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Spiritual and Psychosocial Palliative Care in a Rural Ontario Town: An Exploratory Study of Patient Needs and Provider Experiences

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences
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Abstract

This exploratory qualitative study identified spiritual and psychosocial palliative care needs in one rural Eastern Ontario town, referred to as the pseudonym "Duffy's Hill." Six qualitative interviews with health care providers gathered insights, ideas, and stories related to the provision of spiritual and psychosocial palliative care in Duffy's Hill. Participant responses were analyzed for shared values, beliefs, ideas, practices, and norms in providing this care to determine if the distinct needs observed could be attributed to cultural particularities in Duffy's Hill. Results found that participants viewed Duffy's Hill as distinct from urban contexts in nature of practice and challenges faced. Good spiritual and psychosocial care involved awareness of a tension associated with the terms "spiritual" and "religious," attention to patients' senses of place, and opportunity for patients to maintain, engage in, or heal interpersonal relationships. These results, though exploratory, suggest some level of shared culture in Duffy's Hill.

Keywords: palliative care; spiritual; psychosocial; rural; culture; Ontario; qualitative methods; community-based participatory research

Summary for Lay Audience

The initiation of palliative care—an area of health care offered to individuals facing life-threatening, terminal, or chronic illness—signifies a shift in priorities from curing an illness to maintaining quality of life for the patient receiving treatment. The Canadian Hospice Palliative Care Association states that good palliative care involves treatment of physical suffering through pain management and services to treat spiritual and psychosocial aspects of health. Despite this fact, very little research has been conducted in Canada exploring what it means to treat patients' spiritual and psychosocial needs. These elements of care are particularly under-studied in rural areas. This thesis explores what spiritual and psychosocial needs exist for palliative care patients in one rural Ontario town (referred to in this thesis as "Duffy's Hill") by asking six health care providers about their experiences offering palliative care in this town. Participants shared that patients were not always comfortable discussing spirituality because they associated it with religion, and religious participation, though common in Duffy's Hill, was not always viewed positively. Thus, offering good spiritual and psychosocial care in this town involves careful selection of words when discussing this care, and avoidance of the terms "spiritual" or "religious" unless the provider understands the patient's definition of these terms. Good spiritual and psychosocial care in this context also includes/means helping patients connect with their senses of place, creating opportunities for them to feel like they are at home, as well as opportunities for patients to engage in meaningful relationships with people. These opportunities might involve reconciling with estranged family members. Health care providers face challenges finding adequate time to do this work well, knowing who to involve in spiritual and psychosocial care, providing spiritual and psychosocial care to patients who do not want it, providing culturally-relevant care to non-locals who travel to Duffy's Hill for vacation, and in helping non-

mobile patients access care. These elements and challenges demonstrate that, at some level,

cultural norms, values, beliefs, and practices exist that suggest a shared "rural" culture in Duffy's

Hill that holds implications for spiritual and psychosocial palliative care provision.

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Preface

A significant portion of this research was interrupted by the COVID-19 pandemic. Initially, this project was designed to be a cross-cultural comparison between two rural Ontario communities. This comparison, if able to move forward, would allow for the observation of differences and similarities between two rural contexts, and subsequently a more nuanced exploration of whether a rural culture exists that influences spiritual and psychosocial palliative care needs. In preparation for this study, community partnerships were established in two rural towns, and ethics approval was achieved in both. Unfortunately, upon declaration of the pandemic, data collection was only permitted to proceed in one of these towns, local research authorities at the second site asked me not to recruit health care providers for interviews during the pandemic.

In order to meet the demands of my program of study, a significant change to the research goals, methodology, and analysis were required. The research presented in this thesis now constitutes an exploratory study to examine shared values, ideas, beliefs and practices among health care providers related to the provision of spiritual and psychosocial palliative care in one rural Ontario town. While no longer able to speak to possible cultural distinctions between rural communities, this thesis adds to a growing body of literature discussing whether there is something culturally unique about rural Canadian contexts, and if so, what this implies for the provision of palliative care.

In addition to the reduced data pool with the closure of one data collection site, recruitment in the remaining site was significantly impaired by the COVID-19 pandemic. Understandably, health care providers were extremely busy and facing highly stressful circumstances during this time. Research participation was not a priority, and many individuals

who were invited to participate declined. As a result, recruitment of participants was very challenging. This difficulty accounts for the small sample size observed in this study.

Despite these challenges, I believe the results in this study, though highly exploratory, contribute significantly to the growing body of rural Ontario palliative care literature. Although the possibility of definitive conclusions from this thesis is limited, the results speak to the importance of observing culture in a rural context and reveal why a consideration of culture has an impact on and implications for spiritual and psychosocial palliative care. It is my hope that in reading this thesis, readers will gain a greater appreciation for and understanding of the distinct context presented by a rural Ontario town, and that this understanding may inspire subsequent explorations of the unique palliative care needs of rural communities to promote tailored palliative programming for towns such as these.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

Palliative care is an area of health care offered to individuals faced with life-threatening or terminal illness (WHO, 2020). The initiation of palliative care signifies a shift in priorities from curing an illness to maintaining quality of life for the patient receiving treatment. A recent addition to Canada's specialty health care lineup, palliative care began to gain traction as a discipline in the 1970s (Williams et al., 2010) as a method of pain and symptom management for cancer patients (Brooksbank, 2009). Today, palliative care is employed in the treatment of patients with chronic, incurable, or terminal illnesses, and is increasingly gaining popularity as a holistic approach to care for all patients, not only those with a terminal prognosis. Growing rates of deaths attributable to chronic disease[1] and a rapidly aging population[2] further contribute to the growing need for palliative approaches within the Canadian health care system (Kelley, 2007; Rocker et al., 2016; Williams et al., 2010).

Williams et al. (2010) describe palliative care as a shift away from a "curing" to a "caring" mindset, suggesting that a person undergoing palliation is cared for as a whole being rather than simply a physical body. The Canadian Hospice Palliative Care Association (CHPCA), established in 1991 to advocate for palliative care prioritization in Canada, affirms this notion, stating that good palliative care is holistic and offers treatment of physical suffering through pain management as well as services to treat spiritual and psychosocial aspects of health (CHPCA, 2013). This holistic view of care is often discussed as the "total pain" concept, a term coined by Dame Cicely Saunders to describe how multiple non-physical factors can cause, contribute to, and exacerbate physical pain (Saunders, 1993). Despite such overt

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[1] 79% of Canadian deaths were caused by chronic disease in 2018 (Statistics Canada, 2020a)
[2] 19.7% of the Canadian population was over the age of 64 in 2019 (Statistics Canada, 2020b)

acknowledgement that palliative care involves more than biomedical symptom management to reduce pain, little research has been conducted in Canada to explore what patients' spiritual and psychosocial needs are, and the implications for front-line health care provision thereof.

Although a dearth of knowledge exists regarding practical aspects of spiritual and psychosocial palliative care across the country, these aspects of palliative care are particularly under-studied in rural areas (Robinson et al., 2009). In fact, significantly less palliative care research has been conducted in rural geographies of Canada in general, and rural Ontario in no exception (Robinson et al., 2009). While a number of key researchers have begun to draw attention to the particularities of palliative care practices and needs in rural contexts, most of this research has targeted system capacity building (Gaudet et. al., 2014; Pesut et al., 2017; Kaaselainen et al., 2014). To the best of my knowledge, no studies conducted on palliative care in rural Canada have focused explicitly on spiritual and psychosocial care needs and practices in particular. The emphasis across existing studies has been on care for physical elements of health within palliative care provided at the end of life (Mistry et al., 2015). Although providing for these physical health needs is fundamental, provision of spiritual and psychosocial aspects of care also merit sustained consideration, including research. To offer care to rural Ontarians that is equitable to the care offered in urban areas, spiritual and psychosocial elements of care must be considered alongside physical needs. This thesis responds to a call for increased evaluative efforts in rural areas (Williams et al., 2010) as well as a call for increased attention to spiritual and psychosocial elements of palliative care (Bainbridge & Seow, 2018). It is based on a qualitative, exploratory study that combines these two calls, and begins to fill the gap of knowledge regarding what spiritual and psychosocial palliative care services could look like in rural Canada.

While research conducted in urban Ontario might superficially contribute to the development of rural palliative care services, urban research does not account for the unique social, cultural, geographical, and historical factors that shape needs facing rural Ontarians. Although rural areas are highly diverse across Canada, they share several distinct features and challenges in offering and receiving palliative care. Some of the shared challenges include those associated with travel to access or provide care (Brazil et al., 2013; Kaasalainen et al., 2014), decreased availability of home care services (Seow et al., 2014), higher rates of hospitalization at the end of life (Conlon et al., 2016; Dumont et al., 2015), and lack of specialized palliative care staff and resources (Robinson et al., 2009; Gaudet et al., 2014). It is important that these unique aspects of rural life are considered in the development of palliative programs (Robinson et al., 2009).

According to statistics Canada, 18.7% according to Statistics Canada as of 2016 (Statistics Canada, 2019). Although the definition of what constitutes a "rural area" is disputed and often spoken of relatively, this thesis will use the same definition that Statistics Canada uses, which is that a "rural area" refers to communities of fewer that 10 000 people (dePlessis et al., 2002). The limited palliative care research specifically relevant to rural areas in Canada constitutes a potential barrier to ensuring this care is equitable to that available in non-rural areas in terms of quality and accessibility. Limited research for the particularities of rural Canadian areas prevents a significant portion of the population from benefitting from context-specific evidence-based guidelines. Context specificity is especially important when examining spiritual and psychosocial needs. While all good palliative care is patient-centered, key elements of its provision are also vary socio-culturally. A number of studies tie specific expectations, experiences, and practices of spiritual and psychosocial elements of palliative care to specific

cultural settings (Evans & Ume, 2012; Manzanec & Tyler, 2003; Selman et al., 2011). How these are discussed in the Canadian context will be explored in Chapter 2.

As a concept, "culture" can be difficult to identify in an absolute manner. Leininger (1997), a key reference in the literature on cultural dimensions of healthcare, defines culture as "the lifeways of an individual or group with reference to values, beliefs, norms, patterns, and practices that are learned, shared and transmitted intergenerationally" (p. 38). While this definition describes elements that contribute to culture, it does not limit culture to the confines of racial, social, religious, ethnic, or geographical groups. Rather, it postulates that culture can exist at many levels and in many forms. Additionally, individuals might view themselves as belonging to multiple different cultures at once; for example, a person can harbour a certain professional culture and a certain ethnic culture at the same time. As a result, it is not easy to identify whether a given rural context "possesses" culture or is culturally distinct. It is clear, however, that individuals living in rural communities, as with all localities defined by shared histories and institutions shaping access to resources and norms of interaction, often share values, norms, or learned practices and patterns. The commonalities in experiences through day-to-day existence in a locality can contribute to shared lifeways, as Leininger (1997) suggests. These shared lifeways may significantly impact spiritual and psychosocial palliative needs observed in specific rural contexts. To explore how cultural factors may influence spiritual and psychosocial care needs in rural communities, this thesis explores the needs of one rural Ontario town, referred to under the pseudonym "Duffy's Hill." In doing so, this thesis investigates the following questions:

1) In the views of palliative care providers, what does it mean to offer spiritual and psychosocial palliative care in one specific rural Ontario context?

2) Are there cultural particularities that underlie care needs (and corresponding responses to these needs) that should be considered when serving a rural population such as this?

This is a qualitative exploratory study. It draws on data derived from six in-depth semi-structured interviews with rural palliative care providers living in Duffy's Hill. The interview guide was informed by Flanagan's (1954) Critical Incidence Technique (see Chapter 3), which provides a method of interviewing well suited for surfacing both explicit and implicit understandings of a phenomenon, such as the spiritual and psychosocial care needs in a rural Ontario town.

Although my key interest is in context-specific—and potentially culturally unique—spiritual and psychosocial needs in this setting, these needs are not objectively ascertainable. Spiritual and psychosocial needs become apparent when made visible through their engagement with social actors. Here, my focus is on deepening the understanding of these needs through the eyes of providers—through their definitions, practices, and experiences with what they are understanding as spiritual and psychosocial elements of palliative care. This process involves the adoption of an interpretive constructivist theoretical approach. This approach postulates that there is no one "objective" state of reality (Neuman & Robson, 2012). Rather, individuals continuously create personal concepts of reality based on the ideas, relationships, and symbols they consider meaningful (Neuman & Robson, 2012). The implication of this theoretical lens within the context of this research is that I am assuming individual realities are shaped by social, political, economic, ethnic, gender-related, historical, biographical, and, most importantly for this research, lifeway-specific or cultural factors. I am assuming these realities, or how participants perceive and act in the world, are simultaneously individually unique while

exhibiting shared characteristics particular to the context of Duffy's Hill as a result of being co-constructed by and through social actors' engagements with palliative care needs and provision within this context (Guba & Lincoln, 1994). Exploring the potential cultural specificity of spiritual and psychosocial care within this paradigm justifies seeking connections and commonalities between participants' accounts of care needs and provision in this context, while also remaining open to some elements in their accounts falling outside a shared "culture."

1.1 Key Terminology

A number of common terms are used throughout this thesis. These terms have multiple (and sometimes unclear) definitions outside of this thesis. Within this research, these terms will be consistent with the definitions below.

1) *Culture*

   For the purpose of this research, I will use Leininger's (1997) definition of culture. Leininger defines culture as "the lifeways of an individual or group with reference to values, beliefs, norms, patterns, and practices that are learned, shared and transmitted intergenerationally" (p. 38). It is worth noting that this definition does not limit culture to the confines of racial, social, religious, ethnic, or geographical groups. Rather, it postulates that culture can exist at many levels and in many forms.

2) *Rural*

   There has been much dispute over what constitutes a "rural area" or "rural community" in Canada. In this thesis, I have partnered with a community health centre that serves greater rural areas in addition to the population within its own town lines. Considering this reality, I have chosen to adopt Statistics Canada's definition of a "small town" to describe a "rural" community – that is, a town with a population of fewer than

10 000 people (dePlessis et al., 2002) with the expectation that communities of this size serve peripheral areas with sparse population densities.

3) *Psychosocial Care*

This thesis will refer to "psychosocial care" as care interventions to preserve mental and social health in palliative patients. This type of care might include counseling services, treatment of mental illness, changing the location of care from hospital to home, and the inclusion of family and friends in palliative treatment (Hudson et al., 2010).

4) *Spiritual Care*

Individuals from different backgrounds hold different perceptions and ideas o what the term "spiritual" means. Because of the diverse set of values and belief systems that exist within Canada, I adopt a broad definition of "spiritual care." For the purpose of this study, "spiritual care" will refer to any care offered with the goal of instilling or maintaining a sense of purpose, value, and belonging in a patient's life (Tanyi, 2002). This type of care might look different for each person depending on culture, social position or identity, or religion (Edwards et al., 2010).

5) *Holistic care*

While "spiritual" and "psychosocial" care have different definitions individually, both are considered a part of holistic palliative care. "Holistic care" refers to a comprehensive understanding of health care provision that integrates physical, psychosocial, and spiritual elements of care, and acknowledges that these elements often overlap and interact (Jasemi et al., 2017). The terms "spiritual" and "psychosocial" care are used interchangeably in this thesis depending on which term best encompasses the ideas being

discussed. Readers should note that when one of these terms is encountered, the same ideas can be applied to the other in light of their interactions within holistic care.

1.2 Thesis Outline

This thesis is designed to answer and achieve the above stated research question and objectives. It has been organized into the following chapters to facilitate these achievements.

Chapter 1 introduces the research presented in this thesis, its objectives, and outlines the theoretical groundwork for the study.

Chapter 2 provides background information to rationalize this research via literature reviews on the following topics: (1) How culture is discussed in Canadian palliative care literature, and (2) palliative care research in rural Ontario.

Chapter 3 describes the methods employed in this research to meet the stated objectives.

Chapter 4 introduces the research setting and participants.

Chapters 5 to 10 present the results of this study. **Chapter 5** provides an overview of the palliative care landscape in Duffy's Hill from information provided by participants. **Chapter 6** explores an evident tension between the concepts of "religiosity" and "spirituality" that makes discussing and providing palliative care challenging in Duffy's Hill. **Chapter 7** investigates a patient's sense of place as a critical component of the patient's identity and life course in Duffy's Hill, and the implications that arise relating to spiritual and psychosocial palliative care. **Chapter 8** reviews the role of interpersonal relationships in spiritual and psychosocial care, and how relationships manifest as care needs in Duffy's Hill. **Chapter 9** presents a number of unique challenges that face palliative care providers in Duffy's Hill.

