opportunities for needed or desired moves.

2. Communication

People with EoL care needs are often passed from place to place and between providers with no consistent care coordinator or case manager responsible for communication, ongoing assessment and planning to meet current and future EoL care needs. It is of concern also that EoL information is very limited, and many barriers exist to communicate effectively for the good of the person needing EoL care and their family and other care providers. Information gaps and other issues as a result prevent or delay appropriate care setting transitions from taking place, introduce considerable risk of mistakes and other mishaps occurring with each care setting transition, and lead to inappropriate transitions occurring.

3. Capacity

Many EoL care capacity issues were also identified, with these not only common but serious with regard to their potential for the inadvertent use of hospitals for EoL care place. Low capacity for home-based care and long-term care are highly problematic, as is a limited supply of hospices and hospice beds. EoL care currently tends to be located wherever service capacity is available, as opposed to where services are required to best serve individual and family needs. There are wide variations in practice between Ontario communities which are largely driven by variations in the levels and mix of local capacities to serve people with EoL care needs. This takes us back to the problem of EoL care not being organized as a self-standing and single program for which services, financial resources, and human resources can be planned in accordance with population needs.

C. Findings

Ideally, care setting transitions would respond to and reflect the changing care needs of people as they near the end of life. Care needs often change over the course of a life-limiting illness and also as the end of life approaches for people who have reached advanced ages. However, the insights and evidence from the reports indicate EoL care setting transitions are often problematic as they reflect a model where EoL care setting transitions are “fit in” to existing services, service availability, and service configurations.

Appropriate care setting transitions are often delayed or even denied as a result of service capacity constraints and existing regulatory provisions. This “supply” driven approach has adverse effects, not only on the people who have EoL care needs, but also their families and the healthcare system as a whole. Mistakes and other mishaps arising from care setting transitions are of widespread concern. Delays in “processing” transitions from acute care hospitals leave existing hospice beds underutilised, increase hospital stays, and reduce the possibility of respecting and addressing the dying person’s and their family’s EoL place preference. Similarly, delays in (or failure to) provide community-based team care in homes and long-term care facilities are associated with an increased probability of emergency department visits, hospital admissions, and death in hospital.

While nursing care is provided without charge to all patients in hospitals, the limited supply of publicly-funded home care services leaves many of the people who have EoL care needs at home and their families with the choice of having to pay privately for home nursing care or go without and risk family caregiver overburden and other care crises. These crises often result in unplanned hospital admissions through the emergency department. So, although in principle, an EoL care setting transition from hospital to home might be appropriate, in practice a “care setting trap” exists as benefits are not transferable across care settings.

Care-setting transition problems extend to the way care providers are funded. Although evidence supports the use of the same care team to provide EoL care across settings, funding remains setting or facility-specific with terminally-ill and dying people having to follow funds as opposed to funding following them. Consequently, with each move, there is a loss of the team members who have come to know the person and understand their care needs and interests.

Moreover, the "diagnostic and curative" focus of much of the healthcare system, and in particular the predominant fee-for-service physician remuneration system means that these providers often do not have the capacity to develop a plan for the end of life in consultation with people facing the end of life and their families, and ensure that this plan is implemented and adjusted over time as required. At the same time, the funded and traditional professional scope of practice of the physician in the healthcare system limits the ability of others, such as registered nurses and nurse practitioners, to assume or contribute to timely and effective EoL care setting transitions.

Good communication between different care providers, as well as between providers and patients, is essential. However, good communication takes time and effort. Although there is a fee code for physicians engaging in discussions with their patients regarding advanced care planning, this fee-for-service approach tends to reward the 'ticking of boxes' and fails to accommodate the differing needs of terminally-ill and dying persons as they experience their trajectory to death. Moreover, healthcare and other information does not routinely follow and assist people with EoL needs across care settings because of limitations in infrastructure and policy for information collection and sharing.

Finally, people with EoL care needs are often passed from place to place and between providers with no consistent single care coordinator or case manager responsible for the ongoing assessment of needs and the informed planning required for meeting current and future anticipated or experienced EoL care needs.

In general, EoL care is not planned, managed, delivered, and evaluated as a core healthcare program, but is instead included in care delivered under other disease or facility-based and silo specific programs. This lack of a dedicated core program for EoL care greatly limits the capacity to assess, plan, and evaluate EoL care services in and across the province of Ontario. One of the results of this lack of recognition of the distinct and special needs of terminally-ill and dying persons is that there is limited information available on people with EoL care needs. EoL patients often cannot be identified as such in hospital and other databases. Moreover, information on care setting transitions is largely limited to the potential for counting the number of moves that occur in and out of hospital or through hospital emergency departments;

with no information collected routinely on other care setting transitions such as from one long-term care facility to another or from one private residence to another. Finally, and most significantly, information does not exist on the quality of EoL care provided in any care setting and the quality of care setting transitions.

D. Recommendations

Drawing on the evidence from each part of the analysis, it is clear that the issue of EoL care setting transitions is not simply a matter of people being required to move from one place to another place to have their care needs met or because of a failure of their care needs being met in the current place. Nor is this simply an issue of moving frequently in the last year of life.

Some terminally-ill and dying people do experience too many moves as they are passed between settings because of the inadequate capacity of their current setting to deliver the required care. Of great concern is that shortages and other issues in community-based care often lead to hospital emergency department visits and hospital admissions. In other cases, terminally-ill and dying people may not experience enough moves or the right moves because a system of EoL care is not in place to support appropriate care setting transitions, such as from hospital to home or hospice, and from home to hospice or long-term care facility. Mistakes arising from often hasty and minimally planned care setting transitions, and care mishaps such as delayed moves and the inability to die at home for many are risks of the current piecemeal approach to EoL care.

Unfortunately, many of these issues and concerns have already been recognized in Ontario. For instance, in 2010, the Quality Hospice Palliative Care Coalition of Ontario's strategy for creating an integrated hospice palliative care system in Ontario presented a blueprint for quality EoL care, one that included improved care setting transitions.

The challenge for policy makers and others is therefore to take action to develop policies and strategies now that enable, build, support, and reward optimal and appropriate EoL care setting transitions. Optimal care setting transitions reflect the needs of people as they near the end of life. These needs often change, with changing needs anticipated and expected for quality EoL care. Recommendations for addressing these challenges fall into six broad areas:

1. The organization and provision of EoL care as a core program integrated across all care settings (largely home, hospital, hospice and long-term care facility) through registered nurse case managers and community-based care teams. This would involve:

1.1 EoL care services delivered by interdisciplinary teams that include registered nurses, other licensed nurses and personal support workers, physicians, nurse practitioners, paramedics, and other professionals or para-professionals as required.

1.2 The quantity, type, frequency, and timing of EoL care provided reflect the needs of the person, as opposed to administrative rules and traditional distinct working as funded practices of providers and provider organizations.

1.3 Formal education in EoL care for all team members.

1.4 EoL services are available on a 24/7 basis to meet the needs of the person.

1.5 Additional organizational practices specific to EoL care in health system and accreditation protocols. These should include: (a) the identification of patients with EoL care needs and those who are actively dying, (b) the routine referral of terminally-ill, dying, and frail-elderly people and all persons with potential or actual EoL care needs, to community-based EoL teams or specialist palliative care teams when required; (c) the identification of a case manager for ongoing care assessment and care planning, and (d) the use of designated staff and an information system for the new responsibility of managing and overseeing care setting transitions prior to and for one month following every care setting move,

1.6 The development, expansion, and assurance of specialized palliative care services across Ontario for those in need of specialist management.

2. The development and implementation of mechanisms permitting and enabling the early recognition of EoL care needs or potential for EoL care needs, and subsequent routine referral for EoL care and specialist palliative care. This would involve:

2.1 The development, selection or adaptation of an EoL recognition and referral protocol that is being used in other jurisdictions for adoption across Ontario.

2.2 The introduction of payment and other mechanisms to support the employment of nurse practitioners in long-term care facilities and home care programs.

2.3 The introduction of policy and educational programs to support registered nurses in discharging patients from hospital or other care homes, and EoL medication prescribing by registered nurses within hospitals and other care settings.

2.4 The introduction of policy and other mechanisms to support the employment of registered nurse case managers for EoL care clients across the province.

3. Improvements in the capacity of hospices to provide onsite and community-based EoL care, and improvements in the capacity of homes and long-term care facilities to provide EoL care. This would involve:

3.1 The development of a population needs-based approach for determining the appropriate number and distribution of hospice beds in Ontario.

3.2 The introduction of mechanisms to transfer financial and human resources from hospitals to hospices in line with shifting EoL care capacity.

3.3 Changing hospital policies and practices for transfers and discharges from hospital. This may include changes in professional scopes of practice such as RNs using delegated authority or standing orders to discharge patients and provide them with a list of current medications and care instructions for post-hospital discharge.

3.4 The development and broad-based use of standing orders by registered nurses, paramedics, and nurse practitioners to prevent delays in EoL clients receiving the medications or care needed due to the unavailability of the responsible physician.

3.5 The introduction of formal staff complements (defined quantity and skill mix) in all non-hospital settings based on what is required to maintain EoL clients in each care setting.

3.6 The development of sufficient capacity for assuring family caregivers and EoL clients of respite care services, 24-hour telehealth palliative nurse support services, and increasing support in the home and long-term care facility as death nears or as EoL care needs escalate.

4. The development of an EoL client and care information system, and the assurance of information access care settings including across formal and informal care providers. This would involve:

    4.1 The development of a province-wide patient-based EoL care information system and common chart accessible across all EoL care settings to support decision making, performance appraisal, patient and system monitoring, and policy or service developments.

    4.2 Privacy concerns can be waived by each EoL client, if they chose to have EoL volunteers or other persons and organizations informed of their care needs and interests.

5. The introduction of programs that support appropriate and timely care setting transitions in accordance with individualized EoL care needs and preferences. This would involve:

    5.1 The development and introduction of a province-wide program to support appropriate care setting transitions and avoid financial barriers to EoL clients receiving the right care in the right place at the right time.

    5.2 The introduction of policies that avoid "care setting transition traps" where EoL clients lose benefits as a consequence of transferring from one setting to another. This should include extending full pharmaceutical coverage for all registered EoL clients to hospice, home, and other community care settings.

    5.3 Ensuring that EoL care programs are client based, with resources following clients across settings to ensure capacity in desired care settings, as opposed to clients being placed in whichever setting has the resources or immediate care capacity.

    5.4 Monitoring the number, type, reason for, and outcomes of care setting transitions to enable effective resource planning and evaluation.

6. The introduction of public education initiatives encouraging citizens to embrace advance care planning and determine the type of care they want to receive at or near the end of life, and the setting or settings in which they want to receive care as they approach the end of life. This would involve:

   6.1 Every admission to any health care program or service in the province, and at annual or more often as required or indicated intervals afterward, include a routine request for advance care planning documents, such as Powers of Attorney, and in their absence, expressed wishes and plans for place of EoL care and preferred type of EoL care.

   6.2 EoL case managers reviewing preferences for type and location of EoL care at regular intervals and as required to ensure accommodating any changes in preferences, needs, or care circumstances.

   6.3 Advance care planning documents entered into the province-wide electronic patient chart or record and to be available to all authorized care providers in the province involved in the EoL care for immediate and ongoing care planning or provision.

   6.4 The development and introduction of public education initiatives on television, radio, and print media to enable and encourage citizens to envision their EoL care needs and options, and inform their advance care planning.

E. Conclusion

Although continued stasis in improvements needed for appropriate and high quality care setting transitions is possible, it is not advisable. Given the socio-demographic shifts occurring now and the continuing epidemiological transition towards chronic diseases, we can expect both the annual number of deaths and the number of people who can reasonably be expected to pass away in the next year to increase rapidly now.[102] By 2031, twice as many deaths will be occurring as compared to today. Already, there are close to 270,000 deaths each year in Canada now, with over 100,000 deaths taking place in the province of Ontario alone.[103] Many of the people who develop EoL needs will be elderly and will have few, if any, able-bodied family members to provide EoL care in the home.[104]

Care setting transition issues are of concern now, and they will become more problematic over time to individual Canadians and their families, the healthcare system, and Canada as a whole as this inevitable large-scale socio-demographic movement continues; unless evidence-informed and experienced-based services, changes, programs, and policies are implemented. Many care setting transition issues are apparent now, and with many different types of solutions ready to be tested or used to address them.

Developing policies and strategies to improve the planning, management, and delivery of EoL care setting transitions is essential for health system efficiencies and, more importantly, for improving individuals' experiences of a good death and dying process.

APPENDIX A SUMMARIES OF THE RESEARCH LITERATURE REVIEW

A. Table 1. Reviewed Research Literature Articles – Summary Points

Author(s), year published, and country or region of focus	**Focus of interest**	**Type of article**	**Findings or main points**	**Other factors**
Aaltonen et al. (2012). Finland.[105]	Compare the number and timing of transitions between care settings in the last 2 years of life among older people with and without dementia.	Research – quantitative using national registers, for all those who died in 2002 and 2003 at the age of 70+ (n=70,336). Study admissions and discharges from health and social care facilities (university hospitals, general hospitals, health centres, and residential care facilities) and time spent outside care facilities for 730 days prior to death.	The group that lived at home 2 years before death with a dementia diagnosis had 32% more care transitions than people without dementia, while the group that was in residential care facility 2 years before death people with dementia had 12% fewer moves than those without dementia. The average number of transition was highest in last 3 months of life. People with dementia had their last move more often between care facilities and	Dementia has a significant impact on the number and type of transitions. As the number of people with dementia increases, the quality and equity of care of these patients in their last years constitute a special challenge.

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			hospitals.	
Aaltonen et al. (2013). Finland.[106]	Analyze whether transitions between care settings differ between municipalities in the last 2 years of life among older people in Finland.	Research – quantitative using national registers, for all those who died in 2002 and 2003 at the age of 70+ except those living in small municipalities (n=67,027). Study admissions and discharges from health and social care facilities (university hospitals, general hospitals, health centres, and residential care facilities) and time spent outside care facilities for 730 days prior to death.	83.6% had at least one care setting change in last 2 years of life; median was 5 and mean was 7.7. The frequency increased as death neared as 67% moved in last 3 months of life. The municipality of residence had only a minor effect on the total number of care transitions. Greater variation was found between municipalities when different types of care transitions were examined. The largest differences were found in care transitions involving specialized care. Age, urbanity, and economic situation of the municipality had	It is not evident what factors are responsible for unnecessary care setting transitions; some care setting transitions are appropriate responses to patient needs.

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			an impact on several care transitions	
Aaltonen et al. (2014). Finland.[107]	Examine the frequency of burdensome care transitions at the EoL – last 90 days or less – and compare different types of residential care facilities, and changes from 2002 to 2008.	Research – quantitative using national health care and nursing home data.	9.5% had burdensome care transitions; multiple hospitalizations in the last 90 days were most frequent, followed by any transitions in the last 3 days of life. Some variance by facility type and a slight decrease since 2005 were noted.	Three types of potentially burdensome care transition: (1) any transition to another care facility in the last 3 days of life; (2) a lack of continuity with respect to a residential care facility before and after hospitalization in the last 90 days of life; (3) multiple hospitalizations (more than 2) in the last 90 days of life.
Abarshi et al. (2010). The Netherlands.[108]	Examine the nature and prevalence of transitions between Dutch care settings in the last 3 months of life, and identify characteristics associated with	Research – quantitative using mortality data gathered from general practitioner reports for 2 years, 2005 and 2006.	690 died 'totally expectedly and non-suddenly'. They made 709 transitions in the last 3 months, which involved a hospital two times out of three, and covered 43 distinct care	Multiple transitions between care settings in the last phase of life could jeopardize continuity of care and overall end-of-life patient care. Although the majority of the

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	them.		trajectories. The most frequent trajectory was home-to-hospital (48%). 46% experienced one+ transitions in their last month of life. Males, multi-morbidities, and absence of GP awareness of a patient's wish for place of death were associated with having a transition in the last 30 days of life; age of < or = 85 years, having an infection and the absence of a palliative goal were associated with terminal hospitalization.	'totally expected and non-sudden' deaths occurred at home, transitions to hospitals were relatively frequent. To minimize abrupt or frequent transitions just before death, timely recognition of the palliative phase of dying is important.
Abdulrahman et al. (2014). Province of Quebec, Canada.[109]	Determine variability of care in last 6 months of life for those dying of intracranial tumors.	Research – quantitative, using health care data for province of Quebec, 1,623 decedents.	90% of people had 1+ hospital admission and 23% spent 3 or more months in hospital in last 6 months of life, with 44% having	Higher care burden was associated with dying in hospital.

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			1+ ER visits and 30% being admitted 1+ times to an ER. 18% had a home visit from physician, 10% died at home and 49% died in hospital.	
Almaawiy et al. (2014). Ontario, Canada.[110]	Investigate association between increased family doctor continuity and location of death, and hospital and ER visits in last 2 weeks of life.	Research – quantitative involving health services and other data for 9,467 patients in 2006.	More continuity was linked with less odds of a hospital death, and visiting hospital or ER in last 2 weeks of life.	Patients with 4+ doctor visits per week were unusual as they had higher odds of hospitalization and death in hospital.
Alonso-Babarro et al. (2013). Madrid region, Spain.[111]	Evaluate the frequency of adult in-patient hospital deaths and the use of hospital resources in the last 2 months of life for adult cancer patients in two urban areas of the Madrid Region, and assess differences between one	Research – quantitative using healthcare, census, and mortality data for adults who lived and died in two adjacent areas near Madrid, one with a palliative home care team (this area had more acute	74% died in hospital, 17% at home, 6% in an in-patient hospice and 3% in a nursing home. Hospital deaths were significantly lower among patients in the PHCT area (61% versus 77%), as well as the number of patients using ER	They found a palliative home care team is associated with reduced in-patient deaths and overall hospitalization in the last two months of life. No description of the palliative home care team or their services was provided.

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	area with and one without a palliative home care team.	care hospital beds) and the other without one; for in-patient deaths, ER admissions, and in-patient days among 549 adult cancer patients who died in 2005.	and in-patient services (68% versus 79%, and 66% versus 76%, $p = 0.012$, respectively). After adjusting for other factors, the risk of hospital death was lower for patients older than 80, higher among patients with hematological malignancies, and lower among patients in the palliative home care area.	
Bainbridge et al. (2015a). Ontario, Canada.[112]	Examine the contribution of covariates for long-term care residents dying of cancer for having an ER visit in the last 6 months of life or dying in hospital.	Research – quantitative using health care data for all cancer decedents in Ontario, a total of 1,196 residents.	61% visited an ER in the last 6 months of life and 20% died in hospital. Some comorbidities, being younger, and the region of residence significantly increased the odds of an ED visit and/or hospital death.	Interventions are needed to avoid costly and potentially adverse transfers to hospital.

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Bainbridge et al. (2015b). Ontario, Canada.[113]	Determine predictive factors for not receiving home care, not receiving EoL home care, and late initiation of EOL home care services, and identify outcomes associated with no home care services, such as ER use in 12 to 6 months of life.	Research – quantitative using administrative provincial cancer care and home care and other healthcare and demographic data for 22,262 cancer decedents in the 2006 year.	25% never received home care in the last 6 months of life. People with hematological cancer, a comorbidity, rural region of residence, shorter survival, male, lower income, older age, and less prior ER use were associated with not receiving home care.	Publicly funded home care has been shown to reduce acute care use and improve quality of life for those nearing end-of-life; despite the known benefits of home care, many EoL cancer patients never receive these services.
Bainbridge et al. (2015c). Hamilton area of Ontario, Canada.[114]	Determine the perceptions of the processes of palliative care delivery reflective of horizontal integration from the perspective of nurses, physicians, and allied health professionals working in a palliative care network, and assess the utility of the tool used -	Research – quantitative survey in 2010 to collect information from nurses, physicians, and others.	86 respondents (85% response rate) placed high value on working collaboratively, most reported being part of an interprofessional team. The survey tool showed utility in identifying strengths and gaps in integration across the network and in detecting variability in	Impediments to horizontal integration may be reflective of workload constraints, differences in agency operations or an absence of key structural features.

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	Index of Interdisciplinary Collaboration.		factors according to respondent agency and profession. Support for interprofessional communication and evaluative activities were viewed as insufficient.	
Barbera et al. (2010). Province of Ontario, Canada.[115]	Describe the most common reasons for visits made by people dying of cancer to the ER in the last 6 months of life and the final 2 weeks of life.	Research – quantitative using administrative sources of health care data in 2002-2005.	91,561 patients died of cancer, 76,759 (84%) patients made 194,017 visits to ER in last 6 months and 31,076 (34%) made 36,600 visits to the ER in last 2 weeks of life. In both periods, the most common reasons were abdominal pain, lung cancer, dyspnea, pneumonia, malaise and fatigue, and pleural effusion.	For patients dying of cancer, a visit to the emergency department can be disruptive, distressing and exhausting. Such visits made near the end of life are considered an indicator of poor-quality cancer care.
Barbera et al. (2015). Four	Develop data-driven and	Research – quantitative	Benchmark rates based on the top	There is significant variation in EoL

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provinces, BC, Alberta, Ontario, and Nova Scotia, Canada.[116]	achievable benchmark rates for EoL quality indicators for people dying of cancer using administrative healthcare data from four Canadian provinces.	using administrative healthcare data for patients with cancer who died in 2004-2009 in the 4 provinces: ER use, intensive care unit admission, physician house calls, home care visits before death, and death in hospital.	decile performers were emergency department use, 34%; intensive care unit admission, 2%; physician house calls, 34%; home care visits, 63%; and death in hospital, 38%. Few regions met the benchmark rates.	quality indicators across regions. Benchmarks should help regions determine their relative performance for priority setting and resource deployment, and for quality improvement by decreasing variation and striving for a target.
Beynon et al. (2011). South London, England.[117]	Determine the prevalence and nature of palliative care needs in people aged 65 years or more (65+) who die in emergency departments over the last 12 months of life.	Research – quantitative, using routine hospital data from two ERs in South London. Patients aged 65+ living in the hospitals' catchment area who died in the ER during 1 year (2006-2007) were included. Palliative care	Over 1 year, 102 people aged 65+ died in the ED, frequently following an acute event (n = 90). 63.7% presented out of hours. 98/102 were admitted by ambulance, over half (n = 59) from home. Half (n = 50) had attended the same ER or been admitted to	Considerable palliative care need among older people who died in the ER, of whom only a minority were known to palliative care services. Previous ED and hospital admission suggest opportunities for referral and forward planning. Older people in

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		needs were identified by diagnosis and symptoms, and problems likely to benefit from palliative care documented in clinical records 3 months prior to the final ED attendance were extracted.	the same hospital in the previous 12 months. Over half (58/102) presented with diagnoses showing palliative care need. Of these, 29 had recorded symptoms a week before death and 28 had complex social issues 3 months prior to death. Only 8 were known to palliative care services.	need of palliative care must be identified and managed earlier to avoid undesired admissions and deaths in hospital.
Brumley et al. (2007). United States of America.[118]	Determine whether an in-home palliative care intervention for terminally-ill patients in the last year of life can improve patient satisfaction, reduce medical care costs, and increase the proportion dying at home.	Research – quantitative using data from two health maintenance organizations for homebound terminally-ill patients (N=298) with a prognosis of approximately 1 year or less to live plus 1+ hospital or ER visits in the	Patients randomized to in-home palliative care reported greater satisfaction with care at 30 and 90 days after enrollment and were more likely to die at home than those receiving usual care. In -home palliative care subjects were less	In-home palliative care significantly increased patient satisfaction while reducing use of medical services and costs of medical care at the end of life. This study, although modest in scope, presents strong evidence for reforming end-of-life care.

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		previous 12 months. Randomized control trial of usual versus in-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services.	likely to visit the ER or be admitted to the hospital than those receiving usual care, resulting in significantly lower costs of care for intervention patients.	
Burge et al. (2003). Province of Nova Scotia, Canada.[119]	Determine if greater family physician continuity is linked to the use of ERs in the last 180 days of life among persons dying of cancer.	Research – quantitative using (1992-97) routinely collected health care data.	8% of subjects who had more than one family doctor caring for them were in an ER 2 times versus 0 times for subjects with only one family doctor caring for them. 69% died in hospital, 25% got palliative care	ER use was necessary and appropriate at times.

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			services, half were in hospital 0-16 days and half 17+ days in the last 180 days of life.	
Burge et al. (2005a). Halifax, Nova Scotia, Canada.[120]	Describe the distribution of transitions in care experienced by hospital patients following their admission to a comprehensive palliative care program (PCP).	Research – quantitative using 1998-2002 PCP and hospital data for 3,974 adult hospital patients. Moves or care setting transitions were counted from the day of PCP admission to death.	3,974 patients had 5,903 transitions (mean 1.5; median 1). Those with no transitions (28%) were older (80+), died <2 weeks, had a hospital death, and did not have cancer. 41% were moved 1 time and 31% had 2+ moves. 66% were on an acute care unit before PCP. 54% of moves were to the home (only 60% got home care from PCP staff), 27% of moves were to another hospital unit, and 17.5% to a nursing home. In the last 4 weeks of life, 47% had at least one transition; 36% of moves were in	A late shift in care focus to palliative care was evident as hospitalized patients were often identified as end-stage or dying and then PCP care was initiated. Most PCP patients had cancer. 40% died 15 days or less after PCP admission. 85% of PCP patients died in 6 months or less.

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			final 2 weeks of life.	
Burge et al. (2005b). Nova Scotia, Canada.[121]	Describe trends in family physician visits and other health care in last six months of life advanced cancer patients during a time of hospital downsizing.	Research – quantitative using health care data for 7,212 patients who died of cancer in 1992 to 1998.	15% of visits were in office, 10% at home, 5% in ER, and 64% in hospital despite hospital bed closure and shorter hospital stays.	Physician practice had not changed, except that more visits with patients were in the ER now.
Carey et al. (2015). England.[122]	Describe development and outcomes of an EoL care bundle for hospital patients who may be in last 1-2 months of life. Care bundle has 2 identification questions, 4 time-restricted activities, and systematic daily follow-up.	Research – quantitative, after care bundle was developed and implemented, the outcomes of it were determined for 638 hospital patients in 2011-2012.	Only 42.8% died in hospital (compared to 53% national rate) and only 14.5% were readmitted to hospital via the ER in 30 days of hospital discharge.	It is important to ensure recognition and timely response for patients near the EoL. This care bundle prompts the team to 'stop' and review, better teamwork between healthcare professionals and involvement of patients and those close to them in shared decision-making and individualized care-planning. This includes preferences for

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				place of care but is driven by holistic attention to what is important to the patient including attention to symptom control, and emotional and family support.
Chiang et al. (2015a). Taiwan.[123]	Compare health-care expenditures and survival of terminally-ill patients receiving or not receiving hospice care in the last month of life.	Research – quantitative using National Health Insurance Research Claims data for 3,850 liver cancer patients who died in1997-2011 study period.	16.6% were hospice care patients. No significant difference was found in mean survival time between hospice and non-hospice groups. The mean health-care expenditures per person were US$2370 and US$2072. 385 patients (10 %) received high-cost care (above US$5422) using 38.6 % of the total expenditures spent on the entire population.	Hospice care did not significantly affect survival, and hospice patients had lower per-patient expenditures and were less likely to require high-cost medical care than their non-hospice counterparts.

