

**Utilizing the Auditing Care at the End-of-Life (ACE) Tool to Examine Symptoms Among
Nursing Home Residents at the End-of-Life**

by

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Abstract

Seniors comprise a large proportion of the population and many older adults in Canada currently require a high level of care in nursing homes, including end-of-life care. The number of individuals requiring end-of-life care in this context will continue to grow as the proportion of older adults continues to increase. Currently, research has demonstrated that symptom management among dying residents in nursing homes requires further improvement. Limited research has been conducted within Canada examining the prevalence of pain and non-pain symptoms specific to the last week of life and there is conflicting evidence regarding the association between level of cognitive impairment and symptom experience. The purpose of this exploratory, descriptive study was to examine the symptom experience at the end-of-life (the last week of life) among nursing home residents (N=72). Using data collected from a chart audit, which used the Auditing Care at the End-of-Life (ACE) tool, a secondary data analysis was conducted. Dysphagia, pain and respiratory conditions were found to be the most prevalent physical symptoms, while psychosocial symptoms were minimally observed. There was no statistical significance found between symptoms and level of cognitive impairment, however, 65.6% of residents who experienced pain had less cognitive impairment, compared to 34.4% of those with more severe cognitive impairment. This study also yielded important information regarding assessment and management of symptoms at the end-of-life. The results of this study have implications for nursing practice, education and research.

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Table of Contents

Abstract	ii
Acknowledgements	iii
Chapter One: Introduction	1
Introduction	1
Statement of the Problem.....	1
Significance of the Study	2
Research Study Questions.....	4
Assumptions	5
Definition of Terms.....	5
Summary	7
Chapter Two: Review of the Literature.....	8
Introduction	8
Concept of a Good Death	8
Symptom Prevalence and Management in Nursing Homes.....	11
Physical Symptoms	12
Pain.....	12
Gastrointestinal Symptoms	17
Respiratory Symptoms	20
Other Physical Non-pain Symptoms	23
Psychosocial Symptoms.....	25
Depression.....	25
Anxiety.....	26
Agitation.....	27
Delirium	28
Factors Affecting End-of-Life Care in Nursing Homes	29
Symptom Assessment in Cognitively Impaired Individuals	29
End-of-Life Education.....	32
Communication	33
Advanced Practice Nurses.....	35
Structure and Nature of Nursing Homes	37
Summary	39
Chapter Three: Conceptual Framework	41
Introduction	41
Patient Factors Affecting Health Care and Outcomes of Care.....	45
Structure and Process of Care	45
Outcomes of Care.....	46
Uses of the Conceptual Framework	47
Limitations of Other Conceptual and Theoretical Frameworks.....	48
Summary	49
Chapter Four: Methodology	51
Introduction	51
Study Design.....	51
Secondary Data Analysis	52
Chart Audits and Documentation	53
Auditing Care at the End of Life (ACE) Instrument	54
Purpose of the ACE Tool	54
Development of the Tool.....	54

Tool Content.....	55
Setting	55
Resident Characteristics	56
Sampling Method.....	57
Data Collection.....	57
Data Analysis.....	58
Ethical Considerations	61
Summary	61
Chapter Five: Findings.....	62
Introduction	62
Description of Sample	62
Symptom Experience.....	65
Prevalence of Physical and Psychosocial Symptoms	65
Frequency of Intervention Application	68
Effectiveness of Intervention	70
Symptom Experience and CPS Score	70
Overarching Descriptive Data Themes.....	72
Assessments	72
Interventions.....	72
Conclusion	73
Chapter Six: Discussion.....	75
Introduction	75
Resident Characteristics	75
Symptom Experience.....	78
Symptom Assessment	78
Symptom Prevalence.....	80
Symptom Management	83
Frequency of Interventions.....	83
Routes of Administration	85
Suctioning	87
Use of Oxygen.....	87
Effectiveness of Interventions	88
Implications for Practice.....	89
Implications for Education	90
Implications for Research	91
Recommendations for the ACE Tool	91
Recommendations for Future Research	92
Limitations	93
Conclusion	95
References	97
Appendix A: Auditing Care at the End-of-Life (ACE) Tool.....	122
Appendix B: Percentage Agreements Between Auditors on the ACE Items	128
Appendix C: Letter for Nursing Homes	130
Appendix D: Ethical Approval Form.....	131

List of Tables

Table 1: Demographic Data	63
Table 2: Length of Nursing Home Stay	63
Table 3: Primary Cause of Death	64
Table 4: Cognitive Performance Scale	65
Table 5: Prevalence of Symptoms	67
Table 6: Frequency of Interventions	69
Table 7: Cognitive Performance Scale and Symptoms.....	71
Table 8: Routes of Administration.....	73

List of Figures

Figure 1: Conceptual Framework 44

Chapter One: Introduction

Introduction

The purpose of this introductory chapter is to provide the foundation upon which the remaining chapters build and to set the stage for this research thesis. This chapter will briefly discuss the statement of the problem, as well as the research questions, discuss critical assumptions underpinning the study and provide definitions of key terms relevant to the project.

Statement of the Problem

Canada's population is rapidly changing and older adults comprise the age group that is growing at a faster rate than any other (Public Health Agency of Canada, 2014). As statistics have demonstrated, in 2015, the number of seniors (aged 65 and older) was greater than those aged zero to fourteen (Statistics Canada, 2015). This aging trend will continue and estimates show that the number of older adults will continue to rise (Statistics Canada, 2015). The majority of these individuals have at least one chronic medical condition such as cardiovascular disease, arthritis, cancer, and chronic obstructive pulmonary disease (COPD) (Canadian Institute for Health Information [CIHI] 2011), conditions typically associated with a myriad of symptoms. Many of these older adults will require care that necessitates admission to long-term care settings such as nursing homes, and inevitably, many will require end-of-life care in this setting as well. In western Canada, nursing homes are the second most common location of death for seniors, after in-hospital deaths. For instance, in British Columbia 27% of people died in nursing homes, compared with 20% of Manitobans and 16% of Albertans (CIHI, 2007). According to CIHI (2007) there is a predicted shift in location of death from in-hospital acute care deaths being the leading location to nursing homes. This predicted shift is due to the number of long-term care beds exceeding in-hospital beds (CIHI, 2007). Because older adults will increasingly be dying in

nursing homes, nursing home staff must possess the knowledge, skills, and ability to provide quality end-of-life care. Certainly, one can infer that the residents of nursing homes and their family members expect and deserve quality end-of-life care. This inference aligns with the palliative care philosophy that incorporates astute assessment and intervention of pain and other symptoms that may otherwise hinder one's quality of life (World Health Organization [WHO], 2017). Notably, end-of-life care is but one part of palliative care as it aims to "improve quality of life", however, begins in the later stages of dying until the time of death (Canadian Nurses Association & Canadian Hospice Palliative Care Association, 2015, p. 2). Symptom management is an important element in the provision of quality end-of-life care (Singer, Martin & Kelner, 1999) and thus, warrants investigation in the context of nursing homes. Unfortunately, quality end-of-life care and the experience of a good death have been challenging to consistently achieve in the context of nursing homes.

Significance of the Study

Recent empirical literature (within the last five years) demonstrates that end-of-life care provided in nursing homes needs to be improved (De Roo et al., 2014), including symptom management in residents with dementia (van Uden et al., 2013) and those with a diagnosis of heart failure (Kaasalainen, Strachan et al., 2013). While there are various studies that have examined pain and other non-pain symptoms (Estabrooks et al., 2015; Flock & Terrien, 2011; Hanlon, Perera, Sevick, Rodriguez & Jaffe, 2010; Hendriks, Smalbrugge, Galindo-Garre, Hertogh & van der Steen, 2015; Hoben et al., 2016; Monroe, Carter, Feldt, Tolley & Cowan, 2012; Rodriguez, Hanlon, Perera, Jaffe & Sevick, 2010; Thompson, Doupe, Reid, Baumbusch & Estabrooks, 2017) in dying individuals in nursing homes, limited research has been conducted examining dying residents' symptom experience and management specific to the last week of

life (Hendriks, Smalbrugge, Hertogh & van der Steen, 2014; Koppitz, Bosshard, Schuster, Hediger & Imhof, 2015) and these studies specifically examined this only in residents with dementia. Examining such symptoms during the last week of life is crucial and assessing and managing symptoms at this stage at the end-of-life is not only imperative to improve the resident's quality of life, but is also important for family members who may witness their loved one dying. The varying time frames of recent studies also make it difficult to extrapolate the results to the last week of life. This time frame is important to consider and as Ferris, Von Gunten and Emanuel (2003) aptly stated, "the care provided during those last hours and days can have profound effects...on all those who participate. At the very end-of-life, there is no second chance to get it right" (p. 605).

Healthcare professionals working in nursing homes currently lack end-of-life education and knowledge (Lee et al., 2013) which may hinder their ability to be able to provide quality end-of-life care and this current research study may highlight areas of greater educational need within this setting. Indeed, Jors et al. (2016) found that the majority of experienced healthcare professionals (working in cancer care centers) indicated that they hoped to learn more about pain and symptom management.

There is also conflicting evidence regarding the experience of pain among nursing home residents with more severe cognitive impairment, compared to those with less cognitive impairment. That is, Hendriks et al. (2014) and Vandervoort et al. (2013) found pain did not significantly differ between those with more advanced dementia in comparison to those with less advanced dementia. This differs from the findings of Estabrooks et al. (2015) who found that those without dementia experience pain, dyspnea and pressure ulcers more frequently than those with dementia. Similarly, Thompson et al. (2017) attest that individuals with less cognitive

impairment were more likely to have been assessed as having pain, compared to those with greater cognitive impairment.

Additionally, this research thesis provides important information regarding the data that yields from the Auditing Care at the End-of-Life (ACE) tool and consequently, provides recommendations for the use of this tool. The aforementioned gaps further support the need for this study and drives the research questions to be investigated.

Research Study Questions

The overarching purpose of the study was to examine and describe nursing home residents' symptom experience in their last week life in nursing homes. Specifically, the following research questions were addressed:

- 1) What is the frequency of physical and psychosocial symptoms within a nursing home resident's last week of life?
- 2) In those residents experiencing symptoms in the last week of life, how frequently were interventions applied?
- 3) Are there differences in the frequency of applications of interventions used between various symptoms in a resident's last week of life?
- 4) Are there differences between the effectiveness of interventions applied between various symptoms?
- 5) Is there an association between residents' cognitive status, as measured by the Cognitive Performance Scale (CPS) (documented in the Resident Assessment Instrument Minimum Data Set) and frequency of documented symptoms?

Assumptions

According to Polit and Beck (2012) an assumption is “a principle that is accepted as being true based on logic or custom, without proof” (p. 720). There are several assumptions, both personal and professional, identified by the author that predicate the study and need to be disclosed. These assumptions are outlined below.

- 1) All residents and their family members expect and deserve quality end-of-life care.
- 2) Quality end-of-life care is not only possible in nursing homes, but should also be a requirement.
- 3) Although there are inherent challenges in assessing and managing symptoms in those with cognitive impairment, which may be further exacerbated at the end-of-life, individuals with cognitive impairment experience symptoms at the end-of-life and healthcare professionals’ interpretation of symptoms in this population is appropriate.
- 4) Nurses and other healthcare professionals record residents’ symptoms, the management of these symptoms and the effectiveness of the management in the residents’ chart.
- 5) There are differences in the frequency of applications of interventions used between various symptoms.
- 6) There are differences of effectiveness of interventions between symptoms.

Definition of Terms

While multiple terms are used throughout the literature they may not have the same definition and thus, lack consistency. For instance, end-of-life care and palliative care are often used interchangeably (Fowler & Hammer, 2013), however, these terms do mean different things and thus warrant definition to ensure clarity. Moreover, nursing homes and long-term care are two different terms found throughout the literature. For the purposes of this document the terms

‘end-of-life’ and ‘nursing homes’ will be used throughout and are defined below. Additional key definitions are provided for terms that the reader will encounter throughout the research thesis.

End-of-Life: Hui et al. (2014) and Izumi, Nagae, Sakurai and Imamura (2012) attest that there are varying definitions and time frames of what constitutes end-of-life. End-of-life includes: the “presence of a chronic disease(s) or symptoms or functional impairments that persist or may fluctuate and the symptoms or impairments resulting from the underlying irreversible disease require...care and can lead to death (National Institutes of Health, 2004, p. 5) and furthermore, “the end of life is often the period in which treatments and procedures focus on comfort rather than having the primary goal of curing the underlying disease” (Lowey, 2015, p. 10).

End-of-Life Care: Is care “to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages” (Izumi et al., 2012, p. 616). The term ‘end-of-life care’ will be used throughout the thesis due to the fittingness within the context of this study, as end-of-life care pertains to those residents imminently dying (in the last week of their life).

Quality End-of-Life Care: Includes: “receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones, and strengthening relationships with loved ones” (Singer et al., 1999, p. 163).

Palliative Care: Is an approach to care for both patients and their families that have a life threatening disease and aims to improve their quality of life by way of relieving suffering (WHO, 2017). This includes the assessment and management of pain and other physical, psychosocial and spiritual issues. Furthermore, palliative care is relevant early on in the disease trajectory (WHO, 2017) and while similar to, is not synonymous with end-of-life (Izumi et al., 2012).

Nursing Home: Is a facility with homelike environment that provides 24 hour care for persons with health needs and functional support (Sanford et al., 2015) and includes support from healthcare aides, nurses, nurse practitioners, physicians and other healthcare professionals.

Residents: Those who live and are cared for by healthcare professionals in nursing homes.

Intervention: Any pharmacological or non-pharmacological approach delivered to the resident by a healthcare professional in the attempt to alleviate presenting symptom(s).

Summary

This introductory chapter has provided a foundation that included a brief discussion of the statement of the problem, the overarching purpose of the study and the specific research questions addressed. It also provided the author's assumptions that underpin the study and finally, provided pertinent definitions key to the discussion of end-of-life care in nursing homes. The following chapter will provide a review of the literature that includes the description of physical and psychosocial symptoms and further includes a discussion of recent literature (within the last five years) examining the frequency and management of symptoms experienced by residents at the end-of-life in nursing homes. Furthermore, factors that either inhibit or enhance quality end-of-life care within this context will be explored.

Chapter Two: Review of the Literature

Introduction

This chapter will provide a review of the literature in order to gain a broader understanding of the subject matter and to identify knowledge gaps. Specifically, this chapter will discuss the concept of ‘a good death’ and describe physical and psychosocial symptoms, including the prevalence and management of symptoms among dying residents within nursing homes. Furthermore, factors affecting end-of-life care applicable to the context of nursing homes will be discussed. These factors include symptom assessment and management in individuals with cognitive impairment, end-of-life care education among healthcare professionals, communication (namely between healthcare providers and family members), the use of advanced practice nurses to enhance end-of-life care and the inherent structure of nursing homes.

The literature was retrieved and reviewed from online databases including CINAHL, PsychINFO, and PubMed and was primarily limited to the last five years in order to ensure recent information on the subject matter. Seminal works were excluded from this restriction and in such instances where there was a paucity of literature within the last five years the literature search was extended to include earlier literature. The literature search included combinations of the following search terms: long-term care, nursing homes, residents, symptoms, symptom experience, end-of-life, palliative care, dying and dementia. Reference lists of articles obtained were also studied and relevant citations were retrieved from these lists.

Concept of a Good Death

Prior to delving into the discussion of the symptom experience at the end-of-life in nursing homes, it is fundamentally important to discuss palliative care, end-of-life and the notion of a good death.

As briefly discussed in the definition of terms in chapter one, palliative care and end-of-life care are often used interchangeably (Fowler & Hammer, 2013), and while principles of palliative care extend to end-of-life care, these terms are not synonymous (Izumi et al., 2012). WHO (2017) defines palliative care as “relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (para. 3). End-of-life and end-of-life care have varied meanings throughout the literature and there is no consensus on the time frame constituting end-of-life (Izumi et al., 2012). This inconsistency limits the transferability of results from previously completed studies and furthermore, limits the comparability between studies as different time frames during the dying process may be captured.

According to the Canadian Nurses Association and the Canadian Hospice Palliative Care Association (2015) end-of-life refers to the last stage in the dying process leading to and including death. The concept of palliative care is of particular significance at the end-of-life as distressing symptoms, such as pain and dyspnea often increases in frequency among residents as death approaches (Koppitz, et al., 2015). While not specific to nursing homes, key stakeholders including patients, families and healthcare providers report that pain and symptom management is key in the delivery of quality end-of-life care (Vedel et al., 2014). Of note, palliative care includes not only caring for the individual facing a life-limiting illness, but their families as well (WHO, 2017). As families must live with the memory of their loved one’s death, applying palliative care principles, including symptom management at the end-of-life is critical to allow for the best death possible.

The concept of a good death is not as easily discernible as one may believe. Cipolletta and Oprandi (2014) and Granda-Cameron and Houldin (2012) attest to this notion and suggest

that the definition of a good death may vary between individuals. For instance, one individual may want to receive curative treatment until death, otherwise known as the proverbial “fight”, while another may want comfort care only (Granda-Cameron & Houldin, 2012). While there may not be a universal definition for the concept of a good death, there are some key attributes commonly found throughout the literature often used when describing this phenomenon. Pain and symptom management has been found to be an important attribute in a good death for key stakeholders (Cipolleta & Oprandi, 2014; Granda-Cameron & Houldin, 2012; Holdsworth, 2015). Specifically, Cipolleta and Oprandi (2014) examined healthcare professionals’ (N=37) views on what constitutes a good death and these authors found that although healthcare professionals could not distinctly define what a good death is, they described it as including management of pain and other symptoms, as well as viewing the person as whole (not just solely referred to as their disease), honoring the individual’s wishes and having families remain close with their loved one. Granda-Cameron and Houldin (2012) also suggest while a good death may be subjective and vary from person to person, pain and symptom management is an attribute commonly found in the definition of a good death. Further key attributes of a good death include upholding of “patient’s dignity, family presence, family support, awareness of death, and good communication among patient, family, and health care team” (Granda-Cameron & Houldin, 2012, p. 637). Holdsworth (2015) examined the concept of a good death from bereaved family carers’ (N=44) perspective and again found that symptom management was of particular importance in how the carers perceived their loved one’s death.

The aforementioned descriptions of a good death from recent literature are consistent with findings from seminal works. Steinhauser et al. (2000) examined the concept of a good death from the perspective of patients, families and healthcare providers (N=75) and Singer et al.

(1999) sought to describe quality end-of-life care from patients' point of view (N=126, which included those living in nursing homes). The concept of a good death and quality end-of-life care are interrelated and each of these authors assert that pain and symptom management is a key component in the aim of a good death and in the description of quality end-of-life care. Pain and symptom management is a common thread throughout the literature in the description of a good death and therefore, it is important to examine the symptom experience at the end-of-life in the context of nursing homes.