Chapter 10 discusses the implications of the study for designing palliative care systems and describes elements that appear to underlie "good spiritual and psychosocial care" in this context. It also provides a number of recommendations to support the establishment of spiritual and psychosocial palliative care services in Duffy's Hill. Chapter Ten concludes by discussing the implications of this research for future studies and the advantages and limitations of using a cultural lens in this research.

Chapter 11 concludes this thesis with a brief summary of what was learned.

Chapter 12 lists the references cited in this thesis.

Chapter 2: Literature Review

In this chapter, I present two scoping literature reviews to provide background for this study. In the first review (Section 2.1), I synthesize recent palliative care research in rural Ontario to point out what work has been done and what areas are in need of further attention. This first review exemplifies why research explicitly focused on spiritual and psychosocial palliative care in rural Ontario is needed. In the second review (Section 2.2), I summarize how the concept of culture has been discussed and observed in Canadian palliative care literature. This second review serves to clarify ideas about culture that are or are not agreed upon in a Canadian palliative care context, and why a cultural lens is useful in examining rural Ontario palliative care. Finally, I discuss knowledge gaps that exist within these two areas of research and demonstrate how they intersect to warrant the current study (Section 2.3). The methodology for both of these reviews is modeled after Arksey and O'Malley's (2005) scoping review framework.

2.1 Palliative Care Research in Rural Ontario

To understand the need for research on spiritual and psychosocial palliative care in rural Ontario, it is necessary first to synthesize the work that has been done by researchers to forward the agenda of palliative care in rural Ontario generally. This body of literature, though small, has focused on system capacity building and provider experiences with strong emphasis on care for physical elements of health. In the review that follows, I summarize palliative care research that has been conducted in rural Ontario since 2009 following the publication of a review by Robinson et al. (2009) synthesizing worldwide rural palliative care literature. In reviewing this literature, I discuss how research objectives and recommendations presented by Robinson et al. (2009) have been met or explored in rural Ontario, as well as what remains under-studied within this body of literature.

2.1.1 Methods

In 2009, Robinson et al. published a literature review of rural palliative care in the *Journal of Palliative Medicine*. This review synthesized the findings of studies from countries around the world (including Canada) focused on rural palliative care from 1996 and onward and identified priority areas for future study. Among the major findings of the review, (see Table 1), Robinson et al. (2009) proposed that future research should focus on the following topic areas: (1) models of service provision and the evaluation of these, (2) culturally sensitive models of palliative care for rural populations, particularly Indigenous communities, (3) technology as a means of enhancing palliative care, (4) the role of specialist services in rural palliative care, and (5) the influence of rural place on palliative care experiences. In their discussion, Robinson et al. (2009) also highlighted family caregiver experiences and predictors of place of death as areas in need of additional research.

Table 1: Findings of Robinson et al.'s (2009) review

Patient and caregiver perspectives	Professional attitudes, knowledge, & practice issues	Health care services
Major findings		
• 6 of 24 studies directly addressed patient perspectives • rural patients were not as clear on care intent as urban counterparts • rural patients perceive their choices around death to be limited • the unique needs of Indigenous individuals are not well addressed	• 28 studies explored issues from provider perspectives • 15 explored attitudes, perceptions and barriers to palliative care among professionals and volunteers • travel influenced care provision and professional development • professionals self-identify as "generalists" • difficult to put together interdisciplinary teams rurally • willingness to provide palliative care influenced by knowledge of it • psychosocial aspects are most difficult to address	• 27 articles addressed health service delivery utilization, models of delivery, and volunteer programs • 6 explored hospice and hospital utilization at end of life • Rurality might be a significant factor in hospice usage • 4 studies addressed needs of rural and remote indigenous populations • 5 studies evaluated models for palliative care team development • 2 focused on enhancing pain management
Recommendations for future research		
• role of place in rural palliative care • perspectives of those commuting or traveling to receive care • family caregiver experiences and how they can be supported • predictors of place of death in rural contexts • larger sample sizes and how to recruit in rural areas	• explore value of technology in palliative care provision and education • find innovative ways to support needs of professionals	• hospitalization rates and aggressive treatment trends at end of life for rural patients • health care delivery issues specifically relevant to rural provision • culturally sensitive program development for Indigenous populations

Source: Robinson, C.A., Pesut, B., Bottorff, J.L., Mowry, A., Broughton, S. & Fyles, G. (2009). Rural palliative care: A comprehensive review. *Journal of Palliative Medicine*, *12*(3), pp. 253–258.

While Robinson et al.'s (2009) review has begun to synthesize rural palliative care literature, including that conducted in Ontario, the article was published over ten years ago. Since that time, a number of studies have been conducted in rural Ontario to address some of these identified areas for future research. The current review aims to answer these questions: What research has been conducted on palliative care in rural Ontario since the publication of Robinson et al.'s (2009) review; which, if any, of their identified priority research areas have been addressed in this time, and what gaps remain to be address?
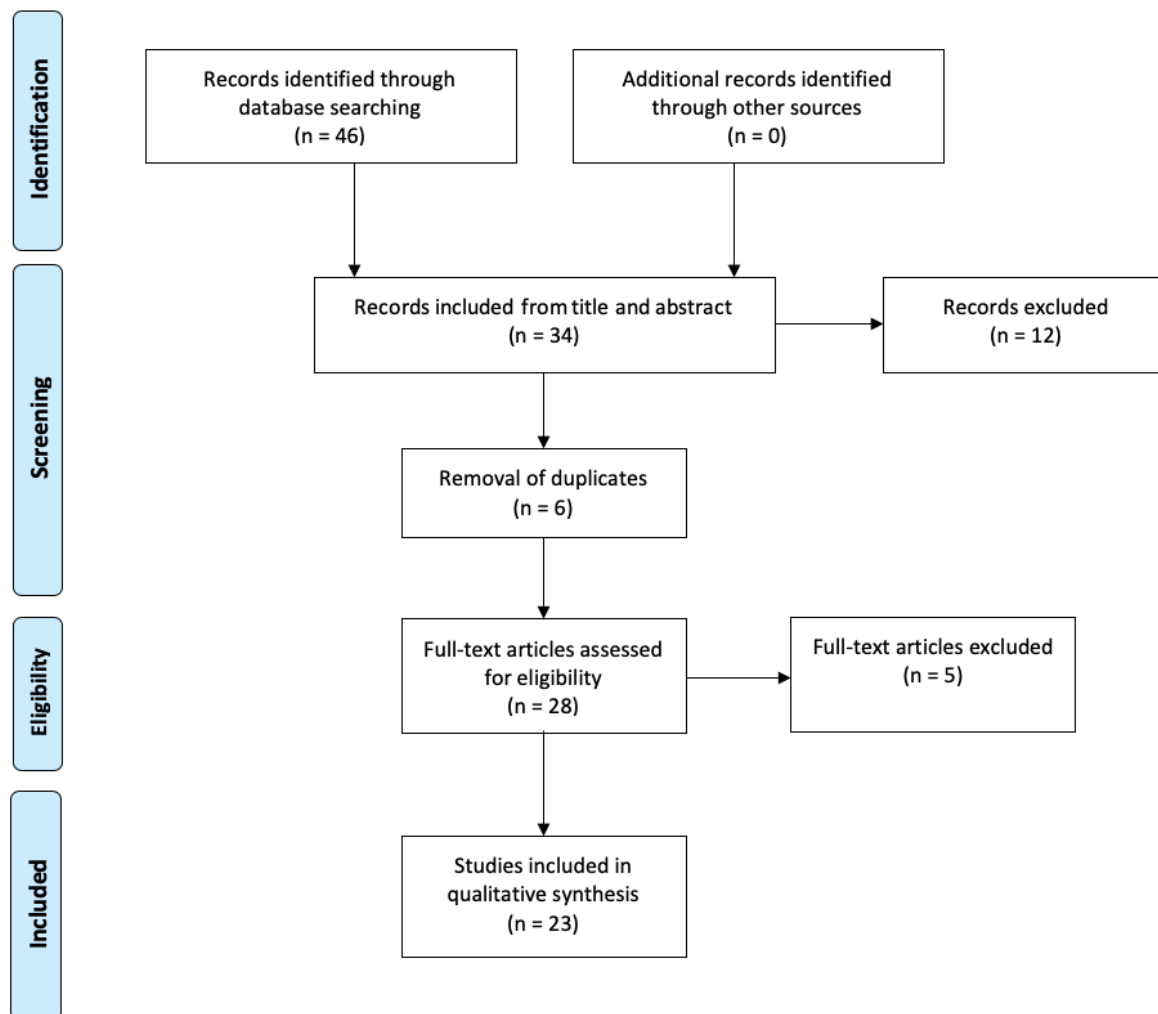
Figure 1: PRISMA record (Moher et al., 2009) of database search and screening process to produce the 23 studies included in this review.

The PubMed database was used to gather palliative care research conducted in rural Ontario to answer these questions. Literature was included in this review if it was published between the years 2009 and 2020. Keywords used in this database search included "palliative care," "Ontario," and "rural." An initial search (Figure 1) using these terms yielded 46 hits. Upon reviewing the titles and abstracts of these hits, 34 were selected for full-text review. After removing duplicates, 28 articles remained. Among these articles, 23 were selected for inclusion in this review based on relevance to the research question. Studies were charted for study topic, results, and conclusions, and analyzed by hand for common themes as outlined in Arksey & O'Malley's (2005) framework for scoping literature reviews.

Since the publication of Robinson et al. (2009), based on the literature, a number of the identified priority areas have been addressed in rural Ontario specifically. In particular, models of palliative service provision and methods of evaluating these models have been given significantly more attention (Kelley et al., 2011; Kelley et al., 2018; Koski et al., 2017; Nadin et al., 2018; Prince et al., 2019; Pereira et al., 2016; Seow & Bainbridge et al., 2018). Further studies analyzing cost and accessibility issues associated with providing palliative care in rural Ontario have been conducted (Conlon et al., 2016; Dumont et al., 2015; Panarella et al., 2019; Schuurman et al., 2020; Seow et al., 2018; Towns et al., 2012; Klinger et al., 2013). Additional studies have continued to explore patient and family caregiver experiences with palliative services (Brazil et al., 2013; Brazil et al., 2014; Freeman et al., 2016; Kelly et al., 2009; McDermott, 2019), health care providers' experiences with offering palliative care (Gaudet et al., 2014; Kaasalainen et al., 2011; Kaasalainen et al., 2014; McKee at al., 2010), and two studies have begun to explore the role of place in designing and providing rural palliative care (Giesbrecht et al., 2012a; Giesbrecht et al., 2012b). The findings of these studies, published from

2009 to 2020, are summarized in the sections that follow, and demonstrate not only where work has been done, but some glaring absences to be addressed in the future.

2.1.2 Models of Palliative Service Provision

Six articles outline and evaluate models for the development of rural palliative care programs in rural Ontario. Four of these focused specifically on developing palliative care programs in Indigenous communities in Northwestern Ontario (Kelley et al., 2018; Koski et al., 2017; Nadin et al., 2018; Prince et al., 2019; Pereira et al., 2016; Seow & Bainbridge, 2018). Each of these focused on the development of culturally relevant programs and used several strategies to integrate programming with cultural norms.

Kelley et al. (2018) used a public health approach paired with community-based participatory action research to integrate palliative care programs in four Indigenous contexts. Each of these programs was unique, and development was facilitated by a workbook of culturally relevant resources to guide palliative care development (Kelley et al., 2018). Prince et al. (2019) continued discussion of a public health approach to palliative care development in Indigenous communities and concluded that capacity building for such work was achieved through community palliative care education.

Koski et al. (2017) used "journey mapping," a process adapted from the marketing concepts of "customer journey mapping" and "value stream mapping," to understand how to improve and better integrate health care efforts by creating a visualization of the people and organizations involved in its offering and utilization. The journey mapping process facilitated the creation of culturally informed programming that avoided certain language (i.e. avoided using the words "palliative," "death," or "dying") and instead used symbols that were significant to the

community in question (Koski et al., 2017). Koski et al. (2017) also indicated that the journey

mapping process allowed for relationship and trust building between external health care

providers and community members prior to the start of the programming, fostering positive

partnerships for the development of services. Koski et al.'s (2017) journey mapping process

contributed to the development of the *Wiisokotaatiwin* program in the Naotkamegwanning First

Nation, a community-based palliative care program outlined in Nadin et al. (2018).

Wiisokotaatiwin, meaning "taking care of each other" or "supporting each other" in

Anishnaabemowin, was named such to reflect local norms, values, and beliefs.

Articles outlining development of non-Indigenous palliative care programs were

presented by Pereira et al. (2016) and Seow and Bainbridge (2018). Respectively, these studies

outlined the implementation of the first rural Hospice in Canada (located in the Champlain

region) and the evolution of 15 specialized palliative care teams in rural Ontario. These studies

highlight the iterative and relational nature of rural palliative teams and serve as case studies for

the development of rural palliative care in rural Ontario (Pereira et al., 2016; Seow &

Bainbridge, 2018).

While the aforementioned models of palliative care development were either new or built

on older frameworks, one article by Kelley et al. (2011) validated the widely recognized Kelley

(2007) model for community palliative care development. Kelley et al.'s (2011) validation

process revealed a number of considerations for the development of rural palliative care when

employing the Kelley (2007) model. Communities that had already begun the process of

palliative care development in some capacity had a greater sense of empowerment that facilitated

growth, but also faced resistance in applying the model because it disrupted previous efforts

(Kelley et al., 2011). Focus and pace of program development were found to vary over time and

were often influenced by external factors such as changing government policy and funding (Kelley et al., 2011). It was also found that consultants implementing the model were more likely to be accepted by local health care providers if the consultants were from the community undertaking the project (Kelley et al., 2011).

2.1.3 Cost and Accessibility

Six studies were found that addressed costs and accessibility issues associated with rural palliative care in Ontario (Conlon et al., 2016; Dumont et al., 2015; Panarella et al., 2019; Schuurman et al., 2020; Seow et al., 2018; Towns et al., 2012). These studies found that Northern Ontario residents were less likely to receive care than rural counterparts in Southern Ontario (Conlon et al., 2016; Panarella et al., 2019), and that receipt of palliative care was associated with age (older individuals more likely to receive palliation), gender (females more likely than males), higher income and proximity to urban centres (Panarella et al., 2019). Northern and Southern Ontario residents alike were more likely to receive aggressive treatment at the end of life (Conlon et al., 2016; Towns et al., 2012), more likely to die in acute care (Conlon et al., 2016), and exhibited higher rates of hospitalization, emergency room visits, and ambulatory care access than their urban counterparts (Conlon et al., 2016; Dumont et al., 2015).

In analyzing palliative care cost difference between rural and urban regions of Ontario, Dumont et al. (2015) found that the average total cost on the health care system per patient over a six-month period was 16.4% higher in rural areas. Dumont et al. (2015) hypothesized that this difference was likely attributable to the higher rates of hospitalization at end of life observed in rural communities. This observation is supported by Klinger et al.'s (2013) result that home-based palliative care is less costly than hospital-based care in rural areas. In their study of

palliative care access for cancer patients by community size, Seow et al. (2018) found that the smallest communities (defined as having fewer than 10 000 residents) had the lowest proportion of patients receiving home-based nursing care, likely due travel challenges presented by wide geographical catchments. In spite of this, Klinger et al. (2013) revealed that specialized nursing and home-based care, where available, were the most accessed resources among rural patients, followed by equipment rentals and occupational and physiotherapy services. Of the patients surveyed in this study, 34 of 95 received some form of psychosocial or spiritual care, corresponding to 224 hours of this service over a 15-month period (Klinger et al., 2013). Of these 224 hours, 205 were attended by cancer patients (Klinger et al., 2013). These results demonstrate that while spiritual and psychosocial palliative care is recognized as important, it is not always accessed, and is used more in instances of certain illnesses than as a blanket priority within general palliative care.

2.1.4 Patient and Family Caregiver Experiences

Three studies were found addressing the experiences of palliative patients in rural Ontario (Freeman et al., 2016; Kelly et al., 2009; McDermott, 2019), and two were found addressing family caregiver needs and experiences (Brazil et al., 2013; Brazil et al., 2014). These studies add to a growing body of literature addressing experiences of palliative care, an area of great need according to Robinson et al. (2009). Freeman et al. (2016) explored the wish to die among palliative patients in an effort to identify risk factors for depression associated with palliative care across Ontario. The proportion of people with a wish to die increased with age and was more likely to appear in clients with only a non-cancer diagnosis (Freeman at al., 2016). Those who were married were less likely to express a wish to die. Additionally, those who expressed a

wish to die did not always display depressive symptoms. Rather, it was found that the wish to die and the expression thereof was more likely used as a conversation starter with their health care provider about their feelings about their illness than a request for death (Freeman et al., 2016). Freeman et al. (2016) therefore concluded that conversations with patients around wishes to die could lead to better targeting strategies for psychosocial and supportive services, rather than be interpreted as definitive statements.