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			The significant predictors of high costs were non-hospice care, days of admission, admission into an ICU, use of a ventilator, cancer therapy, hemodialysis, and higher socioeconomic status.	
Chiang et al. (2015b). Taiwan.[124]	Evaluate the effect of hospice care on survival and healthcare costs for lung cancer patients in their final month of life.	Research – quantitative using National Health Insurance Research Claims Database to analyze data for 3,399 adult lung cancer patients who died in 1997-2011.	Hospice patients had a longer mean (median) survival time. The non-hospice patients had a higher risk of high cost as many hospice ones were had lower costs. The risk of high health care costs were predicted for patients who did not receive hospice care, received chemotherapy, intubation, and those who had more ER visits,	The issue of how to reduce the high health care costs for patients with lung cancer in the last month of life is a challenge for policy makers and health care providers, with publicly-funded hospice care indicated.

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			longer hospital stays and received radiotherapy.	
Chiang & Kao. (2016). Taiwan.[125]	Explore the impact of home hospice care on rate of death at home, hospitalization rates, and healthcare costs among patients with advanced lung cancer in last month of life.	Research – quantitative using national health care data for 568 persons with advanced lung cancer under hospice care who died 1997-2011; 238 (41.9%) received home hospice care.	Home hospice patients died at home more often (55.5%/22.1%), were less often in hospital 14+ days in last month of life (67.3%/40.8%), and had lower last month healthcare costs ($1,385/$2,155).	Taiwan collects data on hospice patients. Home hospice care enabled a 33.4% greater chance of dying at home, spending 8 days less in hospital, and saved 35.7% in healthcare costs in the last month of life.
Chitnis et al. (2013). England.[126]	Assess the effect of routinely delivered home-based EoL care versus Marie Curie palliative nurse provided home care on hospital use at the EoL and place of death.	Research – quantitative using health care and other administrative data to compare hospital use and place of death, for 29, 538 persons over the age of 18 who received Marie Curie care and 29,538 persons over the age of	Marie Curie patients were less likely to die in hospital and be hospitalized. ER visits were significantly less, as were hospital costs.	The longer the length of Marie Curie service, the greater the effects.

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		18 who did not; matched on age, socioeconomic deprivation, prior hospital use, number of chronic conditions and prior diagnostic history.		
Coleman et al. (2006). State of Colorado, United States of America.[127]	Determine if ill elderly patients and their family caregivers who have a transitions coach will reduce rehospitalization rates in 30 or 90 days.	Research – quantitative, using a randomized controlled trial in 2002-03 with 750 patients in hospital randomized to receive intervention or usual care. The intervention included an advance practice nurse acting as a transition coach who met them and worked with them before and after	Intervention patients had lower hospital readmission rates in 30 days (8.3% vs 11.9%) and in 90 days (16.7% vs 22.5%) than control subjects.	They were not terminally ill or dying. The intervention was coaching/educating and monitoring of medications and care by the transitions coach, such as teaching them “red flags” that indicate a worsening condition and with instructions on how to respond to them.

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		discharge.		
Costantini et al. (2003). Genoa municipality, Italy.[128]	Determine whether, for patients with advanced cancer, a palliative home care team modified hospital utilization in the last 6 months before death.	Research – quantitative using healthcare and other data for 118 people who died of cancer in the municipality of Genoa, Italy in 1991 who received care from a home palliative care program and also a 378 person group who did not get palliative home care.	Both groups spent about 15% of days in hospital before the experiment. After admission to a home care program, the percentage of days in hospital increased in both groups as death approached, but was much higher in the control group (30.3%) than in the PHCT group (19.0%). The difference in hospital use between groups was most marked in the last month of life.	A home palliative care program appears to reduce days in hospital and allows patients to spend more time at home.
Darlington et al. (2015). United Kingdom.[129]	Examine nurse and physician experiences regarding transferring critical care patients home to die, with deaths occurring that day typically.	Research – quantitative mail survey of 180 healthcare providers with relevant experience.	These moves were rare; 36.1% had been actively involved in transferring 1 to 5 patients home to die in the last 3 years.	88.8% were supportive of the idea of transferring dying patients home. Critical care nurses went with the transferred patient, with death often

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				quickly happening with technology and/or medication stoppage.
DesRosiers et al. (2014). Cape Town, South Africa.[130]	Evaluation of a novel hospital-based palliative care service to provide outpatient care for patients with advanced organ failure in urban South Africa, to determine whether the service reduces admissions and increases home death rates compared with the same fixed time period of standard hospital care.	Research – quantitative using hospital data for a period of 2.5 months in 2011, the average length of palliative care program services per patient.	For intervention and controls, 40 of 56 (71.4%) and 47 of 48 (97.9%) respectively had at 1+ admission. The mean number of admissions for the intervention and controls was 1.39 and 1.98, respectively. For the intervention and control groups, home death was achieved by 33 of 56 (58.9%) and nine of 48 (18.8%), respectively.	An outpatient hospital-based service reduced admissions and improved the rate of home deaths. It is a feasible and cost-effective model.
Dose et al. (2011). United States of America.[131]	Describe the lived experience of patients and families transitioning from hospital to home hospice care.	Research – qualitative using phenomenology interviews of 19 people for their lived experience and photographs of	Patients and families experienced unexpected disruption during this transition, because of lack of clarity regarding hospice, their	Health professionals define the transition period as an "event," and the patients/families experience it as a "process."

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		move.	scramble to get ready, and a sense of an open house once they got home. The transition experience extended beyond the initiation of hospice care, with uncertainty about what hospice care would mean and disruptions in preconceived hospice expectations.	
Duggleby et al. (2016). Rural areas of Canada.[132]	Conduct a Delphi study to identify and establish key competencies in navigation for older rural persons who are at the end of life.	Research – a 4-stage Dephi study involving 30 rural experts and stakeholders to identify key competencies.	Five competencies were identified: Provide patient/family screening; Advocate for the patient/family; Facilitate community connections; Coordinate access to services and resources; and, Promote active engagement.	There is a need for healthcare system navigators to guide individuals and families through the intricacies of the healthcare system, these help to identify solutions, make decisions in crisis situations, build consensus between the family and care providers, and

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				broker, implement, and review care plans. These competencies are needed to help rural seniors and their family caregivers find the services and resources they require for peace and comfort at the end of life while remaining in their communities.
Elfrink et al. (2002). Rotterdam, the Netherlands. 133	Evaluation of telephone contact with palliative care nurses or clinical nurse specialists after discharge of palliative patients from hospital with home nursing care and technology at home such as a pain medication pump.	Research – quantitative using data collected during telephone calls.	124 patients over 3 years; with 157 calls received from a patient, family member, family doctor, or home care nurse. Most calls were about pain, other symptoms, or technical problems, and occasionally for general advice.	97% of problems could be solved by the nurses without hospital or ER admission. All patients had cancer, median age was 54, and median length of telephone assisted home care was 39 days until death (range 2-815 days). Calls were 1-75 minutes in length.
Fleming et al.	Explore place of	Research –	52% of all 320	Older persons,

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(2010). Cambridge (city), England.[134]	death and EoL transitions in the last year of life for very old (age 85 and older) community-based or nursing home based people.	quantitative using longitudinal study data from interviews and death certificate records of very old people living in the city of Cambridge.	persons died away from their usual address. Three quarters of community based persons died in hospital, only 15% from care homes died in hospital.	particularly older females more often lived in and died in nursing homes.
Forma et al. (2009). Finland.[135]	Compare utilization of health and social services between older decedents and survivors, and identify the respective impact of age and closeness of death on the utilization of services in the last 2 years of life.	Research – quantitative using multiple national registers for 56,001 persons who died 1998–2000 at the age of ≥70, and with pairs matched on age, gender and municipality of residence, who were alive at least 2 years after their counterpart's death. Data include use of hospitals, long-term care and	Decedents used hospitals and long-term care more than their surviving counterparts, but the time patterns were different. In hospital care, the differences between decedents and survivors rose in the last months of life and the study period, whereas in long-term care, there were clear differences during the whole 2-year period. The differences were smaller in the	Closeness of death is an important predictor of health and social service use in old age, but its influence varies between age groups. Not only the changing age structure, but also the higher average age at death affects the future need for services.

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		home care. Decedents' utilization within 2 years before death and survivors' utilization in the same period of time was assessed in three age groups (70–79, 80–89 and ≥90 years) and by gender.	oldest age group than in younger age groups.	
Forma et al. (2011a). Finland.[136]	Assess the effects of dementia and year of death (1998-2003) on health care use and social service use in the last 2 years of life among older people.	Research – quantitative using multiple national registers in Finland for all those who died in 1998, 2002 or 2003 and 40% of those who died in 1999-2001 at the age of 70+ or over (n= 145,944), use of hospitals, long-term care facilities, and home care in	People with dementia used long-term care more often but less hospital and home care than people without dementia. The likelihood of using university hospital and long-term care increased during the study period, while the number of days spent in university and general hospitals among the users	Old people with dementia used long-term care to a much greater extent and hospital and home care to a lesser extent than those without dementia. This difference persisted even when controlling for age, gender and comorbidity. It is important that greater attention is paid to ensuring that old people with

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		the last two years of life.	decreased. Differences in service use between people with and without dementia decreased in this 8 year study period.	dementia have equitable access to care.
Forma et al. (2011b). Finland.[137]	Describe and analyze municipal differences in health care and social service use among old people in their last 2 years. of life	Research – quantitative using multiple national registers in Finland national registers for all those who died in 2002 or 2003 at the age of ≥70 years except those who lived in very small municipalities (n= 67,027); compare use of hospitals, long-term care facilities, and home care in the last 2 years of life.	Younger old persons and males were more likely to use hospitals than very old people and females. There was unexplained variation in service use for residents of different municipalities, especially in the types of hospital used. Of the individual-level variables, age and use of other services were associated with the use of all services. Of the municipal-level variables, indicators describing the	Behind the differences are probably factors which are difficult to describe and quantify, such as historical developments and political realities.

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			service pattern in the municipality were associated with use of all services and average age of decedents with most of the services. The presence of a university hospital increased the probability of using hospitals, but among the users were increased days in university hospital and decreased days in general hospital.	
Fortinsky & Downs. (2014). International. 138	Develop a transitions typology for people with Alzheimer's disease or another dementia as they need increasing levels of support, with transitions across care settings common.	Research – multiple case study involving a review of country strategies for dementia care specific to one or more of 6 transitions, including home to hospital and back, home to	The dementia journey is from symptom recognition to EoL care. Most or all of the national strategies adequately address earlier transitions but fewer strategies address later transitions.	Next-generation national dementia strategies need to focus on later transitions, specify how care coordination and workforce training should make transitions more person centered, and use person-centered

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		residential care, and residential care to hospital: Australia, England, France, Netherlands, Norway, Scotland, and United States.		outcomes in evaluating the success of their implementation and dissemination.
Fulton et al. (2014). United States of America.[139]	Examine the rate of intensive care unit (ICU) utilization in the last 30 days of life and its regional variation among persons with both advanced cognitive and severe functional impairment.	Research – quantitative using the Minimum Data Set to identify decedents 2000-2007 who were in a nursing home 120 days prior to death and had advanced cognitive and functional impairment, and total dependence or extensive assistance in 7 activities of daily living. ICU utilization in the last 30 days	Among 474,829 Medicare NH residents with advanced cognitive impairment, an increase in ICU utilization from 6.1% in 2000 to 9.5% in 2007 was found. Substantial regional variation was noted in ICU utilization, from 0.82% in Montana to 22% in the District of Columbia.	Even among patients with advanced cognitive and functional impairment, ICU utilization in the last 30 days increased from 2000 to 2007, but it varied by geographic region.

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		of life was determined from Medicare claims files.		
Giuffrida. (2015). United States of America.[140]	Describe the development of 2 nursing home programs whose goals were to increase the number of residents receiving palliative care, increase the number of completed advance directives, reduce re-hospitalizations, and increase hospital referrals to the nursing home for palliative care.	Research – quantitative, a descriptive report of the development of two EoL programs done in part to reduce rehospitalization rate of nursing home residents and observe first year effects of program.	The number of residents on palliative care increased from 5% to 25%, and rehospitalization rates decreased from 17.4% to 15.2%.	Each year in the United States, 31% of elders who die do so in hospitals, accounting for over half a million deaths and often involving expensive and unnecessary treatments. Re-hospitalizations of frail elders with end-stage illnesses are a concern for the hospitals that have discharged them and for the facilities in which they live.
Goldfeld et al. (2011). Boston area, state of Massachusetts, United States of America.[141]	Nursing home residents with advanced dementia in 22 facilities (N = 323) were followed up for 18 months to determine use of	Research – quantitative using nursing home and healthcare data for 323 nursing home residents for a period of	The largest proportion of Medicare expenditures were for hospitalizations (30.2%) and hospice (45.6%).	Medicare expenditures among nursing home residents with advanced dementia vary substantially. Hospitalizations

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	hospitals as death neared.	18 months, over which 177 died in 2003 – 2009.	Among decedents, mean Medicare expenditures increased by 65% in each of the last 4 quarters before death owing to an increase in both acute care and hospice. After multivariable adjustment, not living in a special care dementia unit was a modifiable factor associated with higher total expenditures for all Medicare services. Lack of a do-not-hospitalize order, tube feeding, and not living in a special care unit were associated with higher non-hospice Medicare expenditures.	and hospice account for most spending. Strategies that promote high-quality palliative care may shift expenditures away from aggressive treatments at the end of life
Gomes et al. (2015). London, England.[142]	Determine association between place of death, health	Research – quantitative using mortality follow-back	80% of people died where they spent the previous week, 4 factors	Dying at home is better than hospital for family peace and grief,

Author(s), year published, and country or region of focus	Focus of interest	Type of article	Findings or main points	Other factors
	services used, and pain, feeling at peace, and grief intensity for families of persons who died of cancer. We determined factors influencing death at home, and associations between place of death and pain, peace, and grief.	study data for 352 cancer patients who died in hospital (n = 177) or at home (n = 175) in London. Bereaved relatives identified from death registrations completed a questionnaire including validated measures of patient's pain and peace in the last week of life, and their own grief intensity.	explained most home deaths: patient's preference, relative's preference, home palliative care, or district/community nursing. The propensity of death at home also increased when the relative was aware of incurability and the patient discussed his/her preferences with the family. Dying in hospital was associated with more hospital days, fewer general practitioner (GP) home visits, and fewer days taken off work by relatives. Adjusting for confounders, patients who died at home experienced	but requires a discussion of preferences, GP home visits, and relatives to be given time off work.

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			similar pain levels but more peace in their last week of life.	
Gómez-Batiste et al. (2006). Spain.[143]	Compare healthcare services use between current palliative care patients and the same type of patients in 1992.	Research – quantitative using healthcare and other data for 395 patients with terminal-stage cancer receiving attention from palliative care services in Spain, and recruited over a period of 15 consecutive days from 171 participating PCS units. Resource consumption and costs were evaluated for 16 weeks of follow-up, and the findings were compared with those of a study conducted in	Most frequent health care interventions were home care visits, hospital admissions, and patient-consultant phone calls. The palliative care service provided 67% of all services for 91% of patients. Compared with the historical data, there was a significant shift from the use of hospital beds to palliative care beds, reduced hospital stay (25.5 to 19.2 days), and an increase in death-at-home (31% to 42%), a lower use of ER (52% to 30.6%).	Compared to the previous resource consumption and expenditure study in 1992, the current palliative care policy implies a cost saving of 61%, with greater efficiency and no compromise of patient care.

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		1992 so as to assess change over time.		
Goodridge et al. (2010). Province of Saskatchewan, Canada.[144]	Compare rural/urban use of hospitals in last year of life by those persons dying of respiratory illnesses.	Research – quantitative using 2004 provincial hospital data.	Similar rural/urban number of care setting transitions (n=5) in last year of life, and similar place of death (mostly hospital). Urbanites were more likely to get home care services.	Hospital deaths were less likely when 85+ age and never married. Married people had more care setting transitions.
Gott et al. (2013). Two hospitals in England.[145]	Explore transitions to a palliative care approach in hospitals and examine extent of potentially avoidable hospital admissions amongst hospital inpatients with palliative care needs.	Research – mixed methods using health care data from 2 UK hospitals, interviews and focus groups involving patients, families and care providers.	Health professionals had difficulties recognizing a patient in last 12 months of life. Many patients were unaware of prognosis and had little insight into what they could expect from their disease. 7.2% of admissions from home were potentially avoidable.	36% of patients who died met one or more of the Gold Standards Framework prognostic indicator criteria for palliative care needs. The most common GSF prognostic indicator was frailty, with 27% meeting criteria.
Gozalo et al.	Examine health	Research –	19.0% had 1+	Patterns of

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(2011). United States of America.[146]	care transitions among 474,829 Medicare nursing home decedents with advanced cognitive or functional impairment in last 120 days of life.	quantitative using nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007.	burdensome transitions (range, 2.1% in Alaska to 37.5% in Louisiana). Blacks, Hispanics, and those without advance directive were most at risk. Nursing home residents in regions in the highest quintile of burdensome transitions were significantly more likely to have a feeding tube, have spent time in an ICU in the last month of life, have a stage IV decubitus ulcer, or had a late enrollment in hospice.	transition were defined as burdensome if they occurred in the last 3 days of life, if there was a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life. Burdensome transitions were found to be common, vary according to state, and are associated with markers of poor quality end-of-life care.
Guerriere et al. (2015a). Ontario, Canada.[147]	Comprehensively assess modifiable and non-modifiable cancer patient and caregiver factors that account for caregiver burden	Research – quantitative using telephone interview and 2010-2012 healthcare data for home care	The average age of caregivers was 59 years and 70% were female. Caregiver burden increased over time in a non-linear fashion to	Family caregivers of patients enrolled in home-based palliative care programs provide unpaid care and assistance with

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	over the palliative care trajectory.	patients and 327 caregivers.	death. Increased monthly unpaid care-giving time costs, monthly public personal support worker costs, ER visits and low patient functional status were associated with higher burden. Greater use of hospice care was associated with lower burden. Female caregivers tended to report more burden compared to men as death approached, and burden was higher when patients were male. Low patient functional status was the strongest predictor of burden.	daily activities to terminally-ill family members. Caregivers often experience caregiver burden, which is an important predictor of anxiety and depression that can extend into bereavement.
Guerriere et al. (2015b). Province of Ontario,	Assess the determinants of home death for patients receiving	Research – quantitative, a longitudinal prospective	Those with high nursing care costs, high personal care worker costs,	This home care program is 15 years old, and well established with

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Canada.[148]	home-based palliative care.	cohort study involving comprehensive interview and program data for 2010-2012.	wanting to die at home, and co-habiting were more likely to die at home.	specialist and generalist care providers.
Håkanson et al. (2015). Sweden.[149]	Examine where people die in Sweden and associated characteristics.	Research – quantitative using 2012 death certificate date and other population data.	Female home-dwellers were more likely to die in a nursing home and less likely than male home-dwellers to die in a hospital. Nursing home residents were more likely to die in hospital, except for those with dementia or mental/behavioural disorders.	Hospital deaths were more common among unmarried home-dwellers and also those with digestive, respiratory, or infectious diseases; while home-dwellers dying of cancer were more likely to die at home. Urban home-dwellers were more likely to die in a nursing home and urban nursing home dwellers were more likely to die in a hospital. Regional differences were noted in moves prior to death location, with more available

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				hospital and nursing home beds a factor in death place.
Hanratty et al. (2012). England.[150]	Explore older adults' experiences as they move between places of care at the end of life (judged to be in the last year of life).	Research – qualitative using in-depth interviews and thematic analysis of data. Thirty adults aged between 69 and 93 years took part, diagnosed with heart failure (13), lung cancer (14), and stroke (3). Sixteen were from lowest socioeconomic groups.	Four themes: 1) the prioritization of institutional processes, 2) support across settings, 3) being heard, and 4) dignity. As they moved between different settings, much of the care received was seen as inflexibility and a failure of professional carers to listen. Liaison between and within services was not always effective, and community support after a hospital admission was perceived to be, on occasions, absent, inappropriate, or excessive.	Providing care that is shaped around the needs of patients, carers, and families is a challenge in the last months of life, as moves between home and institutions may be frequent. Despite this, there have been few studies of end-of-life transitions in the U.K.
Hatcher et al. (2014).	Document carer perceptions of	Research – qualitative	Thematic analysis revealed carers	Family carers benefitted from

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Australia.[151]	patients' transitions from community to hospital-based palliative care in a rural setting.	using semi-structured interviews of 6 carers, 3 male and 3 female.	made the decision for the patient in their care to transfer from home to hospital. Carers experienced the transition to hospital care positively, particularly in relation to communication of patient's care needs. While communication issues arose while in hospital, they were not related to transitional aspects of this palliative care service.	this new program, which shifted their family members into hospital.
Henson et al. (2016). England.[152]	Investigate socio-demographic, clinical, and community health care service factors associated with aggressive EOL cancer care in last 3 months of life.	Research – quantitative using pooled data from two mortality follow-back surveys. Aggressive EOL care was defined as greater than or	Of the 681 patients, 50.1% were men and mean age at death was 75 years. The majority (59.3%) experienced at least one indicator of aggressive EOL care: 29.7% experienced	Community health care services, in particular contact with community palliative care, are associated with a significant reduction in the odds of cancer patients receiving aggressive EOL

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		equal to one of the following indicators occurring during the last 3 months of life: greater than or equal to two ER visits, ≥30 days in hospital and death in hospital.	greater than or equal to two ER visits, 17.1 % spent ≥30 days in hospital and 37.9 % died in hospital. Patients with prostate or haematological cancer were more likely to experience aggressive EOL care). Patients who received greater than 5 general practitioner (GP) home visits or had contact with district nursing, or contact with community palliative care services were less likely to experience aggressive EOL care. No association was found between aggressive EOL care and patient age, gender,	care. Expansion of such services may help address the current capacity crises faced by many acute hospitals.

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			marital, financial, or health status.	
Houttekier et al. (2014). Belgium.[153]	Examine place of death and factors associated with hospital deaths among persons eligible for palliative care.	Research – quantitative using death certificate data for 2008.	43.5% of decedents were eligible for palliative care; 51% of these died in hospital, 25% at home, and 24% in a nursing home. Those receiving EoL care at home had a 60% in-hospital death rate, 16% of nursing home residents died in hospital. In-hospital deaths were higher in areas with more available hospital beds.	More beds in hospices and other palliative care facilities are needed to support dying people and avoid need for hospital care. More support of home deaths in needed.
Hui et al. (2014). Houston, Texas, United States of America.[154]	Examine how the timing and setting of palliative care (PC) referral were associated with ER use, ICU use, and hospitalizations in last 30 days of life.	Research – quantitative using health care data for all adult patients residing in the Houston area who died of advanced cancer between	Of 366 decedents, 33% had early PC referral (>3 months before death), 46% were first seen as outpatients. Earlier PC referral was associated with fewer ER visits (39% vs.	Patients referred to outpatient PC had improved end-of-life care compared to inpatient PC. Our findings support the need to increase the availability of PC clinics and to

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		9/1/2009 and 2/28/2010 and had a PC consultation.	68%), hospitalizations (48% vs. 81%), and hospital deaths (17% vs. 31%). Outpatient PC referral was associated with fewer emergency room visits (48% vs. 68%), hospital admissions (52% vs. 86%), hospital deaths (18% vs. 34%) and intensive care unit admissions (4% vs. 14%).	streamline the process of early referral.
Jenkins et al. (2000). Alberta, Canada.[155]	Examine demographic characteristics of palliative care inhospital patients, including reason for admission and disease status upon admission, length of stay, and discharge and admission location, were recorded.	Research – quantitative using chart data on 100 patients in the 1990s.	86 of 95 patients had been living at home before admission, 4% were transferred from another hospital, and 3% were transferred from a nursing home. 22% died in hospital and 36% returned home, 17% were transferred to another hospital, 4% to a rehab	Palliative care consult teams can visit patients anywhere in a hospital.

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			hospital, and 6% to a rural hospital.	
Kawagoe et al. (2009). Japan.[156]	Examine case of one older person who received EoL care at home and died at home.	Research - case study using information on one 87 year old man who died of lung cancer.	Dyspnea was most serious symptom. He was able to manage his own care until 2 weeks before his death. He refused external help until the last 2 weeks, when his family and home hospice nurse increasingly helped him.	Home deaths require a wish to die at home by the patient and family. Home care program included 3 times/week visits from a palliative RN, weekly doctor visit, 24 hour on call doctor/nurse, and a volunteer who did chores and who cooked and cleaned for him.
Ko et al. (2014). Four European countries.[157]	Describe and compare care and care setting transitions provided in the last three months of life for cancer patients in four countries (Belgium, The Netherlands, Italy, and Spain)	Research – quantitative using general practitioner physician information system for the years 2009-2011, about 2,037 patients.	4/5 lived at home or with family in last year of life. Over 50% had 1+ care setting transitions in last 3 months of life; 1/3 had a last week of life hospital admission and then died there. 88-98% had distress from 1+ physical symptoms in final	Access to palliative care is recognized as a right in 3 countries and covered by national health insurance in all 4. All countries have a plan or national guideline for palliative care.