Symptom Prevalence and Management in Nursing Homes

According to Thompson, McClement, Menec & Chochinov (2012), family members of loved ones who died in nursing homes who were dissatisfied with end-of-life care were more likely to believe that pain and other symptoms were ill managed compared with family members who were satisfied with the end-of-life care provided. Relatives of dying residents with dementia also report that symptom management remains to be improved (van Uden et al., 2013). As already stressed, symptom management is key to end-of-life care, not only for the resident experiencing the symptom, but for family members who live on with the memory of the end-of-life care delivered and therefore, warrants examination.

The prevalence of physical symptoms, including pain, gastrointestinal, respiratory and other physical non-pain symptoms (fever, skin breakdown, urinary tract infections (UTI's), edema and seizures) will be discussed in this chapter. Psychosocial symptoms, including depression, anxiety, agitation/restlessness, and delirium impact quality of life and the dying experience and will also be discussed. These symptoms comprise the "symptoms and symptom management through the death" domain outlined in the ACE tool and were chosen as they are frequently cited in the literature (Gibson et al., 2008; Hanson et al., 2008). Furthermore, these

symptoms are referred to in the chosen conceptual framework that guides the research study, the concept of quality of life of dying persons in the context of health care (Stewart, Teno, Patrick & Lynn, 1999), which will be discussed in chapter three. The discussion of these symptoms includes a description of each symptom, and the prevalence and management (if applicable and available) of these symptoms among residents in nursing homes as demonstrated within recent literature.

Physical Symptoms

Pain

Pain is ubiquitous and frequently cited throughout the literature examining end-of-life care, particularly in the nursing home setting. Indeed, pain is often touted as the fifth vital sign (Morone & Weiner, 2013; Purser, Warfield & Richardson, 2014), demonstrating the commonality and significance of this symptom. A common definition of pain within healthcare literature is the “unpleasant sensory or emotional experience associated with actual or potential damage, or described in terms of such damage” (International Association for the Study of Pain, 2014, para. 1). Pain is highly individualistic and self-report is the most ideal assessment method (Herr, Coyne, McCaffery, Manworren & Merkel, 2011). The use of self-report of pain (and other symptoms) poses challenges, particularly in the nursing home setting, as many residents have medical conditions that may hinder their ability to verbalize their pain experience. Challenges may further increase when individuals approach death and are unable to verbalize their own symptom experience. Irrespective of dying residents, non-cancer pain is commonly experienced and is often undertreated among nursing home residents (Lapane, Quilliam, Chow & Kim, 2013), as well as those residents with cancer (Pimental et al., 2015). Residents who are dying are

no exception in experiencing pain and many authors discuss pain when discussing palliative and end-of-life care in nursing homes.

Recent literature examining the experience of pain at the end-of-life in nursing homes often focuses on those residents living with dementia (Henriks et al., 2014; Koppitz et al., 2015; Monroe et al., 2012; Vandervoort et al., 2013), which may be attributed to the fact that the majority of residents in nursing homes have a diagnosis of dementia (CIHI, 2010). Pain assessment in residents with cognitive impairment or dementia can be extremely difficult, particularly in the latter stages of the disease. Monroe et al. (2012) argue that residents with mild to moderate dementia are better able to communicate pain as opposed to residents with severe dementia, suggesting that residents with severe dementia have underreported and thus, undertreated pain. These authors further attest that residents with dementia who also have conditions known to cause pain should receive regularly scheduled analgesia rather than on an as needed basis (Monroe et al., 2012). For instance, as discussed in chapter one, many elderly Canadians have diseases such as arthritis, cancer or heart failure (CIHI, 2011), which carry a multitude of painful and/or distressing symptoms. Thus, residents with those diseases and who also have with cognitive impairment may not be able to verbalize their discomfort and therefore, it may be prudent to administer medication prophylactically to ensure comfort. Estabrooks et al. (2015) examined symptom burden in relation to the context of nursing homes in Canada and also found that aside from challenging behaviors, distressing symptoms are often under recognized and undertreated in those with more severe cognitive impairment. Similarly, Thompson et al. (2017) found that residents with more severe cognitive impairment had less pain near death in their recent study examining pain trajectories at the end-of-life; a finding they speculate may be attributed to the fact that pain is poorly assessed and therefore, under-detected in this population.

However, Hendriks et al. (2014) found that prevalence of pain did not significantly differ between those residents with advanced dementia (55% of residents) compared to those with less advanced dementia (50% of residents). Similarly, Vandervoort et al. (2013) found that the symptom experience, including pain, did not differ greatly between various stages of dementia. This study was a retrospective study, examining deceased residents' (N=198) last month and last week of life and was based on the memory of healthcare providers', which is a limitation to the study's findings. That is, the findings of this study were based on what information healthcare providers were able to recall within three months from the resident's death (Vandervoot et al., 2013) and thus, may not accurately recall the nature of the death. The conflicting evidence in the literature regarding prevalence of pain, particularly between those with mild and severe dementia may be due to different conceptualizations of mild and severe dementia used across studies. Assessment and management of pain and other symptoms in cognitively impaired individuals will be discussed further in this chapter.

Although scheduled or around-the-clock analgesia is important in pain management, particularly for residents with dementia at the end-of-life, this system may not always be effective. Hanlon et al. (2010) aimed to examine pain and pain management among nursing home residents (N=303) in US nursing homes. These authors found that many residents experienced pain despite the administration of opioids (Hanlon et al., 2010), which suggests that despite the use of opioids, the attempt often proves to be ineffective in managing residents' pain. This may be due to inadequate dosing or incorrect analgesia prescription and the study did not delineate whether those receiving opioid analgesic and experienced pain were receiving regular medication or receiving analgesia on an as needed basis. Hanlon and colleagues also reported that no analgesics were used in the previous 24 hours in 15% of residents with pain (Hanlon et

al., 2010), however the authors did not identify a reason to explain this finding. Although this number may seem insignificant, any pain should be considered significant and therefore, managed appropriately. Furthermore, the sample of Hanlon et al.'s (2010) study was comprised of residents receiving hospice or palliative care, and limits the generalizability of the findings, as many residents may not receive specialized palliative care services. Koppitz et al. (2015) examined the trajectory of symptoms among residents with dementia in nursing homes (N=65) and compared to the work of Hanlon and colleagues, reported a higher rate of pain, as they found 80% of residents with dementia experienced pain in the last week of life. The findings of this study are "limited due to its retrospective design using a convenience sample" (Koppitz et al., 2015, p. 182). Both Koppitz et al. (2015) and Hendriks et al. (2015) briefly discussed pharmacological management of pain, including the use of opioids such as Morphine and other medications, such as acetaminophen (Koppitz et al., 2015; Hendriks et al., 2015). However, these authors did not describe whether the management was effective in relieving pain, as this was not an aim of either study.

Flock and Terrien (2011) also found a high prevalence of pain among residents (N=100) (not solely with dementia), and 75% of residents experienced pain as judged by their next of kin, though the majority of the residents' next of kin believed the pain to be well managed. Of note, this particular study utilized a convenience sample, which lends itself to the greatest possibility of sampling bias (Polit & Beck, 2012). Furthermore, the majority of the study sample was comprised of residents who received hospice care (in addition to usual care) (Flock & Terrien, 2011), thus again, posing limitations of generalizability of the study findings. That is, the findings may not be generalizable to those residents who do not receive specialized hospice or palliative care. The findings from Flock and Terrien (2011) contradict the findings from

Thompson et al. (2012), who found that 57% of dissatisfied family members thought their loved one did not receive the correct amount of medication in the management of their pain (either too much or too little). The use of family members to provide proxy data may also have limitations, as family members are unlikely to possess the knowledge and skill to adequately assess the correct amount of pain medication for their family member. Lastly, Hoben et al. (2016) examined prevalence of symptoms and the ratings of how burdensome these symptoms were to residents (N=6007) (as judged by managers and staff) (N=40)). The Resident Assessment Instrument Minimum Data Set (RAI-MDS) was used to collect the data about prevalence of symptoms; however, this data is collected once every three months in nursing homes, thus, it is difficult to discern at what point at the end-of-life the data was retrieved. Notwithstanding, this study found pain to prevalent among nearly 33% of the sample nearing the end-of-life.

A review of the literature identified that there has been limited recent research examining pain (and other symptoms) among those living in nursing homes in Canada (Estabrooks et al., 2015; Hoben et al., 2016; Thompson et al., 2017) and no recent literature could be found examining this during the last week of life in Canadian nursing homes. Much of the research has been conducted in European nursing homes (De Roo et al., 2015; Hendriks et al., 2014; Hendriks et al., 2015; Koppitz et al., 2015; Vandervoort et al., 2013) or in the United States (Flock & Terrien, 2011; Monroe, 2012; Rodriguez et al., 2010). This limits the generalizability of findings to nursing homes in Canada in which contextual factors may be different than in other countries (for example, the use of palliative care services and funding). Furthermore, studies examining palliative and end-of-life care in nursing homes are completed in different time frames, making comparison of studies and generalizability to the last week of life difficult. For instance, Hendriks et al. (2015) examined symptoms from the time of admission until death, while Hanlon

et al. (2010) examined pain in the “past seven days” (p. 580), but did not state at what point in the residents’ disease trajectory residents the data was collected. Additionally, the study by Hoben et al. (2016) focused on the burden of symptoms as rated by managers and staff and as previously discussed, utilized the Resident Assessment Instrument Minimum Data Set (RAI-MDS), which is collected quarterly and thusly, may not have been captured close to death (that is, the last week of life).

While often less prevalent than pain, other non-pain symptoms, including gastrointestinal (dysphagia, nausea, vomiting, constipation and diarrhea), respiratory (dyspnea, congestion, and cough) and other physical symptoms, such as skin breakdown necessitate investigation in long-term care settings as these symptoms too impact quality of life near end-of-life (Gonzales & Widera, 2011).

Gastrointestinal Symptoms

Gastrointestinal symptoms include dysphagia, nausea, vomiting, constipation and diarrhea. Dysphagia, or difficulty swallowing, is a symptom that is common among individuals with dementia (Kyle, 2011) and also frequently manifests at the end-of-life (Groher & Groher, 2012). Groher and Groher (2012) further argue that dysphagia has “psychosocial importance” and “it may be one of the most difficult activities to sacrifice in [end-of-life] circumstances” (p. 149). Recent literature examining dysphagia at the end-of-life was limited to nursing home residents with dementia (De Roo et al., 2015; Koppitz, 2015; Vandervoort et al., 2013), which may be due to the frequency of this symptom in this population, or that other studies excluded dysphagia when examining symptoms at the end-of-life. Vandervoort et al., (2013) found that besides pain, difficulty swallowing was the most reported symptom in the last week of life, occurring in nearly 67% of residents with dementia. These authors attest that communication and

care planning regarding food and fluid is of particular importance to discuss with residents early on in their disease trajectory, as well as with family members (Vandervoort et al., 2013). Koppitz et al. (2015) also found “feeding problems” to be highly prevalent, in 70% of residents with dementia, in the last week of life. Relatives (N=92) of residents with dementia related less choking to dying peacefully at the end-of-life (De Roo et al., 2015), thus demonstrating the profound impact that dysphagia has, not only on the resident, but their family members as well. While dysphagia is a symptom that warrants attention, decreased food and fluid intake at the end-of-life is a part of the normal dying process (Harlos, 2010) and perhaps, dysphagia can also be described as a “normal” process as the resident becomes less responsive as death nears. This highlights the importance of astute end-of-life communication regarding dysphagia with all residents (as early as possible) and their family members.

Nausea and vomiting need not be synonymous with one another, that is, one may experience nausea without vomiting and vice versa (Nunn, 2014). Nausea is solely subjective, based on what the person experiencing this symptom reports, whereas vomiting is an objective, physical and visible symptom (Glare, Miller, Nikolova & Tickoo 2011). Rodriguez et al. (2010) found that among residents (N=303, not solely with dementia) 7% of residents experienced nausea and vomiting, however, 88% percent of these residents were pharmacologically undertreated. This study did not specify where in the dying process the symptoms were captured and furthermore, this study defined under treatment as “the omission of a necessary medication for a specific non-pain symptom and was evaluated as a dichotomous variable” (Rodriguez et al., 2010, p. 225). However, nonpharmacological interventions may be considered treatment and furthermore, the authors only briefly described which medications were considered necessary. A small percentage of residents (close to three percent) experienced vomiting near the end-of-life

as found by Hoben et al. (2016). Again, Flock and Terrien (2011) reported that nausea and vomiting had a higher prevalence in comparison to Hoben et al. (2016) and 26% of residents who were dying experienced nausea and vomiting as judged by their family members. Furthermore, next of kin reported that the majority of residents who experienced nausea and/or vomiting had good to excellent symptom management. However, the study sample must be taken into consideration as again, this study utilized a convenience sample. Two of these studies rely on healthcare providers' (Rodriguez et al., 2010) and family members' (Flock & Terrien, 2011) assessment of nausea and vomiting which were grouped together, although these are symptoms may not be experienced together.

While constipation is frequently described based on regularity of stools, constipation can also be described as a subjective symptom (Clark & Currow, 2014). Constipation frequently occurs in nursing homes, especially at the end-of-life as many residents receive opioid medications to manage their symptoms (Gonzales & Widera, 2011). Hoben et al. (2016) found only a small percentage, close to 6% of residents (N=6007) experienced constipation. This is similar to the findings of Rodriguez et al. (2010) who found that approximately only 9% of dying residents (N=303) experienced constipation, which is quite low compared to the 53% percent that Flock and Terrien (2011) found in their postmortem survey of next of kin. This may be due to different varying opinions of what constitutes as constipation and additionally, family members may have difficulty in accurately recalling the symptom experienced by the resident. In the previously mentioned study 26% percent of residents were pharmacologically undertreated (Rodriguez et al., 2010), however, nearly all family members found the resident's constipation was managed well (Flock & Terrien, 2011). The difference in prevalence and management of

constipation may be attributed to the study's sample, as family members may define constipation differently than health care providers.

Diarrhea is “defined as stools that are looser than normal and may be increased in frequency” (Von Gunten & Gafford, 2013, p. 399). Rodriguez et al. (2010) examined diarrhea among dying residents (N=303) and found the prevalence of this symptom to be low (nearly 2%), however, this symptom was undertreated in nearly 74% of those experiencing diarrhea. These findings were derived from staff familiar with the residents in the sample and who reviewed the medical records of the resident. Similar findings were reported by Hoben et al. (2016) who noted that less than six percent of residents (N=6007) had diarrhea. This again is in contrast to the findings of Flock and Terrien (2011) who found diarrhea to occur in 35% of residents (as judged by their relatives).

Respiratory Symptoms

Respiratory symptoms include dyspnea (shortness of breath), congestion (noisy breathing) and cough. There are many terms used to describe the subjective feeling of breathlessness experienced by patients with chronic obstructive pulmonary disease including “frightening, scary, ugly, choking and not being able to breathe” (Kvanjarsnes, Torheim, Hole & Ohlund, 2013, p. 3066). Based on these terms, one can only imagine both the distress and discomfort of experiencing dyspnea and this may be one of the worst symptoms experienced in those living with a life-limiting illness. Further defined, dyspnea is a “subjective experience of breathing discomfort consisting of qualitatively distinct sensations that vary in intensity” (American Thoracic Society, 1999, p. 322). Of note, the “death rattle”, which occurs due to upper airway accumulation of secretions in a proportion of dying residents, differs from dyspnea, as the resident is unlikely to be distressed from this symptom since it frequently occurs when the

person has a decreased level of consciousness (Hipp & Litiza, 2009; Lokker, van Zulyen, van der Rijt & van der Heide, 2014). However, healthcare professionals (physicians and clinical nurse specialists) have reported finding this symptom to be distressing for both staff members themselves, as well as family members (Bradley, Wee & Aoun, 2010).

While examining symptoms during the last week of life, Hendriks et al. (2014) found that 35% of residents with dementia (N=330) experienced dyspnea that was mostly treated with opioids (71%), oxygen (43%), and bronchodilators (20%). However, it was not the aim of this study to examine whether these pharmacological and non-pharmacological management strategies were effective. Using the same data set as the previously mentioned study, although examining symptoms from admission to the time of death, Hendriks et al. (2015) concluded that aerosolized bronchodilators and diuretics were primarily used to treat dyspnea, but closer to death morphine and oxygen were the most frequently provided treatments for shortness of breath. A recent study by Hoben et al. (2016) examined both the prevalence of symptoms (which could be ascertained through the Resident Assessment Instrument Minimum Data Set (RAI-MDS)) and burden of symptoms as judged by managers and staff. In this study, they found dyspnea to be prevalent among nearly 20% of residents near the end-of-life among nursing home residents (N=6007) in western Canada.

Management of dyspnea should be tailored to the individual and there are many options to help alleviate shortness of breath including the use of opioids, diuretics, and in some instances, oxygen (Chan, Tse, Sham & Berit Thorsen, 2010). These interventions are consistent with those used in previously discussed studies. Of note, Campbell, Yarandi and Dove-Medows (2014) studied compared the use of oxygen, medical air and no flow in patients towards the end-of-life (N=32) and based on this study, these authors do not recommend the practice of routinely

placing dying individuals on oxygen. Oxygen use during the terminal phase of life may be adjusted for comfort and in the unresponsive, dying individual, oxygen is unlikely to increase comfort (Harlos, 2014). Based on the studies previously discussed and current best practice evidence, the question remains as to whether dyspnea is well managed in nursing homes. Flock and Terrien (2011) report that dyspnea was prevalent in 60% of residents (again, with or without dementia) and that next of kin believed this dyspnea was well managed. However, this study does not describe how the dyspnea was managed and as previously mentioned, utilized a convenience sample. Furthermore, this contradicts the findings of Thompson et al. (2012), that 44% of unsatisfied family members believed that their loved one's dyspnea was ineffectively managed.

Kaasalainen, Strachen, et al. (2013) found that residents in long-term care living and dying with heart failure were most likely to experience shortness of breath as their main symptom issue. This finding is unsurprising due to the nature of heart failure. The authors further found that nurses need astute knowledge of heart failure in order to treat the distressing symptoms of this disease, particularly important in the latter stages of the disease. Moreover, family members in the study by Kaasalainen, Strachen, et al. (2013) reported that staff need to be able to recognize symptoms, including dyspnea, in residents with heart failure.

Only one study (Rodriguez et al., 2010) was found in the recent literature (within the last five years) examining prevalence and management of cough at the end-of-life in nursing homes. These authors found that cough was prevalent in approximately nine percent of residents (N=303) in nursing homes (not limited to residents with dementia), but unfortunately, these authors further found that cough was undertreated pharmacologically in 69% of residents

experiencing this symptom (Rodriguez et al., 2010), although it is unclear how severe the cough was. These authors did not report which medications were administered to relieve cough.