McDermott (2019) explored patient experiences with the Patient Dignity Question (PDQ), a dignity-conserving intervention that asks the simple question, "What do I need to know about you as a person to give you the best care possible?" This was tested in a rural hospital to investigate its feasibility as a tool for patient support. The PDQ resulted in meaningful legacy documents summarizing patients' histories, self-perceived accomplishments, values, and important messages they wanted to leave behind (McDermott, 2019). Patients and families who engaged with this question felt truly heard and families were deeply moved to have a copy of their loved ones' answers as a legacy document with which to remember them (McDermott, 2019). Staff found that the documents helped them to understand patients better (McDermott, 2019).

Kelly et al.'s 2009 study of palliative care among Northwestern Ontario Cree and Ojibway Peoples revealed a number of specific considerations for patient care in these contexts. First, patients wanted doctors to tell them outright if they were dying, using straight methods of communication that included encouragement without false hope. Speaking about illness with family was not a norm, and patients wanted to be able to choose the circumstances of their death. To facilitate this, patients believed interpretation services were important to facilitate doctor-patient communication in these Indigenous communities, and experienced physicians who had

experience with Indigenous ways of knowing and living were preferred over newer physicians.

Spiritual care was deemed important; patients wanted to have a minister come in to pray and sing

hymns with them. Finally, space was necessary for family and community members to come in

and visit, and having flexibility in moving the remains of loved ones was of high importance

(Kelly et al., 2009).

Brazil et al. (2013) and Brazil et al. (2014) explored the experiences of family caregivers

in rural as compared to urban contexts. The impetus for these studies was that caregivers in rural

settings faced different challenges than those in urban settings and required different services to

lighten the load as a result. These studies found that rural and urban caregivers did not differ

significantly on variables such as perceived burden or social support; however, rural caregivers

were significantly more likely to relocate to offer care to a loved one, as well as significantly

more likely to access family doctors, emergency, and pharmacy services (Brazil et al., 2013).

Rural caregivers reported needing someone to talk to about their duties, as well as assistance

with errands, transportation, rest, and obtaining financial assistance (Brazil et al., 2014). The

authors concluded that their results point to a greater need for pain and symptom management

and respite services in rural areas compared to urban (Brazil et al., 2014, Brazil et al., 2013).

2.1.5 Health Care Professional and Volunteer Experiences

Four studies addressed professional and volunteer experiences in offering palliative care

in rural Ontario (Gaudet, et al., 2014; Kaasalainen et al., 2014; Kaasalainen et al., 2011; McKee

et al., 2010). These studies underline several differences to the work of palliative care healthcare

professionals and volunteers in rural as opposed to urban settings. Studies found that rural health

care providers viewed themselves as "generalists," or as "jacks-of-all-trades" who provided

many forms of care to many different people (Gaudet et al., 2014; Kaasalainen et al., 2014). In their study of interprofessional collaboration to establish palliative care services in rural Ontario, Gaudet et al. (2014) found that the "generalist" nature of rural medicine made it difficult for professionals to schedule the time to meet. Despite this challenge, health care providers felt a strong sense of responsibility to their community and neighbours (Gaudet et al., 2014; Kaasalainen et al., 2014), and participated in development focus groups not because they were compelled by their employer, but because they wanted to (Gaudet et al., 2014). Core development groups included nurses, social workers, hospice volunteers, and physicians; however, many different stakeholders and community leaders were involved in the process, inspired a holistic community-based approach, including clergy, funeral directors, and ambulance drivers (Gaudet et al., 2014). The development of this team was facilitated by informal networks of community members living and working in the area, with one participant noting that "you've got a team automatically" by product of these local networks (Gaudet et al., 2014). Kaasalainen et al. (2011) noted that rural nurses' self-perceptions as generalists paired with these strong networks contributed to a greater sense of confidence in their abilities to provide palliative care compared to their urban counterparts.

Although nurses felt confident in their abilities to provide palliative care, Kaasalainen et al. (2014) reported that the quantity of work for home-based care nurses has been increasing and their self-perceived quality of care decreasing, largely because nurses have less time to spend with each patient. Nurses reported that they spent a lot of their personal time making phone calls, doing paperwork, and completing administrative tasks (Kaasalainen et al., 2014). Additionally, rural nurses spent significantly more time travelling to and from patients' homes than urban nurses (Kaasalainen et al., 2011), often in poor weather conditions (Kaasalainen et al., 2014).

Nurses felt they should be involved in providing spiritual and psychosocial care to patients by facilitating contact with support services such as churches or service clubs (Kaasalainen et al., 2014; Kaasalainen et al., 2011). Nurses felt that they should not be involved in performing diagnostic tests, facilitating access to other end of life services, helping with prayer or rituals, or coordinating after-death assistance such as funeral planning (Kaasalainen et al., 2011).

A study by McKee et al. (2010) explored the role of hospice volunteers in rural palliative care. The study found that volunteers were most valued for their ability to sit and listen; where other health care providers were busy, volunteers were able to give palliative care the time it needed to be done well. The study also found that the shared history between volunteers and patients allowed a way for the dying person to connect with their community outside of their home, and played a special role in contributing to the quality of life of a patient by walking the line between professional and friend. In this way, volunteers were able to fill the informal role of visiting neighbours and friends, reminding patients that they were still an important parts of their communities (McKee et al., 2010).

2.1.6 Significance of Place

Two articles began to address the question of the role of place within rural palliative care, both by Giesbrecht et al. (2016a & 2016b). Within these articles, five forms of boundaries were discussed to explore the role of place: political (provincial borders), jurisdictional (of regional health authorities, First Nation vs. non-First Nation), geographical (defined relationally as "here vs. "there," or "near" vs. "far"), professional (informal organizational boundaries) and cultural (defined relationally as "them" vs. "us") (Giesbrecht et al., 2016b). The study found that place was an important factor in rural palliative care, and that rural communities distinguished

themselves culturally from the surrounding urban regions (Giesbrecht et al., 2016a). Major comparisons were drawn between rural and urban areas, Indigenous vs. non-Indigenous, and Canadian culture vs. newcomer health provider culture (Giesbrecht et al. 2016b). Particular frustration arose for rural residents with health providers who did not understand their local culture (Giesbrecht et al., 2016b).

2.1.7 Discussion

Since the publication of Robinson et al.'s (2009) review, many of their identified target areas for research have been addressed. Literature examining models of care provision in rural Ontario and the evaluation of these models has been given priority in the past ten years, as well as grounding studies examining access to specialist services and cost analyses to justify tailored models of palliative care in rural contexts. Despite this progress, a number of areas have not yet been given attention. These include the use of technology in offering palliative care to rural populations, research on how to recruit larger sample sizes in rural areas, and studies focused on patient experiences of care. One glaring omission is any research focused on the role of specialized care within rural palliative services, including any research explicitly on spiritual and psychosocial aspects of care. The only cases in which these aspects of care were mentioned in any of the studies included in this review was in reference to Indigenous care (Kelly et al., 2009; Koski et al., 2017; Nadin et al., 2018). Even with these studies, none went into detail about what this care included in practice. There remain no studies in rural Ontario focused on understanding how, in the eyes of patients, providers, or families, these aspects of care can be addressed practically.

An additional gap that remains is an understanding of how culture interacts with the rural context to influence care needs, if at all. Several studies in this review state that care delivery looks different in every rural context (Conlon et al., 2016; Giesbrecht et al., 2016a, Giesbrecht et al., 2016b Sussman et al, 2012), and that there is a greater need for studies that explore the specific needs of rural communities through the lens of culture (Giesbrecht et al., 2016a; Giesbrecht et al., 2016b). This being said, it is unclear what these studies mean by "rural" culture, and there is lack of consensus on whether or not such a thing exists in the first place. Several studies included in this review acknowledge that culture plays a large role in palliative care for Indigenous Peoples (Kelley et al., 2018; Kelly et al., 2009; Koski et al., 2017; Nadin et al., 2018; Prince et al., 2019; Pereira et al., 2016; Seow & Bainbridge, 2018), but this is the extent of consensus on the topic within this body of literature. In order to understand whether or not Canadians perceive that a rural culture exists outside of only Indigenous groups, and, if it does, how it interacts with rural palliative care needs, it is necessary for Canadian researchers to clarify what "culture" means in the palliative care context, how it is used, which groups are perceived as having culture and which groups are not, and what elements of palliative care are influenced by this culture. Section 2.2 will address these questions in further detail.

2.1.8 Conclusion

It is clear from the reviewed literature that research on palliative care in rural Ontario is gaining momentum. Since the publication of Robinson et al.'s 2009 review, Ontario's rural palliative care knowledge-base has grown substantially. Major areas of attention in the past ten years include the development of models for palliative care provision, methods to evaluate these programs, understandings of cost and accessibility issues, a limited body of literature examining

patient and family caregiver experiences in receiving and providing this care, health care provider experiences in offering palliative care, and the significance of place in rural palliative care. Areas that could be looked at in the future include examinations of how technology could be used to improve palliative care access, how to recruit rural research participants to support the improvement of local palliative care, the role of specialists in rural palliative care, and more explorations into patient experiences of care. Particularly, there is a need for research specifically examining spiritual and psychosocial dimensions of palliative care in rural settings, as well as studies further examining the role of culture in rural palliative care. The study presented in this thesis begins to fill these two gaps by examining the practical offering of spiritual and psychosocial care in one particular rural context, therefore identifying not only what spiritual and psychosocial palliative care could look like in one specific rural context, but exploring further the possibility of what others have hypothesized: that rural communities possess their own "culture" that can influence care needs.

2.2 The Role of Culture in Canadian Palliative Care

Before I can explore the role of culture in rural spiritual and psychosocial palliative care needs, it is necessary first to understand how the concept of culture is used and discussed in Canadian palliative care literature. Considering Canada is an increasingly multicultural nation, it is critical that Canadian health providers consider culture when creating individual care plans. In order to provide accessible and holistic care, health providers must understand how culture influences palliative care needs and provision in Canada (Mazanec & Tyler, 2003). Unfortunately, few guidelines exist providing health professionals with a framework for understanding the influence of culture on care needs. In the following review, I observe how the concept of culture has been examined in Canadian palliative care research. This review provides

an overview of recent literature connecting culture and palliative care, with the intention of revealing insight on how health care providers can offer culturally relevant palliative care to patients and the implications this holds for palliative care research in rural Ontario contexts.

2.2.1 Methods

In order to gather literature addressing culture in Canadian palliative care efforts, a scoping review of medical databases was conducted (Figure 2). Pubmed, Web of Science, and Embase were chosen as search databases due to their disciplinary nature. Since the goal of this review was to determine how culture and palliative care have been discussed and related in health literature, these databases were best qualified to produce a specific overview of health research in this area.

These databases were screened for study location and topic, as well inclusion of culture as a study concept. The keywords "Canada", "Ontario," "Manitoba," "Saskatchewan," "Alberta," "British Columbia," "Yukon," "North West Territories", "Nunavut," "Newfoundland," "Quebec," "New Brunswick," "Nova Scotia" and "Prince Edward Island" were used with the Boolean phrase "OR" to ensure that all research conducted in Canada was included in the initial search. The keyword "palliative care" was also used, with "end of life care" included in the search strategy as alternative phrasing, as many researchers use the two terms synonymously. Finally, "culture" served as a last search keyword to narrow literature to the scope of this review.
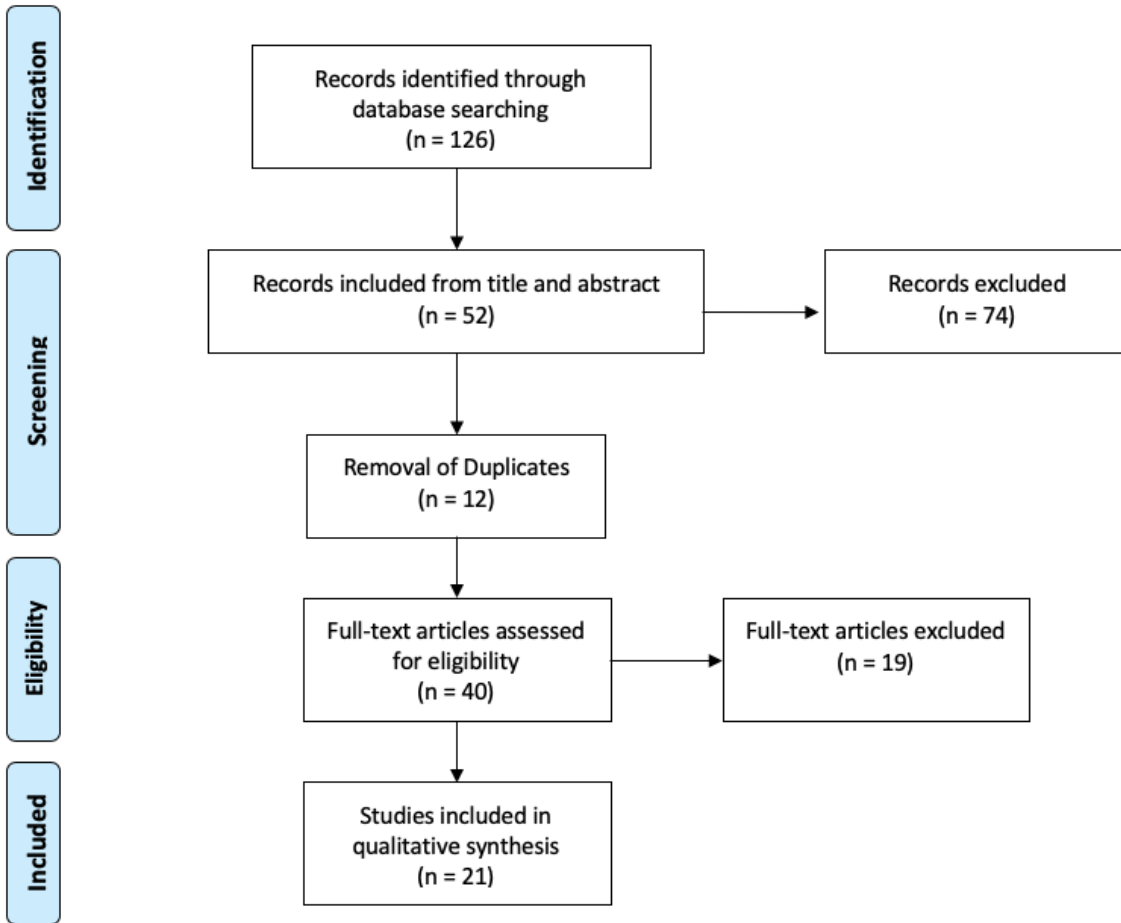
Figure 2: PRISMA record (Moher et al., 2009) of database search and screening process to produce the 21 studies included in this review.

The initial search of all three databases yielded 126 hits. The title and abstract of each of these hits was screened for inclusion or exclusion. Included articles were primary research articles conducted in Canada between 2008 and 2018. This timeframe was chosen in order to get a recent look at how current researchers discuss culture in their explorations of palliative care. Included articles also contained the term "palliative care" or "end of life care" in the abstract. Articles were excluded if they referred to "organizational culture" in the abstract. This term refers to systematic culture within care organizations. Because the objective of this review was to determine how researchers have discussed patient culture in palliative care provision, articles

looking at culture in this light were not included. However, a review of these articles might constitute a project for future research.

Following the assessment of these articles, relevant studies (n=52) were uploaded to Mendeley. Mendeley was then used to remove duplicates (n=12). Further assessment of full-text articles was conducted using the above inclusion and exclusion criteria, producing a final 21 articles that met the criteria of this study. These articles were then charted according to common terms, themes and ideas, as postulated in Arksey and O'Malley's (2005) framework for conducting scoping reviews. Articles were charted according to the following categories: methodology used, definitions or concepts of culture used, population studied, and cultural issues raised within the paper. Using these categories as a starting point for analysis, themes emerged from the literature revealing how Canadian researchers, health care professionals, families, and communities think about culture in relation to palliative care.