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			week of life.	
Kötzsch et al. (2015). Germany.[158]	Survey EoL care from hospital-based palliative care discharge to death, over an average 52 days.	Research – quantitative using data collected in weekly telephone calls, with service provided for 52 days on average per patient.	Most were discharged home (61%), an inpatient hospice (20%) or nursing home (11%), and 56% stayed there (90% of hospice patients stayed there, vs 67% sent to nursing homes and 47% sent to home); 44% had 3.1 care setting transitions on average. Mostly this was from home to hospital and back. Survival time was 52 days on average.	Most (90%) had cancer and 65 was the average age. The most frequent symptoms were weakness (76%), need for assistance with activities of daily living (75%), loss of appetite (62%), overburdened families (52%), and fatigue (44%).
Kozar et al. (2014). United States of America.[159]	Determine the impact of discharges to hospice on risk-adjusted mortality for trauma deaths reported to the Trauma Quality Improvement Program.	Research – quantitative using trauma registries and health care databases, specifically for 167 Trauma Quality Improvement Program centers in	8.4% were discharged from hospital to hospice, and the rest died in hospital. 63.5% of centers discharged to a hospice. Age greater than 70 years, male sex, nonblack race, non-commercial	Record keeping was an issue in relation to actual place of death and place of EoL care.

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		2011; 126.259 patients, with 8,862 deaths.	insurance, and comorbidity counts greater than 2 were associated with hospice transfer.	
Larkin et al. (2007). Six European countries.[160]	Explore transition experiences of advanced cancer patients in UK, Ireland, Spain, the Netherlands, Italy and Switzerland.	Research - qualitative using interviews of 100 advanced cancer patients in 6 European countries.	Transition to dying and to hospice or EoL care is a confusing time of mixed messages, poor communication, and uncertainty.	Those in a hospice were able to make transition more easily.
Lawson et al. (2006). Halifax, Nova Scotia, Canada.[161]	Examine relationship between patient characteristics and total number of transitions by palliative care patients from the date of admission to a palliative care program (PCP) to death and/or in final weeks of life.	Research – quantitative using palliative care program data for all adults who were registered and died between 1998 and 2002. Data were linked to census information.	3,972 patients made 5,903 transitions; but 28% had no place transitions, over 40% experienced 1 and 6.3% 5+. At least one transition was made by 47% in last 4 weeks of life. Women and the elderly had fewer moves. Hospital deaths and cancer diagnosis were associated with many moves. In the last month of	Not only were moves from one setting to another a concern, but so too were care team changes that occurred with moves.

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			life, age was not associated with transitions. Cancer patients and non-cancer ones had similar transitions. Pain and symptom control were significant for greater number of transitions.	
Lawson et al. (2008). Halifax, Nova Scotia, Canada.[162]	Examine ED use by patients registered with the Capital Health Integrated Palliative Care Service (CHIPCS) and CHIPCS patient characteristics associated with ED use.	Research – quantitative using ER and hospital data for palliative care program clients.	27% had at least one ED visit and 54% of these visits resulted in a hospital admission. Visits were not associated with time of day or day of week. Older patients were less likely to make ED visits. Pain was most common reason for visit, followed by shortness of breath. ED visits were linked with hospital deaths, rural residence (for women), and having a parent or	Not only were moves from one setting to another a concern, but so too were the care team changes that occurred with moves.

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			relative other than a spouse or child as the primary caregiver.	
McGregor et al. (2011). Vancouver regional area, Province of BC, Canada.[163]	Examined nursing home facility organizational characteristics that previous research had showed are associated with potentially avoidable hospital transfers and with better nursing home care quality.	Research – quantitative survey of nursing home directors of care. The survey addressed staffing levels and organization, physician access, end-of-life care, and factors influencing facility-to-hospital transfers.	No onsite physicians; and timely response from physician was difficult (64%). Only half of physicians took part in resident care conferences. Only 40% had standing palliative care orders. Four main reasons for transfer to hospital: family requests transfer, no diagnostic tests at site, care plans not made, and no access to physician.	Only 13% of facilities had an onsite nurse practitioner, 24% had a clinical nurse specialist. The nursing homes studied varied greatly in their resources and preparation for providing onsite EoL care.
Menec et al. (2009). Province of Manitoba, Canada.[164]	Examine the extent of hospitalizations and factors related to it in last 180 days of life for nursing home residents.	Research – quantitative involving health care data for residents of 60 nursing homes in Manitoba who died in 2003/04	19.1% died in hospital, and 40.7% were hospitalized once in the last 6 months of life. Living in a for-profit facility was linked to higher	80.9% died in their nursing home bed, which implies effort to keep them in place. Many got care in hospital and then were transferred back

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		(N=2,379).	hospital use. Younger age, for-profit home, and organ failure residents were hospitalized more.	to the nursing home and then died later on there. The quality of care in for-profit homes may be low. Most were palliative for years but not in open planning.
Menec et al. (2010). Province of Manitoba, Canada.[165]	Compare hospital use in rural/urban regions; examine role of healthcare resources; and explore day-to-day hospitalization patterns in last month of life before death between rural and urban areas.	Research – quantitative using hospital data for adults (age 19+ years; excluding nursing home residents) who died in the province of Manitoba in 2003-2004 (n = 6,523).	Residents of 4 of 7 rural/remote regions had increased odds of being hospitalized in last 30 days of life than urban ones. Those aged 19-74 were less likely to die in hospital than age 75+ ones.	Considerable variance was noted in hospital use in rural regions and in urban regions, indicating local factors are relevant to consider, and provincial or national standards and guidelines needed.
Miller et al. (2012). United States of America.[166]	Examine differences in outcomes such as pain and hospital use, according to hospice status of skilled nursing facility (SNF) care recipients, in last 90 days of life.	Research – quantitative using data collected from 3,353 U.S. nursing homes, with data for 4,344 persons with advanced dementia who	Decedents with any hospice received fewer medications, injections, feeding tubes, intravenous fluids, and therapy services and more hypnotics than those without	Residents dying with advanced dementia who received SNF care in the last 90 days of life had fewer aggressive treatments and lower odds of hospital death if

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		died in NHs in 2006 and received skilled nursing faculty services (SNF) care within 90 days of death were studied; 1,086 also received hospice care before death: 705 after SNF care, and 381 concurrent with SNF care.	hospice. Decedents with hospice after SNF care received fewer antipsychotics and those with hospice concurrent with SNF care received more antipsychotics than those without. Decedents with hospice after SNF had lower likelihood of persistent dyspnea and hospital death than those without hospice. Decedents with hospice concurrent with SNF care had a higher likelihood of persistent pain and a lower likelihood of hospital death than those without hospice.	they also received hospice care at any point during that time. Associations between hospice and persistent pain or dyspnea differed according to whether hospice care was received concurrent with or after SNF care.
Miller et al.	Explore the	Research –	44.7% transitioned	Suggestion that

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(2015). United States of America.[167]	quality of transition to EoL care for cancer patients in the ICU.	mixed methods using data gathered on 85 medical patients admitted to a hospital ICU over a 6 month period in the 2013 year.	to EoL care during their ICU stay. Half of patients were too unwell to discuss this transition. 76.3% died in ICU without move. Preferred place of death was known in only 10% of cases. Older age, higher acuity or APACHE II score, and support for organ failure, but not cancer, were associated with transition to EoL care.	advanced care planning for people living with progressive disease prior to acute deterioration and ICU admission is needed to enable patients' wishes to be fulfilled and for ceiling of treatments to be agreed upon.
Mitchell et al. (2004). State of Michigan, United States of America.[168]	Describe and compare the EoL experience of persons dying with advanced dementia in nursing homes and home care settings over the last 6 months of life.	Research – quantitative using data from the Minimum Data Set (MDS)-Nursing home Version 2.0 for the institutionalized sample, and the MDS-Home Care for the community-based sample.	Nursing home residents were older, had greater functional impairment, and more behavior problems compared to home care clients. Few subjects in the nursing home (10.3%) and home care (15.6%) cohorts were	Persons dying with advanced dementia admitted to nursing homes have different characteristics compared to those admitted to home care services. Their end-of-life experiences also differ in these two

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		Variables from the MDS assessment completed within 180 days of death.	perceived to have less than 6 months to live. 5.7% of nursing home residents and 10.7% home care clients were referred to hospice. Hospitalizations were frequent: nursing home, 43.7%; home care, 31.5%. Pain and shortness of breath were common for both settings.	sites of care. However, palliative care was not optimal in either setting.
Morrison et al. (2016). United States of America.[169]	Describe approaches and outcomes of two transitional care programs provided over 4 months before death and serving different populations: one provided by master's-prepared clinical nurse specialists with a chronic disease self-	Research – quantitative using healthcare data for 2014 comparisons between two groups of patients, one getting care from palliative care physicians and one getting care from chronic care nurse	Average age 81 years and 63% were female. CNS patients had significantly fewer ER visits and hospitalizations in the 4 months after the intervention than in the 4 months before it. PPC patients had a nonsignificant reduction in ER visits and a significant	Transitional care is an emerging model of health care designed to decrease preventable adverse events and associated utilization of healthcare services through follow-up after hospital discharge. Each program included post-hospitalization

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	management focus, another by physicians specializing in palliative care.	specialists, and also compared 120 days prior to versus 120 days of the intervention (n=41).	reduction in hospitalizations post intervention.	home visits, but had different foci (chronic disease vs. palliative), assessment and interventions, and population (rural/ urban).
Muramatsu et al. (2008). United States of America.[170]	Examine whether states spending on home- and community-based services affects place of death, taking into consideration county health care resources and individuals' family, sociodemographic, and health factors.	Research – quantitative using exit interview data from respondents in the Health and Retirement Study born in 1923 or earlier who died between 1993 and 2002 (N = 3,362).	Living in a state with higher HCBS spending was associated with lower risk of EoL nursing home relocation, especially among people who had Medicaid. State HCBS support was not directly associated with place of death.	State generosity for HCBS increases the chance of dying at home by lowering the risk of EoL nursing home relocation.
Naylor et al. (2004). United States of America.[171]	Determine if, for elderly patients admitted to hospital with heart failure, a 3 month, comprehensive, transitional care intervention provided by advance practice	Research – quantitative using hospital data in a clinical trial for 118 intervention and 121 control patients, with 190 completing study over 1	The 3 month, comprehensive, transitional care intervention directed by advanced practice nurses increased time to readmission or death, reduced readmissions, and	TC comprised identification of patient and caregiver goals, individualized care plans, educational and behavioral strategies, coordination and continuity of care, and clinical

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	nurses will reduce readmissions and improve quality of life and functioning.	year during which they were expected to die and some did die.	reduced healthcare costs.	services by nurses and APN implementation of an evidence-based protocol (APN visit within 24 h, at least daily visits during index hospital stay, >8 home visits plus additional visits as needed, and APN telephone availability 7 days/week, 8 am to 8 pm, 8 am to 12 pm on weekends; if patients were readmitted, APNs resumed daily hospital visits). Usual care comprised HF management and discharge planning critical paths, liaison nurses to facilitate referrals to home care, comprehensive skilled home health services 7

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				days/week (if referred), and 24 hour access to an on call RN.
Obermeyer et al. (2014). United States of America.[172]	Compare utilization and costs of health care for patients with poor-prognosis cancers enrolled in hospices versus similar ones without hospice care, with a focus on the last year of life.	Research – quantitative using 20% matched sample of Medicare fee-for-service beneficiaries who died in 2011, with mean study time of 13 months per patient (N= 36,300).	Those receiving hospice care had significantly fewer hospitalizations, ICU admissions, and invasive procedures, less likely to die in hospitals or skilled nursing facilities, and had lower total care costs in last year of life.	Medicare Hospice Benefit care is non-curative in nature, and largely consisted of supportive care in the home.
Paris & Morrison. (2014). United States of America.[173]	Evaluate the role of palliative care versus usual care on post hospital discharge outcomes and hospice use for patients with advanced GI cancers.	Research – quantitative using health care data. For 201 adults, 82 had a palliative care consult, all followed for 6 months after hospital discharge. Palliative care patients were matched to usual care	59 died in the 6 months post discharge. Receiving a palliative care consult increased the odds of home death and decreased the odds of hospital death. At 2 and 4 months, more patients in the palliative care group were	Palliative care consultation was associated with increased hospice utilization, decreased likelihood of dying in a hospital, and increased likelihood of dying at home.

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		patients. Study of hospice use, place of death, ER visits, hospital readmission, and survival.	receiving hospice services at death, compared with the usual care group, but there were no differences with ER visits, hospital readmission, and survival.	
Perrels et al. (2014). Cambridge (city), England.[174]	To explore EoL transitions of very old people across the cognitive spectrum, over the last year of life.	Research – quantitative using longitudinal study data from interviews and death certificate records of 283 very old people living in Cambridge city. Average age at time of death was 90.4 years.	In the last year before death, 2/3 lived at home and 1/3 in a nursing home. 2/5 had no cognitive impairment and 1/3 severe impairment. Severely impaired ones lived more often in a nursing home. If not impaired, 58% died in hospital. If mildly impaired half died in hospital, and 1/3 of severely impaired died in hospital. Home deaths were more common among those with no or	Few moved in the last year of life unless transitions up the ladder of care were needed, such as hospitalization until death. Severely impaired community residents were the most likely to move in the last year of life, into a nursing home but were then most likely to stay there until death. Cognitive impairment consequently is a key factor for EoL moves, with none of those who were

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			mild impairment.	impaired dying in a hospice.
Philip et al. (2015) State of Victoria, Australia.[175]	Examine EoL care from diagnosis to death for persons with metastatic lung cancer.	Research – quantitative using hospital and ER data and death certificate data.	Care was not aggressive in last 30 days, 42% died in hospital and 42% died in hospice. Transfers to hospice from hospital were common, but only 18% of patients were referred to palliative care during first hospital stay to gain this diagnosis and many died in this stay.	It takes time for palliative care services to become useful, as it takes time to attend to psychosocial and symptom needs.
Pivodic et al. (2016). London, England.[176]	Determine the degree of and factors associated with bereaved relatives' satisfaction with home EoL care delivered by general practitioners to cancer patients in last 3 months of life.	Research – quantitative using data from a population-based mailed mortality follow back survey sent to bereaved relatives of people who died of cancer (2009-2010), about the deceased's final	Questionnaires were completed for 596 decedents of whom 548 spent at least 1 day at home in the last 3 months of life. 55% reported excellent/very good home care by GPs, compared with 78% for specialist palliative care providers and	There is considerable room for improvement in the satisfaction with home care provided by general practitioners to terminally ill cancer patients. Ensuring an adequate offer of home visits by general

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		3 months of life.	68% for district/ community/ private nurses. The odds of high satisfaction (excellent/very good) with EoL care from GPs doubled if they made 3+ visits compared with 1 or no home visits in the patient's last 3 months of life and halved if the patient died at hospital rather than at home.	practitioners may help to achieve this goal.
Purdy et al. (2015). Counties of Somerset and North Somerset, England.[177]	Investigate the impact of the Marie Curie Cancer Care Choice Programme for impact on ER and hospital admission rates in last 30 days of life.	Research – quantitative using hospital and hospice data for all persons who died in the 2 counties, those who used services and those who did not.	Those using the program in 2008-2011 were 30% less likely to die in hospital or have an emergency room visit in last 30 days of life than those who did not use any part of the program.	The program consisted of an out-of-hours advice and support telephone line manned by specialist palliative care nurses, 2 hospital-based nurses who identified patients who wanted to go home and helped them get there quickly, and two EoL care

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				coordinating centres that plan EoL care.
Reinke et al. (2008). United States of America.[178]	Explore transitions, defined as experiences that patients and family members viewed as milestones in the evolution of their illnesses and therapies, and compare these perceptions with the perspectives of the patient's physician and nurse to provide insights about communication concerning EOL care.	Research – qualitative using interviews of patients, family members, nurses, and physicians.	Six themes identified regarding participants' experiences with transitions. Themes that defined transitions among both patients with COPD and those with cancer included: new or different treatments and no more treatments available. Themes unique to patients with COPD were activity limitations due to functional decline and initiation of oxygen therapy. One theme unique to clinicians was acute exacerbation of illness or hospitalization.	Differences were found in the meaning of transitions for patients versus clinicians and for patients with COPD versus those with cancer.
Round et al.	Evaluate the	Research –	A non-significant	Quality care may

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(2015). England.[179]	Marie Curie Delivering Choice Programme for its effect on place of death and EoL care in last 8 weeks of life.	quantitative analysis of hospital use in the last 8 weeks of life and other hospice data for all patients who died 2006-2008.	increase in home deaths but an increase in health care costs occurred, and the number of hospital admissions and hospital days declined slightly.	have improved, but this is difficult to measure. Dying at home could be more possible for patients with simple care needs and dying in hospital is for those with complex needs.
Seow et al. (2010a). Province of Ontario, Canada.[180]	Evaluate whether Ontario's End-of-Life Care Strategy, which aimed to shift care from acute settings to the home, improved performance on quality indicators for EoL home care patients in use of more home care services and fewer acute care services in last 12 weeks of life.	Research – quantitative using 2005-2007 administrative healthcare data for 9,368 decedents, with patients were divided into three 6-month periods corresponding to the 6 months prior to the strategy's implementation compared with the 12 months after. Average hours per week of nursing and	Per-patient use of home care and acute care did not change. The pattern of average nursing and PSW hours per week used in the last 12 weeks of life did not change, averaging 3.8 nursing hours per week and 3.8 PSW hours per week. The proportion of in-hospital deaths remained stable at 38% and 16% had an ER visit and 32% had a hospitalization in the last 2 weeks of life. The	One year after the strategy's implementation, individual patients' use of EoL home care and acute care services remained unchanged. The strategy may require more time for its impact to be fully achieved.

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		personal support worker (PSW) services were measured for the last 12 weeks of life. The use of acute care services in the last month of life was measured by the proportion of patients who had an in-hospital death, had hospitalizations, visited the ER, and spent more than 14 days in hospital.	proportion of patients who had zero, 1 or 1+ ER visits or hospitalizations remained constant across time periods.	
Seow et al. (2010b). Province of Ontario, Canada.[181]	Investigate whether admission time to home care program and the amount of home care services, as measured by average nursing and personal support and homemaking	Research – quantitative using administrative healthcare data for 9,018 adults dying in Ontario prior to 2007 and using home care services in 2005-2006.	They had an average of 3.11 nursing hours/week, 3.18 PSH hours/week, and 18% were admitted to home care for <1 month. As admission time to death and home care services increased,	Early home care admission and increased home care services will help alleviate the demand for hospital resources at end-of-life.

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	(PSH) hours/week are associated with using acute care services at end-of-life.		the odds of acute care use declined; those admitted earlier than 6 months before death had a 35% lower odds of hospitalization than those admitted 3 to 4 weeks before death; those using more than 7 nursing hours/week and more than 7 PSH hours/week had 50% lower odds of a hospitalization; as compared to those using 1 hour/week.	
Seow et al. (2014). Province of Ontario, Canada.[182]	Determine the effect of exposure to one of 11 specialist palliative care teams providing services in patients' homes, in relation to last 2 weeks of life.	Research – quantitative using health services data for 3,109 patients who received care from specialist palliative care teams in 2009-11 matched by propensity	80% had cancer and 78% received end of life home care services for the same duration. For palliative care teams, 31.2% were in hospital and 28.9% had an ER visit in last 2 weeks of life,	The palliative care teams served different geographies and varied in team composition and size but had the same core group of palliative care physicians, nurses, and family physicians who

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		score to 3,109 patients who received usual care. Focus on being in hospital in the last two weeks of life, using an ER in the last two weeks of life, or dying in hospital.	compared to 39.3% and 34.5% of regular home care clients. Fewer specialist palliative care patients died in hospital as compared to regular home care clients (16.2% v 28.6%).	provide integrated palliative care to patients in their homes. The teams' role was to manage symptoms, provide education and care, coordinate services, and be available without interruption regardless of time or day.
Seow et al. (2016a). Province of Ontario, Canada.[183]	Examine place of care in the last 30 days of life.	Research – quantitative using administrative healthcare data for two groups of 3,109 dying persons in 2009-2011; patients who received care from a specialist palliative care team were matched with patients who received usual care in	79% had cancer and 77% received EoL home care. At 30 days compared to 7 days before death, the specialist group proportions rose from 33% to 41% receiving home care and 14% to 15% in hospital, while the other group's proportions rose from 28% to 32% receiving home care and 16% to 22% in hospital.	More specialist care patients were able to stay out of hospital in last 30 days of life.

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		community. Measured was % of patients in each place of care in the last month of life as a proportion of the total cohort.	Over time the specialist group used significantly more home care services and fewer hospital days. Only 18% died in an in-patient hospital bed compared to 29% in usual care.	
Seow et al. (2016b). Three provinces, BC, Ontario and Nova Scotia, Canada.[184]	Investigate the temporal association of home care nursing for end-stage cancer victims, especially by generalist nurses, with reduced end-of-life hospitalizations in the last 6 months of life.	Research – quantitative using administrative data for 83,827 cancer decedents in 2004-2009 time period. Ontario, Nova Scotia, and BC have home care systems that use generalist nurses to provide end-of-life care. Nursing was split into standard care and EoL care intent in this 2016b study.	55% of decedents were older than 70 and the most common cancer was lung. Nearly 85% had at least one hospital admission. Receiving EoL home nursing care compared to standard home care nursing significantly reduced hospitalization rate by 34%, 33%, and 17% in ON, BC, and NS. In the last month of life those with a rate of greater than five hours compared to one	Home nursing had a protective effect on reducing the need for hospitalization in the last six months of life, as did 5 hours or more per week of standard nursing in the last month of life.

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			hour per week had a significantly lower hospitalization rate (of 15%-23%) across the three provinces.	
Seow et al. (2016c). Three provinces, BC, Ontario and Nova Scotia, Canada.[185]	Determine the association of increased nursing costs (in 2-week blocks) on the relative average hospital costs in the subsequent 2-week block and on the overall total cost (hospital costs plus nursing costs in the preceding 2-week block), for adults dying of cancer and in last 6 months of life.	Research - quantitative using administrative data for 58,022 cancer decedents in 2004-2009 time period. Study focuses on any home nursing care services versus no home nursing care services in last 6 months of life.	For the last month of life, association between increased nursing costs and decreased relative hospital costs in comparison with reference group: the maximum decrease was 55% for Ontario, 31% for BC, and 38% for Nova Scotia.	In the last month of life, increased home nursing costs were associated with lower hospital costs.
Seow et al. (2016d). Province of Ontario, Canada.[186]	Examine the temporal association between home care nursing rate on ER visits in the subsequent week during the last 6 months of life.	Research – quantitative using administrative healthcare data for 54,576 cancer decedents in 2004-2009 who	85% had an ED visit and 68% received EoL home care nursing. Patients receiving EoL nursing at any week had a significantly	Receiving end-of-life nursing in a given week during the last 6 months of life, and of more standard nursing in the last month of life, with a reduced ER rate

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		used home care services in last 6 months of life.	reduced ER rate in the subsequent week of 31% compared with standard nursing of 0-1 hour. In the last month of life, receiving EoL nursing of more than five hours/week was associated with a decreased ED rate of 41%, compared with standard nursing of 1 hour/week.	in the subsequent week.
Serra-Prat et al. (2001). Mataró town, Spain.[187]	Compare healthcare resources consumed during the final month of life for usual patients and those patients undergoing palliative treatment, who died from cancer in the town of Mataró, Spain, in 1998, with respect to whether they	Research – quantitative using healthcare and other data for 155 persons who died in 1998 to compare their use of healthcare services in the last month of life.	Patients in the standard care group were admitted to hospital more often, had longer length of stays, higher use of ER and outpatient visits, and greater use of palliative care units within nursing homes than patients in the home care group. The usual care group were	Home care teams for terminal cancer patients allow for savings to the healthcare system.

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	benefited from the home care teams or not.		71% more costly.	
Tam et al. (2014). Hamilton, Ontario, Canada.[188]	Determine the effect of a rapid response team (ICU physician, critical care nurses with EoL communication training, and respiratory technicians) on end-of-life care in one hospital in Hamilton.	Research – quantitative review of critical care hospital charts for effect of rapid response team on EoL care, and the use of a preprinted set of instructions for EoL care.	After the team was consulted, many patients did not go to the ICU for care. The preprinted set of instructions for EoL care was also helpful for care planning, particularly when suddenly needed.	EOL discussions took place, which helped decision-making.
Tamir et al. (2007). Israel.[189]	Evaluate health services utilization in the last year of life, and compare terminally-ill patients who received home-specialized palliative care services with patients who died receiving home non-specialized palliative care services.	Research – quantitative using healthcare data for 120 and 515 patients, respectively, who died 1999-2000. Age and gender distribution were similar in both groups.	Mean health services cost per person among the HSPCS group was lower by more than 30%. The median cost per patient was as low as one-fifth in the last month. Men and the older age 65+, cost significantly less compared with women and younger patients, respectively, regardless of	The main differences in health services utilization were in hospitalizations and oncology treatments, with specialist care having the advantage.

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			provider setting.	
Temkin-Greener et al. (2013). United States of America.[190]	Assess longitudinal trends and geographic variations in place of death for nursing home residents, and examine association between resident characteristics, treatment preferences, and probability of dying in hospital.	Research – quantitative using Minimum Data Set (NH assessment records), Medicare denominator (eligibility) file, and Medicare inpatient and hospice claims to identify decedent nursing home residents in 2003-2007, on 2,992,261 Medicare-eligible decedents from 16,872 nursing homes.	20% of nursing home residents died in hospital each year; and the likelihood of residents dying in hospitals increased significantly each year between 2003 through 2007.	Increasing need to provide EOL care for nursing home residents; this will require developments in policy, regulation and investment in nursing homes.
Teno et al. (2011). United States of America.[191]	Examine the association between advance care planning, as measured by facility rate of DNR orders in U.S. nursing homes and changes in	Research – quantitative using healthcare and MDS data for a retrospective cohort study of the changing prevalence of DNR orders in	The average facility rate of terminal hospitalizations was 15.5%, fluctuating between 1999 (15.0%) and 2007 (14.8%). NHs starting with low	NHs that changed their culture of decision making by increasing their facility rate of DNR orders decreased their rate of terminal hospitalizations.

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	terminal hospitalization rates.	U.S. NHs. Using a fixed effect multivariate model, examine whether increasing facility rate of DNR orders correlates with reductions in terminal hospitalizations in the last week of life, controlling for changes in facility characteristics.	rates of DNR orders that increased their rates had fewer terminal hospital admissions in 2007. For every 10% increase in DNR orders there was 0.56% decrease in terminal hospitalizations.	
Teno et al. (2013). United States of America.[192]	Describe changes in site of death, place of care, and health care transitions across the 2000, 2005, and 2009 years.	Research – quantitative using Medicare data for a random 20% sample of fee-for-service Medicare beneficiaries, aged 66+ who died in 2000 (n = 270,202), 2005 (n = 291,819), or 2009	The proportion of deaths in hospitals decreased from 32.6% to 24.6%, but ICU use in the last month of life increased from 24.3% to 29.2% and hospice use at the time of death increased from 21.6% to 42.2%. Mean care transitions in the last 90 days of life	Care needs vary considerably among people as death nears, but care needs increase over time; 11.5% of 2009 decedents had 3 or more hospitalizations in the last 90 days of life.