Respiratory congestion, also known as the death rattle, or noisy breathing, is due to “accumulation of oro-pharyngeal and/or chest secretions” (Twomey & Dowling, 2013, p. 81), but due to a decreased responsiveness and gag reflex the dying person is often thought to be unbothered by this symptom (Hipp & Litiza, 2009; Lokker et al., 2014). The experience of death rattle, or noisy breathing, in dying residents in nursing homes has not been examined in recent literature. Hall, Schroder and Weaver (2002) examined noisy breathing in the last 48 hours of life and found this symptom to be prevalent in 39% of residents (N=185), however, was untreated in 49% of those experiencing it. Although the resident may be unperturbed by noisy breathing, families (of cancer patients, not within nursing homes) have reported this symptom to be distressing (Shimizu, Miyashita, Morita, Sato, Tsuneto & Shima, 2014). A Cochrane review examined 32 studies with the overall purpose to evaluate the effectiveness of interventions aimed at alleviating respiratory congestion (Wee & Hillier, 2008). These authors suggest that there is no superior medication compared to placebo in alleviating respiratory congestion, but acknowledge that some interventions may “be worth trying” (Wee & Hillier, 2008, p. 2). Educating families regarding noisy breathing is important (Wee, Coleman, Hillier & Holgate, 2006), particularly as the symptom is unlikely to be distressing to their loved one and this further highlights the idea that effective communication is paramount at end-of-life.

Other Physical Non-pain Symptoms

Other non-pain physical symptoms include fever, skin breakdown, urinary tract infections (UTI's), edema and seizures. These symptoms have been minimally examined in the context of nursing homes, which is similar to several of the aforementioned non-pain symptoms already

discussed. Fever was examined by Rodriguez et al. (2010) and was found to be prevalent in only three percent of residents (N=303). Similarly, Hoben et al. (2016) also found fever to be present among only less than two percent of residents (N=6007) near the end-of-life. In contrast, Vandervoort et al. (2013) found fever to be prevalent among nearly 43% of residents with dementia (N=198) during the last month of life. This study relied on the memory of healthcare professionals and therefore, this is a limitation of the findings. Of note, these authors did not provide their conceptual definition of fever, nor how fever was measured (Hoben et al., 2016; Rodriguez et al., 2010; Vandervoort et al., 2013). Pressure sores are defined as “damage to the skin or underlying structures as a result of tissue compression and inadequate perfusion” (Venes, 2009, p. 1889). Vandervoort et al., (2013) also found pressure sores in nearly 27% of dying residents in their last week of life, similar to Flock and Terrien’s (2011) finding that 35% of residents had “bed sores” as judged by their relatives. Hoben et al. (2016) classified a pressure ulcer, as stage two or greater, and this was present among close to 11% of residents. Possible different conceptualizations of pressure ulcers (for instance, staging) may be attributed to the difference of prevalence among studies. A urinary tract infection is “a microbial infection in any part of the urinary tract including the kidneys, ureters, bladder and urethra” (Kumar, Dave, Wolf & Lerma, 2015, p. 45). Estabrooks et al. (2015) found this symptom to be prevalent in approximately nine percent of those with dementia and ten percent in those without dementia. No other studies could be found examining the prevalence and management of urinary tract infections, which may be due to the lack of investigating and diagnosing of this symptom near the end-of-life. The lack of investigation coupled with the notion that recognizing infection in the elderly may prove to be difficult due to possible differences in clinical presentation, an infectious process may present as confusion and/or delirium (Norman, 2000), may affect the frequency that

infections are recognized in dying nursing homes residents. Edema, or swelling of the tissues, has been minimally examined within this context, again demonstrating the need for further research into non-pain symptoms. One study found edema to be prevalent among less than two percent of residents near the end-of-life (Hoben et al., 2016). The author could not find recent nor earlier literature examining seizures among dying residents in nursing homes. In addition to physical symptoms, psychosocial symptoms also impact the dying experience for the resident and their loved one.

Psychosocial Symptoms

Psychosocial symptoms include depression, anxiety, agitation/restlessness and delirium. Some of these symptoms overlap, which may pose challenges in their assessment and management. This overlap and the challenges posed will be further discussed.

Depression

Depression at the end-of-life may be difficult to discern as it is often confused with grief (Widera & Block, 2012). The World Health Organization (2016) defines depression as “a common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness, and poor concentration” (para. 1). According to De Roo et al. (2015), dying peacefully is correlated with “less emotional distress and more well-being in the last week of life” (p. 4) in residents dying with dementia. Koppitz et al. (2015) found that depression decreased as death neared and in the last week of life only two percent of residents (N=65) had depressive episodes. Flock and Terrien (2011) found that 60% of next of kin believed their loved one had depression, but again, each family member may have their own definition of depression, limiting the results of this finding. Hoben et al. (2016) also found a high prevalence of depressive symptoms among nursing home residents near

the end-of-life, in approximately 37% of their sample (N=6007). Again, as the RAI-MDS was utilized to examine symptom prevalence, it is difficult to distinguish at what point the disease trajectory the symptom experience was captured, as information for the RAI-MDS is captured quarterly. Discerning depression among dying residents may prove difficult when death approaches due to the natural dying process. That is, many may appear depressed due to decreased appetite, decreased energy, more time spent sleeping (and ultimately becoming unresponsive). Indeed, Lander, Wilson and Chochinov (2000) attest that diagnosing depression in the terminally ill is a difficult task as some of the aforementioned symptoms may be caused by the disease. Moreover, depression tends to be under recognized and undertreated among nursing homes residents in general (Levin et al., 2011; Volicer, Frijters & van der Steen, 2011). However, for those residents aware and cognizant of their emotional state, depression warrants attention and treatment, whether through non-pharmacological, pharmacological approaches, or a combination of both.

Anxiety

Anxiety may be difficult to recognize in the terminally ill and individuals “with anxiety complain of tension or restlessness, or they exhibit jitteriness, autonomic hyperactivity, vigilance, insomnia, distractibility, shortness of breath, numbness, apprehension, worry, or rumination” (Breitbart, Chochinov & Passik, 2010, p. 1454). In their study examining the impact of pain, anxiety and depression in relation to the desire for a hastened death in terminally ill cancer patients (N=120), Mystakidou et al. (2005) found that anxiety and depression was the greatest predictor for a hastened death. This finding demonstrates the profound impact that these psychological symptoms pose at the end-of-life. Koppitz et al. (2015) found that anxiety increased as death neared and in the last week of 24% of residents with dementia experienced

anxiety. Again, next of kin reported a higher frequency of anxiety in their loved one and 70% believed their loved one experienced anxiety when dying (Flock & Terrien, 2011). Neither of these studies discussed interventions aimed at alleviating anxiety among dying residents.

Agitation

Goncalves, Almeida, Teixeira, Pereira and Edra (2012) defined agitation as “a behavior that included disruptive vocalizations, such as calling out or screaming, aggressiveness, wandering and noisemaking” (p. 522). Agitation may be a manifestation of pain among those with dementia and arguably, pain should be adequately addressed to alleviate agitation. While there have been few randomized control trials examining the use of opioids in addressing agitation (Brown, Howard, Candy & Sampson, 2015), Husebo, Ballard, Sandvik, Nilsen and Aarsland (2011) found that implementing a pain protocol (including the use of non-opioid analgesics, opioid analgesics and adjuvant medications) significantly reduced agitation in residents with dementia. Despite the recommendation to use medications aimed at alleviating pain, antipsychotics are more frequently prescribed to those living in nursing homes, compared to those living in the community (Maguire, Hughes, Cardwell & O’Reilly, 2013).

According to Hendriks et al. (2014) agitation occurred in 35% of residents (N=330) with dementia (the same percentage who experienced pain). Again, there was little difference in prevalence of agitation in those with advanced dementia compared to those with less advanced dementia. In the treatment of this agitation, at least 79% of residents received pharmacological treatment, mainly anxiolytic and hypnotic medications (Hendriks et al., 2014). As within other studies, there was no mention regarding the effectiveness of pharmacological and non-pharmacological treatments.

In the extension of this study, Hendriks et al. (2015) found agitation was the most common symptom (compared to pain and shortness of breath) and this symptom was the most constant symptom. Unlike dyspnea, however, agitation decreased closer to the end-of-life, which is consistent with the findings from Koppitz et al. (2015). This may be attributed to the natural dying process, as individuals may become more fatigued as the end-of-life approaches. These authors further found that agitation was mainly treated with non-pharmacological treatment, (including massage, occupational therapy and physiotherapy) and subsequently both anxiolytics and antipsychotics (Hendriks et al., 2015). Whether these treatments were effective in reducing agitation is unclear.

Flock and Terrien (2011) reported similar prevalence rates as Hendriks et al. (2015), with 71% of residents in their study experiencing agitation according to their family member (N=100). Furthermore, the majority believed agitation was well managed. However, this study failed to mention what symptom management entailed, which may be attributed to the fact that resident's next of kin were the respondents. Symptom management of agitation may be complicated and the underlying cause may be difficult to distinguish. For instance, agitated delirium may occur in terminal patients and must be dealt with appropriately and swiftly (Bascome, Bordley & Lawton, 2014).

Delirium

Delirium is a “cognitive disorder characterized by acute onset, fluctuating course, and among others disturbances of consciousness, attention, and perception” (Boorsma et al., 2012, p. 709) and the setting of nursing homes may again pose challenges in appropriate identification of delirium at the end-of-life among residents. That is, delirium may be difficult to identify in those living and dying with dementia (Oligario, Buch & Piscotty, 2015). This notion underscores the

exceptional assessment skills needed to assess and manage distressing symptoms at the end-of-life. Estabrooks et al. (2015) examined delirium in dying residents and found it to be present in 31% of residents without dementia and nearly 30% of those with dementia near the end-of-life. Hoben et al. (2016) found delirium less prevalent among nursing home residents near the end-of-life, delirium was present in approximately 17% of residents. The lack of examination of prevalence and management of delirium at the end-of-life in nursing homes may be due to the idea that symptoms may overlap. For instance, a resident who becomes apathetic may be labeled as depressed rather than delirious. Conversely, a resident who is restless or agitated may not be labeled as delirious.

Factors Affecting End-of-Life Care in Nursing Homes

Canadians die in many settings, including at home in the community, in acute care settings across a wide variety of in-patient units and in long-term care settings, such as nursing homes. Each of these unique settings presents factors that impact the provision of quality end-of-life care. There are several factors that impact end-of-life care delivery in the context of nursing homes that were identified within the literature. These factors include symptom assessment and management in cognitively impaired individuals, end-of-life education for nurses and other healthcare professionals, end-of-life communication, the use of advanced practice nurses and the nature and structure of nursing homes.

Symptom Assessment in Cognitively Impaired Individuals

As discussed above, many symptoms are subjective. That is, the experience of the symptom is based on the resident's report and healthcare professionals rely on an individual's ability to report symptoms. However, when the ability to effectively verbally communicate is lost, which may be a consequence of dementia or other conditions including the natural dying

process, other assessment techniques must be implemented. As already discussed, many residents living and dying in nursing homes have a diagnosis of dementia (CIHI, 2010). While literature often denotes that those with dementia have under recognized and undertreated pain compared to those without (Tan et al., 2015), there is conflicting evidence as to whether symptoms are equally identified and managed across various stages of dementia (that is, mild to severe dementia) and/or level of cognitive impairment. Of note, there are varying degrees of cognitive impairment not only attributed to dementia, but other disease processes as well. One tool utilized in nursing homes to assess for and measure the level of cognitive impairment is the Cognitive Performance Scale.

Cognitive performance scale. The Cognitive Performance Scale (CPS) “provides a functional view of cognitive performance, using readily available MDS data” and was developed based on both the Mini-Mental State Examination and the Test for Severe Impairment (Morris et al., 1994, p. 174). The CPS ranges from zero to six (intact to severe impairment) and each numerical value is associated with the level of cognition as follows:

Zero- Cognitively intact

One- Borderline intact

Two- Mild impairment

Three- Moderate impairment

Four- Moderately severe impairment

Five- Severe impairment

Six- Very severe impairment (Morris et al., 1994, p. 178)

The CPS includes the following Resident Assessment Instrument (RAI) and Minimum Data Set (MDS) information as stated by Hansebo, Kihlgren, Ljunggren and Winblad (1998), “short-term

memory, cognitive skills for daily decision making, ability to be understood by others, ADL self-performance in eating and comatose” (p. 643). Essentially, while the CPS does not delineate the underlying cause of cognitive impairment (if any), the CPS does depict residents’ level of cognition. Level of cognition may impact symptom assessment (and therefore management of these symptoms) of residents in nursing homes.

Symptom assessment. Irrespective of the level of cognitive impairment, the loss of ability to effectively communicate one’s symptom experience decreases the ability of healthcare professionals and resident family members to discern what symptom, if any, the resident is experiencing. This may occur with certain disease trajectories, such as in residents with dementia or in the normal dying process. That is, as the resident nears the end-of-life, the ability to verbally communicate may be lost. The recommended approach to assess pain (and other symptoms) in cognitively impaired individuals or those who are not able to adequately verbalize their needs is multi-faceted (Buffum, Hutt, Chang, Craine & Snow, 2007). This includes monitoring for behavior changes, assessing for behaviors and using symptom assessment tools which rely on healthcare professionals’ assessment (Burns & McIlpatrick, 2015). Unfortunately, recent literature indicates that nurses may lack the knowledge to appropriately assess and treat pain and other symptoms in those with dementia and other conditions that impair one’s ability to communicate (Burns & McIlpatrick, 2015; Wysong, 2014). As already mentioned, symptom assessment should encompass multiple strategies, including the use of assessment tools. In their qualitative study of nurses and healthcare assistants (N=13), Krumm, Larkin, Connolly, Rode and Elsner, (2014) found that the implementation of the Minimal Documentation System for Palliative care (MIDOS) tool may increase healthcare providers’ awareness of symptoms other

than pain. Assessment of symptoms using the MIDOS tool can either be completed by the patient (resident) or care provider (Krumm et al., 2014).

In addition to nurses and other healthcare providers, family members may also witness and assess the resident's symptom experience and therefore, provide their perspective on it. The author could find no literature examining congruency of ratings of symptoms by family members and residents in the context of nursing homes. However, Kristanjon and colleagues (1998) examined congruency of symptom rating between patients and family members (N=78 dyads), in which the patients had a diagnosis of cancer. These authors found that family members' rating of symptoms are often appropriate and closely related to patients' rating of symptoms (Kristjanson et al., 1998). In essence, symptom assessment among individuals who are not able to verbalize their own symptom experience is complex and healthcare professionals must possess knowledge and skill in order to adequately address symptom issues at the end-of-life. Unfortunately, current literature demonstrates that many healthcare professionals may not possess adequate end-of-life knowledge and skill, ultimately hindering the likelihood of a good death.

End-of-Life Education

While the aging population of Canada necessitates a greater end-of-life care knowledge base for all nurses (Pesut et al., 2015), this is of particular importance for those working in nursing homes. Unfortunately, recent literature demonstrates there is a great need for improved end-of-life care knowledge and skills in long-term care (Brazil, Brink, Kaasalainen, Kelly & McAiney, 2012; Gill, Hillier, Crandall & Johnston, 2011; Lo et al., 2010). Significant deficiency in knowledge surrounding symptoms at the end-of-life was found among staff in residential care homes for the elderly located in Hong Kong (Lee et al., 2013). Specifically, staff were found to be deficient "in the areas of mortality relating to chronic diseases, pain and use of analgesics,

feeding tubes, dysphagia, [and] sputum management” (Lee et al., 2013, p. 1268). Nurses should have an understanding of chronic diseases in nursing homes as many residents have one or more these chronic diseases. This end-of-life care knowledge deficit may be attributed to the notion that undergraduate nursing curricula leaves graduate nurses ill prepared to provide quality end-of-life care (Wallace et al., 2009) and there is a lack of education and training received by nurses in general (White & Coyne, 2011). This unfortunate finding coupled with the indication that there is currently a lack of education and a need for further ongoing end-of-life care education for nurses working in nursing homes (Sims-Gould et al., 2010) is a barrier that nurses working in long-term care face when providing end-of-life care. Irrespective of nursing homes, in rural Canada, Pesut et al. (2015) implemented a mixed-methods approach with the overall purpose to examine the effects of a palliative care educational intervention among both nurses and healthcare assistants (N=35). These authors found that this intervention had a significant impact on healthcare assistants’ perceived competence and knowledge and nurses’ knowledge increased in the “dimension of spiritual needs, legal and ethical issues and personal and professional issues” (Pesut et al., 2015, p. 150). The findings from this study suggest that education can improve frontline workers’ perceived competence and knowledge. Certainly, not being armed with appropriate knowledge and skills, nurses and other healthcare professionals working in long-term care settings are ill equipped to provide quality end-of-life care and furthermore, may not possess the communication skills necessary at the end-of-life.

Communication

Communication is a vital part of providing quality care in any setting, but particularly at the end-of-life. Indeed, Sims-Gould et al. (2010) found that effective and frequent communication plays an important role in whole-person care near the end-of-life in nursing

homes. Communication is not limited to residents and staff, but effective communication is imperative between nursing home staff and residents; between nursing home staff themselves and resident family members as well (Sims-Gould et al., 2010).

Despite the importance of skilled communication, Kaarbø (2011) found that while the perception of end-of-life care (during the last three days of life and after death) among family members (N=50) was generally positive, they also spoke of some negative aspects. This includes being unhappy with the communication provided, not necessarily closer to death, but in earlier stages, more specifically from physicians. Family members shared that communication was “unsystematic and casual” (Kaarbø, 2011, p. 1129). Indeed, Shield, Wetle, Teno, Miller and Welch (2005) found that individuals (family members or individuals close to nursing home residents) reported physicians to be “missing in action” and there was a lack of communication with physicians (p. 1653). This may be due to their significant workload demands and may further be a result of the way physicians works in nursing homes, that is, they may not be present in the building in comparison to physicians working in the hospital. However, this factor impacts end-of-life care for both the resident and family members. This finding demonstrates the importance of communication from other healthcare professionals, such as direct care nurses or healthcare assistants who play a pivotal role in end-of-life care in nursing homes and often provide the majority of the direct patient care. However, Johnson and Bott (2016) found that over 90% of nursing home staff believed end-of-life care discussions are the responsibility of the physician or social worker, while only 53% believed this discussion should occur from direct care staff. Furthermore, the majority of direct care staff reported they would have this discussion when the resident is at the end-of-life (Johnson & Bott, 2016), suggesting that discussions about death and dying may occur late in the dying process, ultimately impacting the quality of dying.