2.2.2 Concepts Used to Discuss Culture

Studies discussing culture in relation to palliative needs use a number of common phrases and concepts related to culture. Closely examined, these concepts shed light on how Canadians think about culture as a phenomenon and provide insight to dominant perceptions and attitudes regarding its relevance within palliative care research. Here, I will provide a summary of how these ideas have been used in recent literature and how they relate to ideas about the provision of effective palliative care, and discuss gaps, assumptions, implications and limitations of these.

Cultural Competency. A number of studies referred to "cultural competency" as a necessity in the provision of effective palliative care to culturally diverse populations. In discussing this concept, Maddalena et al. (2010) referred to Wells and Black's (2002) definition

of cultural competency as "the process of actively developing and practicing appropriate, relevant and sensitive strategies and skill in interacting with culturally different people" (p. 278). By this definition, cultural competence is a skill in constant development that contributes to a health provider's "capacity to respond to the needs of populations whose cultures are different from what might be called dominant or mainstream" (Wells & Black, 2002, p. 278). Johnston et al. (2013) discuss cultural competency as a lead-in to cultural understanding. They argue that health care providers can gain cultural competence by reflecting on their own biases, emotions and interests that are situated in their own culture, allowing them to recognize when their own cultural norms influence their care decisions (Johnston et al., 2013).

Johnston et al.'s definition of the term exemplifies a problematic potential slippage between acknowledging the importance of being self-aware, encouraging sensitivity to and respect of unfamiliar norms, and claiming cultures are somewhat easily learnable and static (Botelho & Lima, 2020). I return to critiques of the term, at the close of this section. Despite critiques, the term has been widely used in the palliative care literature touching on intersections with culture, and so has laid important groundwork for attention to culturally specific needs or expectations in palliative care provision. Castleden et al. (2010) emphasize the need for training in cultural competency for health care providers. Jovanovic (2012) echoes this recommendation in her study of hospice volunteer experiences, suggesting that building cultural competency is a responsibility of hospice and palliative care providers. She suggests that content for trainings should begin with patients' cultural preferences. Understanding these preferences can generate the creation of training content (Jovanovic, 2012). Additionally, Jovanovic (2012) suggests that maintaining cultural diversity among volunteer and staff travel experiences can contribute to an agency-wide level of cultural competency; if all cultural groups within the served area are

represented by hospice volunteers and staff members, someone will always be available to offer culturally relevant care to patients. Additionally, exposing oneself to different cultures could allow opportunity to practice these skills (Jovanovic, 2012).

Finally, advocacy is a frequently discussed concept in relation to cultural competency. Johnston et al. (2013) suggest that health providers who advocate for cultural competency among their staff create more accessible services for those who do not identify with the majority or mainstream culture. In recognizing distinct values, needs, and beliefs that exist within patients' cultural context, health providers not only provide effective and quality care, but advocate for the human rights and validity of that cultural group (Johnston et al., 2013).

Cultural Sensitivity. Canadian researchers discuss the concept of "cultural sensitivity" as a characteristic of good palliative care. Johnston et al. (2013) suggest that health providers are responsible for creating a culturally sensitive care environment that positively affects patients and families. This is facilitated by intentional efforts to learn the beliefs and values of those accepting care (Johnston et al., 2013). By getting to know the person receiving care, health providers may also get to know their culture. This individualized approach, although requiring a great deal of listening and learning on the part of the provider, creates a comprehensive strategy for offering culturally sensitive care in palliative settings (Johnston et al., 2013). Johnston et al. (2013) also extend this value to research, stating that studies exploring health care in specific cultural contexts must be carried out in a manner that is respectful of that culture's ways. They exemplify this principle in their study of the Mi'kmaq First Nation's palliative needs, valuing relationships within the research process, and beginning their exploration by gaining an understanding of Mi'kmaq historical and cultural context (Johnston et al., 2013). Johnston et al. (2013) end their study with a call for inclusivity within the Canadian health care system,

emphasizing the importance of including different worldviews in the planning, implementation and design of health services to ensure culturally sensitive care for all residents of Canada.

Cultural Accessibility. Within Canadian palliative care research, "cultural accessibility" is often referred to in tandem with a population's willingness to access services that are inconsistent with their cultural norms (Donovan & Williams, 2015, Pesut et al., 2011; Weerasinghe & Maddalena, 2016). In their study of palliative care in rural British Columbia, Castleden et al. (2010) found that health providers perceived those they defined as white and middle-class as more likely to access palliative care services, while Indigenous Peoples were considered more likely to "take care of their own" (p. 489). For these health providers, access to care was considered equal, but they expressed that not all groups were equally interested in accessing this care. In light of this perception, Castleden et al. (2010) highlighted a need for better understanding of Indigenous Peoples' needs and desires for palliative care, suggesting that they may be less likely to access care due to its lack of attention to cultural needs.

Similar results were found in Weerasinghe and Maddalena's (2016) study looking at palliative needs in South Asian immigrant populations in Halifax. This study found that South Asian families were less likely to access formal hospice or end-of-life care for their sick loved ones because of issues with clinical protocol (Weerasinghe & Maddalena, 2016). More specifically, South Asian families expressed concern about (a) not being able to feed family members personally, a custom used to express love even in when appetite is reduced in end-of-life circumstances, and (b) modesty with flimsy hospital gowns and discomfort with opposite-sex nursing (Weerasinghe & Maddalena, 2016). These concerns often led South Asian families to keep sick or dying loved ones at home without the assistance of formal palliative caregivers (Weerasinghe & Maddalena, 2016). Donovan and Williams (2015) observed a similar

phenomenon in Vietnamese immigrant populations, reporting that Vietnamese families were likely to decline a given health care service if they considered it culturally inappropriate, citing that accepting care would be a waste and that it would be better offered to another family.

In their study of rural palliative care needs, Pesut et al. (2011) found that the feeling of "being known" was important for rural community members when accessing care. Palliative patients were less likely to access home or hospice care in rural communities if they knew or thought they would be cared for by strangers (Pesut et al., 2011). Likewise, participants noted that prominent community members were more likely to access and be satisfied with palliative care because caregivers were more likely to know them and give personal attention. This led to an inequity in care quality; those who were leaders or held power in the community received what they perceived to be better care (Pesut et al., 2011). In order to rebalance this inequity, McKee et al. (2010) suggest the employment of community volunteers to act as "cultural navigators" (p. 109). They suggest that these volunteers might know that community in different ways from those providing care and help bridge cultural disparities, or gaps in understanding among health care providers of patients' cultural experience, to provide more personal care (McKee et al., 2010).

Considering the contexts in which these terms are used in Canadian palliative care literature, some assumptions and implications of how they are distinguished from one another arise. First, in the manner presented by the above literature, "cultural competency" appears to refer to a learnable, and perhaps teachable, skill that health care providers should aim to gain in to benefit their practice. While recognizing that calls for cultural competency are well-intended, Botelho and Lima (2020) caution against use of this term in ways that are overly simplistic, and ultimately can undermine those good intentions. While seeking to become more culturally

competent can improve health care providers' responsiveness to culture in practice, it can also

perpetuate assumptions about cultural experience and reduce patients to their cultural

backgrounds. It can also obscure limitations in cross-cultural understanding: healthcare providers

cannot expect mastery over a culture that is not their own. Botelho and Lima further note that if

seeking to build cultural competency, health care providers should not lose sight of the potential

blindspots that can accompany use of the term. They also should not lose sight of the individual

factor in treating patients, and acknowledge cultural aspects of care alongside other social,

historical, and personal factors (Botelho and Lima, 2020).

There is more explicit awareness of culture as one of several dimensions influencing

patient's needs in the literature on cultural sensitivity in palliative care. In the reviewed studies,

culturally sensitivity seems to refer to an awareness of culture that underlies practice, and

acknowledges the individual living in relation to that culture. Finally, "cultural accessibility" acts

as a descriptor for a system of care; is the care offered within this system accessible in its

practice to the cultural groups it aims to serve? Studies suggest that systems are only culturally

accessible to the groups for which it was directly designed. In this sense, the Canadian

biomedical system built to meet the needs of the Western norm may be reasonably transferable

for cultural minorities who do not view health or illness in a Western way. Building culturally

accessible services, then, requires a back-to-basics approach that will examine cultural norms

and design practice to meet needs influenced by those norms.

2.2.3 Key Elements of Palliative Care Influenced by Culture

Having reviewed the ways culture has been discussed in Canadian palliative care

literature, we can now look at what elements commonly arise within these discussions. This

section provides an overview of key elements related to the provision of palliative care through the lens of culture. These key considerations, identified through a review of the literature, a starting point for exploring intersections of palliative care needs and provision and cultural norms in specific settings.

Meanings of Life and Death. Several studies cite differences in views of life and death as barriers to culturally appropriate care (Castleden et al., 2010; Hampton et al., 2010; Johnston et al., 2013; Pesut et al., 2011; Nielson et al., 2013). Hampton et al.'s (2010) study interviewing elders of Indigenous communities found that elders want palliative care providers to understand the meaning of death within an Indigenous context. Elders stated that in their view, life and death were entwined – that death was not a symbol of the end of life, but a part of life itself "as necessary as birth" (p. 9). Elders expressed concern over the constant competition that exists between Western and Aboriginal models of care (Hampton et al., 2010). In their study of perspectives of Chinese immigrants on dying at home, Nielsen et al. (2013) similarly express concern that perceptions of life and death that differ from the Western norm are thought of as inferior. In the Western biomedical context, death is considered the enemy and experienced in a technical manner. From at least some Indigenous perspectives, however, death represented a transition from one life to the next; it is viewed as a journey to the Spirit World (Hampton et al., 2010). Elders in Hampton et al.'s (2010) study expressed wishes that palliative care providers would recognize and respect their Indigenous view of death and create care procedures that fit with this view and assist with the process of "dying healed" (p. 7). In order to ensure this, Nadin et al. (2018) call for partnerships between researchers, health providers and Indigenous communities to determine cultural norms relating to life and death, and to incorporate these into palliative care programs.

Castleden et al. (2010) discuss experiences of life and death as cultural phenomena that are entwined with cultural ideas of what constitutes a "good life" or "good death." The Western idea of a "good death" is often viewed as one that is resisted; in the biomedical view, "fighting" illness is viewed as admirable, and combative language is often employed when speaking of illness (such as a "battle" with cancer) (Veillette et al., 2010). Sinclair (2011) also explored this concept of "good death" in palliative care professionals and found that two views of a "good death" existed: an integrated view, in which death was considered a "continuum of life," (p. 182) and a disintegrated view, in which death is considered unnatural and in discord with a person's hopes for their life. The view of death that a person holds is highly contingent on cultural context (Sinclair, 2011). As such, a person's culture can be telling of their view and provide health professionals with insight into their state of mind as death approaches.

Visibility. The concept of visibility was commonly discussed in Canadian palliative literature, with particular emphasis on the invisibility of minority cultures. Castleden et al.'s (2010) interviews with British Columbian palliative health professionals revealed that outsiders considered the Sinixt Indigenous peoples extinct, despite the fact that they still existed in small numbers. This perception was held largely, according to Castleden et al. (2010), because health professionals had never treated Sinixt patients before. This in itself, the authors posited, may have been due to many Sinixt people not seeking palliative services due to cultural differences (Castleden et al., 2010). Invisibility can also occur because of stereotypical views of what an Indigenous person "should" look like. Interviewed health providers indicated that when an Indigenous individual does not match a stereotypical idea of what non-Indigenous health providers believe they should look like, they have difficulty identifying them (Castleden et al., 2010). Conversely, the opposite happens if Indigenous individuals do match this stereotype. In

these cases, interviewed health providers identifies these individuals as Indigenous, and would offer treatment according to assumptions of what Indigenous patients want, rather than asking (Castleden et al., 2010). Because of this challenge with discernment on the part of non-Indigenous health providers, there is heavy reliance on Indigenous peoples to self-identify in order to access the care they need (Giesbrecht et al., 2012). It is clear from Castleden et al.'s (2010) research that Indigenous people remain mysterious to non-Indigenous health professionals, further alienating them as a care-seeking population and contributing to their invisibility.

Maddalena et al. (2010) found results similar to those noted above, in Nova Scotia's African- Canadian population. Maddalena et al., (2010) found that Nova Scotian African-Canadian families preferred to care for their sick or dying loved ones at home rather than enroll them in hospice, rendering them an invisible population that was not receiving care. Later research by Maddalena et al. (2013) demonstrated that palliative services were of interest to African-Canadian families across the Atlantic provinces, however, those that were of most interest were those that supported their cultural desire to care for loved ones at home. Maddalena et al. (2013) conclude their study with an emphasis on increasing community awareness in a culturally sensitive manner, in this case the holding of a town hall meeting to communicate available services. By exercising intentional efforts to communicate with cultural populations, culturally relevant services become more accessible (Maddalena et al., 2013).

Spiritual/Religious Care. Several studies looking at palliative needs in specific cultural contexts expressed the need for adequate spiritual and psychosocial services. In many instances, spiritual needs mapped to religious needs. In Ebrahim et al.'s (2011) study of Sikh end-of-life preferences, it was expressed that prayer, recitations, and hymns played a large role in family

bereavement. Ebrahim et al. (2011) recommended that in order for hospitals to offer culturally sensitive care, Sikh families must be allowed to perform these religious or spiritual practices in close proximity to the patient.

Weerasinghe and Maddalena's (2016) study of South Asian end-of-life needs found that religious beliefs were entwined with perspectives of death. Examples of this included the Buddhist belief in rebirth – that death signified the end of suffering and a new beginning – and the Hindu belief that a family member's good Karma might provide hope for recovery (Weerasinghe & Maddalena, 2016). Weerasinghe and Maddalena (2016) echo Ebrahim et al.'s (2011) call that Canadian hospitals must be accommodating to religious rituals or practices in order to care for the spiritual well-being of patients and their families.

One study examining palliative needs in Nova Scotian African-Canadian communities identified that sense of well-being was linked to prayer, Bible reading and the involvement of church in palliative care (Maddalena et al., 2010). In one case, a patient wanted to be baptized by immersion while receiving palliative care in preparation to be with God (Maddalena et al., 2010). Throughout Maddalena et al.'s (2010) study, the concept of "fatalism," or the idea that one's fate is in the hands of God, was prevalent.

For Vietnamese immigrants, caring for spiritual health of family members at the end of life meant telling happy stories from the past and engaging in prayer (Donovan & Williams, 2015). In Dutch Reformed communities, religion was labeled as a critical element of cultural identity that affected every care decision (Donovan et al., 2011).

The literature search surfaced several articles which include reference to preparation for the afterlife in Indigenous communities in Canada (Castleden et al., 2010; Giesbrecht et al., 2012; Hampton et al., 2010; Johnston et al., 2013). The desire to practice prayer, ceremonial

sweats, and gathering of loved ones to "let go" of the patient indicate that spirituality and religion played a substantial role in palliative care for many Indigenous residents of Canada and must be given attention by health providers (Castleden et al., 2010; Hampton et al., 2010; Johnston et al., 2013). The results of these studies imply that the Canadian understanding of spirituality as it relates to culture often maps to religious care in a palliative care context.

Family and Community Involvement in Caregiving. Studies examining palliative care in cultural minorities regularly cited family involvement in care and care decisions as a significant issue in palliative care provision. Among the Mi'kmaq, Johnston et al. (2013) found that family members desired to perform personal tasks for their sick loved ones, including laundry, cooking meals, and housekeeping, as an indication of love and support. Family and friends also played a large role in that patient's journey to the Spirit World. It was culturally normal for many people to gather with the patient while they were in the hospital so that they would not have to make the journey alone (Johnston et al., 2013).

Among Sikh patients, family was considered the primary health care decision-maker (Ebrahim et al., 2011). In Sikh families, the eldest son held responsibility for end-of-life decisions for his parents, and it was considered respectful for health providers to consult the family before delivering news of prognosis (Ebrahim et al., 2011). Similar responsibility was observed in Vietnamese families; however, the primary caregiving role traditionally fell to the wife of the eldest son and was almost exclusive to parental care for immediate family (Donovan & Wilson, 2015).

Among Atlantic African-Canadian families, Maddalena et al. (2013) found that home caregiving was the most common form of end-of-life care, and that caregivers considered it a personal sacrifice and ultimate act of love to care for sick or dying loved ones. Similar results

were gathered by Pesut et al. (2014) and Veillette et al. (2010) who found that rural palliative

patients wanted to die surrounded by family and friends, and that cultural meaning was

associated with family providing informal home palliative care. In rural communities, a strong

emphasis exists on the values of community and mutuality (Pesut et al., 2011). Neighbours are

considered "necessary," and hold a role in providing emotional support for palliative patients

(Pesut et al., 2011). These studies point to the importance of including family and community in

the care of palliative patients, and that in doing so, cultural needs may be met within care.