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		(n = 286,282).	increased from 2.1 to 3.1 per patient and the percentage with transitions in last 3 days of life increased from 10.3% to 14.2%.	
Thurston et al. (2011). Edmonton, Alberta, Canada.[193]	Examine current end-of-life care needs and practices in hospital.	Research – quantitative, using healthcare and demographic data from a chart review for all 1,018 persons who died over one year from August 1, 2008 through July 31, 2009 in two hospitals.	79% were admitted through the ER and 9% died in the ER. Most decedents were elderly (73.8%), urbanite with 80% residing in the city where the 2 hospitals are, and cancer was the most common diagnosis (36.2%). Only 13.8% had CPR performed at some point in this hospitalization and 8.8% had CPR immediately preceding death, with 87.5% having a DNR order and 30.8% providing an advance directive. Most	Compared to those in a similar mid-1990s Canadian study, impending death is more often openly recognized and addressed. Technologies continue to be routinely but controversially used. The increased rate of end-stage CPR from 2.9% to 8.8% could reflect a 1994+ shift of expected deaths out of hospital.

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			(97.3%) had one or more life-sustaining technologies in use at the time of death.	
Tuca-Rodriguez et al. (2012). Spain.[194]	Describe the structure, characteristics of patients and basic clinical outcomes in cancer patients receiving care from palliative care hospital support teams (HSTs).	Research – quantitative using healthcare data for 60 HSTs in Spain, all multidisciplinary with wide experience (mean 6.8 years). HSTs coverage was 21.5% of all cancer deaths in Spain. A total number of 364 advanced cancer patients were included in the cohort study; 76% were classified as moderate or high complexity.	The mean length of intervention was 6.5 days (mean three visits per patient). Outcomes were: 34% deaths during the admission process; 38% were discharged home; and 28% were transferred to another medium-term-stay specialist unit. The main symptoms were pain (68%), dyspnea (43%), vomiting (24%), anorexia (72%), asthenia (78%), insomnia (50%), anxiety (45%) and depression (35%). After the HSTs intervention, the symptom severity was significantly	Palliative intervention of HSTs is characterized by being adjusted to patient needs and short duration. Their care was focused on the preterminal phase of cancer patients of moderate-high complexity.

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			reduced for all symptoms, except weakness and anorexia. The mean survival from inclusion was 111 days.	
Unroe et al. (2011). United States of America.[195]	Examine healthcare resource use in last 6 months of life for 229,543 persons with heart failure (Medicare beneficiaries) aged 65+ in last 6 months of life.	Research – quantitative using 5% national 1991-2007 Medicare inpatient, outpatient, and other data.	80% were hospitalized in last 180 days of life, with 8-9% having ICU care. More got ICU care over the year, and more receive hospice and nursing home care over the years.	The use of hospitals declined but remained high, with ICU use but also hospice use and nursing home use increasing over the years.
Unroe et al. (2015). United States of America.[196]	Explore nursing home hospice and non- nursing home hospice patients and their care setting moves in last 6 months of life.	Research – quantitative using national Medicare, Medicaid and Minimum Data Set data for 33,378 persons in the 1999-2008 years.	Half of crossover home-based persons who registered for hospice moved into a nursing home and 1/3 of those in nursing homes moved home with hospice. Crossover hospice patients were longest hospice recipients (median = 91.5 days), and more	Late referrals to hospice were common. Care needs and availability of family caregivers were major considerations as well, in addition to hospice care services.

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			likely to use ER and inpatient hospital services.	
Van den Block et al. (2007). Belgium.[197]	Investigate prevalence, types, and timing of transitions between end-of-life care settings in last 3 months of life in Belgium.	Research – quantitative using 1 year of mortality data collected from general practitioners for 892 nonsudden deaths in 2005.	In the final 3 months of life, 38% were not moved, 37% moved once, 16% moved twice, and 10% moved 3+ times. 73% of home based people moved 1+ times as compared to 36% in care homes. Most moves were in last 2 weeks of life.	A transition was a move between care locations (home, care home, hospital, or inpatient palliative care unit).
Wee et al. (2014). Singapore.[198]	Evaluate the effectiveness of a national EoL transitional care program for elderly adults with complex care needs and limited social support; with transitional care defined as a set of actions designed to ensure the	Research – quantitative using 2009-2010 healthcare data for 5,023 intervention and a matched comparator group.	The Aged Care Transition (ACTION) Program was designed to improve coordination and continuity of care and reduce rehospitalizations and visits to ERs. Recipients of the ACTION program had fewer unplanned rehospitalizations	Dedicated care coordinators provided coaching to help individuals and families understand the individuals' conditions, effectively articulate their preferences, and enable self-management and care planning, and made referrals to

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	coordination and continuity of care as people transfer between locations or different levels of care within the same location.		and ED visits after discharge. Quality of life and self-rated health were better 4 to 6 weeks after discharge than 1 week after discharge.	community resources.
Wilson & Truman. (2002). Province of Alberta, Canada.[199]	Describe use of hospitals in last 5 years of life.	Research - quantitative using provincial hospital data.	Hospital use varied among patients and across the 5 years before death; the last stay in hospital was often resource low. Most high hospital users were rural residents.	Rural hospital beds are more readily available for EoL use, and with ease of movement from rural to urban hospitals.
Wilson. (2002). Province of Alberta, Canada.[200]	Describe and compare EoL dependency among dying persons.	Research – quantitative using healthcare records of all deceased persons who received care over a 6-month period in one Canadian hospital (n = 150) and one home care	Only 36% home care clients died at home; all others (n = 38) were hospitalized. Most had dependency needs on admission to care, with dependency increasing until all were completely dependent near death. Hospitalized home	As death approached, dependency needs emerged and increased.

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		department (n = 59) were reviewed.	care clients had the longest average duration of dependency (81.3 days). Types of dependency (partial and complete) and progression in dependency were similar among subject groups, with the exception of 26% of hospital inpatients, who suddenly developed complete dependency until death. The duration of complete end-stage dependency varied; hospital inpatients (mean of 8.3 days) and home care clients who died at home (mean of 4.1 days).	
Wilson et al. (2009). Province of Alberta,	Gain personal and community viewpoints on the good rural death	Research – qualitative using ethnographic	Four themes in the Alberta data highlight critical elements of the	The need to die at home or in the home community would often

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Canada.[201]	and how these were shaped by their experiences.	insights from a 2006-07 study involved 13 interviews with individuals and focus groups in rural areas of Alberta.	good rural death, one being the need to die at home or in the home community, with this often requiring transfers back.	require moving from an urban hospital.
Wilson et al. (2011). Province of Alberta, Canada.[202]	Compare number of care setting transitions in last year of life by age (<65 and 65+).	Research – quantitative using provincial inpatient hospital and ambulatory care data.	Care setting moves in last year of life averaged 3.9 and 3.4 for younger vs older persons. Older persons also had fewer ER and ambulatory visits and fewer procedures performed in the last year of life, but had longer inpatient stays (42.7 days vs 36.2 for younger persons).	Most moved from place to place, 4% had >10 care setting moves in their last year of life. It is possible that death is a more expected outcome of illnesses in old age, and illnesses suffered by younger people and older people differ in type and severity, so younger people are more in need of acute healthcare services in the last year of life.
Wilson et al. (2012). Province of Alberta,	Compare number of care setting transitions in last year of life	Research – mixed methods using provincial hospital data	Rural residents moved more often than urbanites in last year of life	For rural people, care is scattered in many different places as few local

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Canada.[203]	between rural and urban persons.	and interviews.	(mean 4.2 vs 3.3)	services necessitating travel; travelling is very difficult for dying person and the family.
Wilson et al. (2014). Province of Alberta, Canada.[204]	Examine waiting in 2 hospitals for placement in a nursing home.	Research - mixed methods using two years of provincial hospital data and qualitative interviews.	Only 1.8% of inpatients waited in hospital for placement, and they used 2.2% of all care days. Median wait was 14 days. Some were actively dying in hospital and so were not moved out.	Three themes: coming to a realization of this move, wait is boring and distressing, hospitals are not designed for waiting for placement. Nursing home bed shortage.
Wong et al. (2016). Hong Kong.[205]	Examine the effects of a home-based transitional palliative care program for persons with end-stage heart failure, on hospital readmission rates and other outcomes.	Research – quantitative using health services and other data for 84 discharged patients from three Hong Kong hospitals with end-stage heart failure who were referred for palliative care services.	The intervention group had a lower readmission rate at 12 weeks, 33.6% versus 61% for the matched usual care group. Mean readmissions per patient group also varied significantly, .42 and 1.1. Other outcomes were also positive; less dyspnea, less	The intervention was a weekly visit or telephone call for 4 weeks from a nurse case manager and then monthly follow-up by nurse and with multidisciplinary team support.

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			depression, and higher quality of life.	
Wright et al. (2014a). United States of America.[206]	Determine whether increased hospice use is associated with less-intensive EoL hospital care in last month of life.	Research – quantitative using hospital and Medicare data for 6,956 women diagnosed with ovarian cancer in1997-2007, and died by December 2007, for changes in medical care in last month of life and changes year to year.	Hospice use increased and terminal hospitalizations decreased, but moves inside hospitals and into and out of hospitals increased.	Although enrollment in hospice increased over time, it was typically only started 3 days before death. Late recognition of impending death was a concern.
Wright, Zhang et al. (2014b). United States of America.[207]	Determine if chemotherapy when terminally-ill is associated with intensive medical care in last week of life and place of death.	Research – quantitative, using medical chart data from Coping with Cancer group, 386 patients at various sites between 2002 and 2008.	56% got palliative chemotherapy around 4 months before death, and these patients had higher rates of CPR and/or mechanical ventilation in last week of life, late hospice start, and more likely to die in an ICU and	There was no difference in survival time with having chemotherapy over no chemotherapy.

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			hospital, and less likely to die in preferred place.	
Xing et al. (2013). United States of America.[208]	Examine the incidence of, variations in, and costs of potentially avoidable hospitalizations (PAHs) of nursing home (NH) residents in last year of life and identify the association between NH characteristics and a facility-level quality measure (QM) for PAH.	Research – quantitative, using health care data for hospitalizations of long term nursing home residents in last year of life who died in 2007.	Half of hospital admissions for NH residents in their last year of life were for potentially avoidable conditions, costing Medicare $1 billion. Five conditions were responsible for more than 80% of PAHs (pneumonia, heart failure, UTI, dehydration, and falls). PAH QM across facilities showed significant variation, with chain and hospital-based facilities more likely to have better performance. Facilities with higher nursing staffing were more likely to have better	Variations in facility-level PAHs suggest that a potential for reducing hospital admissions for these conditions may exist. Presence of modifiable facility characteristics associated with PAH performance could help formulate interventions and policies for reducing PAHs at the end of life. Use of nursing homes and deaths in nursing homes are expected to increase greatly in the years ahead.

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			performance, and facilities with higher skilled staff ratio, and those with nurse practitioners or physician assistants, and those with on-site X-ray services.	
Zheng et al. (2015). United States of America.[209]	Examine whether residing in facilities with a higher hospice penetration reduces hospitalization risk for nonhospice residents; and decreases hospice-enrolled residents' hospitalization risk relative to hospice-enrolled residents in facilities with a lower hospice penetration, with the focus on the last 30 days of life.	Research – quantitative using Medicare Beneficiary File, Inpatient and Hospice Claims, Minimum Data Set Version 2.0, Provider of Services File, and Area Resource File data for long-stay nursing home residents who died 2005-2007; 505,851 nonhospice (67.66%) and 241,790 hospice-enrolled (32.34%) residents in	In the last 30 days of life, 37.63% of nonhospice and 23.18% of hospice residents were hospitalized. Every 10% increase in hospice penetration leads to a reduction in hospitalization risk of 5.1% for nonhospice residents and 4.8% for hospice-enrolled residents.	Nursing homes with hospice services can reduce hospitalizations for both hospice-enrolled nursing home residents and those not enrolled.

Author(s), year published, and country or region of focus	**Focus of interest**	**Type of article**	**Findings or main points**	**Other factors**
		14,030 facilities nationwide.		

B. Table 2. Identified EoL Care Setting Transition Issues and Solutions

Divided by Category: (a) health system issues, (b) patient issues, (c) healthcare provider issues, and (d) family issues

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
1. Inconsistent care providers at the EoL, such as many family physicians and specialist physicians providing care, and many other care providers such as nurses and junior physicians, with no one coordinator or no one person responsible for ongoing care.	Burge et al., 2005a[210] Miller et al., 2015[211] Wilson et al., 2012[212] Almaawiy et al., 2014[213] Abdulrahman et al., 2014[214] Bainbridge et al., 2015c[215]	Evidence - Advanced practice nurses are effective transition coaches; they visit before and after move from hospital.	Coleman et al., 2006[216]
		Suggested - One family physician who knows patient should monitor their EoL care.	Burge et al., 2003[217]
		Suggested - Long-term home care services.	Chiang & Kao, 2016[218]
		Suggested – Someone trusted or known by the person with and end-stage illness should talk with them to determine their care ceiling preferences and advance care wishes before a serious illness or crisis emerges.	Miller et al., 2015[219]
		Suggested – Rural people should be able to get all EoL care in own region.	Wilson et al., 2012[220]
		Suggested – Provide integrated package of care over last 6 months.	Abdulrahman et al., 2014[221]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		Suggested – Improve interprofessional horizontal collaboration through less workload and training.	Bainbridge et al., 2015c[222]
7. Not enough long-term care facilities and nursing home beds that provide traditional 24/7 nursing care; which could be a result of the shift of seniors' care to non-institutional sites and assisted living facilities.	Aaltonen et al., 2014[223]	Evidence – Those in traditional long-term care facilities stayed there in last 90 days of life while those in less supportive care settings such as assisted living facilities and for-profit seniors care options were more often hospitalized.	Aaltonen et al., 2014[224]
8. Has no family physician, accessible healthcare clinic, or has another healthcare access issue; rural/remote area of residence.	Menec et al., 2009[225] Wilson et al., 2012[226]	Suggested – Rural people should have all necessary EoL care in their community. Rural families should not be responsible for transportation.	Wilson et al., 2012[227]
14. Planning to send a dying person home from hospital requires a great deal of planning, as this planning often involves 2 or more sets of care	Burge et al., 2005a[228] Coleman et al., 2006[229] Gott et al., 2013[230] Darlington et al.,2015[231] Dose et al., 2011[232]	Evidence - Advanced practice nurse works as a "transition coach" and visits before and after moves to check on meds and encourage assertiveness of patient/family.	Coleman et al., 2006[233] Gott et al., 2013[234]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
providers such as family members and home care agencies.		Suggested – Be able to offer considerable home care immediately after discharge from hospital, and have the same team from hospital care from them at home.	
17. Need to keep terminally-ill or dying person adequately supported and cared for at home, to avoid need for ER and hospital-based care.	Chiang & Kao, 2016[235] Round et al., 2015[236] Guerriere et al., 2015b[237] Houttekier et al., 2014[238] Dose et al., 2011[239] DesRosiers et al., 2014[240] Chitnis et al., 2013[241] Chiang et al., 2015b[242] Seow et al., 2014[243] Bainbridge et al., 2015b[244] Guerriere et al., 2015a[245] Wong et al., 2016[246] Seow et al., 2016a[247] Seow et al., 2016b[248] Seow et al., 2016c[249] Seow et al., 2016d[250] Morrison et al., 2016[251] Naylor et al., 2004[252] Wee et al., 2014[253] Alonso-Babarro et al., 2013[254]	Evidence - Long-term home-based hospice care services to help people stay in their own home until death or to delay hospitalization. Evidence - Advanced practice nurse working as a “transition coach” to visit before and after moves to check on medications and encourage assertiveness of patient/family. Evidence – Hospice program did not significantly reduce hospital admissions and days in hospital in last 8 weeks of life, but may have improved quality of EoL care. Evidence – Home care program was also be help keep people at	Chiang & Kao, 2016[265] Coleman et al., 2006[266] Round et al., 2015[267] Guerriere et al., 2015a[268]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
	Brumley et al., 2007[255] Chiang et al., 2015b[256] Costantini et al., 2003[257] Gomes et al., 2015[258] Gómez-Batiste et al., 2006[259] Henson et al., 2016[260] Pivodic et al., 2016[261] Serra-Prat et al., 2001[262] Tamir et al., 2007[263] Wilson et al., 2011[264]	home until death.	
		Evidence – An outpatient hospital-based palliative care team reduces care needs.	DesRosiers et al., 2014[269]
		Evidence – Marie Curie nursing services in home can prevent need for hospital EoL care.	Chitnis et al., 2013[270]
		Evidence – Hospice services in homes and in hospices reduced ER and hospital use in last month of life.	Chiang et al., 2015a[271]
		Evidence – Specialist palliative home care team can help to keep patient out of ER and hospital.	Seow et al., 2014[272]
		Evidence – More hospice care was linked with less family caregiver burden.	Guerriere et al., 2015b[273]
		Evidence – Weekly telephone call or visit from nurse case manager reduced rehospitalization and improved life.	Wong et al., 2016[274]
		Evidence – Home care nursing reduced hospitalization need in last 6 months of life, as did 5+ hours/week of	Seow et al., 2010b[275]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		home nursing care in last month of life.	
		Evidence – When home care hours and use did not increase, the ER and hospital use did not drop in last 3 months of life.	Seow et al., 2010a[276]
		Evidence – Specialist home care palliative team were able to keep more patients at home until death and reduced hospital days of care.	Seow et al., 2016a[277]
		Evidence – More home nursing care versus little or none in last 1 month or 6 months of life reduces need for and use of hospitals.	Seow et al., 2016c[278]
		Evidence – 5+ hours of home nursing care per week can prevent or reduce need for ER care.	Seow et al., 2016a [279]
		Evidence – Earlier home care and more home care reduces hospitalization rate in last 2 weeks of life.	Seow et al., 2016d[280]
		Evidence – Post-hospital care from a palliative care physician or a chronic care nurse specialist	Morrison et al., 2016[281]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		can reduce ER use and hospitalizations.	
		Evidence – Post hospital education and ongoing care by advanced practice nurse reduces time to readmission and use of hospitals at EoL.	Naylor et al., 2004[282]
		Evidence – A home education program was effective at reducing ER use and rehospitalizations.	Wee et al., 2014[283]
		Evidence – A palliative home care team was able to reduce ER use, hospitalizations, and hospital deaths in last 2 months of life.	Alonso-Babarro et al., 2013[284]
		Evidence – A home care program can reduce ER and hospital use in last year of life.	Brumley et al., 2007[285]
		Evidence – People receiving home palliative care were less often in ER and hospital and in ICU in last month of life.	Chiang et al., 2015a[286]
		Evidence – A home based palliative care program can reduce need for hospital care.	Costantini et al. 2003[287]
		Evidence – Those with home visits from	

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		family physician and home care nursing were more likely to die at home and stay there in last week of life. Evidence – Over time, a palliative home care program can become capable of reducing a need for ER and hospital care. Evidence - Community health care services, in particular contact with community palliative care, are associated with a significant reduction in the odds of cancer patients receiving aggressive EOL care in ER/hospital. Evidence – Family members were most satisfied with home physician visits and care keeping person at home. Evidence – Specialist palliative care team was better able to keep person home in last month as compared to regular home care team.	Gomes et al., 2015[288] Gómez-Batiste et al., 2006[289] Henson et al., 2016[290] Pivodic et al., 2016[291] Tamir et al., 2007[292]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
18. Need to provide enough home care to meet the needs of terminally-ill people and thus keep dying persons at home.	Bainbridge et al., 2015b[293] Seow et al., 2010b[294] Seow et al., 2016a[295] Seow et al., 2016b[296] Seow et al., 2016c[297] Seow et al., 2016d[298] Chiang et al., 2015a[299]	Evidence – Home care can keep dying people at home.	Muramatsu et al., 2008[300]
		Evidence – Marie Curie nursing services in home can prevent need for hospital EoL care.	Chitnis et al., 2013[301]
		Evidence – Cancer victims who used ERs in last 12 to 6 months of life were more likely to get home care services in last 6 months of life. 25% of cancer victims did not get any home care services in last 6 months of life.	Bainbridge et al., 2015b[302]
		Evidence – Home care nursing reduced hospitalization need in last 6 months of life, as did 5+ hours/week of home nursing care in last month of life.	Seow et al., 2016d[303]
		Evidence – When home care hours and use did not increase, the ER and hospital use did not drop in last 3 months of life.	Seow et al., 2010a[304]
		Evidence – Home care services increased over time in last month of life, and this helped	Seow et al., 2016b[305]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		keep people at home or shortened hospitals stays.	
		Evidence – More home nursing care versus little or none in last 1 month or 6 months of life reduces need for and use of hospitals.	Seow et al., 2016c[306]
		Evidence – 5+ hours of home nursing care per week can prevent or reduce need for ER care.	Seow et al., 2016a[307]
		Evidence – Earlier home care and more home care reduces hospitalization rate in last 2 weeks of life.	Seow et al., 2016a [308]
		Evidence – People receiving home palliative care were less often in ER and hospital and in ICU in last month of life.	Chiang et al., 2015a [309]
19. The ER is a gateway to inpatient hospital care, and with ambulances taking ill home or community-based and long-term care facility of nursing home based people to ERs after	Lawson et al., 2008[310] Burge et al., 2005b[311] Barbera et al., 2010[312] Bainbridge et al., 2015b[313] Thurston et al., 2011[314]	Suggested – Admit directly to a hospital unit to avoid ER. Have ambulance companies alerted to "futile" calls, with rapid home visit and no transfer to be aim of home visit.	Lawson et al., 2008[315]
		Evidence – Cancer victims who used ERs in last 12 to 6 months	Bainbridge et al., 2015b[316]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
an ambulance call.		of life were more likely to get home care services in last 6 months of life. 25% of cancer victims did not get any home care services in last 6 months of life.	
		Evidence – 80% were admitted to hospital via the ER to die.	Thurston et al., 2011[317]
21. Lack of advanced support such as specialized palliative health care including pain assessment and pain management in the home to keep EoL patients at home, such as those who are having pain and/or other sudden or worsening health issues.	Elfrink et al., 2002[318] Gott et al., 2013[319] Round et al., 2015[320] Guerriere et al., 2015a[321] Burge et al., 2005a[322] Burge et al., 2005b[323] Chiang et al., 2015b[324] Seow et al., 2014[325] Wong et al., 2016[326] Seow et al., 2016c [327] Henson et al., 2016[328]	Evidence – Hospital-based advanced practice nurses or palliative specialist nurses can take calls about concerns at all hours and days of week from patients, families, and other persons, with this reducing concerns and ER visits.	Elfrink et al., 2002[329]
		Suggested – Ensure after hours care is available to avoid need for ER care.	Fleming et al., 2010[330]
		Suggested – Have universal home care services available for urban and rural persons.	Goodridge et al., 2010[331]
		Suggested – Ensure all dying persons in rural and other areas have a family physician to	Goodridge et al., 2010[332]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		care for them when at home.	
		Evidence – Home hospice support did not keep more patients out of hospital but it could be that complex patients need hospital care and patients with simple care needs can be managed at home.	Round et al., 2015[333]
		Suggested – Much more publicly funded home care is needed to keep more at home to the end, particularly those who want to die at home.	Guerriere et al., 2015b[334]
		Evidence – Publicly funded hospice care services in the home and in hospices kept people at home in last month of life.	Chiang et al., 2015a[335]
		Suggested – Home care nurses may be as helpful as medical doctors visiting the home.	Burge et al., 2005b[336]
		Evidence – Registration in a palliative care program is a component needed for non-hospital death.	Burge et al., 2003[337]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		Evidence – Specialist team is better able then regular home care team in helping to keep patient at home and out of ER and hospital.	Seow et al., 2014[338]
		Evidence – Weekly home visit or telephone call from palliative nurse case manager and also help of multidisciplinary palliative care team reduced rehospitalization rate and improved life quality.	Wong et al., 2016[339]
		Evidence – Specialist palliative care teams were able to keep people at home in last year of life as compared to usual care.	Seow et al., 2016b[340]
		Evidence - Community health care services, in particular contact with community palliative care, are associated with a significant reduction in the odds of cancer patients receiving aggressive EOL care in ER or hospital.	Henson et al., 2016[341]