Discussion occurring later in the disease process may impact advanced care planning, in which the individual may no longer be able to elucidate their goals of care and family members may have to make important decisions quickly (Johnson & Bott, 2016). Similar to the aforementioned studies recognizing suboptimal end-of-life communication, Towsley, Hirschman and Madden (2015) found that communication is lacking in nursing homes and overall, there are “missed conversations” (p. 424), namely regarding advance care planning and the residents’ wishes. They further discuss barriers and facilitators surrounding end-of-life communication as identified by staff (n=10), residents (n=16) and their families (n=12). These barriers include the notion that conversations surrounding death and dying are not easy to partake in, there is a lack of knowledge and conversations are reliant on the individuals involved (Towsley et al., 2015). Only two facilitators were identified within the study and these include one’s own experiences with death and dying and the level of comfort of whom they are talking with (Towsley et al., 2015). Healthcare providers should have the knowledge to discuss end-of-life care, including symptoms and symptom management, with both residents and family to ensure quality end-of-life care. Zheng & Temkin-Greener (2010) used a data from a previously conducted survey study among 107 nursing homes to examine the relationship between certified nurse assistants (likened to healthcare assistants) and end-of-life processes. The findings from this study suggest that nursing homes with improved communication between healthcare assistants and other staff members are associated with both improved assessments at the end-of-life and delivery of care (Zheng & Temkin-Greener, 2010), demonstrating their importance.

Advanced Practice Nurses

According to the Canadian Nurses Association (2008):

“advanced nursing practice is an umbrella term describing an advanced level of clinical nursing practice that maximizes the use of graduate educational preparation, in-depth

nursing knowledge and expertise in meeting the health needs of individuals, families, groups, communities and populations. It involves analyzing and synthesizing knowledge; understanding, interpreting and applying nursing theory and research; and developing and advancing nursing knowledge and the profession as a whole” (p. 1).

Advanced practice nurses include both clinical nurse specialists and nurse practitioners, and each of these roles may impact the delivery of end-of-life care in nursing homes. Furthermore, these roles are often confused and thus, the definition of each role and their role in end-of-life care in nursing homes in Canada will be discussed.

Clinical nurse specialists. Clinical nurse specialists first emerged in Canada 40 years ago and despite their long-standing place within the healthcare system, their full abilities have not been recognized and implemented into the healthcare system (Dicenso et al., 2010). The clinical nurse specialist role has core competencies that include four main categories: clinical care (such as consultation), system leadership, advancement of nursing practice (such as educating other nurses) and finally, evaluation and research (Canadian Nurses Association, 2014). As previously mentioned, the clinical nurse specialist role has been in Canada for an extended period of time, yet there is a dearth of literature surrounding this role specific to end-of-life care in nursing homes. While not specific to end-of-life care in nursing homes, Donald et al. (2013) found in their review of the literature that advanced practice nurses (including both clinical nurse specialists and nurse practitioners) enhance the care of residents in long-term care. Comart et al. (2013) examined the use of a palliative care consult team, which included a clinical nurse specialist, and found that the palliative care team “was effective in reducing emergency room visits and depression and promoted more appropriate care resulting in more favorable clinical outcomes toward the resident’s end-of-life” (p. 874). Clinical nurse specialists possess advanced practice nursing knowledge and abilities that offer a solution to improving palliative care in nursing homes, not limited to symptom management. The Winning Regional Health Authority

includes palliative clinical nurse specialists within their palliative care program (including in nursing homes) and these advanced practice nurses can be consulted to assist in end-of-life resident care, including symptom management (Winning Regional Health Authority, n.d., para. 4).

Nurse practitioners. Similar to clinical nurse specialists, nurse practitioners hold additional education (such as a graduate degree), however, differ in that they can independently order tests, diagnose and prescribe certain medications (Canadian Nurses Association, 2009). Ploeg et al. (2013) found that residents and families were pleased with the whole person and quality care nurse practitioners are able to provide in nursing homes. Specific to end-of-life care, Kaasalainen et al. (2013) examined the role of nurse practitioners in the delivery of end-of-life care in nursing homes in Canada and found that nurse practitioners enhance palliative care through various ways, including a holistic approach to pain management and improved interdisciplinary teamwork. Similarly, Liu, Guarino and Lopez (2012) found that overwhelmingly family members of residents who died with dementia were highly satisfied with the care that nurse practitioners provided at the end-of-life. Indeed, nurse practitioners may be able to facilitate improved quality end-of-life as they may be more readily available than physicians, whom as previously mentioned, may be “missing in action” (Shield et al., 2005).

Structure and Nature of Nursing Homes

The structure and nature of nursing homes poses unique challenges when delivering end-of-life care in this setting. While the author did not note this concept to often be directly discussed in the literature, it is worth mentioning. In addition to some of the factors previously discussed, such as “lack of care provider knowledge about the principles and practices of palliative care” and “lack of physician support”, Wowchuk, McClement and Bond (2007) have

suggested further internal factors from the literature that influence end-of-life care in nursing homes (p. 345). These factors include “staffing levels and lack of available time for dying residents and lack of privacy for residents and families” (Wowchuk et al., 2007, p. 345). These internal factors influence the symptom experience and end-of-life care in nursing homes and certainly, there are challenges to overcome in the aim of quality end-of-life care and a good death within this context.

Nursing homes are just that, homes to residents. While this setting can and does provide nursing and some medical care, there are limitations to the capacity and extent of such care. For instance, if a resident is deemed to require oxygen prior to nursing home placement, their requirement will be assessed as to whether it can be supported in that particular setting (Winnipeg Regional Health Authority, 2015). Thus, some nursing homes do not have oxygen readily available, or a restriction on the amount of oxygen one can receive. Access to scans, such as x-rays, may require transfer to an acute care facility. And, while this may not appear to be an obstacle near death, these limitations may impact end-of-life care. For instance, if a dying resident has severe pain and the root of this is an undiagnosed fracture, the pain may be ineffectively treated. Therefore, along with the aforementioned factors that impact end-of-life care, the very nature of nursing homes also impact symptom assessment and management at the end-of-life.

Despite some of the inherent challenges of providing care and end-of-life care in the context of nursing homes, nursing home staff provide care to residents over an extended period of time and are, undoubtedly passionate about their role. Certainly, Cable-Williams and Wilson (2016) describe this passion in their qualitative study examining the culture of end-of-life and end-of-life care in Canadian nursing homes and state that “with limited resources, staff members

sought to provide the best day-to-day care possible for all residents and to pay special attention to those who were thought to be dying” (p. 5). Furthermore, Cagle, Unroe, Bunting, Bernard and Miller (2017) found in their qualitative study looking into frontline staff perspectives (N=707) of caring for dying residents in nursing homes that, it is not only an honor to care for residents nearing the end-of-life, but an opportunity to create strong bonds. To further support staff and physicians, namely with further education, would help to bolster their passion in delivering quality end-of-life care.

Summary

Pain and symptom management is an integral component in providing quality end-of-life care facilitating a good death. While the experience of symptoms has been examined in the context of nursing homes, there is limited recent research examining symptoms during the last week of life and previous studies implemented during this time frame focused on those with dementia. Furthermore, many non-pain symptoms have been either unexamined or minimally examined in the context of nursing homes, but the prevalence and management of these symptoms are important to consider at the end-of-life. Additionally, there is conflicting evidence regarding the association between level of cognitive impairment and symptoms and the extent to which they are more or less prevalent, which is one factor that impacts the symptom experience at the end-of-life in nursing homes. Additional factors that impact end-of-life care within this context include education, communication, advanced practice nurses and the structure and nature of nursing homes. A limitation found throughout the literature is the varying time frames examining symptoms among residents (that is, one study may consider end-of-life to be different than another). The last week of life is important to examine, particularly for family members who will remember how their loved one died. Arguably, even if one resident has an untreated

symptom it has an effect on their quality of life and the family's perception of their death and thus, warrants attention. The next chapter will provide an overview of the theoretical framework that underpins this thesis study.

Chapter Three: Conceptual Framework

Introduction

According to Melnyk and Cole (2011), “a theoretical or conceptual framework is made up of a number of interrelated statements that attempt to describe, explain, and/or predict a phenomenon” (p. 410) and is an integral component in research as it aids in the description of relationships between variables (Melnyk & Cole, 2011). Indeed, nursing theories, which are more formal than conceptual frameworks (Polit & Beck, 2012), not only organize nursing information, but also help to distinguish nursing from other professions (McEwen, 2014). In essence, a conceptual framework is important in describing relationships between key factors in a research study. For instance, there are many factors which impact the symptom experience at the end-of-life in nursing homes and thus, an appropriate conceptual framework, the quality of life of dying persons in the context of health care (Stewart, Teno, Patrick & Lynn, 1999), was chosen to guide this research study. Essentially, this conceptual framework aids in describing the factors that impact end-of-life care, including the symptom experience. Therefore, while this research study focuses on the symptom experience, this framework helps to discuss contributing factors that impact this symptom experience. This conceptual framework will be discussed, including the examination of its use in other studies and literature. Moreover, comparisons to similar frameworks that also examine end-of-life care and/or symptoms will be made and rationale will be provided as to why this particular framework was selected.

The Quality of Life of Dying Persons in the Context of Health Care Framework: Key Features

According to Stewart et al. (1999), this conceptual framework “specifies and defines all relevant domains that are appropriate for describing and evaluating end-of-life care and how it

affects patients and families” (p. 94), which is particularly important in the use of quality assessment tools (Stewart et al., 1999). The quality of life of dying persons framework builds upon previous seminal work written by Donabedian (1966) who examined the evaluation of quality medical care. Donabedian (1966) stated that defining quality of care is difficult and furthermore, examining the process, the structure, and outcomes of care are methods of evaluating quality of care. Moreover, the utilization of charts and records is one tool of evaluation, although this method poses limitations (Donabedian, 1966). The use of charts as a research methodology will be further discussed in chapter four.

This framework stresses the notion that end-of-life care includes not only the dying individual, but family members as well. This builds on the definition of palliative care (applicable to end-of-life) as previously discussed in chapter one, which emphasizes that end-of-life care is not only crucial for the ill individual, but family members as well (WHO, 2017). The framework also extends the definition of family to include those who work closely with and care for the dying individual, including health care providers (Stewart et al., 1999). This definition may be particularly important in nursing homes as staff often work closely with residents for an extended period of time. Therefore, the strength of this framework is the convergence with the definition of palliative care, as well as the inclusion of both family members and healthcare professionals.

Additionally, this conceptual framework highlights the key notion that health care context and contextual factors play a role in quality of care and the outcomes of care. As stressed in chapter two, the review of the literature, symptom assessment and management in those with cognitive impairment is a difficult task, although an important factor of end-of-life care in nursing homes. Furthermore, end-of-life education, communication, the use of resources

(advanced practice nurses) at the end-of-life and the inherent nature and structure of nursing homes are factors which also impact end-of-life care in this setting. Indeed, some of these factors align with the idea of contextual factors playing a role in end-of-life care, as outlined in this framework. Finally, acknowledging individual preferences is another key attribute of this framework (Stewart et al., 1999) and one that was stressed as an integral part of a good death in chapter two. The quality of life of dying persons in the context of health care framework includes three predominant categories: patient factors affecting health care and outcomes of care, structure and process of care and outcomes of care (Stewart et al., 1999). While the framework does not directly discuss relationships between factors, McEwen (2014) asserts that seeking out assumptions is an important step in theory analysis. Thusly, the theorized major factors and relationships will be discussed and are further depicted in Figure 1 on the following page. Briefly, patient factors and both structure and process of care impact outcomes of care (including satisfaction with care and quality and length of life) (Stewart et al., 1999).

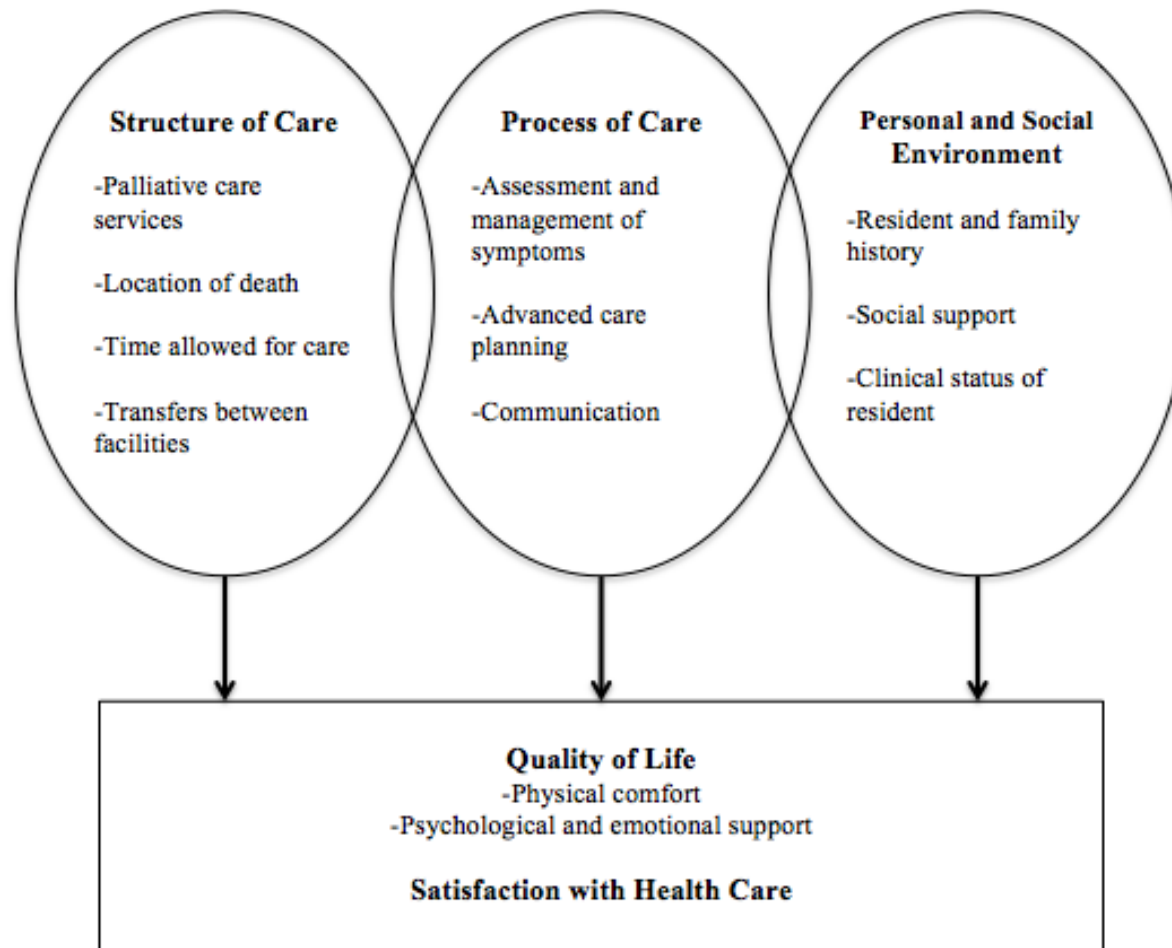


Figure 1. A modified diagram highlighting the integral components and relationships based on: Stewart, A. L., Teno, J., Patrick, D. L., & Lynn, J. (1999). The concept of quality of life of dying persons in the context of health care. *Journal of Pain and Symptom Management*, 17(2), 93-108. doi:10.1016/S0885-3924(98)00131-6. Modified and used with permission.

Patient Factors Affecting Health Care and Outcomes of Care

Patient factors affecting health care and outcomes of care includes “personal and social environment.” This mainly encompasses the idea that individuals and families bring their own history, as well as social supports (or lack thereof) to the caring encounter. Furthermore, this domain addresses clinical status of the individual, which “includes diagnosis, severity, history and trajectory of illness” (Stewart et al., 1999, p. 95). Clinical status may be particularly important to the quality of dying experience in the context of nursing homes, as many residents have a diagnosis of dementia, in which the disease trajectory and prognosis may be unknown, or difficult to predict. Additionally, assessing for and managing symptoms may prove to be difficult in this population.

Structure and Process of Care

Although Stewart et al. (1999) discuss structure and process of care separately, these two factors may be interrelated, and these ideas will be discussed further. Structure of care includes access to services at the end-of-life, which in turn may impact end-of-life care and symptom management (Stewart et al., 1999). For instance, as previously discussed, nursing homes within the Winnipeg Regional Health Authority may consult palliative care clinical nurse specialists or physicians to support residents and their families at the end-of-life (Winnipeg Regional Health Authority, n.d., para.4). Location of death is another factor in the structure of care (Stewart et al., 1999) and as outlined in chapter two, the inherent nature and structure of nursing homes pose challenges in the delivery of end-of-life care. For instance, the workload of health care providers may hinder their ability to provide quality end-of-life care. Indeed, Stewart et al. (1999) report that time (or lack of time) allowed for care is another factor included within structure of care. Stewart et al., (1999) argue that when individuals are transferred to a location that is not their

preferred place of death, negative consequences can occur, including: interruption of care, missed information during transfer and the new staff being unaccustomed to the individual and their family. This may be particularly significant for residents of nursing homes, who may be transferred to emergency rooms and hospitals, although such transfers rarely align with the aims at the end-of-life (Lamberg, Person, Kiely & Mitchell, 2005) and advanced care planning is integral in limiting such transfers (Givens, Selby, Goldfeld & Mitchell, 2012).

This component of the conceptual framework links to the process of care, which includes the critical component of communication (Stewart et al., 1999). Indeed, process of care, includes the overarching concept of communication. Specifically, discussing options, advanced care planning and what to expect during the dying process with both the dying individual and their families are key components in the process of care (Stewart et al., 1999). Furthermore, the authors declare the importance of astute symptom assessment and management at the end-of-life (Stewart et al., 1999). Outcomes of care, including satisfaction with health care and quality and length of life are based on the aforementioned factors.

Outcomes of Care

Outcomes of care include satisfaction with health care, quality and length of life and quality of dying. Satisfaction with health care is dichotomized between satisfaction of health care from the perspective of the dying individual and from the perspective of family (Stewart et al., 1999). While length of life does not necessarily pertain to this proposed research study, quality of life, in which physical comfort is a large component, fits well within the nature of this study. Stewart et al. (1999) attest that physical comfort is an important domain in ensuring quality of life of dying persons. The authors emphatically state “the failure to attend to patients’ physical comfort is often an important indicator of inadequate quality of care that patients receive in their

last days of life” (Stewart et al., 1999, p. 98). Another key component to quality of life within the framework is psychological well-being, which includes emotional well-being, and acknowledging emotions such as depression and anxiety among dying individuals (Stewart et al., 1999). Furthermore, assessment and management of distressing symptoms is not only important for the dying individual’s comfort, but their comfort affects family members’ quality of life as well (Stewart et al., 1999). Quality of dying is briefly mentioned and the authors further explore this outcome of care in their publication about another model, evaluating the quality of dying and death (Patrick, Engelberg & Curtis, 2001), which is further discussed in this chapter. In sum, dying individuals and their families bring their own perspective and background affecting their end-of-life experience. This factor, coupled with the structure and process of care shapes and informs the outcomes of care.