Language and Communication. Three studies reported language as important to the

provision of culturally relevant care. All studies mentioning the centrality of language to

culturally relevant care were conducted in Indigenous populations. Thus, for example, Johnston

et al. (2013) reported the Mi'kmaq preference not to use the phrase "end of life" when discussing

death. This was due to the fact that the Mi'kmaq viewed death as a continuation into the next

life. As such, referring to care as "end of life" care was culturally inappropriate. A study by

Hordyk et al. (2017) exploring Inuit translator experiences with palliative care further explores

this idea of culturally appropriate language. Hordyk et al. (2017) found that interpreters were

usually relied upon to transmit news of death. One of these interpreters expressed that they

should "never interpret word for word" (p. 5) as the way non-Inuit doctors phrased the news was

insensitive (Hordyk et al., 2017).

In addition to the importance of providers understanding culturally-specific terms and

meanings of words when working with Indigenous populations, manner of communication was

also explored in culture-related palliative care literature. Kelly et al. (2009) found that Cree and

Ojibway Peoples in Northwestern Ontario preferred direct communication from doctors and

expressed that they did not want to be given false hope. Along with this, Indigenous individuals

interviewed reported wanting this communication to include words of encouragement however,

there was no specification of what this might sound like (Kelly et al., 2009). It should be noted

that these insights arose from specific groups and in the context of relatively small studies: these

may not be generalizable across diverse Indigenous groups in Canada.

2.2.4 What constitutes a "cultural" population in Canada?

While cultural palliative needs have been studied within a number of distinct groups in

Canada, it remains unclear following a review of the literature what groups are considered

"culturally distinct" and on what bases. Still, an examination of which groups have been the

focus of studies of culture and palliative care in the Canadian context offers a starting for point

for clarifying how cultural difference is defined and applied in the Canadian context.

Eight out of 21 palliative care studies that included culture in their discussion were

conducted in Indigenous populations (Castleden et al., 2010; Giesbrecht et al., 2012; Hampton et

al., 2010; Hordyk et al., 2017; Johnston et al., 2013; Kelley et al., 2018; Kelly et al., 2009; Nadin

et al., 2018). Castleden et al. (2010) justifies the study of cultural palliative needs in Indigenous

communities in their research on palliative care in rural British Columbia, emphasizing that in

order to strengthen palliative care approaches for Indigenous patients, health providers must

acknowledge the cultural, linguistic and ethnic diversity that exists among Indigenous

communities. Each people group has its own set of customs, values and beliefs, and should be

treated and studied as a distinct cultural group (Castleden et al., 2010).

Six studies on palliative care and culture in Canada does focus on non-indigenous

populations. These populations include groups that are labelled in the Canadian census and also

often define themselves as culturally or ethnically distinct, and include Chinese Canadians

(Nielsen et al., 2013), Vietnamese Canadian (Donovan & Williams, 2015), and South Asian immigrants (Weerasinghe & Maddalena, 2016), as well as groups identified as culturally distinct based on racialized identities, such as African-Canadians (Maddalena et al., 2013; Maddalena et al., 2010). The exploration of culturally-specific values and preferences for end of life palliative care have also been explored with a focus on particular religiously defined group, including Sikh (Ebrahim et al., 2011) and Dutch Reformed populations in Canada (Donovan et al., 2011).

The remaining studies included in this review address culture in relation to rural palliative needs (Jovanovic, 2012; McKee et al., 2010; Pesut et al., 2011; Pesut et al., 2014; Veillette et al., 2010). Studies also identify rural culture as distinct from urban culture (Castleden et al., 2010; Pesut et al., 2014), specifying that urban models of care cannot be transplanted into rural contexts because ideas of good care are influenced by rural residents' lived experiences (Pesut et al., 2014). These experiences are shaped by political, social and economic realities that exist within rural contexts (Pesut et al., 2014). Rural individuals believed themselves to have unique perspectives about what constituted a "good death," and held a deep commitment to their community that is not as prevalent in urban areas (Pesut et al., 2014). In contrast, Veillette et al. (2010) warn against the homogenization of "rural" Canada as one distinct culture in itself. Pesut et al. (2014) found that participants in a study on rural palliative care needs considered their community culturally separate from surrounding rural communities and were quick to distinguish themselves from neighbouring towns as a unique context. In order to account for this phenomenon and avoid the generalization of culture to all rural communities, Veillette et al. (2010) examined culture in two different rural regions in Quebec. Veillette et al. (2010) was the only study within this review to make a cultural distinction between rural communities.

Some researchers approach the study of culture at a broad level, such as Pesut et al.'s (2014) study of rural palliative needs, while others address specific ethno-cultural, racial, linguistic, or religious groups, such as Ebrahim et al.'s (2011) study of Sikh preferences or Donovan and William's (2015) study of Vietnamese palliative needs. The defining and locating of culture in such diverse ways indicates potential assumptions as well as challenges of studying culture and palliative care in tandem.

2.2.5 Discussion

Canadian palliative care research examining care needs through a cultural lens is not extensive. Still, it is clear from the reviewed studies that knowledge gained from such research has begun to generate valuable and nuanced insights into diverse, population-specific preferences, expectations, and beliefs associated to palliative care. The variety of populations targeted by this research reveals "culture" to be a recurring term for referencing less clinical, more social and psychosocial patient needs. Also important to underline is that in Canadian palliative care literature, "cultural" factors include religious, ethnic, rational and geographical factors that interact with one another to form a comprehensive and complex mosaic of lived experience that sets the individual apart from the "majority." Interestingly, this "majority" is never explicitly mentioned, but implicitly seems to refer to a population in which an absence of culturally specific needs exist. Culturally relevant, sensitive, and accessible care, if we follow the lead of this literature, is important to the provision of high-quality care to particular individuals considered "other/cultural" when compared to the implied "culture-free" population of non-indigenous, non-racialized, white, urban-residing individuals. Whether or not group is "cultural"

is therefore based on either their Indigenous, ethnic, or racialized identity, rural location, or religious affiliation.

This draws attention to a major pitfall in the Canadian understanding of culture; while cultural difference is usually used to define practices and values of demographic minorities, all social actors in a given national context harbor culture. It is one's position in society, as a member of dominant or non-dominant cultural group, that facilitates the framing of one's practices and values as "cultural," where "cultural" could be equated with "different, vs. normal" (Giesbrecht et al., 2016b).

Many authors (Donovan & Williams, 2015; Johnston et al., 2013; Maddalena et al., 2010; Weerasinghe & Maddalena et al., 2016), consistent with social anthropological theory, define culture as a dynamic force that exists at many levels and disperses through populations in complex ways (Donovan & Williams, 2015). For example, while a distinguishable culture may encompass Canada, another distinct culture might exist that is specific to rural Canada. Again, rural Canada might display multiple cultures specific to communities within it. To layer the concept further, within each rural community there may exist additional sub-cultures, such as specific social, racialized, and religious groups. This layering concept continues at a seemingly infinite level, which can make attending to culture in palliative care a difficult and potentially overwhelming task.

This complexity raises the question: how can the concept of culture be adequately examined in the contexts of Canadian palliative care? One way researchers might approach this idea is through the lens of Leininger's (1997) Culture Care Theory, which will be used in this study to examine culture in the rural context of Duffy's Hill. Based on anthropological principles, Culture Care Theory postulates that cultural factors affect the health needs of *all*

people, not only those who identify with cultural minorities (Leininger, 1997). It proposes that similarities and diversities exist between cultures, that worldview, cultural and social factors influence care outcomes, and that both cultural and professional factors influence how health professionals offer care (Leininger, 1997). When examined together, these aspects of Culture Care Theory provide a rough framework from which Canadian researchers can explore cultural palliative needs. By recognizing the unique cultural context of each population studied, health providers can develop specific strategies to offer culturally relevant and accessible care for palliative patients (Morrison, 2018).

2.2.6 Conclusion

It is clear from this review that culture plays a large role in assuring effective and holistic palliative care for a number of Canadian populations. It has been shown that what constitutes a norm for one community does not directly translate to another. There is a demonstrated the need for cultural competency and sensitivity on the parts of Canadian health providers, particularly those working in urban areas where cultural differences are more likely to be observed. By being reflexive about what we mean by "culture" in a palliative care context, lending attention to common cultural norms related to views of life, illness and death, spiritual and psychosocial needs, involvement of family and community in care, as well as holding an awareness of visibility (or invisibility) of cultural minorities, health providers can create culturally-accessible palliative programs that give attention to social determinants of health and promote healthcare-seeking behaviours (Kreuter et al., 2003). The continued study of values and preferences that are central to defining good care in the context of one's experience of culture will contribute to more holistic health system equipped to care for *all* residents of Canada, not only those identifying

with the cultural majority. The study outlined in this thesis will do so by lending attention to values, norms, beliefs and practices that underlie spiritual and psychosocial palliative care needs in one rural Ontario context, allowing for the development of culturally accessible palliative care programming in this setting.

2.3 Rationale for the Current Study

It is clear from the literature gaps highlighted in this chapter that this study is warranted. A study focused exclusively on spiritual and psychosocial aspects of palliative care in rural Ontario is long overdue. In focusing on these aspects of care, this study responds to a long-standing call for more attention to these areas among Canadian palliative care researchers (Bainbridge & Seow, 2018; Barnabe & Kirk, 2002; Kelley et al, 2003). It is also clear from the literature that spiritual domains of care in particular are intertwined with culture (Castleden et al., 2010; Donovan & Williams, 2015; Ebrahim et al., 2011; Hampton et al., 2010; Johnston et al., 2013; Weerasinhge & Maddalena, 2016). There is no universality to spiritual needs in palliative care: practices, values and expectations related to spiritual care provision are culturally contingent. Thus, to study spiritual care provision and needs in the context of rural Ontario, one needs to simultaneously attend to the potential cultural particularity of that provision and those needs in that context.

While the primary objective of this study is to provide insight into what it means to offer spiritual and psychosocial palliative care in one particular rural Ontario context, it also achieves a secondary objective of determining whether cultural norms underlie this meaning, implicitly contributing to current speculation as to whether rural communities can be considered "cultural" groups. While this question has been posed by several researchers in this review (Castleden et al., 2010; Giesbrecht et al., 2016a; Giesbrecht et al., 2016b; Pesut et al., 2014; Veillette et al.,

2010), no studies have yet explicitly asked the question, "Is there something culturally specific to palliative care needs and the provision of palliative care in this rural community?" While this study is exploratory, and the sample size is much too small to make any definitive conclusions, the discussion presented here will begin to unravel the answer to this question, providing a vignette for what a fuller study to address this debate could look like in the future.

This study has been developed in partnership with a community health centre in Duffy's Hill, here referred to as "Duffy's Hill Community Health Centre," or "DHCHC." An advantage to the conduct of this research in Duffy's Hill is that specific spiritual and psychosocial services have not yet been developed in this town. In gathering detailed descriptions from Duffy's Hill's providers of palliative care about the palliative care needs they observe, and their practice, and analyzing these with an eye to potential cultural (shared and context-unique) particularities to needs and provider experiences, results may inform development of culturally appropriate services.

Chapter 3: Methods

The work presented in this thesis constitutes an exploratory, qualitative study that employs a community-based participatory approach to the study of palliative care needs and provision in Duffy's Hill. Through partnership with a local health authority in Duffy's Hill (DHCHC), qualitative interviews were set up with palliative care providers living and working in Duffy's Hill to determine what it means to attend to spiritual and psychosocial palliative care needs in this context in their views. In the following chapter, I outline the rationale for these methods and provide details on the procedures involved in this study.

3.1 Qualitative Methods

Using a qualitative approach is appropriate for the exploration of individual realities and experiences of offering spiritual and psychosocial palliative care. Qualitative methods are highly attentive to individual cases and contexts. Qualitative methods attempt to look at social life from many different viewpoints to understand the "how" and "why" of everyday life, rather than just the "what" or "who" (Neuman & Robson, 2012). In doing so, qualitative methods allow for interpretation that is attentive to specific social, cultural, historical, and geographical contexts (Neuman & Robson, 2012). The use of qualitative methods for this exploratory study is appropriate, as I interpret results as products of the contexts in which individuals live and work. This research aim to understand why participants hold the ideas they do about spiritual and psychosocial palliative care, and if and how these ideas are shared and constructed among individuals in this context.

The use of qualitative methods is also useful to support the accessibility of results to the population they concern. According to Pesut et al. (2010), rural Canadian communities tend to exhibit more collectivist cultures than their urban counterparts, and these collectivist cultures tend to attribute a particularly high value to storytelling (Hampton et al., 2010). As humans, we live and breathe stories. Thomas King said this beautifully, writing that "The truth about stories is, that's all we are" (King, 2003, pp.2). In choosing to gather and present data qualitatively, the findings of this study are more engaging to participants and their community. The qualitative nature of this study aligns with cultural preferences and norms, making it more relatable for those in the community it concerns, and therefore "culturally accessible" (as discussed in Chapter 2). Additionally, an objective of this research is to inspire health policy makers to act toward creating spiritual and psychosocial palliative services in rural Ontario. Tracy (2010) suggests that a hallmark of good qualitative research is its "resonance" or its "ability to

meaningfully reverberate and affect the audience" (p.844). Tracy (2010) cites aesthetic merit, or

a study's artistic presentation, as a method of ensuring resonance. In highlighting the qualitative

nature of participants' experiences, the results of this study will resonate with the intended

audience (i.e. health professionals and policy makers), inspiring an emotional response that best

encourages action to improve rural palliative services (Reissman, 2008).

3.2 Community-based Participatory Research

This study employed community-based participatory methods to ensure that the results

gathered were directly relevant, useful, and applicable in a particular community. Community-

based participatory research is that which prioritizes the goals and desires of a particular

community (Israel et al., 1998; Israel et al., 2001; Kidd & Kral, 2005; Wallerstein & Duran,

2006). Community-based participatory research involves community members and local

stakeholders in every step of the research process, including the design, conduct, and

dissemination of research (Kidd & Kral, 2005, Wallerstein & Duran, 2006). The primary

objective of community-based participatory research is to facilitate community-appointed

research projects that directly affect those with whom it is conducted (Kidd & Kral, 2005). In

doing so, a community-based participatory approach enhances relevance of research to those

directly affected by it (Israel et al., 1998) and the reliability and validity of results by

incorporating local knowledge into its collection and analysis (Israel et al., 1998). Israel et al.

(1998) suggest that community-based participatory research has potential to link across cultural

differences between partners, making it particularly well-suited for this research.

Community-based participatory research is distinguished by its focus on relationships at

the core of the research (Minkler & Wallerstein, 2003). In order to conduct true community-

based participatory research, I needed sought a relationship with a local partner, DHCHC, and

sought their guidance and involvement in the creation of attainable goals, participant sampling, planning of interview guides, and analysis of results (Kidd & Kral, 2005). This way, although I approached this research with a proposed research question and area of interest, the specific goals of this study were tailored to meet the unique, self-identified needs according to on-the-ground workers in Duffy's Hill. (Israel et al., 1998; Kidd & Kral, 2005). This was an important part of the research process in order to ensure that the community in question directly benefitted from the results gathered in this study. While constituting a master's thesis, this study also functions as a community consultation with the aim of learning from providers of palliative care what kinds of specific services could be offered to address the spiritual and psychosocial needs in the area as part of a broader move to establish a rural hospice.

To establish this partnership, I reached out to the director of client care at DHCHC, who become my key contact within the community. After presenting the study idea via email, an in-person meeting was scheduled to discuss a draft of the research proposal and determine how it might be tailored to fit with DHCHC's goals for the community. Looking to establish a rural hospice in Duffy's Hill, my partners at DHCHC determined that this study could support the development of culturally relevant spiritual and psychosocial palliative services in the area. Once ethics approval was gained from Western University, the study proposal was presented to the DHCHC Board of Directors, who approved the study for commencement.

3.3 Recruitment and Sampling

Interviews were conducted with health professionals involved with palliative care provision in Duffy's Hill and the surrounding area. I made the decision not to interview patients or family members because patients receiving palliative care are often experiencing shock and trauma. Although interviewing these individuals would produce rich and valuable results that

could have significant implication for future palliative programs, it would be necessary for me to seek training in engaging with these vulnerable individuals in order to effectively interact with them in a research capacity (Abrams, 2010). Because this study was conducted as a master's project and completed in two years, I simply did not have the time or resources to seek out this training. As such, interviewing patients and family members is a viable premise for a future research project.