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
24. Lack of EoL care knowledge among long-term care facility and nursing home staff and enough supportive care by staff in long-term care facilities to keep dying residents there.	McGregor et al., 2011[342] Bainbridge et al., 2015b[343] Xing et al., 2013[344] Zheng et al., 2015[345] Temkin-Greener et al., 2013[346]	Suggested – Long-term care facilities need to have enough staff, awareness, and expertise in providing EoL care.	Fleming et al., 2010[347]
		Suggested – Have one nurse practitioner or one physician to care for all people in the entire care facility, and with this person education staff about EoL care.	McGregor et al., 2011[348]
		Suggested – Sweden has specialized long-term care facilities for persons with dementia, so deaths can occur there.	Håkanson et al., 2015[349]
		Suggested – Long-term care facilities need palliative care nurses and other supports currently lacking there for onsite EoL care.	Bainbridge et al., 2015b[350]
		Evidence – Augment nursing home staff with nurse practitioners who can assess and plan and provide care.	Xing et al., 2013[351]
		Evidence – Long-term care facilities with hospice services send residents to hospital	Zheng et al., 2015[352]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		less often in last 30 days of life.	
26. Uncertainty about if there is any advanced care or other EoL plans, such as a desired place of death.	Miller et al., 2015[353]	Suggested – A policy is needed to encourage planning ahead. Suggested – Ask older people where they want to be at or near the end of life. Suggested – Avoid uncertainty about the EoL by having someone trusted or known talk to people with end-stage illnesses to determine their care ceiling preferences and advance care wishes before a serious illness.	Fleming et al., 2010[354] Fleming et al., 2010[355] Miller et al., 2015[356]
27. Palliative care specialists and palliative care services are mainly designed for cancer patients or thought to be reserved for cancer patients.	Fleming et al., 2010[357] Håkanson et al., 2015[358] Purdy et al., 2015[359]	Suggested – Very old persons when dying of any disease should also receive palliative care services. Suggested – Have specific national care standards. Evidence – Only 1/3 patients getting care coordination did not have cancer, but care coordination did benefit them.	Fleming et al., 2010[360] Håkanson et al., 2015[361] Purdy et al., 2015[362]
28. Lack of access	Menec et al., 2009[363]	Suggested – More	Menec et al., 2009[368]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
to or no referral to specialist palliative care, including in hospital.	Miller et al., 2015[364] Obermeyer et al., 2014[365] Paris & Morrison, 2014[366] Jenkins et al., 2000[367]	education of health care providers for more specialists or specialist skills. Suggested – Dying people in hospital should get specialist palliative care, and this care should be started prior to final hospital stay. Suggested – Provide specialist palliative care assessment and planning in hospital before discharge.	Miller et al., 2015[369] Paris & Morrison, 2014[370]
29. Statistics are not kept on the use of palliative care services or referrals to specialist palliative care, or hospice use.	Håkanson et al., 2015[371] Kozar et al., 2014[372]	Suggested – Collect data routinely on specialist palliative services or care use. Suggested – Record place of death and place of EoL care.	Håkanson et al., 2015[373] Kozar et al., 2014[374]
30. No standards or routine guidelines are available for use as a checklist to determine if all needed or possible EoL care planning has been done.	Miller et al., 2015[375]	Suggested – Liverpool Care Pathway was a prompt for staff to consider a wide range of needed care and decisions at EoL.	Miller et al., 2015[376]
31. No EoL quality indicators exist for benchmarking	Barbera et al., 2015[377]	Evidence – Five quality indicators were developed and found	Barbera et al., 2015[378]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
purposes and/or are used for quality improvement.		to vary across regions: ER use, intensive care unit admission, physician house calls and home care visits before death, and death in hospital.	
32. Need for long term care planning for dementia and other long-term illnesses.	Fortinsky & Downs, 2014[379] Teno et al., 2011[380]	Found – Six transitions in care from initial symptoms to EoL occur, 3 of these are relevant to later stages of care planning. Evidence – Long-term care facilities with DNR policies and increase in DNR send fewer residents to hospital for EoL care.	Fortinsky & Downs, 2014[381] Teno et al., 2011[382]
33. No programs exist to draw attention to dying or to provide alternatives to regular care.	Giuffrida, 2015[383]	Evidence – An in-house palliative care program shifted care to palliation and reduced rehospitalization rates.	Giuffrida, 2015[384]
37. Territorial issues, with one physician alone able to refer their patient to palliative care and only one able to discharge patient from hospital.	Gott et al., 2103[385]	Suggested – Standing orders for referral to palliative care and for discharge home.	Gott et al., 2013[386]
40. Available open long-term care or	Unroe et al., 2011[387] Kötzsch et al., 2015[388]	Suggested – Have step down and other beds	Unroe et al., 2011[389]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
nursing home beds, hospice beds, and subacute beds are needed for rapid discharge from hospital, as step down or post-acute settings are needed for early or quick hospital discharge.		available to enable rapid discharge from hospital. Evidence – Hospice beds were most likely to keep patients to death after their discharge from hospitals, as compared to long-term care facilities and homes.	Kötzsch et al., 2015[390]
41. High out-of-pocket costs for non-hospital EoL care and for uninsured services.	Unroe et al., 2011[391]	Suggested – Cover EoL care costs regardless of care setting, close loop-holes in Medicare Hospice Benefit.	Unroe et al., 2011[392]
42. Vague EoL policy documents.	Håkanson et al., 2015[393]	Suggested – Need documents to exist and be specific about the place of death and place of EoL care, the expansion of palliative care to those without cancer, and to ensure an integration of palliative care and chronic illness.	Håkanson et al., 2015[394]
43. Policy or care standard documents are not available or used, such as if they are from another country.	Philip et al., 2015[395]	Suggested – Encourage or enforce, and otherwise ensure the use of EoL/palliative care standards or policy documents.	Philip et al., 2015[396]
44. Lack of information	Håkanson et al., 2015[397]	Suggested – Research studies and other	Håkanson et al., 2015[398]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
collected and available about the quality of dying and of EoL care in hospitals, long-term care facilities, and homes.		efforts such as using quality standards from other countries are needed to develop quality standards, and then ongoing/routine quality monitoring is needed.	
45. For-profit agencies or providers provide minimal care and/or shift patient to hospital and thus reduce their agency costs.	Philip et al., 2015[399] Chiang et al., 2015b[400]	Suggested – Public agencies and public healthcare systems are better able to plan and provide comprehensive EoL care. Evidence – Publicly funded hospice care services in the home and in hospices kept people at home in last month of life.	Philip et al., 2015[401] Chiang et al., 2015a[402]
46. Need to discharge from hospital to the right care setting after a terminal diagnosis and/or stabilization in health.	Kötzsch et al., 2015[403]	Suggested – Have an onsite assessment and planning process to determine the best long-term setting for each patient (hospice, long-term care facility/nursing home, or home).	Kötzsch et al., 2015[404]
47. Hospital beds are more available than hospice beds.	Houttekier et al., 2014[405]	Suggested – Open up palliative care hospital beds and other non-hospital beds for EoL care.	Houttekier et al., 2014[406]
48. Long-term care	Temkin-Greener et al.,	Suggested - Need	Temkin-Greener et al.,

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
facilities do not have enough services to keep ill, terminally-ill, and dying persons there.	2013[407] Xing et al., 2013[408] Miller et al., 2012[409]	policy, regulation, and investment in long-term care facilities to enable deaths there. Evidence – Long-term care facilities with x-ray machines and nurse practitioners can keep residents there onsite. Evidence – Long-term care facilities with palliative care services and skilled nursing services were able to keep residents there and out of hospital in last 90 days of life.	2013[410] Xing et al., 2013[411] Miller et al., 2012[412]
(b) Patient issues	**Sources**	**(b) Care setting transition solutions suggested or tested/found and as evidenced**	**Sources**
4. Some hospital patients and families do not ask and some do not want to be told they are seriously ill/dying.	Gott et al., 2013[413]	Suggested – Determine the right person and right time to give the diagnosis and prognosis; use the “surprise” question to help with planning.	Gott et al., 2013[414]
5. Requires frequent or considerable medical care, other health care	Ko et al., 2014[415] Almaawiy et al., 2014[416] Morrison et al., 2016[417]	Evidence – Monthly family physician care, specialist physician in 1/3 to 2/3 cases, and 1/3 to 78% had	Ko et al., 2014[421]

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
services, and supportive care at or near the EoL, when the community-based person is elderly or advanced in age.	Aaltonen et al., 2012[418] Forma et al., 2009[419] Forma et al., 2011b[420]	informal caregiver overburdened. Evidence – More continuity of doctor care reduces need for hospitalization, except when patient needs 4 or more doctor visits each week in last 2 weeks of life. Evidence – Post-hospital care from a palliative care physician or a chronic care nurse specialist can reduce ER use and hospitalizations. Evidence – Higher use of hospitals when dementia present and living at home, and lower use of hospitals when living in a care home with dementia.	Almaawiy et al., 2014[422] Morrison et al., 2016[423] Aaltonen et al., 2012[424]
6. Long term cognitive and/or physical disability, prior to end-stage dying.	Perrels et al., 2014[425] Aaltonen et al., 2014[426] Xing et al., 2013[427] Zheng et al., 2015[428] Aaltonen et al., 2012[429] Forma et al., 2011a[430]	Evidence – Those with cognitive impairment can stay in a nursing home until death occurs. Evidence – Those in long-term care facilities had less transitions, while those in other forms of housing were more often transitioned in	Perrels et al., 2014[431] Aaltonen et al., 2014[432]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		last 90 days.	
		Evidence – Long-term care facilities with nurse practitioners and X-rays machines can detect and treat common illnesses of residents.	Xing et al., 2013[433]
		Evidence – Long-term care facilities with hospice services reduce hospitalizations in last 30 days.	Zheng et al., 2015[434]
		Evidence – Older persons living with dementia used hospitals less if they were living in a care home versus community.	Aaltonen et al., 2012[435]
		Evidence – Persons with dementia were more often getting care in a nursing home in last 2 years of life while those without were more often in hospital in last 2 years of life.	Forma et al., 2011b[436]
		Evidence – Very old people were more often in long-term care facilities while younger ones were more likely in hospital.	Forma et al., 2009[437]
10. Care needs	Burge et al., 2005a[438]	Suggested - Study care	Burge et al., 2005a[459]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
change as death nears, often in last 1 to 2 weeks or month of life.	[439] Chiang & Kao, 2016[440] Kawagoe et al., 2009[441] Ko et al., 2014[442] Kötzsch et al., 2015[443] Miller et al., 2015[444] Purdy et al., 2015[445] Tam et al., 2014[446] Teno et al., 2013[447] Wilson et al., 2009[448] Wright et al., 2014a[449] Reinke et al., 2008[450] Seow et al., 2014[451] Van den Block et al., 2007[452] Barbera et al., 2010[453] Aaltonen et al., 2013[454] Fulton et al., 2014[455] Tuca-Rodriguez et al., 2012[456] Wilson et al., 2011[457] Thurston et al., 2011[458]	needs as there is a need to anticipate care need changes and so be better prepared for them. This is needed to try to reduce moves and their possible negative consequences of discontinuity of care, poor coordination of care, financial burden and psychological stress with each move for patients and families. Some local LTC facilities have services to retain dying residents there.	
		Suggestion - Bypass the ER and admit directly to hospital.	Chiang & Kao, 2016[460]
		Evidence – Use long-term home care.	Kawagoe et al., 2009[461]
		Evidence – Team home-based palliative care with additional support in last 2 weeks.	Ko et al., 2014[462]
		Evidence – Palliative care teams.	Miller et al., 2015[463]
		Suggested – Be prepared for deterioration with chronic illness.	Purdy et al., 2015[464]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		Evidence – Care coordination was found to reduce EoL need for ER and hospital care.	Tam et al., 2014[465]
		Evidence – Have a rapid response team to assess for dying, futile care in ICU and introduce a preprinted set of instructions for EoL care.	
		Suggested – Make palliative care a priority for government, such as National Priorities Partnership for (USA) health care. Have hospices and hospice care available, and support more people to die at home such as through Medicare Hospice Benefit policy and services.	Teno et al., 2013[466]
		Suggested – Provide nursing care at home to avoid hospital admission or long stay.	Wilson & Truman, 2002[467]
		Suggested – Expect differences in care needs over time and between old/young persons. Expand access to specialized	Wilson et al., 2009[468]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		palliative care teas/services.	
		Suggested – Have long-term care facilities or hospices available as places to go to from hospital, or home with home care. Allow actively dying persons to die in hospital if stay is hours long.	Wilson et al., 2012[469]
		Suggested – Uncontrolled symptoms result in hospital use near the end, these need to be prevented and addressed early at home or elsewhere. Need to have earlier and more regular discussions with patients who may die and their families.	Wright et al., 2014a[470]
		Suggested – Be prepared for sudden care needs or change in last 2 weeks of life as this is common time for transition to hospital.	Kötzsch et al., 2015[471]
		Evidence – Specialist palliative home care teams can help keep patient out of ER and	Seow et al., 2014[472]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		hospital.	
		Evidence – Nursing home residents were sent to hospital less often then home-based people in last 2-4 weeks of life.	Van den Block et al., 2007[473]
		Evidence – Symptoms in hospital in last 1-2 weeks could be reduced, with 1/3 able to go home.	Tuca-Rodriguez et al., 2012[474]
11. A long terminal illness.	Burge et al., 2003[475] Fortinsky & Downs, 2014[476]	Suggested – Longer terminal illnesses allow time and opportunity to plan ahead.	Burge et al., 2003[477]
		Suggested – A typology for long term planning was developed, for use in reducing moves during a long illness.	Fortinsky & Downs, 2014[478]
12. Rapid deterioration in health, with sudden EoL dependency care needs emerging.	Larkin et al., 2007[479] Miller et al., 2015[480] Tam et al., 2014[481] Philip et al., 2015[482] Wilson & Truman, 2002[483] Wilson et al., 2011[484] Thurston et al., 2011[485]	Evidence – People had to accept major changes in own health and accept their need for care and support from others.	Larkin et al., 2007[486]
		Suggested – Sudden deterioration is common, be prepared for it.	Miller et al., 2015[487]
		Evidence – A high percentage of people with lung cancer die	Philip et al., 2015[488]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		on first hospital admission with metastatic diagnosis made.	
		Evidence – Have a rapid response hospital team to assess for dying, futile care in ICU and introduce a preprinted set of instructions for EoL care.	Tam et al., 2014[489]
		Suggested – Shift EoL care to home and nursing home, for both rural and urban dying people.	Wilson & Truman, 2002[490]
13. Pain and other symptoms suddenly appear or cannot be managed at home or in the long-term care facility/nursing home.	Lawson et al., 2006[491] Lawson et al., 2008[492] Mitchell et al., 2004[493] Tuca-Rodriguez et al., 2012[494]	Evidence – Admit to a specialist care unit for pain and symptom management (to stabilize) and discharge home.	Lawson et al., 2006[495]
		Suggested – Planning for the care of patients in pain and short of breath is needed in advance of crisis and ER use.	Lawson et al., 2008[496]
		Suggested – Improve palliative care in homes and long-term care facilities.	Mitchell et al., 2004[497]
		Evidence – A specialist palliative care team in hospital was effect at	Tuca-Rodriguez et al., 2012[498]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		reducing most symptoms, with 1/3 able to go home.	
16. Wants to die at home, or to have most or all of their EoL care take place at home.	Unroe et al., 2015[499] Darlington et al., 2015[500] Guerriere et al., 2015b[501] Gomes et al., 2015[502] Wilson et al., 2009[503]	Evidence – Nursing home and hospice residents were able to go home with home hospice care, but these persons were the most likely to be hospitalized and in an ER before and during hospice care. Evidence - Nurses with experience in taking a stable dying critical care patient home to die are more positive about this move. Evidence – Those persons who wanted to die at home were more likely to do so. Evidence – People who said they wanted to die at home were more likely to do so, and especially if the family also wants them to die at home.	Unroe et al., 2015[504] Darlington et al., 2015[505] Guerriere et al., 2015b[506] Gomes et al., 2015[507]
20. Lives at home alone.	Kawagoe et al., 2009[508] Guerriere et al., 2015b[509] Houttekier et al., 2014[510]	Evidence - Home deaths require a wish to die at home by the patient and family. Home care program has 3 times/week visits	Kawagoe et al., 2009[512]

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
	Wee et al., 2014 [511]	from a palliative RN, weekly doctor visit, 24 hour on call doctor/nurse, and a volunteer who did chores, such as cooking and home cleaning.	
		Evidence – People who lived alone were much more likely to go into hospital to die there, despite some publicly funded personal care worker support at home, suggested that more hours of care and support are needed for these people.	Guerriere et al., 2015b[513]
		Evidence – An ongoing post hospital discharge program of home education and referral to community services program was effective at reducing ER use and rehospitalizations.	Wee et al., 2014[514]
38. Unpredictable dying processes, particularly with organ failure such as heart failure.	Unroe et al., 2011[515]	Suggested – Start palliative care and EoL planning on diagnosis of organ failure, including a discussion of goals of care with patient/family.	Unroe et al., 2011[516]
49. People who are	Hui et al., 2014[517]	Evidence – Outpatients	Hui et al., 2014[518]

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
hospitalized get accustomed to the hospital and it is difficult to move them home even if palliative care consultation and care planning occurs; people accustomed to outpatient care are more likely to stay home.		were not as often hospitalized as those receiving inpatient specialist consult.	
(c) Healthcare provider issues	**Sources**	**(c) Care setting transition solutions suggested or tested/found and as evidenced**	**Sources**
2. Late recognition of possible terminal illness or dying state and thus the need for palliative care, and possible reluctance to abandon or stop curative care.	Burge et al., 2005a[519] Gott et al., 2013[520] Menec et al., 2010[521] Philip et al., 2015[522] Wright et al., 2014b[523] Unroe et al., 2011[524] Unroe et al., 2015[525] Houttekier et al., 2014[526] Gozalo et al., 2011[527] Abarshi et al., 2010 Carey et al., 2015[528] Beynon et al., 2011[529] Fulton et al., 2014[530] Goldfeld et al., 2011[531].	Suggested - Earlier recognition of terminal illness, and early registration with a palliative care program. Suggested – Plan for very old people to have a palliative specialist provide care for them. Suggested – Nursing home care planning is needed to ensure EoL care is given. Suggested – It takes time for palliative care	Burge et al., 2005a[532] Fleming et al., 2010[533] Menec et al., 2010[534] Philip et al., 2015[535]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		services to work effectively and therefore reduce symptoms etc.	
		Suggested – Routine palliative care referral for cancer and other diseases with risk of death.	Wright et al., 2014b[536]
		Suggested – Long-term care facilities need incentives to start palliative EoL care sooner, and to provide onsite EoL care.	Unroe et al., 2015[537]
		Suggested – Ensure enough hospices are available and used earlier in last 6 months of life.	Unroe et al., 2011[538]
		Suggested – Burdensome transitions in acute care are to be viewed as poor quality EoL care.	Gozalo et al., 2011[539]
		Evidence – A care bundle for early hospital recognition and post hospital care was developed and reduced hospital and ER use in last 1-2 months of life.	Carey et al., 2015[540]
3. Hospital patients are not told that	Gott et al., 2013[541] Hanratty et al., 2012[542]	Suggested – Routine discussions early after	Gott et al., 2013[543]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
they are terminal or dying; some are given false hope and some do not have open and timely conversations.		diagnosis or early in illness. Suggested – Care providers need to meet to plan for a palliative approach to care, and when discussions with patient and their family are best done. Evidence – Have education of healthcare staff to enhance communication, and palliative care teams providing home care. Evidence – Have consistent staff who develop a relationship with the patient.	Gott et al., 2013[544] Ko et al., 2014[545] Lawson et al., 2008[546]
22. Continues to receive regular health care and without frank discussion and planning for care to be shifted to EoL or palliative care services.	Obermeyer et al., 2014[547] Giuffrida, 2015[548]	Suggested – Shifting to hospice/palliative care is needed or else regular approaches to illness care, including tests and hospitalizations will occur. Evidence – An in-house palliative care program increases recognition of dying and reduces hospital admissions.	Obermeyer et al., 2014[549] Giuffrida, 2015[550]
23. Aggressive EoL	Wright et al., 2014a[551]	Suggested – Use	Wright et al., 2014b[555]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
symptom and other treatment is provided, such as chemotherapy and ICU care in last days, weeks or months of life.	Zheng et al.,2015[552] Gozalo et al., 2011[553] Fulton et al., 2014[554]	research findings to show no survivor benefit from chemotherapy and stop its use, particularly as aggressive EoL life care continues after this.	
		Suggested – Improve the quality of decision making for elderly persons suffering from dementia to avoid ICU care.	Fulton et al., 2014[556]
34. Established care practice patterns are not questioned or changed to accommodate EoL care.	Gozalo et al., 2011[557]	Suggested – Aggressive life supporting care near EoL should become known as low quality care.	Gozalo et al., 2011[558]
36. Physicians, nurses, and other persons are not familiar with specialist palliative/hospice care or home care services and so do not refer patients there.	Unroe et al., 2011[559]	Suggested – Education of staff about hospice/EoL services.	Unroe et al., 2011[560]
39. High level of EoL monitoring done, or thought needed, including diagnostic tests in	Unroe et al., 2011[561]	Suggested – Standards of EoL care, for each disease process.	Unroe et al., 2011[562]

(a) Health system issues	**Sources**	**Solutions suggested or tested/found**	**Sources**
last weeks or months of life.			
(d) Family issues	**Sources**	**(d) Care setting transition solutions suggested or tested/found and as evidenced**	**Sources**
9. Requires considerable or frequent family caregiving support, and a need for the prevention of family overburden or burnout.	Ko et al., 2014[563] Kötzsch et al., 2015[564] Gott et al., 2013[565] Guerriere et al., 2015b[566] Houttekier et al., 2014[567] Hatcher et al., 2014 Guerriere et al.,2015a[568]	Evidence – 1/3 to 78% of home based dying patients had informal caregiver overburden. Suggested - Courses or education of healthcare providers, national palliative care guidelines, more palliative care support teams, more openness about talking with patients about terminal care, and national and international palliative care associations take a role in improving care. Evidence – A home based palliative care program assisted people and their family caregivers to achieve a home death. Suggested – Carefully assess care needs before discharge home	Ko et al., 2014[569] Guerriere et al., 2015b[570] Kötzsch et al., 2015[571]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
		and be prepared for 2 week before death increase in needs. Evidence – Family burden was associated with ER use, as very ill person requires immediate attention.	Guerriere et al., 2015b[572]
15. Families of terminally-ill people, as well as dying people and general duty health care providers do not have much, if any, experience with providing EoL care and have low knowledge of EoL care.	Purdy et al., 2015[573] Chitnis et al., 2013[574] Naylor et al., 2004[575] Wee et al., 2014[576]	Evidence – A care coordination center that took referrals from anyone organized packages of care for home based care. One of these provided direct care services and the other used other agencies to provide care. Evidence – Home-based care from Marie Curie nurses reduces hospitalizations for EoL care. Evidence – Post hospital education and ongoing care by advanced practice nurse reduces time to readmission and use of hospitals at EoL. Evidence – A home education program was effective at reducing ER use and rehospitalizations.	Purdy et al., 2015[577] Chitnis et al., 2013[578] Naylor et al., 2004[579] Wee et al., 2014[580]

(a) Health system issues	Sources	Solutions suggested or tested/found	Sources
25. Families insist that the nursing home resident goes to hospital when very ill or dying.	McGregor et al., 2011[581] Houttekier et al., 2014[582]	Suggested – Routine advance care planning and open communication.	McGregor et al., 2011[583]
35. Uncertainty among families, and also dying persons, about if there will be enough EoL care provided for current or future needs in the home, the nursing home, or other non-hospital places.	Unroe et al., 2015[584]	Suggested – Develop a policy assuring EoL services so that people can choose setting for EoL care, and that ensures enough EoL care to avoid need for ER and hospital EoL care.	Unroe et al., 2015[585]

APPENDIX B SELECT QUALITATIVE RESEARCH STUDY PARTICIPANT QUOTES

The following quotes illustrate the three themes that emerged through this study to explore EoL care setting transitions issues and solutions through informed participants across Ontario: (a) communication complexities and related solutions, (b) care planning and coordination gaps and related solutions, and (c) health system reform needs and related solutions.

A. Communication Complexities and Solutions

1. *Information gaps and information technology issues.*

> "The visiting home nurses in our system get absolutely no information from the hospital. You know, they get a referral that says – for palliative care. Sometimes they don't even get a diagnosis. And they have to take that and run with it, and provide good care for their patient when they have no idea what's happened in the hospital, they get no notes. So that type of communication needs to be improved" (#02).
>
> "One of our biggest issues is communication. There's a direct correlation between the quality of care and the quality of communication" (#04).
>
> "Communication and transfer of information is not good, officially. And I don't think we have open discussions about why and when people get moved" (#05).
>
> "There isn't a common chart. So I think we're assessing people to death still and that was the case 20 years ago…. I don't think we transfer the information well" (#05).
>
> "Communication is always a big problem. The silos are there…. CCAC has all kinds of documentation that they do send along (to the hospice), but often, it doesn't get to the nurse, who is the primary person in the home with regards to the family from my experience. I think when they do go from more active treatment into palliative and end-of-life care, it's really difficult for families to cope with the number of people coming into their home right at the beginning of that transition for all the different assessments and whatnot" (#06).
>
> "Communication between the professionals and also the professionals to the client between those settings I think is a challenge…. it's transfer of information in relation to their illness, what has happened, what are the goals of care and the discussions that have happened but also all the other pieces that come to that and what medications were they on, what was discontinued, so you get them into the home setting and you're talking to them and what we have in terms of that level of information to continue on with that care plan is not accurate or they may be missing information. It may sometimes even have inaccurate information" (#17).

"I think the issue that's really important is the lack of information around what's possible in the home care setting and I do think the other thing that I'm seeing is advance care planning and decision making" (#17).

"The patient is in a psych facility and the psych facility wants them out because they really do need long-term care; however, they're receiving one-on-one supervision and they don't disclose that to the CCAC, it doesn't come up in the health records and I don't know whether it's because there's no place to put that information; … but they don't want to disclose anything that would prevent the transfer" (#23).

"There are no consequences (with transfer issues). No real consequences because the enforcement, the Ministry of Health is not stepping in" (#24).

"A lot of Canadians feel that the government is always going to be there to take care of them and they almost, they begrudge or you know, kind of give you a hard time like they're shocked when we say you may have to, you would benefit from paying for a personal support worker and they look at us like why would we have to spend our money on that. But it certainly is going to help people and I think that part of our health care system, which is great, is that there is a lot covered but I think people don't always realize that they kind of put their own money into it too and it's going to benefit the family in that way too" (#25).

"Biggest challenge is information. What I consistently hear from patients and families is not necessarily information about their disease per se, but information about what, in general, is happening with them logistically. So, for example, patients who are awaiting transfer to home and who do get home, that period of time between arriving home and whomever it is that will be seeing the patient, if it is in outpatient clinic, if it is a home visit, there's pretty consistently uncertainty and unfamiliarity that I would say patients and families live with" (#33).

"If you ask most people, I think they'd probably say, "I want to die in my own home, in my own bed." But that isn't really totally possible, because as people deteriorate and change, as their functioning declines … they need different types of things. We need to be able to manage their incontinence" (#35).

"I think there needs to be a lot more in terms of electronic records that are accessible, but our systems don't talk to each other" (#02).

"We have to get consistent, we have to learn how to navigate people, and we have to have some kind of a system that's going to work. Because to me it's not working right now. We have too many people that, oh the hospital experience was awful, the home care experience was awful. Well why? Why was it awful and what do we do to improve it?" (#04).

"I do think educating the (family) caregiver around what to expect and what their role is, how to be the caregiver, how to be the advocate, where to find information, who to ask for that information. I think that's an important part that as people transition across care settings, is that in each of those settings that they'd transition is the families' and the caregivers' and the clients' need to be informed around what this looks like, what's their role, how they navigate the system" (#17).

"Navigating the system is one of the biggest challenges and by educating them (patients and families) better or giving them resources that they can easily -- giving them a website for older folks is not something that everybody thinks that's the way to go and we are getting better with websites and obviously for some folks that's the perfect thing but a multi-prong approach to an education and resource management for the people using the system" (#18).