Uses of the Conceptual Framework

Articles that cited the concept of quality of life of dying persons in the context of health care framework merely mentioned components of the original article, and did not discuss the framework at length, nor discuss the use of the framework in guiding research. This may be because many journal articles do not discuss the underpinning conceptual or theoretical framework guiding the research study, which may be due to a limitation of space. While much of the literature only cited the Stewart et al. (1999) article, Lindstrom, Gaston-Johansson and Danielson (2010) utilized the framework to develop an end-of-life chart audit tool with the overarching aim of identifying patients’ participation in their care during the end-of-life. Temkin-Greener et al. (2009) also used Stewart et al.’s (1999) conceptual framework (along with Donebedian’s (1966) model) in their development of an instrument aimed at measuring end-of-

life processes in nursing homes. Indeed, Stewart et al. (1999) suggest that their conceptual framework be implemented in the creation of such tools.

The quality of life of dying persons in the context of health care conceptual framework illustrates concepts and relationships between these concepts that are key to end-of-life care. In essence, this conceptual framework attests there are three main variables that impact quality and length of life, as well as satisfaction of care and these include; patient factors, structure of care and process of care. Notably, the framework highlights the notion that symptom management and comfort is key in the quality of life of dying persons.

Limitations of Other Conceptual and Theoretical Frameworks

There are several other conceptual and theoretical frameworks examining end-of-life care (Nolan & Mock, 2004; Patrick et al., 2001; Ruland & Moore, 1998) and/or the symptom experience (Lenz, Suppe, Gift, Pugh & Milligan, 1995) that the writer explored to determine their applicability to this research thesis. Patrick et al. (2001) built upon the quality of life of dying persons in the context of health care framework, however, these authors focus on quality of dying (in the last week of life) rather than quality of life. Although quality of dying fits with the current study, this framework emphasizes the application of the framework in examining whether individual preferences were honored during their death and as previously discussed, is an important attribute for a good death, but does not fit well within the nature of the proposed research. Additionally, this framework does not mention many of the symptoms as outlined in the selected framework. Ruland and Moore (1998) stress the importance of physical comfort, relief from distressing symptoms and the link between nursing care to outcomes at the end-of-life. However, similar to the work of Patrick et al. (2001) their theory entitled the peaceful end of life does not emphasize the importance of context. While Nolan and Mock (2004) further discuss

contextual factors impacting end-of-life care, they argue that spirituality should be given greater attention than the physical domain.

Nolan and Mock (2004) assert:

“the spiritual domain is given greater emphasis than the functional, physical, and psychological domains because persons at the end of life identify spiritual issues as being of paramount importance and use spiritual beliefs and practices to transcend suffering in the functional, physical and psychological domains” (p. 352).

However, as Clary and Lawson (2009) astutely point out, spiritual issues may only be attended to once an individual is physically comfortable. Perhaps this is true for family members of dying individuals as well. That is, they may be unable to grapple with emotional and spiritual issues if their loved one is uncomfortable or their symptoms are managed poorly. Furthermore, they may be unable to appropriately and effectively grieve if the memory they are left with is of their loved one dying in pain or experiencing unaddressed distressing symptoms.

While Lenz et al. (1995) developed a middle-range theory entitled, theory of unpleasant symptoms, this theory was not developed among dying individuals and is not specific to end-of-life care. Certainly, these authors created this theory with the intention for it to be utilized among a wide range of both populations and symptoms (Lenz et al., 1995), however, this does not fit well for the purpose of this research study. This is evidenced as “performance” is an integral part of the theory, including functional, cognitive and physical performance as outcomes (Lenz et al., 1995). These outcomes may not be as important (or even relevant) in the last week of life.

Summary

This chapter provided a synopsis of the chosen conceptual framework, the concept of quality of life of dying persons in the context of health care, which underpins this research study. In addition, comparisons were made and rationale was provided as to why this particular

framework was chosen rather than other extant conceptual and theoretical frameworks. The following chapter will discuss the methods and procedures of this research study.

Chapter Four: Methodology

Introduction

Research in nursing homes, particularly at the end-of-life, is challenging. Many nursing home residents are unable to directly participate in research because they “are either too ill to participate, not identified as dying, or have already died before they are able to elucidate their perspectives” (Thompson & Chochinov, 2006, p. 379). Tilden, Thompson, Gajewski, Buescher and Bott (2013) also report methodological challenges in nursing home research including high staff turnover, concerns from staff regarding time to participate in research and concerns from residents themselves regarding confidentiality. Thus, selecting a feasible and appropriate method to address the proposed research questions is key to the success of the study. This chapter will discuss the methodology that was used to conduct the research. Discussion of the Auditing Care at the End-of-Life (ACE) tool, setting, resident characteristics, sampling methods and methods utilized to collect and analyze data will also be provided. Finally, ethical considerations of the research study will be examined.

Study Design

The study design is an exploratory, descriptive study examining the symptom experience among nursing home residents at the end-of-life utilizing quantitative secondary data analysis. The original study focused on the creation of the ACE tool, which was developed to examine care delivered at the end-of-life among nursing home residents. Data was retrospectively collected from charts of 90 from four different nursing homes that included examination of symptoms at the end-of-life (during their last week of life). My thesis advisor, Dr. Genevieve Thompson both generated the tool itself, as well as the data set utilized within this research

study. Both secondary data analyses and chart audits have their merits and disadvantages that will be further examined.

Secondary Data Analysis

Secondary data analysis includes using data to answer questions that may be different from the original study and enhances feasibility, as this type of research saves both time and money (Polit & Beck, 2012). Dunn, Arslanian-Engoren, DeKoekkoek, Jadack and Scott (2015) also report similar benefits of secondary data analysis and stress that data collection is often the most time consuming and expensive step in the research process and that utilizing secondary data analysis still addresses key research questions. Furthermore, this form of research often contains large data sets (Dunn et al., 2015) and “the larger the sample, the more representative of the population it is likely to be” (Polit & Beck, 2012 p. 284). However, there may have been pertinent data that was missed during the primary study (during the data collection phase) (Dunn et al., 2015) and there is a lack of control of the data collected in the original study (Schlomer & Copp, 2014). Of importance, the data should be appropriate in addressing new research questions (Dunn et al., 2015). Consequently, the data set should be analyzed and assessed to ensure the data fits well for the secondary analysis (Dunn et al., 2015). As the purpose of this research study was to explore the symptom experience at the end-of-life among nursing home residents, the original data set was appropriate. That is, the data set provided data that could be quantified and subsequently analyzed, examining various physical and psychosocial symptoms, as well as the various interventions associated with symptoms. Furthermore, the sample size (N=72) provided a large data set that was robust enough to analyze through access to the original primary investigator (Dr. Genevieve Thompson). Finally, Windle (2010) reports that due to the potential limitations of secondary analysis there should be access to the primary investigator of the

original research study, such as in the case of this research study. For instance, should questions arise regarding procedures or data collected, it is beneficial to have access to the researcher of the primary study.

Chart Audits and Documentation

Medical charts are not only integral to patient or resident care, but also elicit information that lends itself to research (Broderick & Coffey, 2013; Wang, Hailey & Yu, 2011), such as in this research study. Chart audits (also called chart reviews), occur in which the data is retrieved from the medical records of individuals (in this study, the residents of nursing homes) and is utilized for research purposes, wherein the original medical information exists for patient care, rather than research (Hess, 2004; Jansen et al., 2005). However, while the classic concept of “if it wasn’t charted, it didn’t happen”, exists, Jeffries, Johnson and Griffiths (2010) found in their meta-study of nursing documentation that charting is often inconsistent. Thus, a drawback of the proposed research study is that the charts may not adequately capture the symptom experience at the end-of-life. Notably, as discussed in chapter one, this research is founded on the pretense that healthcare providers have appropriately documented symptoms, management of those symptoms and effectiveness of this management. Furthermore, chart audits are one type of research to overcome the obstacles, which poses challenges in nursing home research (as previously discussed). More specifically, the data set derived from the original study provided information regarding the symptom experience as assessed and documented by healthcare professionals. Therefore, this research methodology addresses one of the obstacles outlined in the introduction, which is the notion that many residents are unable to participate in research due to various factors (Thompson & Chochinov, 2006). Furthermore, this methodology does not take additional time for staff, as documentation is a part of regular resident care.

Auditing Care at the End of Life (ACE) Instrument

The ACE tool (Appendix A) was created to assess end-of-life care throughout the dying trajectory, that is, not solely during the imminently dying phase. Specific purposes of the original study and the creation of the tool will be further explored within this section, as well as the development of the tool and the content contained within the tool.

Purpose of the ACE Tool

The purpose of the original study was to create and subsequently test a chart audit tool to be used to assess the quality of care near the end-of-life within a nursing home context (G. Thompson, personal communication, November 2, 2015). More specifically, the original study aimed to identify components pertinent to quality end-of-life care in nursing homes for the chart audit tool itself, develop and make revisions to the tool, and finally, implement and evaluate the practicality of the tool itself (G. Thompson, personal communication, November 2, 2015).

Development of the Tool

Briefly, the original study was a three-phase mixed methods design. Initially, a review of the literature was completed to identify important elements for the chart audit tool. Following the literature review, in phase two, a convenience sample of experts within the field was recruited to partake in focus groups for their feedback on the audit tool. These experts included registered nurses (n=5), clinical nurse specialists (n=2), a social worker (n=2), a pharmacist (n=1) and nursing home administrators (n=3). In the final phase of the development of the tool, a trial of the audit tool was completed (G. Thompson, personal communication, November 2, 2015). It is during this trial of the chart audit tool that the data for this secondary analysis was generated.

Tool Content

The ACE tool encompasses six domains that are relevant to the end-of-life care in the context of nursing homes and throughout these six domains there are a total of 27 questions. These domains include: demographics, situation around death (for example, was the resident transferred to acute care in the last month of life?), clear decision-making (for example, was there a healthcare directive?), preparation for death (was end-of-life seen to be near?), spiritual health and cultural aspects of care and finally, symptoms and symptom management through the imminently dying phase (the last week of life). This time frame was chosen as the original plan of using a one-month time frame was found to be unfeasible. That is, the amount of data regarding the symptom experience throughout the last month of life would be “unacceptably” time consuming for a chart audit (G. Thompson, personal communication, November 2, 2015). Furthermore, as discussed previously, examining the symptom experience during this time frame is important not only for individuals experiencing symptoms, but also for their family members as well. Symptom and symptom management includes both physical and psychosocial symptoms. The tool dichotomizes whether the symptom was experienced (that is, yes or no), if the symptom was experienced the tool describes the management and the evaluation of this management (namely, was the management of the symptom noted to be effective in the chart). Of note, there are sections within the symptom management and evaluation of management to write narrative (textual) data. This research study primarily focuses on this section of the ACE tool.

Setting

Data was collected from resident charts in four nursing homes within Winnipeg, Manitoba. According to the Winnipeg Regional Health Authority (2015), a personal care home

(nursing home) “provides personal care services to individuals who can no longer manage independently at home with family support and/or community services, such as home care, and where other assisted and supportive housing options are not suitable” (p. 3). In their research, Estabrooks et al. (2013) not only describe resident characteristics and draw comparisons among nursing home residents (N=5196) throughout 30 nursing homes in the prairie provinces, but also provide facility descriptions and highlight key differences. In Manitoba, the location of the proposed research, 88% of nursing homes have a clinical educator and 38% have a nurse practitioner, the highest out of all prairie provinces. Manitoba also has the highest average number of allied health services (9.4), which includes geriatric mental health counseling, access to a geriatrician, psychiatrist and palliative care services. Furthermore, all facilities have a medical director (Estabrooks et al., 2013). Out of the four nursing homes selected for this study, two of the nursing homes were both faith-based and non-profit, and two of the nursing homes were not faith-based and for profit, which provides a more heterogeneous sample.

Resident Characteristics

Within the same study previously mentioned, Estabrooks et al. (2013) found Manitoban residents to differ from other provinces as Manitoba residents are older, “more likely to be female, more likely to have dementia, and less likely to be highly physically dependent, with more-stable health status and taking fewer medications” (p. 227). Specifically, the average age of Manitoban residents was found to be almost 87 years old, nearly 78% were female, 66% had a diagnosis of Alzheimer’s or other dementia and almost 37% had moderate or severe cognitive impairment. Remarkably, over 22% had daily pain, which is less than the other two provinces and this finding may be linked with the cognitive status of Manitoban nursing home residents. That is, more Manitoba residents had a diagnosis of Alzheimer’s (or other dementia) and

cognitive impairment and thus, may be less likely to report pain (as discussed in chapter two, review of the literature). Finally, almost 43% were deemed to have the need for extensive physical assistance with their activities of daily living (Estabrooks et al., 2013). In sum, residents are elderly with the majority having some form of cognitive impairment and many require heavy physical care. The demographic and resident characteristics collected within this research study will be explored in chapter five.

Sampling Method

In the original study, 20% (N=90) of residents who were deceased during the years of 2013 and 2014 were randomly selected for the chart audit (G. Thompson, personal communication, November 2, 2015). The recommended sample size for such a chart audit is N=50 (Banks, 1998) and therefore, the original study met this criterion. An inclusion criterion to partake in the study was that there was documentation indicating that the death was expected. For this secondary data analysis, that chart audits were excluded if they were designated “practice” by the research assistants (who completed the chart audits). That is, ones that were completed for practice were not included within this secondary data analysis. Furthermore, one (n=1) chart audit was excluded, as the CPS score could not be retrieved for the resident due to a transcription error of their demographic information. Therefore, the sample size of this secondary data analysis was N=72 with each nursing home contributing 25% of the sample (n=18). Sample size and post hoc power analysis will be discussed in chapter six. More specifically, sample size as a potential limitation to this study will be explored.

Data Collection

As mentioned, data was previously collected during the original study and two independent auditors completed data collection and originally included 90 randomly selected

charts. Both auditors had some clinical experience in gerontology and palliative care and were trained to utilize the chart audit tool. Inter-rater reliability, an important measure in research, “in which the goal is to have observers share a common interpretation of a construct, and to reach consensus” (Polit & Beck, 2012, p. 334) was calculated using percentage agreement (G. Thompson, personal communication, June 12, 2016) and varied between 61%-100% (Appendix B) among the 27 questions throughout the tool. Percentage agreement was chosen as Cohen’s kappa relies on the distribution of the data (de Vet, Mokkink, Terwee, Hoekstra & Knol, 2013). The average time to complete the chart audit was 28.2 minutes, with a range between 15-60 minutes. Worth mentioning, the handwriting in the charts themselves was difficult to discern, there was a lack of standardized assessment of pain and assessment of whether an intervention was effective or not and therefore, the chart auditors found the symptom management question most difficult (G. Thompson, personal communication, November 2, 2015). For further, primary data collection of this research thesis, the contact person at each of the four nursing homes was sent a letter (Appendix C) seeking their assistance in retrieving the latest CPS scores from the Resident Assessment Instrument-Minimum Data Set (RAI-MDS), as the CPS score was not a variable within the original ACE tool. The CPS score was required to examine cognitive status in the residents and to address one of the research questions.

Data Analysis

Statistical support was provided from the statisticians, as well as the research coordinator from the Manitoba Centre for Nursing and Health Research, within the College of Nursing. Using the Statistical Package for the Social Sciences (SPSS) version 24 Grad Pack for Students, data was input into and analyzed by the investigator of this research thesis. While some of the data collected was narrative (that is, string), this data was transformed into nominal data (that is,

yes or no). For example, the use of anticholinergic medication was recorded as narrative data, however, this was coded as either “yes” or “no” in having received an anticholinergic medication for respiratory congestion. This allowed for statistical analysis of the data. Nominal data is “the lowest level of measurement involving the assignment of characteristics into categories” (Polit & Beck, 2012, p. 735) as the research questions yield a yes or no answer. For example, either the resident had documented pain or they did not. According to Morgan, Leech, Gloeckner and Barrett (2013) this type of variable can also be called a dichotomous variable. Data was then cleaned and examined for any outliers.

It is important to note that some modifications were made to the original chart auditors coding of data, more specifically, to the coding of pain and dyspnea. As the original chart auditors noted, it was difficult to discern what was meant by “for comfort”, which was documented in 16.7% of residents (n=12) (as presented in the following chapter). This could mean many different conditions (such as pain, shortness of breath, anxiety, to keep the resident comfortable or to prevent distressing symptoms, etc.) that cannot be distinguished within a chart audit. Therefore, a separate category of “for comfort” was created. Dyspnea, as discussed in chapter two is “a subjective experience of breathing discomfort consisting of qualitatively distinct sensations that vary in intensity” (American Thoracic Society, 1999, p. 322). Therefore, the true definition of dyspnea may not have been upheld in the original chart audit, as data was originally coded as dyspnea in instances where oxygen was utilized or other objective clinical signs were present. Subsequently, the overarching category of “respiratory condition” is defined as any sign or symptom (including tachypnea, decreased oxygen saturation, shortness of breath) that prompted an action/intervention to alleviate the respiratory sign or symptom. Apnea was excluded from this definition, as it is a normal occurrence when an individual is dying and

furthermore, did not receive an intervention in an attempt to alleviate the sign. The researcher kept a log of difficult to code data and the original researcher and thesis advisor, Dr. Thompson, reviewed the data and confirmed coding.

While the CPS scores are at the ordinal level of data, these scores were dichotomized into both $CPS \leq 3$ (cognitively intact to moderate impairment) and $CPS \geq 4$ (moderately severe impairment to very severe impairment). This dichotomy was chosen as the data naturally fell wherein nearly half (52.8%) of residents had a $CPS \leq 3$. Furthermore, Bartfay, Bartfay and Gorey (2013) report that a CPS score equal to or greater than four ($CPS \geq 4$) indicates severe cognitive impairment and Thompson et al. (2017) also utilized this cutoff point in their recent study examining the pain trajectory of residents who are nearing death.

To address the aforementioned research questions, descriptive statistics (frequencies and percentages) were utilized to examine the demographics of the residents, and research questions one through four. The Chi-square test was used to examine possible relationships between the CPS scores (research question five) and frequency of symptoms. The Chi-square test was utilized as the data is at the nominal level. According to Morgan et al. (2013) the Chi-square test can provide information about relationships between variables (at the nominal level), but does not distinguish the strength of relationships. For variables that held an expected cell count less than five, Fisher's exact test was used. Statistical significance was set at a p-value of 0.05. Finally, the narrative data retrieved from the chart audit was also analyzed and common findings regarding the symptom experience were extracted. More specifically, data that stood out from an empirical point of view was recorded on a separate document (totaling one page of data) and was analyzed for emerging patterns.