Sampling was achieved purposively and opportunistically through community partners. Key contacts from community partners made the initial contact with potential participants (doctors, nurses, social workers, personal support workers, hospice volunteers, spiritual care providers, traditional healers, or any other health professional who has experience caring for palliative patients). This contact involved key contacts forwarding an email from me to potential participants explaining the nature of the study. Interested participants were invited to contact me directly, without informing key community contacts who forwarded the email. I anticipate that finding potential participants might be difficult in rural areas, as most rural communities do not have designated palliative teams. Since many rural areas, including Duffy's Hill, do not have designated "palliative teams," participants need not have considered themselves "palliative professionals" to participate; rather, they may have considered themselves "generalists" who care for those with life-threatening or terminal illness (Kaaselainen et al., 2014). Invitations were directed to health professionals who had experience treating patients in palliative positions (i.e. facing terminal, chronic, or incurable illness).

3.4 Procedures and Informed Consent

Once participants expressed interest in participating in the study, they were invited to attend an interview with me at a time and place of their choice. Before the interview began,

participants were asked to read and sign an informed consent form outlining the study objectives, procedures, and intended outcomes. This form exercised full transparency of the goals of the study and allowed participants to sign the form of their own accord upon deciding to participate (Smythe & Murray, 2000).

Interviewees were assured that they could choose not to answer any question with no detriment or consequence to them. Interviews were audio-recorded with participants' permission. This consent for audio-recording was obtained separately from consent to participate; participants had the option to check a "yes" or "no" box on their consent form, identifying whether they wished to be recorded. All participants gave consent to being audio recorded in this study. I also conducted field notes during the interviews, making note of facial expression and body language, as well as any initial themes I noticed in their stories. These themes were used as a preliminary analysis, identifying recurring or unique elements of stories that struck me as particularly significant. In accordance with the interpretive constructivist approach (described in greater detail below), these notes were informed by both participants' explicit and implicit statements in response to interview questions. Alongside explicit points of emphasis and key themes outlined by participants, my notes reflected the potential meanings, values, norms, and attitudes towards spiritual and psychosocial care needs and provision implied by the examples and answers provided by participants.

Participants were asked to choose a pseudonym for themselves to be associated with each of their transcripts to protect their identity. Transcripts, audio-recordings and notes were encrypted and stored in a password-protected folder on Western's Microsoft OneDrive server.

3.5 Data Collection: Qualitative interviews

In order to gather qualitative data, I conducted semi-structured interviews with health professionals who have experience treating palliative patients. Questions asked during these interviews were developed using Flanagan's (1954) Critical Incidence Technique, as well as input from community partners. The Critical Incidence Technique postulates that important facts or insights can be gathered from human behaviour in specific incidents, and that these insights can be used to solve practical problems and develop broad principles to guide practice (Flanagan, 1954). In keeping with this assumption, participants were asked to recall and describe three patient cases (or "incidents"): one where the provision of spiritual and psychosocial care was challenging for them, one where they felt spiritual and psychosocial care was important to the patient, and one where they felt spiritual and psychosocial care was provided well. Additional questions asked participants to share what spiritual or psychosocial care means to them: what is it, what about it is important, and why does it constitute a major focus in holistic palliative care?

While the primary source of data for this study was the narratives presented in interviews, a number of additional questions were asked of participants preceding these narratives. These inquired about their connection to the community, what they thought was unique about it and what it was like living and working there. Participants were also asked to explain what they thought spiritual and psychosocial palliative care meant, and how they viewed their role in providing these services. A number of these questions were added at the request of community partners at DHCHC to answer some questions they had for the development of their hospice.

In summary, each interview was comprised of three sections: section one gathered information on participants' views of their communities, independent of palliative care; section two asked participants to explain their views of spiritual and psychosocial palliative care; section three asked them to share stories about three critical incidents.

In order to ensure the highest level of "accuracy" possible within this qualitative study, participants were invited to review and to verify their stories after they were written into the final report. Four of the six participants accepted this invitation. By returning the report to participants for affirmations, results are shown to be consistent with Ballinger's (2006) criteria for validity and reliability within rigorous qualitative research.

3.6 Analysis

Findings presented in this study are based on application of an interpretive constructivist approach to the analysis of interview data. As noted in Chapter 1, an interpretive constructivist approach is appropriate to analyzing healthcare needs and practices through a cultural lens, as culture, including values, norms, or attitudes, are often tacit or taken for granted. Applied to interviews, an interpretive constructivist paradigm involves analyzing participants' statements for implicit as well as explicit meanings; this includes implicitly and explicitly described values, norms, and attitudes underlying needs and practices of palliative care provision being described by participants (Neuman & Robson, 2012).

Each digitally recorded interview was transcribed verbatim. Interviews were coded individually for ideas that struck the research team as significant to the participant. Ideas within individual interviews were then compared between interviews to identify shared and contrasting perspectives among health care providers that could reveal cultural particularities about the Duffy's Hill context. Related ideas identified between interviews were collated into themes and are presented in the results chapters of this thesis (Chapters 5-9). Analysis was conducted iteratively, with room for themes to change with the addition of new information from subsequent interviews.

Results are presented ideographically in this thesis; by this I mean that I attempt to give a highly detailed description of what spiritual and psychosocial care means in this context based on participant answers, and make connections between these, revealing shared meaning when it arises (Neuman & Robson, 2012). In this way, the thesis shuttles between the particular and the shared—aiming to do justice to the meanings of spiritual and psychosocial palliative care in Duffy's Hill as lived by individual providers, while also identifying shared themes and emerging potential social and cultural norms that explicitly connect and sometimes appear to underlie these shared themes or perspectives.

3.6 Ethical Considerations

Ethics approval for this study was granted by Western's Non-medical Review Board. A number of ethical issues were carefully considered in the development of this study. First, the possibility existed that trauma or feelings of discomfort could arise for participants as they share their answers and stories (Smythe & Murray, 2000). Although this was impossible to predict, steps were taken to prepare for these instances should they occur (Smythe & Murray, 2000). If participants seemed willing, I sat with them to talk through their thoughts, gradually bridging to ordinary conversation to the point where participants felt ready to leave. This ensured that they were not leaving with an air of discomfort, but rather left the interview on a positive note.

Second, it was important for me to acknowledge that though I was familiar with the area, I entered the Duffy's Hill context as an "outsider"; that is, a non-member of the observed community (Minkler, 2004). Because of this, I recognized the possibility that my role as a researcher may be intimidating or imposing to others who were unfamiliar with me and my work. As such, I was aware of my position in the eyes of my partners and participants and recognized that I needed to work actively to build trust and advocate for their goals within the

project (Minkler, 2004). It is only through this awareness that I was able to effectively assist my partners in producing accurate results to benefit their communities first.

Finally, a major ethical consideration in this research was how to ensure anonymity in gathering health professional stories. This was particularly difficult in a rural area, as although I used pseudonyms to protect the identity of participants, many participants likely know or work with one another and may be able to identify each other by the personal details included in the stories they share. With this in mind, participant anonymity was held in highest priority in the production of this manuscript, and I make every effort to avoid the use of potentially identifying details within the report. I made it very clear in the letter of informed consent that participants should not share any sensitive details that they do not want colleagues, patients or neighbors to know. It was also made very clear that participants could choose to withdraw from the study at any point, even after their interview had been conducted, in which case all information provided by that participant would be destroyed and not used in the final report. Finally, I asked participants to read over the report before publishing; first to ensure that what I have written is correct and resonates with those who shared their stories, and second to ensure that all participants feel that their identity has been appropriately protected.

3.7 Reflexivity

Additional rigour in this study is achieved by the inclusion of transparent and liberal reflexivity (Finlay, 2002; Ballinger, 2006). In the paragraphs that follow, I am explicit about how my own perspectives contribute to my interpretation of the stories gathered. In being reflexive about my own biases, perspectives, motivations and experiences related to the research topic, I aim to demonstrate how I come to the results presented in Chapters 5–9 and make overt my role in their construction. It is my intention that readers will be able to observe my position as a

researcher within the study along with the value and honesty of results (Finlay, 2002). In the following description, I attempt to reveal myself as an active participant in my own research, allowing readers to follow my thought process in coming to analytical conclusions and observe the influence I have on the results (Finlay, 2002).

While I would not describe myself as "from" Duffy's Hill, I am from the area. I thus have spent a lot of time in Duffy's Hill throughout my life; so much so that I would categorize Duffy's Hill as a part of my concept of "home." Being from a small town of similar demographic character, it is easy for me to feel a connection with this place and the way people live. I regularly return to my rural Eastern Ontario town because it is where my parents live, and because it is surrounded by a countryside where much of my extended family lives. Our ties to the Duffy's Hill region run many generations back, to the point where no one alive knows with confidence where our ancestors originally came from.

I share demographic characteristics with the majority of Duffy's Hill; I am a white, Christian woman and have lived in rural Eastern Ontario for most of my life. I can pass unnoticed in this town, and yet know many of those I meet when there. This contributes to my feeling of belonging and home in Duffy's Hill.

Part of my interest in spiritual and psychosocial elements of palliative care stems from my connection with the local church. Growing up, I attended church with my family nearly every Sunday. I still attend this same church regularly when I return home as an adult and maintain many friendships there. We refer to the congregation which we attend as our "church family." In many ways, this group functions as an extended family unit; we celebrate one another's joys and successes and mourn together over loss and tragedy. Growing up in this community, I was familiar with the concepts of spiritual and psychosocial care at the end of life long before I was

introduced to the term "palliative care." When a member of our church congregation became sick, we would pray together for both their physical and psychosocial healing. Our pastor would often make clerical visits to the sick or dying and bring messages of their well-being to the congregation so that we could send cards or words of encouragement. In the wake of death, meal trains were quickly organized to support the deceased's family in their time of grief. Congregants would make what we refer to as an "intentional" (that is, deliberate and pre-conceived) effort to spend time with grieving family members, to mourn with them, to remind them that they are not alone, and to take comfort in the belief that their loved one is with God, and no longer suffering. These practices taught at a young age the important role of community in caring for the non-physical needs of both patients and their families. I have observed first-hand how non-medical care that is specifically spiritual or psychosocial can play a large role in achieving a peaceful or "good death" for a loved one, and believe that research aimed at articulating how and why this occurs among Canadians will be beneficial to the Ontario health care system.

While I lived in my small, rural hometown for most of my life, I moved away for the first time to attend McMaster University in Hamilton and pursued a degree in Life Sciences. This program was science-heavy and equipped me with a strong understanding of the human body, broadening my already piqued interest in medicine and health care. During my time at McMaster, however, I discovered a second interest: anthropology. It was through taking various anthropology courses that I developed a strong interest in culture; particularly, how different cultural norms, values, beliefs, and practices influence health care needs and expectations among groups experiencing them. I was given the opportunity to explore this interest further through a volunteer experience with the Humanitarian Health Ethics research group at McMaster. It was

during this time that I was first introduced to palliative care and developed an awareness of the socio-cultural specificities of this care that can arise in different contexts.

It is my view that palliative care lends itself as an ideal model through which cultural particularities related to health care can be observed, especially those related to spiritual and psychosocial aspects of care. What constitutes a "normal" response to serious illness, death, and dying in one context might not be considered so in another. I became curious about which contexts this phenomenon could be observed in. Are there cultural particularities about my hometown that contribute to a "normal" view of palliative care that might not be shared in other rural Ontario contexts? Or is there something unique about rural Ontario that is shared between small towns when compared to urban contexts that is generally observed? In order to start exploring these questions, I decided to study spiritual and psychosocial palliative care needs in Duffy's Hill, in partnership with DHCHC.

In establishing a partnership with DHCHC, it was very important to me that this study address the specific needs of the people living in Duffy's Hill. For me, engaging with a local health care authority was necessary in order to ensure that my work was tangibly helpful to citizens of this town. I am invested in this town as a member of its community. I view this master's degree as an opportunity for me not only to pursue my academic interests, but to engage with my community, effectively fulfilling a commitment I feel to "give back" to a town in which I feel at home, and contribute to its goals as a member invested in its development. In this study, I serve my interests, but also my sense of who I am and where I am from at once.

My pre-conceived understanding of this town could also play a role in why I feel that applying a cultural lens in this case is important. While it is easy for me to feel at home in many predominantly white, Christian, rural Ontario contexts, I believe there is something different

about Duffy's Hill and the surrounding area that gives it particular meaning to me. In this study, I aim to articulate, for myself as much as for others, what lies behind my suspicion that there is something unique about life here. I aim to uncover, from the experiences of those who live here, what is meaningfully unique in this context that I could sense at some shallow level before this study was undertaken. Driving this study alongside its scientific goals, therefore, are some very personal interests in how spiritual and psychosocial care can be better inserted into Canadian health care, serving the community I consider core to my sense of home, and clarifying how the difference of life in Duffy's Hill place as compared to other non-rural places I have been in Canada may imply different ideals or needs for palliative care provision. In reading the following results, I encourage that all statements be considered within the context of my own worldview.

Chapter 4: Introduction to Setting and Participants

In this chapter, I introduce the study setting. This chapter has two parts. First, I describe Duffy's Hill and its character as a small, rural Ontario town, its unique history, its landscape and its demographic and economic profiles (Section 4.1). Second, I introduce the participants interviewed in the course of this study (by their pseudonyms) and their professional backgrounds (Section 4.2). The introductions in this chapter set up the context in which results are situated, presented in Chapters 5–9.

4.1 Duffy's Hill

Duffy's Hill is a small town of 9 000 people located in Eastern Ontario, Canada. Established in the mid 19th century on land granted to a Loyalist settler in the late 18th century, the town is situated about an hour's drive away from two mid-sized cities. Located on a major

waterway, the town boasts a busy downtown street with thriving local businesses, a train station, multiple local heritage museums, a recently built arena and community centre, and a small hospital. Duffy's Hill and the surrounding area serve as "cottage country" to many city-dwellers, and it embraces its character as a small-town getaway destination, proud of its quaint and picturesque aesthetic.

Demographically, the town follows the Canadian trend of having an aging population. In 2016, the national census determined 24% of the population to be 65 or over, and this proportion continues to climb. About 95% of its residents speak English, with the remaining 5% split between French and other non-official languages. Ninety-seven percent of the population belong to the majority of white, European descent, with just 3% made up by racialized minorities. The average annual income for full-time workers sits around $48 000.

Politically, Duffy's Hill is a predominantly conservative area. The town's seats in federal and provincial parliament have been held by conservative candidates since the mid-1980s. The most recent federal election saw the Conservative candidate winning with 48% of the riding's votes. Many individuals in the area openly identify as conservative, though a shift has been observed towards the Liberal party amongst younger age groups.

Medically, recent Health Unit analyses for the area reported higher incidence of chronic conditions such as high blood pressure, asthma, mood disorders, and COPD than the provincial prevalence. Lack of dental insurance, food insecurity, physical inactivity, injuries from falls, and reports of high work stress were also cited as concerns. The town has close ties with another nearby community, and shares much of its patient-base and health care staff with the hospital there. DHCHC, the partnering organization involved with this research, provides many different services to clients. Among these are telemedicine, chiropody and foot care, dietetic consultation,

preventative oral health care, mental and lung health services, smoking cessation services, diabetes education, and well-being and exercise programs.

Despite the small nature of Duffy's Hill and limited scope of health care services available within town lines, Duffy's Hill has many organizations working to offer and improve palliative care in the area. Three out of five small hospitals in the region offer specific palliative care services, one of which features a registered psychotherapist focused solely on spiritual and psychosocial aspects of care. Similar to other rural communities in Ontario (Conlon et al., 2019; Dumont et al., 2015), most palliative individuals in Duffy's Hill die in hospital. This being said, several organizations in Duffy's Hill offer home care to palliative patients, with the goal of allowing them to choose where they would like to spend the end of their life (at home or in the hospital). These services include visits from health care providers and volunteers to help manage pain, everyday tasks, and provide companionship. One local organization offers a day hospice where mobile clients and their families may gather to spend time together, enjoy various activities, and support one another. A recent endeavor that health authorities in the area are planning to undertake is the development of a rural residential hospice. This study, as mentioned previously in Chapters 1 and 2, was developed in dialogue with DHCHC, with this goal in mind, to inform its development.