"Have the training beginning at the board level and with executive directors and then go down into the organizations including individuals and families, so that they're aware of what's happening and they're part of the training process too…. And in hospitals, its transition courses" (#20).

"More public awareness earlier on about the supports that are available to families and other caregivers" (#22).

"We need to have a death plan, or end of life plan" (#35).

"The (palliative care) population that we care for is cared for frequently from diagnosis to end of life. And that period of time can be quite lengthy, a month to years, at times even decades…. So we are fortunate in that when we are referred early, I think that's a key for us, is that patients be referred early along the illness trajectory, in order that there's a relationship that's built" (#38).

2. Information privacy issues.

"Volunteers are great. If they followed the patients from one place to the other and anybody would listen to the volunteer, they could give them all kinds of information that would be so helpful, but privacy would stop this" (#06).

"The LHIN had initiated a year ago a kind of … Health Links…. They did a study on 91 people in the catchment that had accessed some of the services, you had to sign off a stack of confidentiality papers before you could go in the door" (#14).

"There is no common electronic medical record and then hesitation amongst providers about who is in the circle of care and who can they share information about and list" (#19).

"There is a lack of respect (about long-term care). There are a lot of roadblocks in long-term care that we face with the hospital. There's not a willing to communicate or share information. So often times, as we get roadblocked with 'This is a privacy issue' or we can't talk to you because you're don't have the power of attorney" (#21).

3. *Workload issues and related considerations.*

> "Workload is huge, yeah, yeah. There's times when the nurse is just caught at one home that she can't leave if the person's imminently dying or something urgent is happening, like a bleed or something. And they end up having to work until 7 o'clock at night to get their visits completed because there's no one to cover for them for the rest of the day if they're caught somewhere. So the whole way our home care system is staffed and funded is often to the detriment of good care" (#02).
>
> "Nurses are constantly pressured into getting their work done as quickly as possible…. The nurses don't have time to read her information, and we're consistently pressured by CACC to perform certain amounts of work in a certain amount of time and at end-of-life care, it does take time" (#05).
> "CCAC does provide information but there are reams of records, but I don't think the (home care) nurses have time to find out what it is they really need" (#06).
>
> "Those (home care) nurses are seeing from 16 to 25 patients in a day and the traveling distance in our area is huge. So I think some of it was just sheer overwork and if they were there for a dressing, they just looked at the dressing and that was it. No slanting sideways to see the patient can hardly breathe" (#06).
>
> "I think the (nursing home) nurses have so many residents that they're looking after, that they can't keep up with all the (health or illness or EoL) changes" (#06).
>
> "Everybody's too darn busy. Our expert team shouldn't be going out to see a patient without having the family doctor or the community nurse or somebody there to mentor because if the team just goes out and takes over, then the generalists don't learn from that. But I think it's a whole question of time" (#06).
>
> "When we have very high demand for those acute beds, being somebody who's had worked in a hospital for more than 30 years, you know I've seen particularly in the last few years, we've seen the push home…. We also notice that they're not taking the time to have that specialized palliative care and taking the time for those patients that potentially are fairly high needs patients" (#18).
>
> "Unnecessary admissions? Sure. We see them from both sides because we see families get to the end of the rope, right? They'd just say I don't know what else we can do, right? We just can't take this anymore and we're not getting the support" (#18).
>
> "Our CCAC supports home care visitations but its minimal shift nursing support…. A model needs to be developed which provides night care by a personal support worker with palliative care experience and hopefully a remote palliative care nurse on call to address issues and monitor…. each nurse in this plan monitors 48 homes and is dedicated to remote availability and remote monitoring of vitals throughout the night" (#20).

4. Avoidance of difficult conversations about death and the avoidance of using terms such as palliative or dying.

> “(Moves to hospice occur) after the patient has been kind of procrastinating with the decision to move…. At the point they get to hospice they don’t live very long. So the hospice experience, which is rich, people don’t have the chance to enjoy it. I had a 92 year old man tell me today that he didn’t wasn’t to go to hospice as they is where people go to die. And this is a man with stage 4 cancer for which there’s no treatment” (#02).
>
> “One participant reported that a dying woman was sent home from hospital and who did not have an able elderly spousal caregiver at home to care for her, there was concern that the hospital did not have “a realistic heart-to-heart with them about what (a home death) would involve” (#02).
>
> “People are still afraid to talk about hospice. So when we talk about people transferring to a residential hospice; ‘I’m not ready yet’, I hear that frequently” (#05).
>
> “Unless goals are set, people are going to get into situations where they end up in Emerg and Emerg isn’t sure what the goals are and so they just end up in ICU. I’ve seen this so many times, in the ICU on respirators or whatnot for people who really that’s not what they would’ve chosen if somebody had sat down with them and talked to them” (#06).
>
> “I think the issue that is specific to all of the settings is the communication and pre-discharge or pre-transfer planning…. There is the communication to the patient and family about why the person is being transferred from one care setting to another, which would vary from care setting to care setting. So for example, if someone is being transferred from an acute care setting into the home because really active treatment isn’t needed anymore or they’re not eligible, there is a conversation about the person’s diagnosis and prognosis which gets into all of the issues about how comfortable this healthcare professionals and physicians in particular are, how comfortable they are in talking about that with patients” (#07).
>
> “The patients go home and they don’t even know they’re dying or they don’t know that the chemotherapy or the radiation was really just for symptom relief. It’s not going to cure them” (#07).
>
> “In North America there’s a disdain for death and dying, and it’s considered a failure on the profession. So to say that our new residents or a new doctor, even our old doctors for that matter aren’t comfortable talking about advance care planning, aren’t comfortable talking about code status, aren’t comfortable talking about death and dying; I don’t think it’s because they’re ignorant, I think it’s because it hasn’t been normalized yet enough in society” (#11).
>
> “She never was allowed to go back to her own apartment again. She was put into a long-term care and that was huge. It wasn’t like an easy transition…, it’s a very

rushed thing. She was very unhappy. She never adjusted to the long-term care because she just felt she was put in there to die, 'This is my last stop' she would say" (#13).

"Our (home care) nurses build a rapport with the clients and the families to better understand what their wishes and wants are…. our nurses tried to initiate those conversations in the relationship and the family have actually said, "You know, we have no idea what you're talking about. We've never been told that dad is dying. We've never been told that dad has six months or less" (#17).

"If I hadn't been standing there, my mother (93 years old, ill, and going for surgery) would have been listed as full code because she (the doctor) couldn't ask her the question" (#24).

"Nobody talked to grandpa about 'how do you want your life to end.' Nobody talked to grandpa about his values and beliefs and his life wishes after his dementia diagnosis while he was still capable of making those decisions" (#27).

"With sick kids they don't use the term palliative care. They're called the advanced care team" (#28).

"Breaking bad news and one of the issues that we identify is that in terms of sharing difficult information with patients and families the issue of language is crucial" (#30).

"No one likes to hear the words death, and no, prognosis is, no one wants to hear sort of end of life no, any other word that is big as this you shouldn't tell them that you know you're palliative because most people assume associate the word palliative with death, so if you're told you're palliative that means automatically you're going to die" (#32).

"A long-term care (facility) has the physician, who comes in once a week but then refuses to give any prognosis" (#34).

"One of the biggest barriers or biggest problems is that we don't have the discussion with the patient and family about what they want their end of life to look like, where they want to die, by actual physical location. I think that as a Canadian that our health care system, we're very proud of it, and it's there for us when we need it. And that people have an expectation that I'll just go to the hospital…. There's no discussion, there's no planning….People are reluctant, I think, to have that discussion" (#35).

"At the Cancer Center… nobody was having that conversation with them. Because we're hopeful and we want to cure cancer" (#35).

"1% of people will die suddenly…. It's a very small number. And the other 90-something percent of us are going to slowly deteriorate over time. So we've got to make plans and have the discussions" (#35).

"Biggest challenge is sometimes these things are done in a crisis, where it would have been – the transitions that occur that are a little more planned out or anticipated or talked about ahead of time tend to go a little bit more smoothly, I think, for the patient and for the family. So just having those conversations ahead of time in terms of, you know, you have an individual you know is dying, when we don't know that trying to determine – how do you see this happening? Where do you want to have your end of life care? Having those conversations and having those plans in place, or back-up plans, so that they're not making a decision in a stressful moment, that they had the opportunity perhaps to come and tour the hospice so they know exactly what it will look like when they arrive. I think that that preparation ahead of time is invaluable for the transition to occur as smoothly as possible. And it's a difficult time regardless. And we know not everybody wants to enter into that conversation, but those conversation needs to happen, and people need to know where their resources are and to think things though, and to have some control over what happens, so that we're not reacting all the time" (#37).

"In health care we need to get a lot more comfortable with having difficult conversations. Talking to people realistically about what they understand about their disease, what they can expect on their prognosis, and then really trying to find out what is important to them and so that we can certainly direct their care and services and opportunities that we know are in line with what they really value and what they hope to achieve with the time that they have. I think that's something palliative care teams really do very well (#03).

Another said that conversations should take place "much earlier, much earlier than it's already happening, as soon as someone has a life-threatening illness. I think you have to start early with palliative care and try to get the person, the client, to buy into what do they want at the end. As you go along that journey, they need to be informed more of where they're at and what their option could be…. So Plan A is yes you'd like to die at home, this is what we can do to set this up. What would Plan B, what would that be if that didn't work out or it went on too long and everyone got tired and the person's condition was not being controlled? The pain wasn't being controlled. Where would the next option be? And let's have that plan in place. So we take here backup plans, so people that their plan and it's great if it can work out at home. But if it doesn't work out they can phone here. And if we have a bed (open in the hospice), we'll bring them in here" (#04).

"Advance care planning discussions, we need discussions long before that last year (of life)" (#05).

"I think it needs to be done very early in the illness … talking to them about what would make your quality of life such that you would want to stop life-prolonging interventions. I think CPR is the easy one, but I think things like feeding tubes and ventilators and stuff like that are a little harder, dialysis. But I think we really need to talk with people earlier about some of those things" (#06).

"The LEAP Program for palliative care…. We have these physicians and the nurses and the social workers and the physiotherapists and pharmacists taking courses about all the dimensions of palliative care, social, emotional, as well as the nitty-gritties of pain management, etcetera" (#07).

"We're trying really hard to normalize conversations in death and dying. And I would say that we do have with our regional palliative care program and a volunteer organization, some initiatives and events such as the Death Café … to help people talk about this, is just practical planning, this is part of life, try to advance the idea that you were planned nine months from birth. You should really invest some time into planning your death" (#19).

"We did a public education campaign with talking about it was called 'Looking Ahead' and it was how do you support people and have individuals themselves talk about the issues. And this was done on radio, paper and it was major and issued in the community. And in fact, one of the small communities, they said that this was the best news story they had of that year. So it's quite interesting. So people are hungry for in the information but the information is only taken to heart when it touches you" (#20).

"Community information. I don't know if you remember years ago the Ministry of Health did great campaign called 'Your Health Care Let's Be Involve'" (#29).

"More education that palliative is not death" (#32).
"We need to have the conversation routinely, "What do you want?" …when someone's in their eighties… we should talk about it. I think that the elderly want to talk about those kinds of things" (#35).

"Before people come to hospice, they know exactly what our philosophy of care is, we have the same expectations, the same goals. So when they're here, the residents and the family understand completely what we'll be focusing on. And so there's not a discrepancy or inappropriate expectations. So having that conversation and that knowledge of that person ahead of time really simplifies things. Because we're not negotiating blood transfusions here. That's been made clear prior to their arrival" (#37).

"Our patients have palliative care directives that are reviewed on a yearly basis with the family. And for those who have agreed to do-not-resuscitates, or no CPR, or no ventilation, no intubation, a DNRC form is completed" (#38).

5. *A lack of effective communication processes and methods or tools to facilitate communication among all persons or groups needing to be involved in the communication.*

"A lot of the planning goes on without them (the patient and/or family members) being present. They're not always told when the meeting is going to happen, or when there's going to be a discussion. And if they do end up at the meeting and are part of the discussion, sometimes not all the information is there" (#02).

"Primary care is using one electronic medical record, the hospital using a different form and system, the community is doing either electronic documentation or paper, so having that one system that communicates would certainly be helpful and be one last barrier" (#10).

"There are issues in Ontario around consent. There are still a lot of nursing homes and long-term care facilities that are using Level of Care forms as a blanket consent and even when the patient is capable of making decisions, without any prior discussion with the patient and therefore, no consent, are moved to hospital" (#11).

"If everybody assessed on the same tool level, we probably wouldn't have so many voids or overlaps. And I think if we have that care planning from the hospital it would help, but ... their whole goal is to get them out" (#14).

"We had every player in that industry at one table and one of the main things that came out of that early on was that if we all assessed with the same tools, you'd better be able to service the resources or health care needs of a patient, but it came from the hospital perspective" (#14).

"The processes, the systems, they flow better at a regional level versus at a setting level and so there is better flow of information because it's the one region is on one electronic chart, that's one policy and procedures, one versus all our system issues. When you're transferring them from hospital to home, or hospital to long-term care, you're dealing with two separate systems, right? It's still part of the healthcare system but it's from hospital to home, it's a referral to CCAC then CCAC needs to do the assessment, the assessment needs to go to a provider, the provider needs to agree that they have the staff. And so it's way too many pieces -- not transition points, but touch points (#17).

"There needs to be a series of conversations. Some of the communication things, for example, would be the advanced care plan, who the person's actual substitute decision maker is. And then discussions around what this person actually wants at end of life, so their preferred place of death. And then further discussions about burden to the family and their sustainability for caregiving. I don't think people have good conversations about that particular bit of planning and that it's okay that even though you promised your mom that they could stay at home to die that as things fall apart that that's okay you did your best" (#19).

"There isn't a present central source of information or database. In different LIHNs, different communities, there are different tools to use. I think that comes down to, so I think we also see varying degrees of discharge planning support in hospitals, frankly. You do run across some situations where there's a discharge planning position in place, whatever they call that position, to me it is a discharge planning function, who are fairly knowledgeable with at least the local community and many who are not. The hospitals are discharging to such a vast geography and community services are not terribly consistent to be able to figure that web of support out" (#22).

“One of the problems is that we, even in the home setting, they will find that different health professionals come in and ask the same questions. I have one beautiful little old lady who said, don't you people ever get together?” (#26).

“Nobody has actually called the family physician to find out A- are they aware of what their patient situation is, or the condition is or what may have changed is this physician available to provide care and willing to provide care, so as a basic step people don't make contact with family physicians, they rely on discharge summary which may come out days later or sometimes weeks later or some sort of hand printed discharge summary or printed discharge summary, or a hand-written discharge summary, that is completely inadequate” (#30).

“There are indicators around hospital re-admissions… but we need indicators for high quality end of life care” (#31).

“I'll often transfer a client into the hospice and I might not get the paperwork for two days and they're already dead” (#34).

“At CCAC, at one time, they were tracking preferred place of death. And I'm not sure if they're still doing it now. So it's in their computer system, it's in CHRIS, there's a template for a note. And I don't know if that was captured or not, because they have different ways of capturing different information there” (#35).

“It's a referral form. And the CCAC's role in that is to ensure that the individual requires twenty-four hour nursing and PFW support (before they go to a hospice). So they give us the demographics on the individual, and they have indicated that it is appropriate for – this person's care needs are such that a hospice would be appropriate for them” (#37).

“Having a consistent voice is such an important factor in making transitions go smoothly for patients. If it’s the case manager or a family advocate, we see the benefit of that” (#03).

“We need to have some kind of a document that travels with the patient or an electronic documentation that we can access so they (the patients and family) don’t have to keep repeating their story” (#04).

“Nobody gets through all the paperwork. It would be nice if there was some way to have just a conversation (between care settings)” (#06).

“If the long-term care home is sending the patient to the hospital, then they’re responsible for providing that communication and if the patient is going back, then the hospital really is responsible for communicating back to that long-term care home” (#07).

“Conversations around what does CPR means for you and the DNR-C form for transfer of care with paramedics and that whole paramedic piece is an area we’re trying to be sure that the paramedics when they go in the home that they’re very aware of what the situation is. One of the things in order to cope with the lack of an electronic record is a paper record. CCAC is trialing a good old paper record in the home for patients who are requiring palliative care" (#07).

"One of things that our hospital is doing and I think others are going there, there's a big focus on something called TOA, which is Transfer of Accountability…. It's called a warm hand-off, which means a voice-to-voice report, a transfer of information and accountability" (#08).

"It's always helpful to have the whole team meet together doing more case conferencing with clients" (#10).

"A common medical record that can be accessed by all care providers and that would be documented on in this spot would go a long way to start at least having information shared" (#18).

"There's a tracking system (for errors) in a long-term care home. It's communicated back to the place that transferred the resident. And then if it is a standalone event, if it were to resolve in a resident's death or adverse reaction, then that is reported through various processes such as the Ministry of Health" (#21).

"Our team tracks the patient's preference for place of death and we find that something like 80 to 85 percent of people will be able to identify that and then we track where they actually die. Of course, we will change that if they change their mind towards the end because often they will not be able to stay home even though they had wanted to because of insufficient ability to get maybe enough help from CCAC and maybe the family are not coping with the care" (#23).

"Get rid of all these forms that are inappropriate. We see tons, I'm not saying that forms are the solution, but forms do drive some of the practice and when we have these forms that are incorrect, and that's leading people down the wrong path, so then you're confusing the situation (#24).

"We need to look at process mapping or, basic that integration of particularly home, hospital to home and I think we need to have a process map there and I think there are redundant steps I think there are poorly designed pieces to this and that, so that we need to look at that whole process, first of all process mapping and that should be a collaborated effort between hospitals and CCACs (#30).

"Many limitations in terms of people being able to access information that clearly kind of inform us at those crisis moments, if the patient gets seen in emergency department that's not where they've been receiving care, there's not a whole lot that that team has to go on in terms of understanding of where are they and in the course of things and more aggressive approaches may be offered or pursued than if the patient had that meaningful conversation with the care providers who are involved in treating it. I don't think we've got good communication tools for folks to actually see clearly defined goals of care and care plans across the setting" (#31).

"There should be some ways to flag either in the system or through questioning, 911 operators as an example, there were ways to indicate that a person is on a palliative care program" (#33).

B. Care Planning and Coordination Gaps and Solutions

1. Most EoL moves are not well coordinated.

Moves are "not smooth, not well coordinated…. There should be some sort of (written) directive available to use to determine where to transfer the patient to or when to keep the patient" (#01).

"Transitions never go smoothly ever…. When it comes to transition from hospital to home they're often a disaster. People come home without proper assessment, without the medical orders being provided without the equipment, being ordered to be in the home ahead of time, and that kind of thing" (#02).

Another said even when a transfer has been planned and everything is ready to bring someone home from hospital for EoL nursing care, the actual transfer home is not made quickly enough, as "the equipment's in the house, supplies are in the house, I'm (the palliative home care nurse) phoning, the visiting nurses are phoning, the occupational therapist is phoning, everybody's phoning to make a home visit. The patient wasn't even home yet. And then the patient dies in hospital" (#02).

"It's not usual for hospital employees to promise them (patients or families) a lot more than the home care system is able to deliver. And people just assume, oh you're going home for palliative care. They think you're going to have 24-hours of care at home each day. And it doesn't work that way" (#02).
"I don't think that they (families) know what their options are. They think that they're going to get home care at home and they're going to be taken care of 24 hours a day and I don't think they have anyone that can navigate that system with them and tell them what their options are" (#04).

"(From hospital) they can be sent home without the proper meds, they can be sent home without the proper care put in place or into the facility without the proper care in that particular facility. When you're looking at retirement homes and long-term care facilities, there's a vast difference and now with the Silver Tsunami that we might say is coming forward, a lot of retirement homes that aren't regulated are becoming like a long-term care holding place" (#14).

"They (nursing homes) don't have the expertise. They don't have the knowledge. They don't have the staffing that's required to care for those people" (#13)

"The transition, it just seems to be everybody's running at it. And it's such a reactionary process right now, which is very sad. In my opinion, I think it needs to be much more proactive and care planned (#14).

"(The move to hospital) it's not planned or scheduled. It's an emergency … they're moving into this sector because of a crisis of one type or another" (#16).

"To get them out of the hospital, we hear regularly that they were given a very strong impression that they're going to support them at home…but what they mean support and what actually happens are two different things. Proper disclosure I guess will be the other part of what if in fact they are going to have the support that they need, what kind of costs that are associated with that, small things as well just education around particularly in a cancer situation where they're having medications. Some of these medications that they're having, they're going home, they don't have proper protective equipment, they don't have proper training. They're exposing themselves maybe to chemotherapy drugs due to spills and understanding of the medication on how to best dispose it if they had spill. We see concerns from that area for not only the patients and their family, but also the paramedics and the other people that are working within sometimes a private residence" (#18)

"If somebody is hours away or less than a day away from death like somebody is imminently dying, sometimes those transfers won't happen quick enough s the person ends up in their preferred place of death" (#19).

"We had our home care coordinator go to a home to meet with a couple about respite care…. When she got there, what she found was an elderly couple in the home and yes somebody had referred them for respite care, but his wife was sent home from the hospital eight weeks prior. She was palliative and was told that home care would be in the home. He'd have a call from home care within the next day or two but nothing happened. The home care agencies got a referral, so there was a breakdown. He didn't reach out for whatever reason. So he'd been home caring for his wife for eight weeks, when he should have had nursing probably almost every day, nursing and personal support" (#22).

"This large percentage of patients that fall between the cracks…. We call it a collaborative care plan, of course a best case scenario, but you're always looking at what is the patient's preference" (#23).

"I don't think that we have a formal tracking for readmissions. We have actually talked about looking at that to see if that would be a solution for why our patients get readmitted other than a lot of our patients do get readmitted for numerous different reasons. So we have thought about even looking at why they are coming back" (#25).

"After a number of transfers at different care settings, she kept moving because she kept worsening and where she was before couldn't take care of her. She'd been at home to begin with. She lived in at home for 50 years, then fell and was taken to the hospital and needed stitches. So, she moved in to a retirement community where she was from and she never went to the home again. The family home had to be sold. She broke a bone in her back and she called an ambulance from this retirement community and was in the hospital again. So, she couldn't return to the care setting she'd been in and my sister took care of it and got her into a retirement community where we paid, well my mother paid. Fortunately, she could afford all this. She paid for all the extras. I mean by the end they had to dress her. I wonder what happens with people who can't pay. It was $5,000 a month and on top of that, there were all kinds of extras too. She got the oxygen. She got a guardrail. I mean that was one time cost but there were a lot of extras. She went from respite room again to an apartment back to respite. She had to be taken to the hospital because she couldn't catch her breath and she had to be on 24/7 oxygen after that for the last two months of her life in hospital" (#28).

"Often, they don't even see a case manager. My sister went to all her appointments as Mom could not remember" (#28).

"Anxiety that develops from the patients and the families in terms of preparing for a transfer. Often, they don't feel that they had much time to prepare for the transfer. I mean we understand, for instance, in hospitals that we get the availability of a bed at last minute so one never knows when that real move will occur. So that often is upsetting if perhaps a family member can't be there during the transfer and especially when it involves elderly patients or patients with dementia or some kind of emotional deficits that could escalate during that time" (#29).

"I would absolutely love to see some type of system where people who worked in hospitals came out to the community, and people who are in the community go to hospitals even for short-term experiences to see what happens either way. I certainly had opportunities to do that. People worked in different departments in the hospital and found that they learned a lot about how the other half lives" (#02).

"We need to educate those people (patients and family members) as to what are the (EoL care) options" (#04).

"One of the things with our residential hospice does is have a nurse from the hospice go out and do a preadmission visit and that is really good so that when the person comes into hospice, they've already met one of the nurses. They know what the facility is like and that sort of thing and that's worked really well" (#06).

"We'd love a centralized database to call (for historical and real time patient information); "Oh, Mr. Jones, he's on the palliative program?" (#07).

"The first time I started seeing the word transition was with Accreditation Canada (that assesses for some transition requirements)…. We stopped using the word discharge because we realized that they go somewhere, right? It is really is a transition to somewhere, to home or to another setting…. And then in the case management world, I became very aware of the word transition and in the US, there's the National Transitions of Care Coalition" (#08).

"We send a volunteer and do an assessment and … we monitor that because things can change day by day, week by week with a person that's end-of-life or life-limiting, and so we could help them" (#14).

"There might be a palliative order set … that might be initiated because this is somebody that's moving towards end-of-life and these things would be of benefit. And they have a common language tool like for instance the PPS that they use as screen" (#16).

"Something needs to happen to have some kind of mandate that there's a group that gets together every once in a while within the sectors" (#21).

"An Integrated Client Assessment Response Team is in a LIHN now, and it started at a couple of the smaller hospitals, where we've cross-trained coordinators from the CCAC from community support and from the SMILE program, where a screener would be completed on any clients 75 and older who was either being discharged from the hospital or who had gone through Emerg to determine if they had Activities of Daily Living needs, as to how they were coping in the community, so that before they went home, they wouldn't get an array of calls from various agencies; each coordinator has the ability to look into each other's client records to know if they're an existing client, so to smoothly assist their transition to home by bumping up existing services if needed or putting in new services as needed" (#22).

"The care coordinator's kind of the central one in which that person would present the options to the patient and family and steer them, trying to determine what is their place of preference. If it is their place of preference to stay home, that would be obviously acknowledged and supported, but then usually there is a suggestion of the back-up in case things become more difficult and at that point here's the options that are available" (#23).

"I'm a nurse practitioner at this hospital, I don't work under a doctor, on a geriatric rehab unit I manage all their medical care and then right through to their discharge and discharge planning. So, I, the biggest part of my population is probably 85 years of age and up and they are going anywhere, when they come to our unit, their plan has to be to discharge home and I can do that most of the time as that is their home where they've been the most comfortable before…. Some need to go to a retirement home or nursing home, and we lead them through that process because most of them don't know about how the process works (#25).