Ethical Considerations

Permission to complete this secondary data analysis study was obtained from the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba (Appendix D). In the original study, four nursing homes agreed to participate in the testing of the ACE tool. As previously mentioned, the contact person at each nursing home was approached in order to retrieve the latest CPS scores from the RAI-MDS (the investigator did not have access to these files), which is routinely collected quarterly by each nursing home. During the original study, resident names were removed from the collected chart audits and replaced with a code. The list of resident names was utilized to retrieve the CPS scores from the four nursing homes. Hardcopy files of the audit have been stored in either Dr. Thompson's locked filing cabinet, or the researcher's locked filing cabinet during this secondary data analysis (at either office in the Helen Glass Centre for Nursing or personal filing cabinet). Electronic files were stored on both Dr. Thompson's password protected computer, as well as the researcher's password protected computer and password protected and encrypted USB disk. Any hardcopies of consent forms, participant lists and data will be kept in a locked filing cabinet in Dr. Thompson's office before being destroyed in confidential waste in December of 2022.

Summary

This chapter provided an overview of the proposed methodology, including the setting and sample characteristics, as well as, data collection and analysis techniques. Ethical considerations to the proposed research study were also provided. In the following chapter, the results from the analysis will be presented.

Chapter Five: Findings

Introduction

The overarching aim of this study was to use the ACE tool to examine the symptom experience of residents in nursing homes at the end-of-life. This chapter will discuss the description of the sample (N=72), including demographic data, length of nursing home stay, primary cause of death and CPS scores. The symptom experience, including prevalence of symptoms, frequency of interventions applied and effectiveness of interventions will be provided. Possible relationships between symptoms and CPS scores will also be explored. Finally, major themes that emerged from the narrative data from the chart audits will be discussed.

Description of Sample

Demographic Data

As outlined in Table 1, 70.8% (n=51) of residents were female. The average age of the residents (N=72) was 86.2, with a range from 53 to 104. The breakdown of age groups is provided in Table 1. Notably, the highest percentage of residents, 40.3% (n=29) were between the ages of 90 to 99.

Table 1*Demographic Data of Residents (N=72)*

Characteristic	Frequency (n)	Percent (%)
Gender		
Male	21	29.2
Female	51	70.8
Age		
<60	1	1.4
60-69	3	4.2
70-79	10	13.9
80-89	27	37.5
90-99	29	40.3
≥100	2	2.8

Length of Nursing Home Stay

The average length of stay (in months) for residents was 40.3, with a range between one month and 145 months (or, nearly 12 years). The length of stay that had the highest number of residents (n=26) or 36.1% was equal to or greater than 49 months (greater than approximately four years). Interestingly, the next timeframe that held the subsequent highest number of residents (n=20) or 27.8% was zero to twelve months (or one year or less).

Table 2*Length of Nursing Home Stay in Months (N=72)*

Length of Nursing Home Stay (in Months)	Frequency (n)	Percent (%)
0-12	20	27.8
13-24	17	23.6
25-36	3	4.2
37-48	6	8.3
≥ 49	26	36.1

Primary Cause of Death

The primary cause of death listed on residents' death certificate was categorized into one of six categories as outlined in Table 3. The highest percentage of residents, 22.2% (n=16) had a respiratory cause listed as their primary cause of death, followed by old age or natural cause with 20.8% of residents (n=15).

Table 3

Primary Cause of Death Listed on Death Certificate (Grouped by Category) of Residents (N=72)

Primary cause of death	Frequency (n)	Percent (%)
Respiratory cause ^a	16	22.2
Old age/natural cause	15	20.8
Other ^b	14	19.4
Cardiovascular disease ^c	13	18.1
Dementia	9	12.5
Cancer	5	6.9

Note. ^a Respiratory causes includes pneumonia and respiratory failure ^b Other includes bowel obstruction, renal failure, general debilitation and any other cause of death that is not readily categorized ^c Cardiovascular disease includes congestive heart failure, stroke and any cause of death associated with the circulatory system

CPS Scores

As outlined in Table 4, the highest number of residents (n=24), or 33% had a CPS score of 6, which is associated with very severe impairment. The next highest percentage 27.8% (n=20) falls within a CPS score of 3, which is associated with moderate impairment.

Table 4

Cognitive Performance Scale (CPS) Score of Residents (N=72)

CPS Score	Frequency (n)	Percent (%)
0 (Intact)	2	2.8
1 (Borderline intact)	3	4.2
2 (Mild impairment)	13	18.1
3 (Moderate impairment)	20	27.8
4 (Moderately severe impairment)	6	8.3
5 (Severe impairment)	4	5.6
6 (Very severe impairment)	24	33.3

Symptom Experience

The symptom experience of nursing home residents in their last week of life was explored using descriptive quantitative analysis. The prevalence of both physical and psychosocial symptoms will be explored, as well as the frequency in which interventions are applied in those experiencing a symptom and the effectiveness of these interventions will be discussed.

Prevalence of Physical and Psychosocial Symptoms

The prevalence of symptoms among nursing home residents in their last week of life is outlined in order of frequency in Table 5. Dysphagia was the most prevalent symptom that occurred during the last week of life and occurring in 52.8% of residents (n=38). Forty-four percent (n=32) of residents were noted as having pain, followed closely by respiratory conditions

in 43.1% (n=31). As discussed in chapter four, respiratory condition within this study was defined as any sign or symptom (including tachypnea, decreased oxygen saturation, shortness of breath) that prompted an action/intervention to alleviate the respiratory sign or symptom. Of note, in the last week of life among nursing home residents, psychosocial symptoms were infrequently documented. Indeed, the most prevalent psychosocial symptom, agitation and restlessness occurred in only 9.7% (n=7) residents.

Table 5

Prevalence of Physical and Psychosocial Symptoms Among Residents (N=72) in The Last Week of Life

Symptom	Frequency (n)	Percent %
Physical symptoms		
Dysphagia	38	52.8
Pain	32	44.4
Respiratory conditions	31	43.1
Skin breakdown	22	30.6
Congestion	21	29.2
Fever	13	18.1
“For comfort”	12	16.7
Vomiting	9	12.5
Constipation	9	12.5
Cough	7	9.7
Edema	6	8.3
Dry mouth	5	6.9
Diarrhea	5	6.9
Seizures	2	2.8
Nausea	2	2.8
Urinary tract infection	1	1.4
Other physical symptoms		
Twitching	2	2.8
Diaphoresis	1	1.4
Rectal bleeding	1	1.4
Bladder spasms	1	1.4
Psychosocial symptoms		
Agitation/restless	7	9.7
Delirium	3	4.2
Depression	2	2.8
Anxiety	1	1.4

Frequency of Intervention Application

As outlined in Table 6, the majority of residents who had documentation of a symptom occurring in the last week of life received an intervention for the occurring symptom. In a number of symptoms, *all* residents who experienced the symptom including: pain, respiratory condition, skin breakdown, fever, “for comfort”, constipation, dry mouth, nausea, urinary tract infection, diaphoresis, rectal bleeding, bladder spasms, agitation/restlessness, depression and anxiety received an intervention. However, in those who experienced cough (n=7), only 28.5% (n=2) received an intervention.

Table 6*Prevalence of Symptoms and Frequency of Intervention Application*

Symptom	Frequency that experienced symptom (n)	Frequency that experienced symptom and received an intervention (n)	Percent (%) that experienced symptom and received an intervention
Physical symptoms			
Dysphagia	38	35	92.1
Pain	32	32	100
Respiratory conditions	31	31	100
Skin breakdown	22	22	100
Congestion	21	17	81
Fever	13	13	100
“For comfort”	12	12	100
Vomiting	9	6	66.7
Constipation	9	9	100
Cough	7	2	28.5
Edema	6	5	83.3
Dry mouth	5	5	100
Diarrhea	5	2	40
Seizures	2	1	50
Nausea	2	2	100
Urinary tract infection	1	1	100
Other physical symptoms			
Twitching	2	1	50
Diaphoresis	1	1	100
Rectal bleeding	1	1	100
Bladder spasms	1	1	100
Psychosocial symptoms			
Agitation/restless	7	7	100
Delirium	3	1	33.3
Depression	2	2	100
Anxiety	1	1	100

Effectiveness of Intervention

The majority of residents who experienced a symptom and received an intervention either had no documentation of the effectiveness of the intervention (diarrhea, cough, skin breakdown, UTI, depression and delirium) or it was documented as being effective in all those who experienced the symptom and received an intervention (pain, nausea, vomiting, constipation, dry mouth, seizures, for comfort, anxiety and agitation). Only one resident (n=1) who experienced dysphagia and received an intervention had documentation of the effectiveness, and in this case, it was not effective. In those who experienced a received an intervention for a respiratory condition and had documentation of the effectiveness, it was effective in 85.7% (n=6) of residents. Similarly, in congestion 83.3% (n=5) had documentation that the intervention was effective. This was significantly lower in those who experienced edema and 33.3% (n=1) had documentation that the intervention was effective. Finally, for residents experiencing fever and who received an intervention, 80% (n=4) had documentation that the intervention was effective, 20% (n=1) had missing data from the chart audit. That is, the auditor noted there was documentation of the effectiveness, but it was not clear whether it was effective or not and therefore, it was coded as missing.

Symptom Experience and CPS Score

As demonstrated in Table 7, there was no statistical significance between CPS score and symptom prevalence with statistical significance (p-value) set at 0.05. Notably, pain approached significance [p-value = 0.051], however was still slightly greater than 0.05.

Table 7*Prevalence of Symptoms by CPS Score*

Symptom	Residents with CPS ≤ 3 that experienced symptom (n)	Residents with CPS ≥ 4 that experienced symptom (n)	χ^2 (where applicable)	p-value
Physical symptoms				
Pain	21	11	3.82	0.051
Nausea	1	1		1.0
Vomiting	4	5		0.727
Constipation	5	4		1.0
Diarrhea	3	2		1.0
Dysphagia	18	20	0.95	0.331
Respiratory conditions	17	14	0.93	0.761
Congestion	13	8	0.99	0.320
Cough	5	2		0.435
Dry mouth	4	1		0.361
Fever	6	7	0.28	0.597
Skin breakdown	10	12	0.68	0.409
Urinary tract infection	1	0		1.00
Edema	4	2		0.677
Seizures	0	2		0.219
“For comfort”	6	6	0.45	0.833
Psychosocial symptoms				
Depression	2	0		0.495
Anxiety	1	0		1.00
Agitation/restless	6	1		0.111
Delirium	3	0		0.242

Note. Fisher’s exact test was utilized when cells had an expected count less than 5.

Overarching Descriptive Data Themes

In addition to the statistical tests utilized to address the research questions, further findings were derived from both the quantitative data, as well as the narrative data from the chart audit. Two overarching themes of assessments and interventions at the end-of-life will be further explored below.

Assessments

While examining the chart audits, objective signs (that is, vital signs) were noted to be assessed and subsequently documented. For instance, temperature was documented in 13.9% of residents (n=10), with a range of temperatures from 37.3 degrees Celsius to 38.8 degrees Celsius. Oxygen saturation was documented in 5.6% (n=4) of residents, although the use of oxygen was implemented in a greater number of residents. That is, 37.5% (n=27) had documentation of the use of oxygen, ranging from 1.5 liters to 5 liters of oxygen. Pain was infrequently assessed utilizing a formal assessment tool. Only 6.9% (n=5) of residents had evidence of a formal pain assessment, often the use of a flow sheet utilized within the nursing home (and still, not a formal pain assessment tool). Of note, neither the PAINAD tool nor the faces scale were used to formally assess pain. Further discussion of various interventions utilized, including route of administration, will be further discussed within the next overarching theme that emerged from the narrative data.

Interventions

As mentioned above, many residents within this sample (n=27) received oxygen in their last week of life. For those who experienced congestion (n=21), 71.4% (n=15) were administered an anticholinergic medication (Scopolamine), either subcutaneously or via transdermal patch (n=2). Additionally, 47.7% (n=10) were suctioned. Many residents, 90.3% (n=67) had

medication changes within the last week of life. Interestingly, at times, the rectal or intramuscular route of administration was either ordered and/or administered. For instance, anti-emetics and benzodiazepines were ordered intramuscularly. Both analgesics and anti-emetics were also ordered and administered rectally. However, for those residents who received a pharmacological intervention for both pain and “for comfort”, the subcutaneous route was predominantly utilized. The routes of administration utilized for those residents who experienced pain, “for comfort” and fever and received a pharmacological intervention are provided in Table 8.

Table 8

Route of Administration for Residents Whom Experienced Pain (n=32), “For Comfort” (n=12) or Fever (n=13) and Received a Pharmacological Intervention

Symptom and Route of Administration	Frequency (n)	Percent %
Pain		
Subcutaneous	24	75
Oral	3	9.4
Rectal	1	3.1
Missing	4	12.5
“For comfort”		
Subcutaneous	8	66.7
Rectal	4	33.3
Fever		
Rectal	11	84.6
Missing	2	15.4

Conclusion

The findings of this secondary data analysis provided quantitative data regarding the symptom experience of nursing home residents at the end-of-life and addressed the research

questions. Further results were derived from the narrative information retrieved during the chart audit. This includes the assessment of residents during their last week of life, as well as the route and type of administration aimed at ameliorating symptoms. The findings of this study will further be explored in the discussion in the following chapter.

Chapter Six: Discussion

Introduction

In this chapter, findings of the study will be further discussed including a discussion of the overall symptom experience among nursing home residents in the last week of life. These findings will be discussed in relation to pertinent literature and tie into the discussion of the literature review provided in chapter two. Furthermore, implications for practice, education and research will be explored. Finally, limitations of the study will be provided.

Resident Characteristics

Prior to delving into the symptom experience of residents of nursing homes, it is vital to describe resident characteristics of the sample. As outlined in chapter three, the chosen conceptual framework indicates that history of the resident impacts end-of-life (Stewart et al., 1999). Thus, the gender, age, length of stay, primary cause of death and level of cognitive impairment are important considerations when examining the symptom experience at the end-of-life. The resident characteristics will be compared to a recent study by Estabrooks et al. (2013), who as discussed in chapter four, examined resident profiles of prairie provinces, including Manitoba, the location of this research thesis.

The majority of the sample was female (70.8%), which is similar to findings by Estabrooks et al. (2013) who found that 78% of Manitoba nursing home residents were female. This high proportion of female residents found within this sample is unsurprising as females in both Canada and Manitoba have a greater life expectancy than males. That is, the life expectancy of a female in Manitoba was reported to be 82 years old, compared to 77 years old for males (Statistics Canada, 2012). Consequently, females are living longer and most likely have one or more disease processes, such as dementia, that requires care in nursing homes.

The average age of residents within this sample was 86.2, with a range from 53 years old to 104 years old. Likewise, Estabrooks et al. (2013) found Manitoba nursing home residents to have an average age of 86.9 years of age. An overwhelming majority of residents within this sample, 80.85% (n=58), were over the age of 80. More specifically, 40.3% of the sample (n=29) was between the ages of 90-99. As mentioned previously, seniors often have at least one chronic disease (CIHI, 2011) that may carry a number of different symptoms and the disease and symptom burden may increase with age.

The average length of stay (in months) was 40.3, with a range between only one month and 145 months. Evidently, nursing home residents are often living (and dying) in nursing homes for an extended period of time, thus allowing close ties to form with staff and physicians, as well as between residents' families and staff and physicians. In contrast, Estabrooks et al. (2013) found the average length of stay for Manitoba nursing home residents to be less, 645 days (or nearly 21.6 months). This may be due to the time period in which the data was captured, as the resident may have still been living when the data was captured and therefore, would not have had as long as stay as the residents within this sample who were deceased. In any case, residents often receive care for an extended period of time in nursing homes, in comparison to those living and dying in an acute care facility for instance.

Although respiratory causes were the principal cause of death, among 22.2% (n=16) of residents, old age and/or natural causes (n=15), other causes (n=14) and cardiovascular disease (n=13) followed closely and sequentially behind. Interestingly, although many residents within this sample had some form of cognitive impairment, only 12.5% (n=9), had dementia listed as their primary cause of death, which may be due to a number of factors. Firstly, individuals who have a diagnosis of dementia die from complications from this disease (such as pneumonia), and

therefore, their primary cause of death may have been listed under respiratory causes. Secondly, old age and/or natural causes may constitute a myriad of conditions, including dementia. Finally, although the majority of residents had some form of cognitive impairment, they may not have had a diagnosis of dementia, as the CPS score does not discern the cause of cognitive impairment.

Briefly, there was no stand out primary cause of death and each of these causes of death are associated with possibly distressing symptoms and therefore it is important for nursing home staff and physicians to be aware of both pain and non-pain symptoms. For example, as mentioned in chapter two, Kaasalainen, Strachen et al. (2013) report that residents with heart failure are more likely to experience dyspnea and that family members reported staff need to be equipped to recognize symptoms among residents with heart failure. Symptom assessment, which both needs to be astute and may be difficult in those with cognitive impairment and/or at the end-of-life, will be discussed further in this chapter.

Certainly, only two residents (or 2.8%) had a CPS score of zero, which is associated with being cognitively intact. Those with moderately severe impairment to very severe impairment (CPS score ranging from four to six) comprised nearly half of the sample (47.2%), which again, is greater than the findings of Estabrooks et al. (2013) who found 36.4% of residents in Manitoba had a CPS score of four or greater. Again, this may be attributed to the point in time in which the data was collected (that is not near the end-of-life). Irrespective of this, it is clear that many residents within this sample had some form of cognitive impairment and many had at least moderate cognitive impairment.

In sum, the majority of this sample consisted of females, had an increased age, a lengthy stay in the nursing home and some form of cognitive impairment. The experience of symptoms

within this sample will be discussing, including symptom assessment, prevalence of symptoms and management of these symptoms.

Symptom Experience

Prior to discussing the prevalence of symptoms, including the examination between symptom prevalence and cognitive impairment level, and management of these symptoms, it is important to discuss symptom assessment information gleaned from this chart audit. As discussed in review of the literature, symptom assessment in individuals with cognitive impairment is challenging and perhaps, even more so at the end-of-life (as the resident may become less responsive).

Symptom Assessment

During analysis of the chart audits, it was noted that vital signs were assessed and then documented. Temperature was assessed in at least 13.9% (n=10) of the residents and the temperatures ranged from 37.3 degrees Celsius to 38.8 degrees Celsius. Although fever may be thought to be an objective sign, a temperature of 38 degrees Celsius or higher (Cleary, 2009), Thompson (2005) asserts in a concept analysis of fever, that “there is no universal temperature at which fever is defined” (p. 489) and treatment should be considered if the fever causes discomfort to an individual. Furthermore, older adults may have a blunted fever response to infection (Norman, 2000).

In addition to temperature assessment, oxygen saturation was assessed in at least 5.6% (n=4) of residents, although the use of oxygen was much higher in 37.5% (n=27). This suggests that either the oxygen saturation was not recorded during the chart audit, or that, oxygen saturation was not assessed among residents, despite the use of oxygen. Again, the use of oxygen as a management for respiratory conditions will be further discussed in this chapter.