4.2 Study Participants

An estimated 60 individuals were invited to participate in this study by means of direct invitation or advertisement in a local health care newsletter. Six agreed to participate, all of whom were women. Participants in this study have been given pseudonyms to protect their identities. Here, I introduce each of the participants by their pseudonym:

1) Audrey, a home care nurse practitioner who recently moved to Duffy's Hill for work

2) Barbara, a psychotherapist who has lived in Duffy's Hill her whole life

3) Natalie, a nurse practitioner providing home care in both rural and urban areas, who has also lived in the region for most of her life

4) Shannon, a nurse working in a local hospital, who moved to Duffy's Hill from another rural context

5) Petra, a volunteer involved with bereavement groups for grieving families after the deaths of their loved ones, who was born and lived in Duffy's Hill for most of her life

6) Carol, a volunteer coordinator who moved to Duffy's Hill as a young child from a small city

In the results sections that follow, I present the views of each of these participants regarding what it means to offer spiritual and psychosocial palliative care in Duffy's Hill. Chapters Five to Nine describe, with supporting quotations, particularities of palliative care needs and provision in Duffy's Hill, as described by these participants.

Chapter 5: Providing Palliative Care in Duffy's Hill

In the first section of their interviews, participants were asked to reflect on and discuss what they believed was unique about the Duffy's Hill context. In considering this, participating health care providers noted number of particularities about the community that they believe separate palliative care provision in Duffy's Hill from that offered in urban areas. In doing so, they also revealed what about the context they enjoy and why they choose to live and work in the area. These reflections, presented in participants' own words, are summarized in the following sections.

5.1 Not like the city: the difference and appeal of practicing palliative care in Duffy's Hill

When asked if she could describe what the culture of Duffy's Hill was like at first

thought, Shannon answered sheepishly:

> *White, rural, conservative, and small-town minded. And not worldly, I'd have to say. And not in a disrespectful way, I just find that they're so happy with living here they don't care to see the rest of the world. (Shannon)*

We shared a light-hearted laugh at this, me nodding in understanding.

"Is that enough insult?" she continued. "I feel as though I've just insulted everyone

here."

I assured her she was not. While worried her characterization of the town might at first

seem offensive, Shannon's statement sums up perfectly what I and many others experienced

living in Duffy's Hill: a sense that this town *is* one's world. Everything one needs, everything

that is important to a person, is right here. This is not to say that residents of Duffy's Hill are not

interested in travelling or experiencing new things; "small-town minded" is not synonymous

with "small-minded." Rather, Shannon's statement implies that residents of Duffy's Hill are

primarily interested in returning home when they have finished their adventures. It is where their

family is, where the where their roots are, and that is exactly what makes it a joy to live there.

In describing how people think about Duffy's Hill, Petra explains that "it gets pegged as a

very old community, like an old-fashioned, narrow-minded community, and there's so much

more to it…the whole area is, it's a rural area, but it's diverse." In Petra's view, people in

Duffy's Hill are diverse "[i]n their worldview more than anything." While she does not think the

area is culturally diverse, she explains that people are "still open to different cultures and

different peoples," and that in terms of worldview, residents of Duffy's Hill possess a "wider

lens than people first imagine." Petra's characterization of the town presents Duffy's Hill as a

place where people are "very respectful of one another." While many different worldviews may

exist within town, residents "stay open and realize that people are walking with lots of different ways of seeing the world," in Petra's view.

Shannon, who had lived in a few different rural towns in the area, described that "they all have a small-town feel, so none of them were kind of fly by night, you know? Everybody seems invested in investing in their community." This characterization of not being "fly by night" draws attention to an important aspect of small-town life in Ontario; it does not involve anonymity or disengagement. Petra shares a similar view of what it means to be a community member in Duffy's Hill. She considers herself and her husband to be members of the Duffy's Hill community "because we live here. And we grew up here, and family is here. We try and support local businesses and work community-oriented, so it's important for us to be at home here." Carol shares a similar observation regarding what it means to be a member of this community. She believes herself to be a member because "I care about the community. I like to see people…people's needs being filled." She continues that "this community is…it seems to really work on building community." Petra and Carol's characterizations reveal more about what it means to engage in a community in way that is not "fly by night" as Shannon calls it. Petra's idea of being "at home" in Duffy's Hill means seeking out involvement with the wider community and contributing to its development or maintenance in some way. For Petra, this means engaging with and buying from local businesses and making her work about serving other community members. For Carol, it means working alongside other community members to build their town and to see residents' needs filled.

In Shannon's view, community members generally know everyone living around them, are involved in the goings-on of their town, and interested in making it a place worth living.

*You get to know everybody. And everybody has a certain trust in each
other then, too, because they know that you're looking after them because you're so-and-
so's daughter. So you have that little feel to it which is nice, and I prefer that. (Shannon)*

Though now well-embedded in community life in Duffy's Hill, Shannon explains her

first impressions of the town upon first moving here.

*At first I thought it was going to be hard to break into the community because everybody
seems so settled, but then I started realizing they're actually really friendly and really
welcoming, so that's been good. I don't know, I guess it's just not knowing the history of
everybody is probably the challenge. (Shannon)*

These statements from Shannon and Petra begin to reveal some implications that exist for

providing palliative care in a rural context. First, people know each other by their connections

within the community. "Everybody has a certain trust in each other…because you're so-and-so's

daughter." In understanding that their provider is invested and connected in the community, a

sense of trust can be established between patients and providers. Conversely, a challenge is

presented for newcomers in "not knowing the history of everybody." This impacts on trust, but

also has practical implications. In Shannon's view, understanding a person's history within the

community is a part of understanding how to care for them. In Chapters Seven and Eight, I

explore aspects of this history that are integral to a person's sense of self and belonging in the

region, namely their relationships and sense of place.

Audrey, a nurse practitioner in Duffy's Hill and the surrounding region, explains the

benefit these small-town connections have on the care of palliative patients in the area.

*There is a sense of community which helps with access. So if I've got somebody in the
community that needs to go into the hospital, it's easy to call and talk to somebody and
tell them what the story is, and things happen. Which is—you can't say the same for
larger hospital centres. So I really like that. I feel that there is support in the community
for the work that I do. (Audrey)*

In Audrey's view, the small and inter-connected nature of the community facilitates an

easily accessible professional network of local health providers. This network makes it easier for

providers to communicate and collaborate regarding a patients' care. Natalie, also a nurse

practitioner, comments similarly on the convenience and benefit of this communication:

> *I'm a big proponent for just picking up a phone and calling a colleague who is also in a circle of care, and I'm having a conversation about concerns or plans of care so that we're all providing consistent messaging. So I will often call a social worker, or I've done joint visits with social work to say this is…we're here together, we both want to hear what you have to say so that we can both provide some insights and we can both continue to support you separately so that we start off on the same page. (Natalie)*

The ease of being able to pick up a phone and call a colleague, as well as conduct visits

together, is an advantage that could be uniquely feasible in rural communities such as this. While

providers may work for different organizations and treat patients in different contexts, they are

able to collaborate to provide that care, ensuring that the care their patients receive is complete in

their eyes.

Natalie remarks that she has observed a difference in attitudes regarding what health care

looks like in rural Ontario that contrasts with attitudes nearby cities. She observes "[f]rom a

clinical perspective, there's just, there's a very… different respect for people, for primary care

providers' willingness to do palliative care in [the city]." In Natalie's view, these differences are

observable in both providers and patients:

> *As soon as I got out into the more rural areas, the docs were like, 'Yeah, that's totally no problem. Here's my office number, here's my pager number, here is my cell phone number, here is my home number, here is my cottage number just in case you need to get ahold of me.' They were very much more willing to be available to their patients and very much might have an approach of, 'I care for my patients from birth to death and when they need me, they need me.' And actually, that attitude meant that those patients had that expectation and they didn't overstep the boundaries of calling their doctor on the Saturday afternoon at the cottage to ask a stupid medical question. They were very respectful of the fact that their physician or their [nurse practitioner] provided this contact information for them even outside of an end of life situation. (Natalie)*

This relationship between patients and providers can only exist because of the mutual

"respect" to which Natalie refers. Primary care providers, who are also members of this

community, often treat their patients from "birth to death." They have been treating these

patients regularly for many years and see them through each stage of life as it arises.

Furthermore, health care providers often see their patients casually in the community while

running errands or out for a meal. They are not only their patients, but their neighbours as well.

This creates a unique dynamic of trust between patients and providers: patients trust their

providers to give them the attention they need when they need it, and, in return, patients respect

the time of their health care providers and call on this attention only when necessary.

In Barbara's view, these personal connections within the community is part of what

allows her to provide good spiritual and psychosocial palliative care to clients. Barbara outlines

one way her connections within the community have aided her in offering good spiritual and

psychosocial care:

> *There have been times, thankfully, where I've been able to reconnect some of these isolated people with their former community of faith. How they kind of dropped off the radar screen because they became too ill to get out, maybe they lost their license because they were elderly and unable to drive themselves, no longer having their own means of transportation to get to their local community of faith. So it's a privilege sometimes to be able to reconnect and to say to a church, 'Would you like me to make a connection for you to that church you used to attend?' 'Oh, I don't even know who the minister is,' they'll say. And I'll say, 'Well, I do, and how can I help ensure that you get that?' And that's a real privilege when you see people reconnecting. And so that church then re-embraces that person as someone that they do their own visitation with now, so that I can back off. (Barbara)*

For Barbara, facilitating these connections between patients and the community is "a

privilege." She views a large part of her role to be facilitating that connection, and that it is what

allows her to do her job well. "That's my connection to the ministerial, right? I know the

ministers to reach out to. I know how to get that for them."

While Barbara's connections in the community have benefitted her ability to care for

patients, Audrey brings forward an alternative idea that demonstrates how these connections

might act as a double-edged sword. Newer to the area and less socially connected than some

other participants, Audrey shares:

> *I'm not as socially connected in my community as other people might be. And that's partly my choice. And I actually am glad, because in this role I am seeing people in the community who are, a lot of them, well connected. They've been here for generations. And it's easier for me to be able to be professional and maintain confidentiality when people don't know me, if you know what I mean. They know I'm not connected in the community, so I feel professionally it's almost easier in some ways. I don't feel that it has hampered my ability to work with people at all. (Audrey)*

Audrey's insights reveal a caution that palliative care providers might want to consider in

treating patients. In a small town where "everybody knows everybody," patients may be hesitant

to share their spiritual or psychosocial health needs for fear of ridicule, or concern that what they

share might be shared inadvertently with someone they know. Health providers seen as

"outsiders," then, might be at an advantage in terms of where they begin the therapeutic

relationship, because there will not be fears like that to deconstruct as the connection is

established.

A final aspect of care unique to a rural context, in Natalie's view, is that, because of the

rural and home-based nature of her practice, she is able to spend much more time with her

patients than if she worked in a city hospital.

Because of the way the program is run, I decide how long I stay with the patient during a visit, how often I see them. It's completely based on the patient and family's needs. (Natalie)

Natalie's statement implies that, from her perspective, providing good palliative care in

this context means taking the time necessary to meet the patient's needs in a given session. As

will emphasized again in future chapters, participants were clear that a lack of time can limit the

quality of palliative care. Such care cannot be done quickly. Natalie's concept of palliative care

involves slowing down to spend the necessary amount of time to discuss and address what the

patient, and family, needs in that moment. The freedom Natalie has to take time to spend with a

patient, and really invest in their care, is an advantage of her practice. In Natalie's view, the

combination of provider availability and time invested beget respect from patients. These things,

embedded within the unique social and cultural profile of the setting, are what make rural doing

palliative care unique.

5.2 Why here? Providers' Motivations to Work Rurally

When asked what she enjoys about working in palliative care in a rural context, Barbara,

a psychotherapist working in Duffy's Hill reflects,

> *I've always just liked the smallness of it. We're large enough to have resources, but small enough that I always know where, if someone says, 'I live on such and such street,' I say 'Oh, yeah, I think I know where that is.' Or, if they tell me they live out in a little rural community I can say, 'Yes, I know exactly where that is.' So I have already a pre-existing familiarity with the region because I did live in [town] at one time. I lived both in [town] and outside of [town] in my history. So that part of it I think is nice, 'cause it's...there's that familiar feel; there's that constancy. (Barbara)*

Barbara is not the only one to consider smallness and familiarity a draw towards working

in rural contexts. Shannon comments that she prefers "the family aspect of it." "I like the

personal side of things rather than just being another face, another number sort of thing," she

continues. Carol's view aligns with Barbara's and Shannon's. She shares a story that reveals how

the personal side of care is exactly what makes rural palliative care provision unique:

> *How often do you hear about a [health care provider] baking cookies? Baking cookies for the client and bringing them to them in the hospital. I just find people around here are like that. They just…if there's nothing really that can be done, it seems, but they find something. And wow, that means to much to the client. I see it everywhere in what I do. People thinking out of the box. (Carol)*

This "personal" aspect of providing care in the rural context is taken one step further in

the provision of palliative care specifically. In reflecting on why she chose to work in palliative

care, Barbara recalls, "[I] began to look for some place I could use more of what I felt my giftset

was. Which is one-on-one with people."

Barbara views her strengths, or "giftset" as she refers to these, as stemming from her particularly adept ability to connect with people one-on-one. In her view, this skill to connect is what allows her to offer palliative care well. She has a personability that motivates her to initiate meaningful conversations with patients that are crucial to whole-person palliative care (McNeilly, 2000; Mikesell, 2013; Lewellen, 2015). Natalie's reflections reveal similar feelings regarding her skills.

> *When I really sat down to think about it, my experience really came to the forefront and I remembered really feeling like those times when we were withdrawing [life-sustaining treatment] on patients, or we were having family meetings and we were contemplating withdrawal of life-sustaining therapy, those were the times when I felt I really shone. Those were the times when I really felt like I was making the most difference. (Natalie)*

Natalie feels that her ability to connect personally with patients and families, to be present with them in their difficulty and to walk beside them through the experience of end of life is what makes her "shine" in this role.

> *They've never done this before, right? I say that often to my patients and families. I watch, I journey along with people who are in their dying days, months, weeks of life all the time. I recognize this. I'm comfortable with this. I see patterns, right? And that's my job, is to help them to see the normalcy of what they're going through. (Natalie)*

Petra shares a similar reflection about what draws her to work with bereavement groups.

> *It's where my heart has always been in the sense that it's very real and very deep quickly. Those relationships, there's no powder, you know? It's very real right away. And I'm comfortable with the topic. (Petra)*

These reflections from Petra and Natalie echo a view expressed in some way by all participants: this work requires a certain disposition and skillset concerning how providers interact with patients. In order to provide palliative care well in this context, providers must excel in conversing with patients about that which is most meaningful to them. In Audrey's view, this means understanding their background as much as their illness journey. "I don't set up my meetings as 'question/answer,'" comments Audrey. "I set it up as, you know, 'here's my

understanding of your story[.]" Natalie notes that as a palliative care provider, she must also

possess a willingness to dive into conversations centered on difficult topics. She comments,

> *I often get a feeling that, inside myself, I don't want to ask this question, but I know I should. And when I get that feeling, I know that there's something underlying. And it's that recognition of my discomfort, but knowing that asking this question is likely going to be really important for this patient. (Natalie)*

This intuition, as Natalie calls it, characterized by a desire to avoid a topic of

conversation in her view, is what enables her to proactively delve into a meaningful line of

conversation with patients and families. In doing so, she is able to address the "underlying"

aspects of a patient's health and assist in bringing that area to the surface by facing it head-on.

Shannon, in considering why she was drawn to palliative care, explains,

> *Palliative patients take up a lot of your time in a work day, and in community it's all about getting your patients. You get paid by the patient rather than the hour, so they didn't like to slow down for two hours at one place. So I just started picking up all the palliative patients 'cause I loved it so much. (Shannon)*

Shannon's comment draws attention to intentions providers must have in providing

palliative care in this context: you cannot be in it for the money, because this area of care is not

where the money is. It takes time to do well, and therefore cannot be done in the name of

efficiency. Shannon's "love" of offering palliative care suggests that she feels a calling of these

calling towards this area of care. Natalie comments that she also feels this calling, explaining:

> *On the days when we were having it really heartfelt conversations and sharing such difficult news or actually performing the withdrawal of life-sustaining therapy, I felt like I really made a difference and I felt like my presence was really helpful for the families and for the other stuff. And it was in recognition of that, and other people, my colleagues, those are the times when they were like, 'I don't want to do this, I can't. I hate, hate withdrawing on patients, I hate having family meetings.' Like so stressed about it. But I recognize, obviously, there was something different in me and that I felt much more powerful and much more at ease in those situations versus most people. So I recognized then that maybe palliative care was something that I had a calling for. (Natalie)*

Natalie's believes her calling for palliative care nudges her to believe that there might be something "different" about her and her view of what it means to provide care well in this context. "In this role I feel like I am utilizing all of me, as a [health care provider] and as a person, to be able to care for my patients and families." Natalie's reflection reveals an interesting line of thought concerning those who choose to do palliative care: it is fulfilling work because they must use all of themselves to do it, both personal and professional aspects and skills. In this way, the goal of whole-person care is achieved through the whole-person provision of that care.