"If there's someone who has cancer who's on sort of fairly foreseeable trajectory of their illness and choose to go home to die, that's one thing we can do and we actually on the palliative care team now and in the community we do fairly well. One of the nice things about it is that we have the EDITH Program which Expected Death in the Home, whereby a nurse works with the patient and family to come up with a DNRC

> and then a plan for expected death in the home and that we our MRP, our physician listed and a back-up listed and we've arranged with the nursing agency so that they can pronounce and then the MRP will sign the death certificate and the funeral home knows so then basically at the time of death there's no calling 911, there is no bells and whistles, no neighbors running to the door to see what's happening and basically it's all done very smoothly and very nicely I may say" (#26).
>
> "At the HOSPITAL, they have a patient navigator for that. She had a great nurse from the community who came in I think three times a week" (#28).
>
> "What we would like to see is that we have here a primary team which would be a family physician, primary nurse of the community supported by expert nurses, expert physicians palliative care coordinators and well the other we don't have in the community, things like social work and spiritual care. The social work and spiritual care are very limited resources in the community" (#30).
>
> "Have patient come in from home and not go through the admitting department in the hospital or the emergency department" (#31).
>
> "Ideally we make a system that is not dependent on families needing to advocate or needing to navigate" (#33).
>
> "In hospice, either I have met the patient and family prior to their admission to the hospice, or a member of our outreach team has met the patient and family prior to their admission to hospice. And so the person doesn't arrive unknown to us. We have a good sense of their story, their history, their current situation. So that is a process that works very well" (#37).

2. *Some patients and families pose challenges that restrict or impede care planning and care coordination and care options.*

> "I totally have always been of the belief that transitions are where the problems lie in our healthcare system and I can't feel that strongly and never emphasize that strongly enough. But there really needs to be a lot more done to smooth the transitions. And some of the projects that are going on now where they try and get you into great care only work for selected populations. We've had some experiences in spite of everything in the press about some of the integrated programs that are happening, we've had some really bad experiences where a person's been, somebody with lung disease and cancer of the lung" (#02).
>
> "They had some language difficulties because they were immigrants…. Several times, he had to go into Emerg and it was very difficult because usually it was behavior problems that she just couldn't get him calmed down and whatnot. So he ended up being taken to Emerg and then of course, no goals of care and no plan of treatment to follow him. So those were very difficult times for that family and probably for the Emerg staff too because they didn't really know where they were going with him. So

anyway, the last time he went to Emerg, she just was totally burned out (from caring for him). So they decided they would leave him in the hospital. Well, then because of his behavior, they had him tethered to the bed and it was very difficult in the hospital for them but there was a bed in hospice that came open, like within three days or whatever. So he was moved into hospice and the goal was to treat the symptoms and just let him die, … he did die about a week later and it was a good experience for them after he got to the hospice but in the hospital, it was very difficult because of keeping him sedated so the behaviors didn't rise again, like they do with pain" (#06).

"Sometimes, it's cultural … like the South Asian culture where the patient may just want to defer to the son or whoever, to talk to them" (#07).

"It's not something that fits that black and white, follow the steps one through five every time for every patient. Everyone is so different and every situation's unique" (#10).

"Palliative care patients live typically less than three months….Patients with less than one-year prognosis are living for two or three or four or five years, and so what happens now in the context of a nonmalignant diagnosis, it becomes more and more challenging to find placement for these people, because the long-term palliative care unit is saying this diagnosis is not OK" (#11).

"I don't think we're ever going to get to a point where every single individual is going to want to die at home. I think there are lots of reasons why families don't take patients home to die, a lot of them are system based, but I also think at the end of the day, there will be some personal choice. Not every family wants to have their love one die at home and not every loved one wants to go home and die" (#11).

"Someone who's got dementia, who's pleasantly demented, who's eating, was feeding, who sleeps well during the night, can probably function at a retirement home or a nursing home. If that patient is regularly agitated, regularly not eating, having pain, having nausea, having symptoms, having things change, where does that person go? Because where that person goes right now is from the nursing home to the Emerg" (#11).

"The family can influence these transitions based on their understanding of what's the care plan, and if they can be or want to be involved….You're lucky if a family member will advocate appropriately so that everything's clear" (#12).

"We didn't have a choice (about a care setting for her father with Alzheimer's) because my mom was really afraid because he was getting very violent, so she phoned the police. And once the police got involved, it was sort of like a domestic assault and so we were just told he was never allowed to go home again. So we weren't allowed to sort of bring him home again and then sort of take same time to figure out. So the hospital basically just said this place has an opening, that's where he's going" (#13).

"My mom is 91, and she lives on her own. And she's very independent, but like we would really love her to move in with my younger sister, she has a basement suite, but there's no way. My mom, "I'm never going to live with any of you, kids. I'm not a burden, that's not the way it's supposed to be," and my one sister really wants to push my mom to do this. I think at 91, if she doesn't want to do it, then why put her through that stress and we all communicate and get along great, but it's amazing when different issues like this, very emotional issues come up, all of a sudden, maybe you (the family) don't get along so well" (#13).

"Globally, the adult children don't always live close to their parents" (#14).
"(All patients and) families to have a significant amount of anxiety at a time when they really don't need anxiety. What they need is someone to be able to provide answers and have a system that supports them during this difficult time (of transferring)" (#18).

"There is a need to ensure that people with intellectual challenges can exercise the same right and have access in services and support available to the general population but they do have challenges. People just don't fit in a cookie cutter. So ideally, the right place is where the individual stays verbally or otherwise that the individual desires. Many people with intellectual challenges have been supported in their community, be at a supportive housing or group living, and they say that that is home and wish to die there" (#20).

"The family says they'd go against the long-term care patient's wishes, and you know I said, you need to go with the patient's wishes" (#21).

"A lot depends on the actual situation with the patient and related to their illness; if somebody's on a very clear trajectory that's declining and you know that it looks very likely that they're end of life in the next weeks to months, it seems a lot different to me than somebody who has a trajectory of a chronic illness that is palliative such as congestive heart failure, COPD, where you know they actually could in fact live for another couple of years and you might be considering alternative options such as long-term care" (#23).

"The palliative chronic care patient where long-term care may be an option, … it's an extremely challenging, difficult time for patients and families and you know the fact that they can't get the place near where they are, the waitlists and the whole onerous process of long-term care placement, I think is horrendous and for people at that time of life, it just must add that much more. I mean you know very often with the dementia patient how long they're going to live, it could be another 2, 3, 4 years; we've seen people live for very long periods of time" (#23).

"He's quite violent at this point, wife can't take care of him, so he's sitting in a hospital, … and they felt he needed to be restrained temporarily, but then they told the family, look if we restrain him at all, no long-term care home will take him" (#24).

"Some go home with little help, it is really their choice so we recommend things like Lifeline and Meals on Wheels and even accepting home care, sometimes our patients don't want to accept a stranger coming into their home to assist them, so those people are certainly at risk. I would think the mobility and the cognitive impairment are the two big risks and seniors if they are isolated, if they don't have family or friends to check on them" (#25).

"We have a family right now that they knew that their Mum was going to be going home soon from hospital and so they have no just stopped returning our calls and they're not coming into visit their mother anymore because they're afraid that we're going to discharge her home" (#25).

"We have to get an interpreter. Often times because it involves a consent to do something and we can't rely on family members to interpret for them because of course have their own biases, so that's a challenge. The cultural challenge is fascinating actually because a lot of different cultures and people from different countries and different religions have definite ideas about what the dying process is going to look like" (#26).

"If you're prone to wandering or striking out, you're almost impossible to find a (nursing home) bed for. If you have unique dietary requirements as a result of cultural or religious fact, it's harder to find a bed. If you'd rather be in a Slovenian nursing home or Ukrainian nursing home, well guess what, they're also full" (#27).

"I'll talk about frail elderly because it seems they probably have most transitions in care. They are what's called frequent flyers. They're in the emergency department a lot and then transferred out but if the discharge summary isn't complete, that's a problem. If during their stay their medication is changed or new meds are added, that can be an issue too. And this is another issue, if the person, the patient, doesn't have an advocate with them, a family member or someone, their cognitive abilities sometimes decline as you get older and they don't remember all the medications they're on. So you really need someone to speak for you to navigate the system and to get what you need and that's in the hospital and at home too" (#28).

"They do their documentation on the forms, this negative judgment is reflected on the forms and can influence the next facility on whether they're going to accept the person or when they do accept them, the families have already been marked as a problem family" (#29).

"Within the Asian community because a lot of the elders still do not speak fluent English. Their traditions are very much alive still but they're children who had been raised and schooled even born here in Canada, they have almost two values clashing present in that set of challenges" (#29).

"More complicated in non-cancer diagnoses like COPT or CHF those conversations just don't happened as readily and so I think many of those patients are truly only accessing those services at the very end of life or coming in to a hospital and dying here" (#31).

"Goals of care and how those are changing over time and for some patients those are changing rapidly, in alignment what their values and wishes and beliefs and, you know constantly evolving thoughts and worries and concerns with all of this, it's not static so I think people can have conversations an anticipation in some things that may happen but it always has to be recontextualised when there's something new evolving or developing with their disease" (#31).

"Concern for the patient safety in the transition process would be if you have patients who are alone and they would become more of a priority I mean from our perspective we try to ensure that there's a home review safety completed" (#32).

"If our patient is Polish … generally their kids will come and they'll translate for them, because the kids probably speak the parents' language. But we have had some like Vietnamese families, that sort of thing, where we've had to get some translation going. And it has been difficult to do. And then on top of that some of the cultural things….You have to understand and respect the different cultures, because they have different ideas around death and dying. Within some cultures, they do not believe in not resuscitating, and it's almost their duty to always try and preserve life at all costs, until there's just nowhere to go. So they would never sign a do-not-resuscitate order, no matter what condition somebody is in" (#36).

"If they do live alone and do not have a lot of support, then we know that there's a very, very good chance that they're not going to have somebody that's going to take over and be a responsible caregiver for them. So we know that they're going to have to be elsewhere at end of life" (#36).

"Recently we've had some immigrant families benefit from our service, and we have been very fortunate that the particular population has interpreter support that is exceptional, and so it does facilitate communication around decision-making at end of life and transitioning. But with regards to – so it's not only the spoken language, but it's the understood, and this cultural – so not all cultures have a sense of what palliative care is. So we run into some cultures that there's no word in that culture or that language that adequately reflects palliative care. Or their religious beliefs, their values, and their morals prevent them from engaging in such activities at end of life" (#38).

"I do think people now are really good about recognizing cultural perspectives and respect for cultural differences is really improving" (#07).

"If there's a language barrier, and when the CCAC has gotten in an interpreter who does that for a job and not have the family in the room, that there's more information coming from the patient simply because they didn't want to upset the family. They don't want to say it in front of them. You can't depend on the family to interpret as they have their own interests" (#07).

"There's always opportunity for error in moves. In our (long-term care) setting, we do a really thorough process as far as a med reconciliation review when a new resident comes in and the same thing if they're transitioning out" (#21).

"When they first come in (to the nursing home), we meet with them more than two weeks to go over care plans and discuss what's important to them, and in that trajectory to end-of-life that's the path that we're going down" (#21).

"There's no end to the need for education. We provide palliative care education and it really helps" (#23).

"What we do in our hospital unit is every single one of our patients has a discharge support meeting and the patient can invite whoever they want to their meeting, but it's typically the patient, their spouse if they have one or their children, and they are, when they, the first week that they are here, they are given a date and a time of when this meeting is and then at the meeting I (nurse practitioner) am there to present the medical information, we have a physio or an OT that presents the rehab information about this is what your mobility is, this is how you are transferring, this is how you're walking, this is the equipment that you need in your home, these are the medications you are going to go home, let me confirm your pharmacy, let me confirm your family doctor, we also have home care ghosts at that meeting as well, so the care coordinator for our unit goes and gets information, touches base with them, tells them an assessment will be done two to three days before your discharge date and who do you want me to call to let you know what the home care hours are going to be and that is done on every one of our patients" (#25).

"There are group of volunteers that came together many years ago just to send help support people in the community, elderly people mostly, in the community. Actually, they're client based became almost exclusively hospice or palliative care working very closely with the hospital. It's a little bit different from the way other communities deal with it. They have quite an active service here, which is there provide sometimes just respite care. Other times, it's more involved and more engaging with the family at that. Because hospice volunteers are common wherever there's a hospice, but this comes and goes a few steps further. It makes quite a significant impact on the community and it engages the community too" (#28).

"Consent and Capacity Board is there for tension between the caregiver and the staff, but to find out what's the appropriate care for this particular person when we don't know what their living will is" (#29).

C. Health System Reform Needs and Solutions

1. A shortage of beds and services to support dying persons.

"Sometimes patients are sent to the ER when they in fact need a palliative care bed…. But a shortage of hospital beds would mean that someone could "lie on an uncomfortable stretcher in the ER of one or two days until a bed becomes available" (#01).

"It comes down to families, if someone's at the end of life, it comes down to calling 911 and taking their person to Emerg. (What other options are there?) Someone has a PPS, palliative performance scale, of 10% and they either have a seizure or their pain is out of control, family doesn't know what to do, and they end up calling 911 and they are taken to Emerg and then Emerg doesn't have the background and they don't know what to do with this palliative patient" (#04).

"People at home, in the middle of the night panic, when the person's in pain. They just send them to Emerg. Like, many times, it's Emerg. And we may not have a (hospice) bed either" (#04).

"Out in the community, it's impossible for a nurse to get to someone's home quickly when there's an issue going on, because a nurse is booked for the whole entire day sometimes with as many as 15 patients in a day" (#02).

"Our particular community has a really excellent palliative care team and they service a large geographic area, but then they are spread so thin. I know they have honestly like 60 patients on their roster at any time and it's only two people (#03).

"Hospitals historically have been good (at telling patients and families that) they're going to get all kinds of service in the community and the CCAC said, 'Well, no, this is all we can provide," and meanwhile, the family expectations have been set with the fact that they're going to get all this wonderful 24-hour care in the community, but we all know that funding-wise it's just not possible anymore until the very end for patients" (#07).

"The generalists are not always comfortable caring for dying people, they need mentoring from specialists" (#06).

"If a patient says his preference of place of death is at home, they might die in hospital because we might not have enough (home care) staff available to support the person in the home…. Multiple hospital admissions are a concern as the more transitions there are, the higher the risk of adverse drug events" (#10).

"In the Emerg, it's overcrowding or waiting a long time just to get seen. In long-term care, they might not have the on-call staff to deal with the problems that come up, so they end up having to send somebody to the hospital where if they have the staff to take care of the problem" (#10).

"Caregiver burnout, if we're not able to provide enough staff or they're just seeing a whole lot of different faces coming in the home; that can be stressful for the family. I mean if their loved one is comfortable at home, having to go back and forth to the hospital because there's not that support in the home can be very stressful" (#10).

"The major transition is to home … and consistently the biggest challenge is the degree of support in the community. I have a patient on the oncology floor who has been told that her prognosis can be measured in months and she absolutely clearly wants to go home, home is a house she shares with her only son, his wife and their three young kids. What this woman would qualify for, even though she is the shortest lifespan, like she's at less than three months, she still going to only get about four hours a day of CCAC personal support worker support (#11).

"How do you say to a 75-year-old patient in (ONE CITY), "You have a malignancy and you have to go to (ANOTHER CITY) for your oncological care because that's where her regional cancer center is" (#11).

"Our palliative care unit has 56 beds, 34 are short-term and 22 are long-term. Try to get a patient in there with dementia is probably impossible. CHF and COPD would probably fall in that same category. And then there are the neurological diseases like ALS or MS. I do not know of a single long-term palliative care unit in Ontario that has BiPAP. So the question is where do patients that require BiPAP at the end of life die? Either at home or in an acute care hospital bed" (#11).

One volunteer at a nursing home said "my lady was in BLANK, I know that cutbacks and changes are happening there and all the nursing homes; the nurses and personal support workers, they were all spending less and less time with her. They'd breeze in and out. She said, "They used to come in and they'd sit and talk to me for a while." And that aspect of it is so important too, that they don't feel like they're just in a holding pen, next place is death" (#13).

"Hospices continue their subsidization of operating budgets, and this is straining the capacity of many hospices and so they're doing fundraising when they should be doing other things" (#20).

"How do we ensure in Ontario that the option to die in their place of choice is possible?" (#20).

"Funding is a big issue…. lack of support that we do have for palliative care for residents and families, you know, that's a big barrier. In my setting, 30% of the population I think die within the first year going into long-term care. That there's a huge lack of funding for that and the option to specialize in palliative" (#21).

"There are areas that only have one or two nurse consultants working with the CCAC team in certain regions … they have large areas and they carry caseloads that are quite high. They can go anywhere up to 60 patients at one time which of course is not 60 very end of life patients, they wouldn't be able to cope with that, but still bring people on early and we try to deal with pain and symptom management issues early" (#23).

"Funding is obviously a big thing. I think I've never seen such lack of services provided through CCAC even at end of life, people have to be practically days before death until they can get what they used to be able to get…we used to be able to provide up to 56 hours which still isn't enough…. My staff are constantly complaining to me that there is not enough help and where I see help that has been cut that I find very disturbing, is in the area of counseling and social work and spiritual support" (#23).

"Most hospitals have illegal discharge policies … they are just trying to transfer people out no matter what, so they lie to people. The hospitals and CCAC's at the hospitals will say, you can't apply for long-term care until you go home. That's not true, you can apply from anywhere, but they're telling people that… because they want to clear out their beds and they have funding implications if they don't clear you out and it, as they will call people bed blockers, they are not bed blockers, they need the care but they can't move" (#23)

"Long-term care sometimes transfer to the hospital when the person needs palliative care, but all long-term care homes are supposed to be able to provide palliative care. That's in the legislation" (#23).

"One of the things that we're finding now is because of the no long-term care beds. It's like waiting lists are everywhere (#23).

"The long-term care homes have the right to refuse people and I respect that right except that I think that they manipulate that right, because of minimal staffing… some homes are cherry picking; you know because they don't want the difficult people are to serve" (#24)

"We need resources. We need to look at the system as a whole and not these silo's, so I appreciate that hospitals are separately funded from CCAC's, the CCAC's are separately funded from all that, but that's being used as get this person out, because they are too expensive to service. It's not really looking at care needs, it's looking at money. We need specialized places to deal with people who have these marked behaviors and that are dangerous, and the staff are not trained. The PSW's are not trained to take care of those people, neither are a lot of the nurses (#24).

"We've been working for 25 years to get a residential hospice here. We finally have one so that sort of has really opened up the options for people who want to stay at home for as long as possible, but then don't wish to die in their home setting. The hospital is a really, really poor setting for the acute care setting for anyone who is palliative, unless they are sort of admitted to very limited palliative floor in which case it's still very much hospital setting. Any of my palliative's who've ever presented in Emerg have horrendous stories about what has gone on there" (#26).

"The family look at me in amazement because what they have to do is if someone chooses to pass away at home, they have to drum up all the family support they possibly can, because we don't have the resources available to provide anything like round the clock care" (#26).

"We don't have enough advancing care facilities and we don't have enough resources to help people in the community. So, the government has start imposing some arbitrary limitations on what they can offer and inevitably people fall through the cracks. Some acute care facilities have very aggressive discharge policies and others are very lax, some naturally charge like ultimate level of care fee and others do not. Some naturally charged it and others do not. The CCAC is quite limited in the amount of care that they can provide to somebody in our community. The general rule being something like three hours a day. So now, you've got people whose families would want them to come home but they can't master the resources to make it safe for the individual. So you're looking at family burnout when they provide care. You're looking at people who for another couple of hours a day of care would be able to stay in the community instead of going into health care facility but the system doesn't fund that." (#27).

"I pushed and I don't like feeling pushy but my brother and sister were pushy too. We all were saying she (older woman with congestive heart failure) needs a palliative consult" (#28).

"Hospice care is wonderful. I mean my mother, there was another transition she made, she was transferred to the hospice two days before she died and that's a problem too. You don't get to the hospice until you're sure ready to die within hours usually. Actually, it was less than 24 hours for my mother" (#28).

"The social worker's role has changed a lot in hospitals. They focus on discharge planning and I feel this from my observation that the emotional support from social workers aren't as much as they use to provide before. It's not that they don't want to; they just have so much to do" (#29).

"I think that the common element in all the transitions is a lack of any kind of real regional integration, and I would use term regional particularly in interior where you know with the limbs and with the launch of the internal pile of care network we really are looking at planning services regionally which I think is appropriate and correct. but today we have, what I think is not very good or poor integration across care settings whether that be at home or at hospital it's most often one silo referring out to the other without and real good integration in terms of making those prophesies happen" (#30).

"Maybe there's a hospice that's available, maybe not and you go to the emergency department. Access to palliative care beds is limited" (#30).

"I think there are probably unavoidable hospital admissions, there will always be patients who become really symptomatic it's not going to be fusible to manage them at home it's too frightening for the family, setting of that as an expectations is just going to be unrealistic and sets everybody up for failure and feeling guilty and everything else, however when I see patients who get admitted to a palliative care unit and a family members are saying my Gosh we needed this three weeks ago" (#31).

"Equipment is a big concern for people that I deal with and ensuring that what families need at home but they're allowed only a certain amount of equipment and there's a time constraint which then the families fund. Who picks up that cost so this one's more stressed and trying to smoothen that transition to the home?" (#32).

"Those who need a 24/7 care is trying to transition them to a PCU or a hospice beds and sometime that way could take up to 3 days just because the availability it's there is not an available bed within the area where we need without sending them to the city or to somewhere else so I find that sometimes becomes a bit hard on families" (#32).

"We're a registered charity, we have to do most of our fund-raising and it's from, through families giving back and so we get about 23 percent from the Ministry and so we say to families like there's no charge for your loved one to come in but we ask that you put donations to Hill House Hospice in the obituary and we don't expect money from the family, but it will come from your circles of friends. Well when our criteria is 4 weeks or less, then we have a turn over, if we did three months, we wouldn't be able to afford to exist" (#34).

"Getting the ambulance vehicles to a non-urgent call to take someone to a hospice bed can be really a challenge, because that service isn't designed for moving a palliative patient…. those patients become a non-urgent call, they're a lower priority, so an example where I had a patient where we had a hospice in the morning, and it took almost the entire day to get him here. His PPS was very low, at about like a 10%, and he did survive the transport, but we set the plan in motion in the morning to get him here, figuring it would be within a few hours, and it took a lot longer. I had to actually rush to the home and administer some medicine, because the home care nurse was discharged because we expected him to be at the hospice.… the paramedics basically told me that if they changed the priority they would have to take him to the nearest hospital instead of a hospice bed" (#35).

"There should never be a palliative crisis or emergency, but there often is, because (of low) availability of the beds, availability of services at home from CCAC…. there's like a 0.3 chance of getting a hospice bed" (#35).

"(To manage the shortage of equipment) the home care process is, if your PPS is 40%, you're eligible for incontinence supplies. But if your PPS is 50%, you're not. If it's 40% you can have equipment, unlimited pieces. It's left to some sort of other interpretation. If you're 60%, you can have one piece of equipment for thirty days. It's very black and white.… And when someone is actively dying, we can't get the help and support and services in there quick enough. It always seems like if we thought more upstream about – we know people are going to die. So what are they going to need to do that successfully? We know that 99.9% of people lose the ability to swallow; we know that they're going to need sub-cut medications at end of life, in the final hours and days. But if we don't have a doctor that is willing to order those things, then patients don't have that, they go without. And then they either die in pain, or they end up at the ER from a 911 call" (#35).

"You have to think about the cost too, there's a lot of people that are living on the margins of society…. They can't afford a retirement home. They're renting where they are, but they need help. They can't be alone. Safety-wise, they can't be alone anymore. Unfortunately the hospital ends up filling that gap" (#36).

"I don't think there's been any growth in long-term care beds. The population's aging, people even in retirement homes are probably in worse shape than they used to be;

they used to be up and around, just lightly-assisted living patients, but now they're getting to be sicker even in the retirement settings, because there doesn't seem to be enough long-term care beds” (#36).

“We are able to use our ambulance system on a non-emergency basis to bring people to the hospice. But then there's a delay as a result of that, because these people are considered a low priority for transfer. So they could be waiting – they could make the decision to come to hospice from home, but they may have to wait several hours before transportation, before the ambulance arrives and brings them. And sometimes we even have people that have had to wait until the next day. So that can be a very, very difficult and stressful time, because the decision to come is difficult enough, and then to wait around and not know when the transportation's going to come that's an issue. The benefit, though, is that there's no cost to the family or to the patient as a result, because the service is covered through OHIP if they're a CCAC client” (#37).

“So it's a transition from an acute perspective to a palliative care philosophy. It's also frequently a transition in location, so you might be leaving an acute care setting such as a hospital and going home to die or going to hospice, as the hospital is not the right place to die” (#38).

“You can’t have one RN for 30 people when you have palliative long-term care clients. So in that palliative part of the long-term care, they need to staff it properly for good quality palliative care” (#04).

“I think it’s going to get worse. I don’t have much hope for it being too much better, but I think it would go a long way to have dollars put into EoL care midwives, or death doulas that would work with people early on to define their goals and to look at when their goals would change and what circumstances would they want to make changes in their pattern of treatment sort of thing” (#06).

“The LEAP Program for palliative care…. We have physicians and the nurses and the social workers and the physiotherapists and pharmacists taking courses about all the dimensions of palliative care, social, emotional, as well as the nitty-gritties of pain management, etcetera” (#07).

“Having access to staff that can change orders is needed in home care…. Sometimes you could prevent hospital admissions if only there was maybe a nurse practitioner or somebody who could come in and assess and order something” (#10).

“First and foremost, we need more palliative care beds. We need more palliative care short-term beds. We need more palliative care long-term beds…. A third of them never make it there, they end up dying on a hospital unit waiting for a bed” (#11).

“We need more palliative care services and community for those whose families want to take care of those loved ones at home” (#11).

> "We need to build a (family EoL caregiver) workforce. We're looking at people between the ages of 60 and 75 to do this work. It's not the people who are still working that are going to be caregivers, that would be people who are retired who are going to be doing the bulk of the caregiving…. Veterans affairs in the US provides supplementary income to caregivers on the condition they take a training course. That's one way, but not the entire solution, but its finding some ways to support the family with the training, education and supplementing their income" (#12).

> "I would like to see more money put into home care. I know lots of people have said that but I really do think that if we were able to get more resources for probably more personal support workers at home I would" (#25).

> "The common answer to that question (of limited home care) is more resources" (#27).

> "it is a cancer system, and so with some specific client populations that may have more barriers in terms of being able to access care, I think you can talk about two things, there can be a concept of navigator or a person who's got some accountability, responsibility it's a new name for case management and many respects but maybe some added responsibilities layered onto that or we have models of navigation, where it's much clearer how a patient is mobbing along a pathway and transparent to them and there's patient and family friendly information that's helping them understand all of that too" (#31).

> "At the nursing home, they've formed a comfort care team, and … some people have money and they'd make a palliative room at their (long-term care) facility…. And arranged to have a palliative care team there" (#35).