There is evidence within this chart audit that either some or all vital signs are being performed at times. In a study examining vital signs during the last days of life among cancer patients (N=357), Bruera et al. (2014) found that both oxygen saturation and blood pressure dropped during the final three days of life. Furthermore, temperature increased during this time period. This demonstrates that it is not uncommon for changes to occur in vital signs when death is near. These authors assert that while both healthcare professionals and families often pay close attention to vital signs and may depend on these objective signs as an indicator that death is near, they do not recommend routine assessment of vital signs near the end-of-life (Bruera et al., 2014). This recommendation is based on their suggestion that vital signs are not necessarily an accurate indicator that death is approaching and furthermore, may be disturbing to both the patient and their family (Bruera et al., 2014). One must critically appraise the intent behind assessing vital signs in a dying resident and ask the question of whether it is appropriate or not to be doing so in those imminently dying.

Finally, although pain is considered the fifth vital sign (Morone & Weiner, 2013; Purser et al., 2014), there was limited evidence that formal pain assessment tools were utilized. Only 6.9% of residents (n=5) had evidence of some formal pain assessment and this was often the flow sheet utilized within the nurse home. There was some descriptive data on behavioral signs of pain (such as calling out, grimacing, etc.), which may be a component of a formal pain assessment tool (for example, the PAINAD tool (Warden, Hurley & Volicier, 2003) or faces scale). However, no consistent formal assessment was utilized in the charts reviewed for this study, and as Burns and McIlfatrick (2015) indicate, standardizing assessments of pain in individuals with dementia is a vital part to managing this symptom. Further to pain, there was no indication that another assessment tool was utilized to examine other non-pain symptoms, such

as dyspnea. However, no standardized assessment tool could be found within the literature specific to assessing for symptoms in the last week of life. As discussed in chapter two, most symptoms are considered subjective and therefore many tools, such as the Edmonton Symptom Assessment Scale (Bruera, Kuehn, Miller, Selmsler & Macmillan, 1991), utilized to examine the symptom experience in palliative care (and at the end-of-life) rely on an individual's ability to self-report the symptom(s) they are experiencing (if any).

Symptom Prevalence

The three most prevalent symptoms were dysphagia, pain and respiratory conditions. Dysphagia was found to be the most prevalent symptom in the last week of life and was prevalent among 52.8% (n=38) of residents. This is unsurprising, as there was both a high level of cognitive impairment and additionally, the swallowing reflex naturally decreases as the end-of-life approaches. Vandervoort et al. (2013) found a higher prevalence of dysphagia (67%) during the last week of life, however, this study focused on residents solely with dementia, which may have resulted in a higher prevalence. Similarly, "feeding problems" were found to be prevalent among 70% residents with dementia in their last week of life (Koppitz et al., 2015).

Pain was found to be prevalent among 44.4% (n=32) of residents in this research thesis, which is lower prevalence than found in other recent studies. A higher prevalence of pain was found during the last week of life in two recent studies, pain was present among nearly 80% of residents (Koppitz et al., 2015) and 52% of residents (Hendriks et al., 2014), each sample consisted of those solely with dementia. This may be a result of not using a standardized pain assessment tool or that pain was not documented as such, but rather management "for comfort."

The third most prevalent symptom was respiratory conditions, which was prevalent in 43.1% (n=31) residents. The mere definition of respiratory condition (that is extended beyond

dyspnea) within this study makes it difficult to compare to findings from similar studies examining symptoms among nursing home residents (either during the last week of life or beyond this time frame). Although, Koppitz et al. (2015) included objective signs (use of accessory muscles, cyanosis) in their definition of “breathing abnormalities” and subsequently found this symptom to be prevalent in 50% of residents with dementia in the last week of life. Hendriks et al. (2014) found that shortness of breath was prevalent in 35% of residents with dementia during their last week of life. This lower rate of shortness of breath may be attributed to the previously mentioned challenges in comparing the findings of this research thesis to other recent studies. Additionally, the most prevalent primary cause of death was a respiratory cause (such as pneumonia) and many residents also had a cardiovascular disease listed as their primary cause of death. Therefore, respiratory symptoms would most likely be associated with either of these causes of death.

Psychosocial symptoms were found to be minimally prevalent within this study. Agitation and/or restlessness was the most prevalent psychosocial symptom, among only 9.7% (n=7). Hendriks et al. (2014) found agitation to be one of the most prevalent symptoms, although they found a higher prevalence, in 35% of residents with dementia in the last week of life. Delirium was found to be prevalent in 4.2% (n=3) and the author could find no recent studies examining delirium during the last week of life among nursing home residents. Depression was found to be present among 2.8% (n=2) of residents in this research thesis. This low prevalence of depression was also found by Koppitz et al. (2015), who found that depression decreased towards the end of life and only 2% of residents in their study had depressive episodes during the last week of life. Anxiety was found to be prevalent among 1.4% of residents (n=1), which is different than the findings of Koppitz et al. (2015) who found that anxiety increased near the

end-of-life and was prevalent among 24% of residents during their last week. Evidently, there are varying rates of psychosocial symptoms, but generally, as found in this research thesis, there is a low prevalence of these symptoms. This low prevalence may be attributed to the notion that these symptoms decrease as the end-of-life approaches or perhaps these symptoms are not being assessed towards the end-of-life. In their study examining documentation in residents with dementia at the end-of-life, Høgsnes, Danielson, Norbergh and Melin-Johansson (2016) state “that a great extent of documentation of end-of-life care is related to physical symptoms and that there is basically none about the residents’ existential issues” (p. 1671), which is similar to the findings of this research thesis.

Symptom Prevalence and Cognitive Impairment Level

With statistical significance set at a p-value of 0.05, no symptoms (whether pain or non-pain) were found to have a statistically significant relationship with cognitive impairment. Worth mentioning, when examining pain and cognitive impairment level, the p-value approached 0.05 (0.051), however, was not rounded down and therefore, considered not statistically significant. Although not statistically significant, notably, residents with a CPS score of 3 or lower comprised 65.6% (n=21) of residents who experienced pain, compared to 34.4% (n=11) of residents with a CPS score of 4 or greater. This difference may be attributed to the lack of using a standardized pain assessment tool at the end-of-life and those with more severe cognitive impairment have greater difficulty in vocalizing their pain. This poses challenges in the assessment of pain, a highly subjective symptom. Interestingly, Hendriks et al. (2014) also found that pain was not significantly different between those with advanced dementia compared to those with less advanced dementia in the last week of life, although their definition of cognitive impairment differed from this research thesis and moreover, their sample was comprised of

individuals only with dementia. Whether physical or psychosocial symptoms, or across different levels of cognitive impairment, it is important to examine the management of existing symptoms when further discussing the symptom experience.

Symptom Management

In discussion of management of symptoms, the frequencies to which interventions were applied for symptoms will be provided. Furthermore, discussion of findings from the narrative data will be discussed, including routes of administration utilized, the use of suctioning and oxygen in relation to current literature on these types of interventions. Finally, the effectiveness of interventions will be examined, along with the documentation practices.

Frequency of Interventions

In the majority of symptoms, *all* individuals who experienced the symptom received an intervention. That is, every time a symptom occurred, an intervention was applied as well. This includes: pain, respiratory conditions, skin breakdown, fever, “for comfort”, constipation, dry mouth, nausea, urinary tract infection, diaphoresis, rectal bleeding, bladder spasms, agitation and/or restlessness, depression and anxiety. This is unsurprising as this demonstrates the nursing process, specifically; a healthcare professional assessed a symptom, provided an intervention and subsequently documented these actions. However, this does not hold true for all symptoms documented. For instance, in those residents experiencing cough (n=7), only 28.5% (n=2) received an intervention. No recent literature could be found examining the application of an intervention for cough during the last week of life and therefore, these results could not be compared to other studies. It is important to note that this chart audit does not discern the severity of the symptom (whether the cough was severe, persistent or self-limiting) and thus, it is difficult to distinguish if the cough appropriately warranted intervention. The majority of

residents experiencing congestion (n=21) received an intervention (n=17), while 19% of those experiencing this symptom did not receive an intervention. In a similar study by Hall et al. (2002), 49% of residents who experienced noisy breathing did not receive treatment. The results of this research thesis in comparison to Hall et al. (2002) suggests that improvement has been made regarding frequency of intervening in those experiencing respiratory congestion. As previously discussed, the individual experiencing respiratory congestion is likely to be unbothered by this symptom due to their level of consciousness (Hipp & Litiza, 2009; Lokker et al., 2014), however, family members may be distressed by this symptom (Shimizu et al., 2014), therefore, any resident experiencing this symptom should receive an intervention, whether pharmacological or otherwise. Education provided to family regarding respiratory congestion is an important role of the nurse in helping to alleviate any distress the family may be experiencing due to the noisy breathing.

Further symptoms that were present and did not receive an intervention were minimally prevalent among nursing home residents during the last week of life. For example, 50% of those experiencing seizures received an intervention, however, only two residents experienced this symptom. Although, one could argue even one symptom left untreated in one resident warrants further examination, there are an abundance of symptoms examined in this study and many symptoms that could occur at the end-of-life. Therefore, for feasibility, more prevalent symptoms may warrant more focus. While the majority of symptoms experienced received an intervention for all individuals, there were important differences noted in the interventions themselves (that is, the management). These include the routes of administration used and the use of suctioning and oxygen during the last week of life.

Routes of Administration

The majority of residents, 90.3% (n=67), had medication changes in the last week of life. This is unsurprising as not only do care needs change during the last week of life, but the ability to safely swallow oral medications is often lost. Therefore, alternate routes of medication may be considered and in discussing the management of pain, “for comfort” and fever it is important to consider the routes of administration, which was one common theme that emerged when reviewing the narrative data. In the management of pain, when a pharmacological intervention was utilized, the subcutaneous route of administration was predominantly used. More specifically, 75% (n=24) of residents who experienced pain received a pharmacological intervention subcutaneously, 9.4% (n=3) received a pharmacological intervention through the oral route of administration and finally, one resident (or 3.1%) received an intervention via a suppository. In those receiving a pharmacological intervention “for comfort”, 66.7% (n=8) received an intervention through the subcutaneous route of administration, in comparison with 33.3% (n=4) via a suppository.

The use of suppositories to treat fever was even higher in those experiencing fever, 84.6% (n=11) received an intervention via a suppository. This is unsurprising as one treatment modality is the use of acetaminophen and when the oral route of administration is lost, this medication may be administered via a suppository. However, although temperature often increases towards the end-of-life (Bruera et al., 2014), those who experience fever are not necessarily bothered by this symptom (Bobb, Lyckholm & Coyne, 2009). Therefore, the risks versus benefits of treating fever in the final days of life should be considered (Larkin, 2010) and the use of suppositories may not only be uncomfortable (Harlos, 2010), but there is also a risk of decreased dignity. Furthermore, non-pharmacological and less invasive interventions are

available in the management of fever (Bobb et al., 2009). Previous literature regarding the assessment of temperature and management of fever highlights both an area for future research and education, which will be further discussed in this chapter. The author could find no recent literature examining the management of fever near the end-of-life in nursing homes to compare the findings of this research thesis.

Further to routes of administration noted in the treatment of pain, “for comfort” and fever, it was noted that the rectal route was also ordered and/or administered, as well as the intramuscular route of administration in the management of other symptoms. For instance, both analgesic and anti-emetics were ordered and administered via suppositories. As well, anti-emetics and benzodiazepines were ordered intramuscularly. While the oral route of administration is ideal, if this route is lost, then the subcutaneous route is preferred (Alberta Health Services, 2013), which was the route predominantly found to be used within this study. In contrast, the intramuscular route of administration is not only painful, but there is variable absorption (Alberta Health Services, 2013). While the rectal route of administration has benefits, including decreased cost and effectiveness, it is not appropriate for everyone (Alberta Health Services, 2013) and furthermore, there is a chance of discomfort and (Harlos, 2010). De Witt Jansen et al. (2017) found in their qualitative study examining nurses’ (N=24) experiences with management of pain among individuals with dementia that they preferred the use of suppositories as it was thought to cause less discomfort than through a subcutaneous injection. In contrast, Górlén, Górlén and Neergaard (2013) found that among frontline staff (N=16) those who had experience with using an indwelling subcutaneous catheter preferred this route of administration. These studies coupled with the findings from this research thesis suggest that

further education may be needed regarding the optimal route of administration when the oral route is lost.

Suctioning

Although the majority of those experiencing respiratory congestion and received an intervention were administered an anticholinergic medication 71.4% (n=15) (either through a subcutaneous line or patch), 47.7% (n=10) either received suctioning additionally or on its own. Despite the use of an anticholinergic, which has been found to be effective in decreasing respiratory congestion and is thought to be the recommended class of medication in attempting to alleviate respiratory congestion (Wildiers et al., 2009), there were a large proportion of residents experiencing respiratory congestion who were suctioned. This highlights an area for further education, as suctioning is not often recommended in attempting to alleviate congestion at the end-of-life and may inadvertently cause greater discomfort (Henderson & McIntyre, 2012). Notably, while Wee and Hillier (2008) acknowledge the commonality of using anticholinergics near the end-of-life, they attest that these medications are no more effective than a placebo. Wee et al. (2006) suggest that educating families regarding respiratory congestion is paramount in alleviating possible concerns they may have regarding the disturbing noise. Furthermore, Miller, Lima and Thompson (2015) assert that nursing homes with a greater level of palliative care knowledge are associated with lower rates of suctioning, thus again highlighting the need for further education. Implications for education will be further discussed within this chapter.

Use of Oxygen

Oxygen was used in 37.5% (n=27) of residents at the end-of-life. Only one recent study examined the use of oxygen during the last week of life (in residents solely with dementia) and oxygen was used in 74% of those experiencing dyspnea (Hendriks et al., 2014). The use of

oxygen was not examined in the total sample and therefore, it is difficult to compare the results from Hendriks et al. (2014) to the findings from this research thesis. The reason for use of oxygen at the end-of-life remains unclear and is an area for further research (Quinn-Lee et al., 2012), although Abernathy et al. (2010) suggest that oxygen is often delivered out of compassion. The use of oxygen and other treatment modalities for dyspnea varies from person to person. Based on their findings from their study examining the efficacy of oxygen in alleviating respiratory distress, Campbell et al. (2013) suggest that the routine use of oxygen at the end-of-life is not warranted. Similarly, Abernathy et al. (2010) studied the effectiveness of oxygen and room air in alleviating dyspnea among 239 individuals from outpatient clinics and found that oxygen does not provide additional symptomatic benefit in comparison to room air. The above-mentioned studies imply that critical thinking regarding the intent of oxygen in those with impending death is needed, which extends beyond the results of this study. That is, this study does not distinguish the specific circumstances under which oxygen was utilized, however, the findings of this research these do implicate that both further education and research is needed regarding the use of oxygen at the end-of-life. Again, these implications will be discussed further in this chapter.

Effectiveness of Interventions

Notably, the individuals who collected the data from the charts noted there was a lack of consistency regarding effectiveness of interventions. That is, at times when an intervention was applied there was documentation that the intervention was effective and other times there was no documentation. For the purposes of this research thesis if there was any documentation of that an intervention was effective it was considered as such. However, it is important to note that effectiveness of an intervention was not consistently documented. Assessing for the effectiveness

of an intervention is an important part of the nursing process in general, as is subsequently documenting the effectiveness. Arguably, documenting the effectiveness near the end-of-life holds even more weight, as many “as needed” medications may be used. This communicates to other healthcare professionals whether an intervention was effective and if not, changes to the intervention may need to occur in order to ensure the resident is comfortable.

There were a number of symptoms in which an intervention was applied, however, no effect of this intervention was documented. These include: diarrhea, cough, skin breakdown, UTI, depression and delirium. This may be a result of effects not being seen during the last week of life. For instance, skin breakdown may not have remedied during this time frame. Conversely, there were a number of residents that had documentation of effectiveness including: pain, nausea, vomiting, constipation, dry mouth, seizures, for comfort, anxiety and agitation. Only one resident who had dysphagia had documentation of the effectiveness of the intervention and in this case, it was not effective. In those who experienced a respiratory condition and received an intervention, it was documented effective among 85.7% (n=6) of residents, comparable to respiratory congestion, in 83.3% (n=5). However, this was significantly lower in those who experienced edema, as only 33.3% (n=1) had documentation that the intervention was effective, although this is unsurprising as the causes of edema near the end-of-life are multi-factorial and this symptom is not uncommon (Alberta Health Services, 2013). The results of this research thesis and discussion of these findings have implications for nursing practice, education and research in the context of nursing homes.

Implications for Practice

The use of standardized pain assessment in the context of nursing homes should be implemented, which may prove particularly useful in assessing pain at the end-of-life. Utilizing a

formal pain assessment tool is the recommended approach to assessing pain in individuals with cognitive impairment (Burns & Mcilpatrick, 2015). Certainly, nurses have described the challenging nature of pain assessment in residents with dementia (Monroe, Parish & Mion, 2015) and using a multi-faceted approach, including a standardized assessment tool may help overcome the difficulty in pain assessment among those with cognitive impairment (Herr et al., 2011).

As discussed previously, there was inconsistency in the documentation of effectiveness of interventions. This suggests that although standardized documentation policies may already be in place in nursing homes, healthcare professionals may not adhere to such policy. For instance, the documentation of “for comfort” is ambiguous and therefore, both education and policy may provide guidance on documenting specific assessment information, as well as efficacy of interventions. Certainly, one must have astute assessment skills in order to do so, which will further be discussed in implications for education.

Implications for Education

As dysphagia, pain and respiratory conditions were the three most prevalent physical symptoms, education for frontline staff targeting these symptoms may be warranted. As studies have suggested, workload issues (Cable-Williams & Wilson, 2016) and time constraints (De Witt Jansen et al., 2017) are barriers in providing continuing palliative care education within the context of nursing homes and thus, focusing on the most prevalent symptoms first may be more feasible. Assessing for and managing each of these symptoms has their own challenges, in addition to communication with families, and therefore, increasing nursing home staff knowledge may help improve the symptom experience at the end-of-life.

As indicated by the findings from this chart audit, vital signs were assessed as the resident neared the end-of-life, despite current research suggesting that the routine assessment of

vital signs is not recommended in those for whom death is expected and imminent (Bruera et al., 2014). Nurses may have increased confidence utilizing objective clinical signs as part of their assessments, as numbers are concrete. However, further education may be provided to nurses on appropriate assessments of residents near the end-of-life, including both symptom assessment and signs that the end-of-life is approaching.

The findings of this study indicate that that the subcutaneous route was often utilized to administer medications, however, the intramuscular and rectal route of administration was also ordered and/or implemented. These routes of administration were prescribed and/or implemented despite current practice indicating that the subcutaneous route of administration is preferred once the oral route is no longer safe to use (Alberta Health Services, 2013). Therefore, further education may also be provided to both nurses and prescribers upon the best routes of administration once the oral route is lost due to the inability to swallow. As indicated by (Gorlén et al., 2013), nurses who have experience with indwelling subcutaneous lines are more likely to utilize them, implying that there may be a knowledge gap for some healthcare professionals working in nursing homes. Finally, education regarding the management of both fever and the use of oxygen at the end-of-life and suctioning in the management of respiratory congestion is warranted.