2. *Silos, with many different public and private organizations delivering only their specific package or narrow set of care services and often only in a certain geographic area.*

> "Some of our agencies are paid by the hour and some are paid by the visit. And so the individual nurse will, in some cases, self-schedule and give herself a lot of patients in a day to make more money. And other times the agency is doing that because they want to get paid for her number of visits…. So the whole way our home care system is staffed and funded is often to the detriment of good care" (#02).

> "Communication breakdown is the biggest problem I see. Within our local (small/rural) community sometimes it's easier to rectify because we have enough familiarity with the patient and their family, we can sort of case manage them from setting to setting. But when it's a large geographic (or urban) area and people are transitioning between multiple care providers that things get missed, mistakes happen, and certainly patient outcomes suffer from that" (#03).

> "We often get people from outside our immediate community. Sometimes the transferring of care, like between CCACs becomes challenging, getting information back" (#03).

"Those (cancer) treatments centers really do identify with cure, so when they stop treatment, it is an abrupt stop, you stop going to them" (#05).

"Pay inequity (between healthcare organizations) is probably a problem everywhere, but certainly between long-term care and the community. It's also kind of like recycling bad apples. They get turfed from one place and then the need is so great that the nursing home might say, "You know, I'm just desperate. I have to have somebody to cover the shift…. Until there's full-time jobs and some pay equity and whatnot, I don't think we're going to build up that really good set of nurses out in the community" (#06).

"There's a health care component and there's usually a social service component. And if it's more healthcare needed, then healthcare kind of takes the lead. If it's more social services needed, then they take the lead. The problem really comes when there are both needs because we don't do it well combined" (#08).

"If the patient isn't going to a hospital, this means that the palliative care doctor and nurse couldn't come to our community and see these clients" (#09).

"Nursing home policies, such as residents having to have physiotherapy, don't always accommodate compassionate care" (#09).

"With EoL care, there are more people involved from different agencies and I think that the different areas tend to kind of almost work in silos; in hospitals doing one thing, primary cares doing another thing, communities doing another, there's not always excellent communication and so that transition piece is an area where there an increased chance of break down in that communication" (#10).

"The doctor he doesn't work after five. No, he doesn't do weekends and, certainly, no he does not do house calls. Have there been physicians that stepped up to that plate…, but in 12 years, I can count those physicians on one hand" (#11).

"We are a palliative care consult team here at (a LARGE HOSPITAL) and the bulk of our patients are from the oncology and general medicine. After a few years here, we all started noticing how many patients are we seeing that really aren't from our area, and the number was a lot…. The patient doesn't come to us directly, the patient comes to us through oncology" (#11).

"Given that we have local health integration networks (LHIN), should we have LHINs? Are the LHIN borders appropriate? Do they reflect historic referral patterns? Is there value in those historic referral patterns or they just happened? And more importantly, how do you say to the patient about these patterns?" (#11).

"(People in this area don't know where to get care), possibly 60,000 people without knowing where to resource from. There's a whole host of different services. I don't even know the extent of what they did and could do." (#14).

"An individual that really was adamant about wanting to stay at home … we (home care nurses) didn't have the supplies. They didn't have the supplies and there was no way of getting them in time to manage a crisis in the home. They went to Emerg, and had some interventions done, and were sent home, but it was very nearly a great error because what got sent home and what had been done, the patient wasn't able to relay the information to the nurse and so they almost got back into the same crisis of pain that they've originally sent to the hospital with because of the lack of communication and lack of infrastructure that connected pharmacy to physician orders to actually receiving equipment supplies and orders in the home" (#16).

"The traveling record is in some regions, some areas of Ontario… We did a traveling record and it would go to acute care (from home care). The records that exist in Ontario tend to be more so charts in the home and they tend not to cross the boundaries of setting. When they do cross the boundaries of settings, they often disappear" (#17).

"One of our clients who is at home and is having exacerbation of his symptoms so they have to go into the emergency room to have symptom control" (#19).

"Communication is always an issue I think in any setting that we have and also because of those silos that we have in the healthcare system" (#21).

"When clients' transition to the community from the hospital, there's obviously no follow-up…. it's not really anybody's fault, just the systems are so separate" (#22).

"The issue of caregiving…. The financial considerations of caregiving at home, until they make the transition. It's requiring extra services in-home … at this point in time, there is insufficient services very often for people through very end of life through CCAC, so it's a huge financial burden because often people have to access additional services and if they are not, if they don't have their own benefits, say they're self-employed, then it becomes even more complicated. This increase in compassionate care that the government has put in is a tremendous opportunity but it's only of course available to those who have employment insurance." (#23).

"(Private supportive care facilities) some of them have no registered staff on site during certain times, now particularly at nighttime. How do you manage things like pain pumps there, they'll allow CCAC to come in but they don't really want to be improving their capacity, they just want CCAC to handle it, they don't want to have to hire more registered staff. I mean it's, it's a business and it's very much got a business model and there really isn't the availability of services (there to keep dying patients onsite) (#23).

"The hospital… every facility has a different policy and the policies shouldn't be all different, the legal framework's the same. Some hospitals will say you have to pick or short list long-term care homes. There's no law on that. You can pick any place and you don't have to pick five places, you can pick one…. It's about money, that's why they're interpreting things in different ways" (#24).

"The care coordinators in hospital will develop a plan but they can't confirm that that plan is accepted" (#30).

"One of the thing that is a bit more challenging is we're transitioning somebody from hospital to another region…the issues that we run in to there are that each of the CCAC has got their own set of policies and guidelines they're not always the same so what we might expect…, those cross-boundary transitions can be difficult and they're more time consuming" (#30).

"That are boundaries and what's available there someone is like you've crossed this imaginary wall once you cross the city's boundary it's different the amount of resources are less" (#32).

"CCAC case managers put up roadblocks because it's easier to just keep them in the hospital than of course to transfer services outside" (#34).

"When patients are in distress, or they have a problem that we can't solve, they need to go to the hospital…. they don't really want to be there, and they hang out in the emergency department. And sometimes they die there…, once you're bedridden, we need to have physicians making home visits, and we need to be able to do things at home for symptom management. Not just prescribe medications, but if someone needed a thoracentesis or paracentesis, or an NG tube. Those kinds of things that are acute things, could they be done at home? Because often at end of life, those measures are still a comfort measure. And so we need to make that happen without sending someone in an ambulance for a procedure" (#35).

"When we're talking about a cancer patient, and they're referred to palliative care at the end of life, then it's more difficult to engage a family, more difficult to transition them from the acute care team that they were cared for… is felt to be abandonment by the acute care team. This is one of the negatives of transitioning late in the illness to palliative care" (#38).

"A planned move from hospital to hospice at times there's a delay that day, because of medication orders and equipment. There can be a lag time of at minimum four or five hours. So again, those spontaneous kind of, you know, we've finally decided and we'd like to go, and we'd like to go now, sometimes that's delayed. So that we find somewhat frustrating, and we work very hard at alleviating that by planning ahead and getting our prescriptions in early, but sometimes that's still – and if you're doing this at the end of the day, so if it's six o'clock on a Thursday or whatever day, the pharmacy closes at nine, or they stop delivering at nine o'clock in the evening, so there is absolutely no way to prepare medications for that transition" (#38).

A hospice representative reported: "Emerg will call us sometimes because we take admissions 24-7 and we, yesterday actually, even admitted someone from Emerg so they didn't have to stay there at all. They weren't admitted there" (#04).

"It is important that they (dying people) go somewhere that they're familiar with and be around familiar people" (#04).

“Have the hospice as the hub as we have our staff, and we have all the community nurses that do palliative care. So all the nurses that do hospice care and palliative care in the community they can all come under the hospice. And they’re trained the same way, so that when they're out there, they can look at those signs and symptoms and be able to assess them the way we would here. Because it is a specialty, and they would know different solutions, they would know different avenues to take rather than just bring them to hospice. So I think we could manage people better. We could even manage staff, could go from hospice to community, and from community to hospice which would make it more interesting for the staff. They would be cross-trained, they would be managed by the hospice, they would work for the hospice, but we would have a community team” (#04).

“At 3 o'clock in the morning, they’re panicked and they don't know what to do. They can phone the hospice instead of phoning 911. And then we know if we have a bed and we know we have a chart on them, we know what their condition is, and we either send a nurse out, one of the community nurses that we have, we send them out to do an assessment to maybe make some changes. Or we know that patient, and they’re just kind of waiting to come in. So then we admit them direct from home to the hospice” (#04).

“We’re very fortunate because we’re developing this outreach palliative care team, so the doctors on that team are accessible, we have people here covered 24/7…. The outreach team is a community-based secondary level team. It takes time and general practitioners are starting to use us the right way. It has been in the past that the general practitioners, family doctors would say, “Bring in the palliative care physician. Okay, I’m out of here.”

“The secondary level expert (community-care palliative care) team that we have here follows the patient wherever they are. So if they go into hospital, that team can go into the hospital and say (to the staff there) this is what was happening in the community” (#06).

“Create awareness of what is available in the community. So from a physician perspective, when they’re talking to their patients and their families, they’re more aware of what’s available in the community and also they talk about how to have the conversation about palliative care with the patient, which is part of some other study. The whole advance care planning piece is something that not only is really important for educating all health care providers, but also the public which is happening more and more with The Speak Up Campaign and every other opportunity at forums and senior fairs so that people are just more comfortable with the idea that palliative care doesn’t mean you’re dying and I guess maybe that’s part of the confusion back to the language is that palliative care is often seen as meaning that you’re dying” (#07).

“There’s the Hospital to Home Initiative that’s happening in various places where you got the hospital nurse who’s going to see the patient in the home…. And, you don’t have handoff from the palliative care team in the hospital to the palliative care team

in the community; it's the same one. So that reduces medication errors, it helps with the whole planning for the patient if they go back from one setting to the other; the same team is following them, they know what's going on in both settings" (#07).
"Who's helping the client? I am the case manager and I share with somebody called the patient navigator; someone is needed as it is really hard to coordinate care" (#08).

"We've gone on social media, which is really good and that has kind of increased our following…. We do an annual community education and we had speakers from every agency and organization there, and we've had about 150 people in attendance" (#14).

"What's the best place to bring somebody who's imminently dying? … We have direct admit to our hospice unit. Those ambulance or paramedics, they need to be … bring them to the hospice. So we are working on a process like that" (#19).

"We do have the largest specialized nurse consultant team, …that it is a tremendous asset because they are overseeing and ensuring that these steps are in place and working very closely with the CCAC contracted nurses and the CCAC care coordinators because we actually go into the homes together and make sure all the plans are put into place" (#23).

"Our hospital unit is quite lucky that we have a CCAC person who is based right on our unit and she does an assessment with the patient about two days before they go home and their home care is all lined up and often our patients go home, like say they're going home on a Tuesday, they leave at 10 o'clock in the morning and they will have PSW set up for that night already. The plan is set up for two weeks when they go home and then a case manager, a care coordinator will call them around the two week period to see how they are doing (#25).

"I'd like to see is a palliative team of different health professionals going into the hospital to be on the discharge, the discharge conference, that way the people, especially the patient, sees a familiar face when they go home into their home environment" (#26).

"We're trying it with something called a Rapid Response Nurse and it does seem to make all the difference in the world. They go in and assess them in the hospital and then they see them the day they come home and I think this has helped prevent readmissions of patients" (#26).

"if you look at transitions, if you look at that, say a patient that was cared for at home by a nurse and they go to hospice to die. That nurse doesn't get paid to come over here to continue that relationship, they're doing it on their own time (but should be paid for it)…. And when someone dies at home, basically the nurse goes and pronounces, cleans up the supplies, picks up the chart, and that's the end of that relationship too…. They should be allowed to make a bereavement visit and get paid, they should be allowed to go to the funeral if they need to for the family" (#35).

“Our palliative physicians … they will go into the hospital, and they look after the palliative care floor there. And those same physicians look after the patients out in the community, and our palliative care team goes into retirement homes because that's considered their residence” (#36).

“It can be difficult transferring an unstable patient at end of life from one institution to the other. The distance itself might make it difficult. And families might – and when they're worried about that distance or time length, worried that the patient might die in transit, then they're less interested in moving the patient from the acute care setting to the palliative care setting, such as a hospice, or even to home where they could be with family in their own environment….the hospice is on the same campus as the hospital, and so we easily move them… into the hospice” (#38).

“We do keep a stock of dose meds, we do have our own pumps, in case we're faced with this scenario (of a patient suddenly coming to hospice) (#38).
“Patients need to be referred early (to palliative care), so that we can establish a relationship with the families” (#38).

3. *A lack of core services, services that can be assured of being available in all parts of the province.*

“Travel (to the patient’s home) is an issue and it’s something that we are looking at right now, a nurse, it could take her an hour to get there. That’s a long time when someone’s in pain” (#04).

“Somebody that has a cancer diagnosis must go out of the community for cancer care” (#05).

“Patient navigators try to help families get through the system. CCAC was supposed to do that, but I don’t see them everywhere” (#06).

“With many people retiring into the country, these small hospitals are getting overwhelmed and they don’t have the resources” (#07).

“Coming to a center like Toronto, you can’t afford to park your car, right? …. It’s going to cost you $20 a day so that’s a significant burden for people. A bigger burden for people from small towns, and coming to the downtown is a stressor just to get somebody into the building” (#08).

“In our town, we lost our hospital last March (so our hospice and community care are busier now)…. There is fair commute to any hospital that’s within our area. It’s a 30-minute commute and lots of elderly live here. It’s hard for them to get there because we don’t have any public transportation” (#9).

“The discharge planner is employed by CCAC. They’re trying to economize. I’ll say three years ago the discharge planner had the ability and be okay to make sure that everything was in place before someone went home so that they didn't arrive home (without all the needed things)" (#09).

"Part of this is really knowing what resources are in the community. Every community, of course, is a little different….Because we're in a small community, the discharge planner only comes once a week, every Tuesday and sometimes it would be twice a week…. It was very difficult because you had to work around her schedule on when she was coming and when you could talk to her and arrange things" (#09).

"It all depends on where you live and which LHIN you are and the CCAC coordinator in the hospital will tell you what's available…. Policy in this hospital is you don't see the CCAC coordinator until the day before you're scheduled for discharge. And we only have one, she doesn't work after five and she's not here on the weekend. Oh, and she's sick this week, so someone's covering" (#11).

"Health Links, that was set up in Northern Ontario, that was very successful and it's too bad that it couldn't have been as a success here" (#14).

"The residential hospice right now, the funding model is not great. It requires communities to fundraise a great deal of money to build the facilities, on-going maintenance of the facilities, and a short-fall in the operating fund as well" (#22).

"We're lucky that we're … salaried employees. We have a global budget and so we can see all kinds of patients in need. (I fear they could be) cutting our program (#23).

"We deal with such a variable landscape in terms of the intensity and density of the services that are available from region to region even neighborhood d to neighborhood we get very tangled up by catchment areas, community based services" (#31).

"It was the doctor not wanting to facilitate the transfer, not wanting to do the paperwork because it was sending somebody out of the area is a lot more work" (#34).

"First issue would be transportation … because when somebody needs to be moved, and if their functioning is higher, usually you can go by car. But if you their functioning is lower, their PPS is low, how do we actually transport and move them? And fortunately, where I work, we're able to rely on the regional ambulance service to do that without a cost to patient and family most of the time. But in other areas I've worked, it's a charge, and sometimes people can't afford that" (#35).

"Our program is the only one (in the province) that offers 24/7 coverage. So we always have an outreach nurse and a palliative care physician on call to patients who are registered with our outreach program. If there's an issue in the middle of the night, instead of that family panicking, they can call us, and we can perhaps avoid a transition to hospital, for example, through emerge, that we can support them until morning, until we can sit down and – you know, okay, what do we do now? Do we look at hospice, do we look at hospital or what have you? They're not left to figure it out on their own in the middle of the night or on the weekend" (#37).

"We're looking at a possibly satellite (hospice) in that area because if you live in a small town you don't necessarily want to try travel even up to an hour to get to another hospice" (#04).

"So they (the family or patient) may call and you know, if nobody's here in an hour they call 911. I think if they need a live person to connect with, the hospices are open 24 hours. So they can phone into the hospice to get the advice as to what they need to do" (#04).

"It's really important that there's an advocate for the elderly or the people that mainly are not cognitively able, and the caregivers" (#09).

"One of the best things have happened to us in a funny kind of way was our hospital closing because then four working groups were formed in the community to look at the future of healthcare in our community" (#09).

"Not everybody has access to palliative care. We need to carry out the routine palliative care for folks who are dying. The bigger population of the frail elderly who've accumulated many medical comorbidities need goals of care consultations, and their care staff need to understand the principles of continuity of care in establishing a proper care plan for your frail elderly. I get that there is a lack of access to a palliative care specialist; so if we recognize how useful the palliative care approach can be, then promoting palliative care approaches is the way to go" (#12).

"There are people going home to stay at home….We want to have excellent symptom management so that nobody is suffering. Number two, people need to be cared for. They need to have their dignity. They need to be bathed. They need to be clothed. They need to be set if possible. They need to have somebody who can attend to them and that's the issue of having caregivers and up to a certain point, 24-hour caregiving although that person may not be necessarily doing anything physical every 24 hours of the day, but they just need to be watched over…. A third thing is there's an element of chaos where not everybody is prepared for this type of situation. You know, you've got a person who's at home but you've got to also support the family and the caregivers" (#12).

"There's such a variation of (nursing home) care out there and such a variation of standard as to what nursing homes can provide. We really need to get to that point where we can say this is what we provide in a long-term care setting" (#21).

"Palliative care has developed as grass roots movement, with pockets of excellence over here and over there with little going on in between and we're at the point where that's not good enough anymore and that we really do need regional approaches where there's some consistency in standardizations across a region about how we do things so the things, so the processes and the service delivery is reliable and predictable. And develop a regional pool of experts who actually commit to providing those services in rural areas" (#30).

"There needs to be clear and consistent definitions of programs" (#31).

"If you have a skilled team that works together, if you have skilled people, like physicians and nurses that are experienced in palliative care, case managers or care coordinators, PSWs, dietitians – whoever it is within the interdisciplinary team,… a better overall experience with the patient" (#35).

4. An overreliance on the family physician to solely or primarily plan, coordinate, and provide care over the last year of life.

"In the community, people are relying on their family doctor…. But it's a lot for them to coordinate" (#03).

"Family physicians, I mean I feel sorry for them because they don't get the training that they need. They don't get extensive palliative education. They get very minimal, minimal education. And then they're asked to (care for dying people), it's such a specialized area where the medications are used in a much different way in different doses, than they're used to. It doesn't compare anything to if someone just had pain from a sore knee comparison to someone's dying" (#04).

"General practitioners or family physicians, they really need help. Like I guess that's probably where family or patients look for help, with care setting transitions, right? My assessment would be that's one of the issues or problems, doctors are so overtaxed" (#09).

"While everyone recognizes advance care planning, very, very few people actually have that conversation with a family physician" (#10).

"90% of the time, the family doctor is completely uninvolved in the case. The patient may have been diagnosed with some malignancy and the physician sort of left the picture at that point or in the case of a more chronic debilitating long-term disease, the neurologist or the respirologist or the cardiologist has become in essence the primary physician for care of this patient because it's their organ system that's the challenge" (#11).

"Family physicians who they would like to keep caring for their palliative patients as they move towards end-of-life, but don't want to provide 24-hour coverage. They're not available for the community team to call but they want to maintain MRP (Most Responsible Physician) as we move towards end of life. There has to be some 24-hour availability in terms of least linking to a mechanism for on-call" (#16). .

"Who is the most responsible physician assuming the care? Our (home care) nurses get stressed all the time when … the client is dying … and home from hospital. The client wasn't well. He was actively dying and we could not locate anybody to assume the medical care. So even though there was a physician, that was their primary health care physician, supposed to be in the community. He was not available, not answering his calls. This was an EoL client whose blood pressure was all of a sudden through the roof. He was having other symptom issues and it was in a small rural community and the nurse called the physician, the number that we had, called the office and left messages. She called me and said, "Help me see where I can go?" We went to the local rural hospital and asked to page that physician and any covering physician over locating" (#17).

"The primary care physicians have a tendency just to say, "Well, take him to the Emerg" (#18).

"Most physicians are wanting to transfer their patients at the end of life, which is of course, disruptive in a number of ways. Patients and families most of all have a hard time understanding that" (#23).

"The patient populations I guess I worry about the most are the non-cancer populations because we often are not following them directly, these are people with heart failure, COPD, end stage dementia where the primary providers will have vary levels of skill in terms of managing the issues and so it's more around and the issues of competency out the community, we hope referrals of these patients to the community of palliative care MDs to work with family physicians around their care" (#30).

"I hear from family physicians is that there is a desire to be much more integrated into the transition process, but that the barriers around information are the biggest issue.… I think that we've done a poor job at supporting family physicians during their training to provide care of complex patients in the home first of all and then second not supporting them with on-going professional development or mentorship in collaborative shared-care models" (#33).

"Primary care physicians, I think they just have so many people to look after, and they refer on to whoever, and I don't know what the quality of their practice is. Because I feel especially the personal relationships are gone, it's just so busy, and everyone's got so much to do" (#35).
"The outreach team. It's not the same model that is utilized elsewhere, we work with the family physicians, we're just sort of are in the background for support. But we do follow people along the entire trajectory, the entire time that they're on the palliative care program" (#36).

"People who are the palliative experts, they need to mentor some of these young doctors" (#04).

"A paramedic or anyone can refer them to the CCAC. This can include patients who they recognize are requiring palliative care, because there are many patients in the community missed. They just don't get referred by the family doctor. So the paramedics are also a source of referral to the CCAC" (#07).

"Everyone should have advance care planning done. It's something that certainly our home care organization has policies around and stresses, and end-of-life is a discussion that should be had between the (home care) nurse and the client and family, and putting a clear plan in place as to who's going to do what, where the person wants to die, who they want at their side, who's going to come and pronounce death, is there a communication plan with the physician, really looking at every detail. Our nurses in the community are very good with palliative care and they're very comfortable with that."(#10).

"The community nurses can really convey, be ambassadors for all different sectors of care" (#16).

"We need to do a lot more integration of common understanding, common tools, common approaches to palliative and end-of-life care across all primary physicians" (#16).

"The paramedic could be a player in this, but it still does sometimes require medical advice or the medical interventions with regard to treatments or prescribing of an order that does require a physician or a nurse practitioner" (#17).

"(Have) the actual home care nurse go to that setting and actually meet that client and meet with that other team" (#17).

"The primary care physician, when this is end-of-life, usually they have handed care off to a palliative care physician, some other type of specialist or a hospice palliative care nurse practitioner for needed care"(#19).

"We do have a group of nurse practitioners who monitored the discharge from hospital and transition back to a long term care at home which is a really valuable resource" (#30).

"We just don't have a problem with transferrin to our local hospice, first of all the hospices know exactly what they need and most often is us the palliative care physicians doing that" (#30).

5. Scope of practice and role capacity issues.

One RN participant reported "in a hospital, I used to do discharge planning, and now they call them clinical navigators which is really a more appropriate name since it was more of a navigation role. They are hospital employees and they're all nurses. But here, in BLANK, the people who plan discharges are social workers. They don't have a clinical background…. (You need to have a) discerning eye that looks at the patient and goes hmm this little old lady, that's not just her hip that's causing her to be so low. There's something else going on here…, maybe we really shouldn't be planning the discharge at this point…. The clinical judgement is just not there (#02).

"There's a lack of triaging skills (among social workers)…. We often see people getting inappropriately admitted to places that probably aren't the best setting of care for them" (#03).

"We're lowering the bar for the (home care personal support worker staff) qualifications regularly in the community, and so how can you support people at home?" (#05).

"They called and said she died…. I said I do hope that she wasn't got out of bed in the morning for her breakfast by the personal support workers because … unless they're dead in their bed, you have to get them up. I said, I hope you didn't do that to my mother-in-law because I wouldn't have liked to think that you dragged her out of bed at six o'clock only to have her die by eight" (#06).

"The family is terrified about what they would or could do at two in the morning (if she came home to die). She also resides in a part of our city where there are no visiting palliative care physicians. So she would have access to personal support workers, she would have access to RNs, and she would have access to a nurse practitioner, but in terms of any medication orders or medical advice…" she would need someone to fulfill these roles (#11).

"I think the paramedics (can do more) responding to those needs for crisis transfer or you know, appropriate transfers, responding to and acting on or making sure and confirming that we have a DNR-C form for instance in place so that decisions to not engage in CPR for instance if they arrest enroute are respected and understood. I think there's an appetite for learning more about what is palliative care, what is the palliative approach, but to my knowledge, it hasn't gone further than that" (#16).

"There is now the DNR Safe form, the DNR confirmation form that's a message or directions to the emergency medical system that they can follow because it's a direction from a regulated health professional. So in other words, EMS must resuscitate unless they get a direction from a regulated health professional to not resuscitate, because they are not permitted to make the judgment because they aren't regulated health professionals. But the regulated health professionals can direct them" (#24).

"How many people get discharged from long-term care a year? Like one or two…. Everyone that goes into long-term care is palliative…. So why aren't we having the conversation as soon as they arrive there? And when "deemed palliative" the nurse-practitioners (if working there) can't order some of the controlled substances (i.e. pain medications)" (#35).

"So she (at home receiving home care) would have access to personal support workers, she would have access to RNs and she would have access to a nurse practitioner doing home visits" (#11).

"Create Centers of Excellence in the community for hospice/palliative care, as there's different aspects of palliative care that are currently provided by different providers.

There's home care, visiting nursing clearly has a big role in palliative care in the home, hospice palliative care visiting, not always, but through the same agencies, sometimes it's a different agency. Also we have Palliative Pain and Symptom Management Coordinators, there embedded in different agencies and each LIHN, I think. I know at my Region they are all embedded in the hospice/palliative care organization, so that really, that really encourages collaboration between professional providers and the volunteer delivered services which can be really an essential piece of support during that last year or so" (#22).

"There is definitely some evidence that we've (community-based specialist palliative care nurses) impacted in terms of reducing ER visits. It's a very difficult thing to figure out how to demonstrate, but we have been able to do some of that and also to support patients for dying in their place of preference" (#23).

"This CCAC has incorporated five nurse practitioner positions in palliative care, they are so needed for high quality EoL care" (#23).

"A lot of PSWs that do amazing work and they're very dedicated. And that's getting lost in all the negative news. So if we could support the PSWs by regulating them and putting more expectations on them, we wouldn't have the problems that we have right now, especially in nursing homes" (#29).

VI. ENDNOTES

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