Implications for Research

Recommendations for the ACE Tool

As the original study namely focused on the creation of the ACE tool itself, this is the first study using and analyzing data generated from the tool and subsequently, recommendations for future use of this chart audit tool were derived. These recommendations concern the demographic and symptom management components of the ACE tool, as well as training for

future chart auditors. More specifically, the CPS score provides an indication of the level of cognitive impairment, an important factor impacting residents near the end-of-life in nursing homes. The CPS score was not a part of the original tool and therefore, should be added to the tool itself. The symptom component of the ACE tool was the section that the chart auditors found most difficult to use (G. Thompson, personal communication, November 2, 2015) and this research thesis brought forward some areas in which this component of the tool may be refined. For instance, providing clear, specific definitions of study variables, such as done by Koppitz et al. (2015) may help to increase inter-rater reliability. As further discussed in this chapter, one of the limitations of this research thesis is that some of the variables had an inter-rater reliability less than 80%. For example, fever had an inter-rater reliability of 61%. This may be attributed to the notion that an intervention was applied for a temperature as low as 37.3 degrees Celsius, which may not be considered a fever. The definition of fever for the ACE tool may be: an increase in temperature that is distressing to the resident, or a symptom in which an intervention was applied to reduce the resident's temperature. Another suggestion would be to extract narrative data in the description of the symptom, the intervention to alleviate the symptom and the effectiveness of the intervention, as the narrative data provided a richer data set and also eased in the coding of the data. Using the ACE tool to collect future data may be obtained with greater ease from those with clinical palliative care experience.

Recommendations for Future Research

While this research thesis yielded data regarding the symptom experience, gaps in the knowledge persist and based on this study, as well as previous research, suggestions for future research include exploration of nurses' experiences with assessing and managing symptoms during the last week of life in nursing homes, additional factors that impact the symptom

experience, as well as implementation of an education program for healthcare professionals providing end-of-life care in nursing homes. More specifically, future research could explore nurses' perceptions on the assessment and management of symptoms at the end-of-life. For instance, exploring whether there are there certain factors (such as family input or severity of symptom) that impact their assessments and management of symptoms. As this study examined one key factor (cognitive impairment) that may impact the symptom experience, it may be also be beneficial to examine other factors that impact the symptom experience. For example, examining the impact that advanced practice nurses have on the symptom experience during the last week of life (as discussed in chapter two) or other factors as outlined in the conceptual framework (as discussed in chapter three). Additionally, as there is now baseline data derived from the use of the ACE tool, future research could examine the implementation of an education intervention and compare the results pre-intervention (such as using the data from this research thesis) with results post-intervention. A study by Finucane, Stevenson, Moyes, Oxenham and Murray (2013) indicated that such nursing education interventions have improved end-of-life care in nursing homes, however, future studies could examine the effects specific to symptom assessment and management at the end-of-life.

Limitations

Despite the important findings of this research thesis and the implications for practice, education and research, there are limitations that must be discussed. Briefly, these limitations include the sample size, limitations of the ACE tool itself, limitations of chart audits and important data that impacts end-of-life care in nursing homes, yet was not a part of this research thesis.

The sample size of this chart audit may be viewed as a study limitation. A similar study examining the symptom experience during the last seven days of life among hospice patients utilized a sample size of N=100 (Hermann & Looney, 2001), while this research thesis had a sample size of N=72. A post-hoc power analysis was completed for guidance on sample size for future studies using the ACE tool. Using a power set at 80% and alpha at 0.5 with a medium effect size, a sample size of N=154 is recommended if using the ACE tool with a similar research purpose and research questions (R. Rabbani, personal communication, June 15, 2017). While these findings are important for nursing, it is key to remember the possible limits regarding the generalizability of the results to the greater nursing home population. Additionally, this sample included residents wherein death was foreseeable, which may provide different results than if the sample included residents where death was not expected. Future research using the ACE tool is needed to increase the generalizability to the greater population.

As discussed in chapter four, using a chart audit to examine the symptom experience at the end-of-life in nursing homes is useful in overcoming some of the challenges of research within this context. However, there are limitations to this approach as well. The foundation of a chart audit is set on the notion that healthcare professionals appropriately documented their assessment, intervention and effectiveness of the intervention. However, as also discussed in chapter four, Jeffries et al. (2010) found in their meta-study of nursing documentation that charting is often inconsistent. Therefore, this research thesis may not have captured the full symptom experience of nursing home residents during the last week of life. Added to this limitation is the challenge of accurately retrieving and coding data from the charts themselves. Inter-rater reliability was calculated using percentage agreement, however, some of the symptoms held a percentage agreement less than 80%. These symptoms include: pain (71%),

cough (77%), dry mouth (61%), skin breakdown (72%), other physical symptom issues (72%), delirium (77%) and other psychosocial symptoms (72%). While this was a limitation to this research thesis, recommendations to strengthen the use of the ACE tool were provided.

This study examined the symptom experience at the end-of-life in nursing, with a focus on symptoms and while this research thesis examined possible relationships between cognitive impairment and the symptom experience, this study did not examine other key components to end-of-life care within this setting. This includes the impact of advanced practice nurses as discussed in chapter two, review of the literature and key factors outlined in the chosen conceptual framework (such as communication with family), as discussed in chapter three. Rather, these factors were provided and discussed to help frame factors that impact the symptom experience within the context of nursing homes. Furthermore, this study did not examine the experience of family members (although previous studies have done so) and it does not encapsulate both the passion that many staff have in providing end-of-life care in the context of nursing homes, nor the bonds formed between staff and residents and their families.

Conclusion

Canadians deserve a good death, and in that aim, quality end-of-life care requires astute symptom assessment and management. This study added to a growing body of knowledge regarding the symptom experience at the end-of-life in nursing home residents and previously there was limited research regarding the symptom experience specifically during the last week of life. This study found dysphagia, pain and respiratory conditions to be the three most prevalent physical symptoms. Psychosocial symptoms were found to be minimally present during the last week of life in nursing homes. Furthermore, this study highlighted areas for improvement in nursing practice, including the implementation of standardized assessment tools and

documentation. Evidently, further ongoing education regarding the assessment of individuals near the end-of-life, as well as management of distressing symptoms is needed. Finally, future research is needed examining the experience of healthcare professionals in providing care and more specifically, assessing and managing symptoms during the last week of life.

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Appendix A: Auditing Care at the End-of-Life (ACE) Tool

Auditing Care at the End of Life (ACE) Tool



Resident Code #: _____ Facility Code: _____

Nursing Home (NH) Chronic Care

Audit Date: ____/____/____
 dd / mm / yy

Auditor Name/Classification: _____

Section 1. Demographics

1. Date of Birth: ____/____/____
 dd / mm / yy

4. NH Admission Date: ____/____/____
 dd / mm / yy

2. Date of Death: ____/____/____
 dd / mm / yy

5. Length of NH Stay (in months): _____

3. Gender: Male Female

Section 2. Situation Around Death

6. Indication on health record that death was expected? No Yes
(If not expected, select an alternate chart to audit)

7. RAI Outcome CHESS Score (from last MDS assessment): _____

Date of last assessment: ____/____/____
 dd / mm / yy

8. Primary Cause of Death listed on death certificate: _____

Cause of Death unknown

9. Place of Death: NH Chronic Care Acute Care Palliative Care Unit

10. Was the Resident transferred to acute care (emergency or for admission) in the last month of life?

No (skip to question 11) Yes (complete table below)

Date of Transfer	Reason for transfer	Away from facility longer than 24 hrs?	Was ACP level changed during hospitalization?

Note. Used with permission from Dr. Genevieve Thompson

Section 3. Clear Decision-Making

11. Was there a Health Care Directive? No Yes

Describe Instructions:

12. Was there an Advance Care Plan (ACP)?

No (skip to question 15) Yes

Goal of Care chosen: Medical Care and Interventions including Resuscitation
 Medical Care and Interventions excluding Resuscitation
 Medical Care and Interventions focus on Comfort
 ACP not up-dated in past year
 ACP not completed/missing
 Other

13. Date of last ACP review: ___ / ___ / ___
dd mm yy

14. Any changes to the ACP made at last review: No Yes

If yes, what and why:

Section 4. Preparation for Death

15. Is there evidence in the progress notes that staff recognized changes in the Resident's condition that acknowledged that end of life was near?

No Yes

Describe: (for e.g. initiation of EOL care plan, documentation of EOL consults, team meeting)

16. Were there changes or adjustments made to the Resident's physician/NP orders in the last month of life?

No Yes

Describe: (for e.g. medications discontinued, medications added, accu-checks discontinued, diet changes, tube feeds, hydration)

17. Were there any medication changes made in the last week of life?

No Yes

Describe:

18. Is there evidence in the progress notes of communication with family members or friends about EOL care?

No Yes

Describe:

19. Is there evidence that psychosocial support was provided to family members or friends during the dying experience?

No Yes

Describe the involvement: (e.g., stayed overnight, food/beverages provided, comfort care basket, books)

Section 5. Spiritual Health and Cultural Aspects of Care

20. Resident's spiritual health preferences documented: No Yes

21. Evidence of Resident's or family wishes regarding rites and rituals, or spiritual considerations acted upon (e.g., minister/pastor called, last rites administered): No Yes

Section 6. Symptoms and Symptom Management through the Death

22. Is there evidence that Pain was assessed? No Yes

If yes, what tool as used:

a. WRHA NH Pain Assessment Tool FACES SCALE PAINAD

b. Other: _____

23. Is there evidence that the WRHA NH Pain Monitoring Tool was used? No Yes

24. In the table below, indicate the presence of physical & psychological symptoms, and the care provided to the Resident that is documented **at a minimum, in the last week of life**. If you answer **YES** to any question below, indicate how symptoms managed/care provided and whether management/care effective.

Care Domains	If Yes, describe the management (document all medications for pain and symptom management that were administered, including dose, route and frequency)	Evaluation of management (e.g., documentation that intervention was effective)
Physical Symptoms		
Pain <input type="checkbox"/> No <input type="checkbox"/> Yes		
Nausea <input type="checkbox"/> No <input type="checkbox"/> Yes		
Vomiting <input type="checkbox"/> No <input type="checkbox"/> Yes		
Constipation <input type="checkbox"/> No <input type="checkbox"/> Yes		
Diarrhea <input type="checkbox"/> No <input type="checkbox"/> Yes		
Dysphagia <input type="checkbox"/> No <input type="checkbox"/> Yes		
Dyspnea <input type="checkbox"/> No <input type="checkbox"/> Yes		
Respiratory Congestion <input type="checkbox"/> No <input type="checkbox"/> Yes		
Cough <input type="checkbox"/> No <input type="checkbox"/> Yes		
Dry Mouth <input type="checkbox"/> No <input type="checkbox"/> Yes		

Care Domains	If Yes, describe the management (document all medications for pain and symptom management that were administered, including dose, route and frequency)	Evaluation of management (e.g., documentation that intervention was effective)
Fever <input type="checkbox"/> No <input type="checkbox"/> Yes		
Skin Breakdown <input type="checkbox"/> No <input type="checkbox"/> Yes		
UTI <input type="checkbox"/> No <input type="checkbox"/> Yes		
Edema <input type="checkbox"/> No <input type="checkbox"/> Yes		
Seizures <input type="checkbox"/> No <input type="checkbox"/> Yes		
Other <input type="checkbox"/> No <input type="checkbox"/> Yes		
Psychosocial Symptoms		
Depression <input type="checkbox"/> No <input type="checkbox"/> Yes		
Anxiety <input type="checkbox"/> No <input type="checkbox"/> Yes		
Agitation/restlessness <input type="checkbox"/> No <input type="checkbox"/> Yes		
Delirium <input type="checkbox"/> No <input type="checkbox"/> Yes		
Other <input type="checkbox"/> No <input type="checkbox"/> Yes		

25. Personal Care/Comfort Provided in Last Week of Life?

- | | | | | | |
|---------------|-----------------------------|------------------------------|----------------------|-----------------------------|------------------------------|
| a) Mouth Care | <input type="checkbox"/> No | <input type="checkbox"/> Yes | c) Incontinence Care | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| b) Bathing | <input type="checkbox"/> No | <input type="checkbox"/> Yes | d) Positioning | <input type="checkbox"/> No | <input type="checkbox"/> Yes |

26. Evidence of the WRHA Care in Final Days Toolkit used? No Yes

- If Yes: Was Step 1 of the Toolkit used? No Yes
 Was Step 2 of the Toolkit used? No Yes
 Was Step 3 of the Toolkit used? No Yes

27. Was a consult made in the last month of life to:

- | | |
|---|--|
| <input type="checkbox"/> WRHA Palliative Care Program: <input type="checkbox"/> CNS/ or Physician | <input type="checkbox"/> Other MD/NP, specify _____ |
| <input type="checkbox"/> WRHA LTC CNS | <input type="checkbox"/> Speech Language Pathologist |
| <input type="checkbox"/> Site CNS | <input type="checkbox"/> Social Work |
| <input type="checkbox"/> Therapeutic Recreation | <input type="checkbox"/> Spiritual Health Practitioner |
| <input type="checkbox"/> Hospice Palliative Care MB Volunteer | <input type="checkbox"/> OT/PT/Rehab |
| <input type="checkbox"/> Respiratory Therapist | <input type="checkbox"/> Registered Dietitian |
| <input type="checkbox"/> Facility Volunteers/Volunteer Program | <input type="checkbox"/> Manager of Food Services |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Information not Available |
| <input type="checkbox"/> Other (specify) _____ | |

Ethics Committee: If selected, please describe the reason for consult:

Summary comments on any notable findings from chart review:

Appendix B: Percentage Agreements Between Auditors on the ACE Items

Instrument Item #	# of Scores in Agreement (n=18)	% Agreement	Description of Question on ACE
6	18	100	Indication on health record death was expected
9	18	100	Place of death
10	18	100	Was the resident transferred to acute care (ED) in the last month of life?
11	18	100	Was there a Health Care Directive?
12	18	100	Was there an Advance Care Plan (ACP)?
12a	17	94	Goals of care chosen
14	15	83	Any changes made to the last ACP?
15	18	100	Is there evidence that EOL was near?
16	16	88	Were there changes to resident's orders in the last month?
17	18	100	Were there medication changes in the last week?
18	15	83	Is there evidence of communication with family?
19	17	94	Is there evidence that psychosocial support was provided to the family?
20	16	88	Resident's spiritual health preferences documented?
21	15	83	Evidence of resident's or family wishes regarding rites and rituals, spiritual considerations acted upon?
22	17	94	Is there evidence that pain was assessed?
24a	13	71	Pain present?
24b	18	100	Nausea present?
24c	16	88	Vomiting present?
24d	18	100	Constipation present?
24e	15	83	Diarrhea present?
24f	17	94	Dysphagia present?
24g	15	83	Dyspnea present?
24h	15	83	Respiratory congestion?
24i	14	77	Cough present?
24j	13	72	Dry mouth present?
24k	11	61	Fever present?
24l	13	72	Skin breakdown present?
24m	17	94	UTI?
24n	17	94	Edema present?
24o	18	100	Seizures present
24p	13	72	Other symptom issues?
24q	17	94	Depression present?
24r	16	88	Anxiety present

24s	18	100	Agitation present?
24t	14	77	Delirium present?
24u	13	72	Other psychosocial symptoms present?
25a	16	88	Was mouth care provided in the last week of life?
25b	14	77	Was bathing provided in the last week of life?
25c	16	88	Was incontinence care provided in the last week of life?
25d	17	94	Was positioning provided in the last week of life?
26	17	94	Was the Regional Health End-of-Life Toolkit used?
27a	18	100	Was a consult made for the Regional Palliative care program?
27b	18	100	Was a consult made for other MD or NP services?
27c	18	100	Was a consult made to the site CNS?
27d	18	100	Was a consult made to the Hospice Palliative care volunteer program?
27e	18	100	Was a consult made to the Facility Volunteers?
27f	17	94	Was a consult made to the Speech Language Pathologist?
27g	17	94	Was a consult made to the Spiritual Health Practitioner?
27h	16	88	Was a consult made to the Registered Dietitian?
27i	18	100	Was a consult made to the Regional NH CNS?
27j	14	77	Was a consult made to the Therapeutic Recreation?
27k	18	100	Was a consult made to the Respiratory Therapist?
27l	18	100	Was a consult made to the Pharmacist?
27m	16	88	Was a consult made to Social Work?
27n	12	66	Was a consult made to the OT/PT/Rehab services?
27o	18	100	Was a consult made to the manager of food services?
27p	14	77	Were other consults made?
27q	18	100	Was a consult made to the Regional ethics committee?

Note. Used with permission from Dr. Genevieve Thompson

Appendix C: Letter for Nursing Homes

Dear (Name of contact at nursing home),

I am a graduate student in the College of Nursing at the University of Manitoba and am currently writing my thesis, which examines the symptoms at the end-of-life in nursing home residents. This is a secondary analysis of a chart audit, which your organization participated in previously during the summer of 2014. The original study's purpose was to create and refine the Auditing Care at the End-of-Life (ACE) Tool, completed by my advisor, Dr. Genevieve Thompson. We would like to thank you for participating in the original study, which yielded the ACE tool, a valuable tool measuring care at the end-of-life.

The majority of the information that I require to conduct the secondary data analysis has already been collected as part of the original study. The additional data that I require is the level of cognitive impairment in residents; data that will be useful in not only describing the participants but also will give me the ability to compare care based on CPS score. ***This letter is seeking your permission to facilitate the retrieval of the last Cognitive Performance Scale (CPS) score from the charts of residents who were part of the original study.*** All of the provisions guaranteed in the original study (confidentiality, etc.) will be maintained in this extension of the study. Your further participation in facilitating this information would be greatly appreciated. We can provide you with the list of resident names for which we require the data retrieval. Furthermore, results of the study would be made available to you at the conclusion of my thesis.

I can be reached via email at [REDACTED] or by phone at [REDACTED]. My thesis advisor, Dr. Thompson can also be reached via email at [REDACTED]. Thank you in advance for your time and consideration in this request.

Sincerely,

Lisa Timmerman

Appendix D: Ethical Approval Form



Research Ethics and Compliance
Office of the Vice-President (Research and International)

Human Ethics
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Canada R3T 2N2
Phone +204-474-7122
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APPROVAL CERTIFICATE

August 29, 2016

TO: Lisa Timmerman (Supervisor: Genevieve Thompson)
Principal Investigator

FROM: Zana Lutfiyya, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2016:094 (HS20047)
"Symptom Experience at the End-of-Life in Nursing Homes"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only and will expire on August 29, 2017.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Coordinator in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.