5.3 Chapter Summary

This chapter reveals not only what aspects of practicing palliative care rurally in Duffy's Hill are unique, but what motivates health care providers to work there. Participants point out that in a small community like Duffy's Hill, everyone is engaged and invested in their community. Because everyone knows everyone, there exists a certain trust that health care providers will care for their loved ones well. With this trust, however, comes a responsibility to provide quality care to community members. Out of this trust and responsibility arises a mutual respect that allows health care providers to care for patients throughout the life-course, often sharing personal information like home phone numbers to ensure that they receive the care they need when they need it, in trust that patients will respect their lives outside of providing medical treatment. It is exactly this personal nature of care that motivates health care providers to work here; providers in this context are required, by character of the setting, to offer individualized care that involves more than just treatment, but the development of a long-term therapeutic relationship with patients. This understanding of personalized care lends itself well to those looking to provide spiritual and psychosocial care in these contexts. Natalie summarizes this idea beautifully:

> *I think that that sort of overall holistic attitude that encompasses rural medicine as a whole really aligns in a lovely way with palliative care and the idea of holistic, whole-person, patient-centred care. (Natalie)*

Chapter 6: Tensions Between "Religion" and "Spirituality"

In discussing what spiritual and psychosocial care meant and included in the Duffy's Hill context, associations between spirituality and religion arose as a point of tension for all participants. Participants expressed that patients were not always comfortable discussing spiritual aspects of care and preferred not to identify as "religious," even if church attendance or belief in God was a part of their background. In this chapter, the differences between "spiritual" and "religious" care as explained by study participants will be explored. What emerges from participants' account of these distinctions is a tension, if not stigma, for many when it comes to overt mentions of or associations with religion in the context of this small town. This tension, if not properly acknowledged and addressed, could lead to hesitations in accepting or asking for spiritual care.

6.1 "Church is no longer in the center of culture; it's on the fringe of culture."

When asked how they defined "psychosocial" and "spiritual" palliative care, all six participants expressed that these two areas of care were very difficult to separate and could not or should not be distinguished from one another. This observation is consistent with past discourse about spiritual and psychosocial care: as part of holistic care, these dimensions often overlap significantly, and distinctions between the two are not always clear (Steinhauser et al., 2017). One participant, Barbara, understood the separation into two terms of "spiritual" and "psychosocial" patient and family needs as socially and historically specific. This, in her view, needed to be understood in the context of a shift towards secularism in Duffy's Hill, and a

72

reduction in the centrality of the Church and its leaders as providers of support for both spiritual

and psychosocial needs in the community. She explains:

> *I'm going to draw from the fact that, historically, ministers in the community provided spiritual/psychosocial care for the parishioners. And then as we advanced as a culture, as we moved forward as a culture, we began to divide and separate these things as if they could be divided and separated so that ministers began to be the people who only looked after the religious needs of people. I think that was disadvantageous to our society as a whole, when we began to break those off into separate realms. Because the minister in those days was providing the psychosocial, spiritual care. They were doing [both] of them. And so now we have this division where I don't think there should be a division. But again, you've also got this piece where the church is no longer in the center of culture; it's on the fringe of culture. Which is perfectly fine, because maybe that's where it needed to be all along. So for me, I find it very difficult to completely divide...to draw a line around whether this need belongs to social worker care, whether this need belongs to psychological care, or this need belongs to spiritual care because there is such a huge overlap. (Barbara)*

Two implications for local perceptions of palliative care can be drawn from Barbara's

statement. First, historically, the Christian church played a large role in caring for the spiritual

and psychosocial needs of those living in Duffy's Hill. Thus, church participation likely shaped

attitudes toward spiritual and psychosocial care in the area; patients who grew up in the area

may, based on this history, associate any form of spiritual care to be linked with religious care.

This historically and context-specific association informs Barbara's practice. Because of this

common association, Barbara views her role, in large part, to be a "liaison to the ministerial,"

communicating regularly with local ministers in order to connect patients with those who may

assist in meeting their religious spiritual and psychosocial needs.

A second implication that emerges from Barbara's statement is that, in her view, the

church now exists on the "fringe of culture" in this town. As Barbara explains, historically, the

Church was at the core of spiritual but also social life in the community. Church leaders

positioned themselves and were drawn upon by at least some residents as resources for a range of

supports, including spiritual and psychosocial care. Petra affirms that this notion remains the

case for some residents, stating that "in the community the parishes and churches will have their own support systems for people." Having said this, Petra observes that "more and more people are not connected to an organized religion." The central role of the Church and its leaders in whole-person care is no longer the norm. Religious participation, while historically conventional, has become less popular among community members in recent years. It is neither expected, nor particularly common. Indeed, in Duffy's Hill today, it is rare to hear people identify themselves explicitly as "religious". Socially speaking, doing so is neither expected nor viewed as positively as it once was.

The historical dominance of Christian churches in the area, as well as the reduced importance of the church and religiosity in Duffy's Hill, may help explain patterns observed by providers of palliative care in the community of some patients' apparent hesitancy to discuss, or even apparent discomfort with, the subject of their spiritual needs or preferences.

In Audrey's experience, palliative patients who continue to associate with a church are more comfortable discussing their spiritual and psychosocial health than those who are not. She suggests that "[the church] is such a structure in the community, and an acceptable structure, that when people keep those beliefs to their lives, I think they just feel really supported in those beliefs." Echoing this, Shannon observed that many patients seemed nervous in discussing their religious beliefs with palliative care providers for fear that they might be "looked down upon."

Barbara's reflections on what it means to provide spiritual and psychosocial care in the community aligned with Audrey's assessment, even while speaking of non-church going residents. The following quote underlines the challenge of discussing spiritual aspects of care given many in the area she serves do not want to be associated with the church, and assume spiritual care is about religion:

74

> *A lot of people, though, are very closed to even the concept of having the spiritual care person come…they have the immediate negative connotation sometimes, erroneously, that spiritual care is equal with religious care. (Barbara)*

While the church and religion are "on the fringe" in the minds and lives of some in Duffy's Hill, so too are non-Christian religious beliefs. This is a town where Christianity was and continues to be, despite its reduced active membership, the dominant religious culture. At least one provider interviewed found that patients and families whose spiritual beliefs are not as "mainstream" (i.e. non-Christian beliefs) were, in her experience, less comfortable discussing spiritual and psychosocial aspects of care, based on an understanding that their religious difference in the context of Duffy's Hill would be judged or unsupported:

> *Those who have spiritual beliefs that are kind of off the mainstream are less comfortable talking about it because they aren't sure how they're going to be perceived, I think. I think people who are out of the mainstream church belief system may feel that their spiritual beliefs aren't as well supported or understood. And I guess maybe there isn't necessarily a sort of central body that provides that community support of those types of beliefs. Mind you, on the other hand I think people who are more spiritual as opposed to religious tend to maybe want to keep it that way. I don't know. Just being... not needing that community of people to help them maintain their spiritual beliefs. (Audrey)*

These observations reveal important tensions that exist in offering palliative care in Duffy's Hill. The church was once, and for some, still is, such an important spiritual body in the community, spiritual care is often immediately associated with religious care. Spirituality is equated with Christianity based on the town's history. These contextual associations pose a problem, however, in that many residents no longer wish to associate with a religion or Christianity. Thus, a question arises: how can health care providers in this context effectively offer spiritual and psychosocial care in a way that lends attention to this tension, and how can they discuss these aspects of care without provoking an immediate rejection of this offer based on its association with Christian religion?

6.2 "You can be spiritual and not religious"

One phenomenon noted by five participants in offering spiritual care in this context is that patients are much more willing to identify as spiritual once it is established that "spirituality" is not necessarily synonymous with "religiosity." Four participants mentioned that many of their patients prefer to identify as "spiritual" rather than "religious" when asked about how they could be supported in spiritual and psychosocial ways. "Which is surprising in a small area," comments Shannon, "because people have tended to keep their small-town values and go to church. And so I find more and more now that people are becoming spiritual, not religious."

In expanding on this observation, Shannon suggests:

You can be spiritual and not religious, for sure, and I try to make that clear whenever I'm interviewing my patient for the first time. I get to that section of are you, do you have any spirituality or any religion of choice, or are you drawn to any particular religion? And they start to hesitate, and I say, "You know, you can be spiritual without being religious," and they said, "That's what I am, I'm spiritual." (Shannon)

The difference between "spirituality" and "religiosity" in a health care context has been explored and debated in past literature (Hill & Pargament, 2003; George, Larson, Koenig & McCullough, 2000; Miller & Thorenson, 2003; Pargament, 1997; Zinnbauer et al., 1997). While "religiosity" can be defined as a commitment to a fixed, formal ideological system (Hill & Pargament, 2003; Miller & Thoreson, 2003) and can be measured by one's participation in certain institutional activities (i.e. attending a formal service, engaging in prayer, belief in God) (Cotton et al., 2006), "spirituality" can be defined as the personal or emotional expression of that which is sacred to an individual (Miller & Thoreson, 2003; Cotton et al., 2006). Spirituality is not dependent on a formal institution (Pargament, 1997), and can be measured in feelings of peace or well-being (Cotton et al., 2006). The extent to which these terms are connected in public perception differs depending on context. While the perceived connections between religiosity and spirituality have not been directly explored in Canada, the 2011 Canadian census

reported that the number of Canadians who identify with an organized religion declined by

16.4% from 2001 (Statistics Canada, 2011). Furthermore, a recent increasing movement towards

identifying as "spiritual, but not religious" (SBNR) as opposed to either fully religious or fully

atheist has been observed in Canada in recent years (Beyer, 2015). According to participants, this

movement is present also in Duffy's Hill. Natalie draws attention to this change, pointing out

that:

> *Demographics change and people aren't necessarily as religious as they have been in the past, but sometimes the religious aspect of spirituality feels overwhelming for people. And so I think being able to recognize that spirituality is more than just religion and that the spirituality of humanity and being humans together allows anyone to provide that spiritual support. It just really takes time and willingness to be present during those difficult moments, and being uncomfortable, and that's not easy for everybody. (Natalie)*

In Natalie's view, a distinction between "spiritual" and "religious" care exists in the

broader nature assumed by the former. One notable aspect of Natalie's explanation is her

connection of the spiritual to people. While religious involvement may present as a

manifestation of a person's spiritual beliefs in ritual or outward behaviour, one's spirituality is

actually "much more," and involves an acknowledgement of, in Natalie's words, "humanity and

being humans together." Spirituality in this context, therefore, involves connections with other

people as much as connection with a higher power. Thus, the term "spirituality" encompasses a

number of things that vary from person to person and may or may not include religion. For

example, the spiritual significance of interpersonal relationships was emphasized by participants

in this study and is further explored in Chapter Eight. It can be interpreted, then, that members of

this community perceive spirituality as an idea to be more ontological, or metaphysical, than

religious involvement.

For now, questions remain regarding how health care providers can attend to spiritual

needs given that spirituality is not the same as religion, and how they might work around the

tension that accompanies these terms. This is not always easy. "The spiritual beliefs of people that don't fit into a category are the ones that are harder to support," summarizes Audrey. In her view, the first step for a provider is to identify those spiritual and psychosocial needs that may be based on a number of values and priorities which do not correspond to "religious" ideas or needs. In Audrey's experience, where patients are not able to really spell out their spiritual and psychosocial needs, these can be revealed and met through their coping strategies:

> *Not being able to cope to me is spiritual. The folks who are spiritual but not necessarily religious, they have different coping [strategies] I think it's just the way that they look at things and accept things and try to look for the best in their situation. (Audrey)*

Natalie echoes Audrey's thoughts on the subject and lists a few examples of non-religious coping mechanisms she has observed in her practice. Particularly, engaging with nature and connecting with family and friends stand out as important coping strategies. More on these will be discussed in later chapters.

In considering the spiritual and psychosocial side of a person's care, Barbara explains that she looks at the aspects of a person's life that brings them meaning, value, and purpose. Similarly, Carol views a person's spirituality to be "meaning making." To Carol, this meaning making involves recognition of "what's meaningful for the client or the patient."

> *For some people it's birds. You know, some people are more mystical. And then some people have a religion where they also draw strength and support from. It doesn't mean spirituality, but they draw on some spiritual aspects through their religion. (Carol)*

Carol's statement reveals that what creates meaning for people within their lives varies from patient to patient. While in some cases this might involve connection with a church or practicing religious rites, in others it may involve engaging in a hobby or spending time with loved ones.

It should be noted that while religious experience might predispose a person to desire spiritual care, this does not mean that those who do not affiliate with a religion do not understand their own spiritual needs. Barbara shares:

> *[I've had] an individual who recognized and knew that they needed spiritual care to be able to die well. And that individual wanted to talk about all of the different meanings of spiritual care. It was as if they had read the book on the subject. They said to me, "I want to know how to leave legacy. I want to make sure that I am leaving my family with what I need to leave them with." (Barbara)*

In cases like this, it is much easier for health providers to know how to help a patient. while providers cannot rely on patients to have "read the book" on spiritual and psychosocial care in every case, this story demonstrates that patients are invested in their care, and with the proper guidance, even those without religious affiliation can be offered effective spiritual care. This simply requires an awareness on the part of health providers that other belief systems outside of the mainstream do exist in the community. Audrey believes that "as momentum continues to grow with acceptance of beliefs in that area then there will be more availability for those communities when they need it."

6.3 Navigating the Line Between "Religious" and "Spiritual" Palliative Care

In a culture where "spiritual" care is heavily associated with religion, but "religious" care is not always desired or viewed positively, it can be challenging for health care providers to navigate conversations about spiritual and psychosocial care with palliative patients. While providers share that they are not afraid to bring up spiritual and psychosocial care in conversation, they do fear that patients may misunderstand their meaning. Barbara draws attention to this:

> *When somebody says, "Absolutely I want spiritual care," sometimes what I discover is they actually have the wrong meaning for it. What they're really saying is, "I want*

religious care." And that happens frequently, as does the reverse. They will refuse spiritual care if they believe it's about religion, right? (Barbara)

Two major scenarios emerge in which the "wrong" definition of spiritual care (i.e. spiritual care is equated with religious care) may impede a patient's willingness to discuss or receive spiritual and psychosocial palliative care. First, patients might think they are being "pushed" towards religion upon its offering. Because the word "spiritual" is immediately associable with "religion" in this context, non-religious folks may feel intimidated or uncomfortable upon hearing it offered for the first time. Second, patients might fear that their spiritual beliefs, religious or otherwise, may be looked down upon due to lack of understanding on the part of health care providers. This second scenario is exacerbated by the increasing shift away from religious involvement in the community. Because religious participation is less "popular" than it once was in Duffy's Hill, patients fear social repercussions from discussing it with their provider. If their health care provider does not believe in religion, will they be uncomfortable with their discussion of it?

In her experience volunteering with bereaved family members, Petra has found that approaching conversations about spirituality from a place of openness, without definitive answers to offer, can help people feel at ease. "I try to stay open to where people are at," she explains, "not try to convince anybody of anything…it's not a dogma. You know, we're not trying to provide specific answers. Particularly because the topic of death and afterlife and all of that comes up." Petra hopes that, by staying open to the beliefs of others and doing what she can to communicate that openness, bereaved family members might be more comfortable sharing and discussing their experiences.

In an attempt to open conversations about spiritual and psychosocial care with patients in a manner that is non-leading, Shannon shares two questions she uses to inquire about the spiritual beliefs of a person:

> *What do you think happens after you take your last breath? Do you think there's more to life than this or...? And sometimes they'll say, "Nope, that's it," or they say, "Yeah, I'd like to think there is." So then I get into that little realm of where they are spiritually, because that's going to be a big component of how I help look after them while they're dying. (Shannon)*

These questions are particularly useful because they do not explicitly mention religion, however, if a patient holds religious beliefs that relate to these questions, they may feel invited to share them with their provider. "I'm not pushing them towards religion," shares Shannon. "I'm not going to make a minister come in and have a prayer with them, you know. Just make sure that they're comfortable with whatever is going on in their heads."

Carol shares that she will assist a patient in accessing religious care "only if the patient asks." She explains that she has had "patients that have asked specifically for a volunteer that would, for example, pray with them. There's also been Buddhist clients who've wondered if we had had a volunteer that was Buddhist." Carol's statements reveal that while there is a role for religion within spiritual care, it should be accessed only upon direct request from the patient in an effort to avoid "pushing them towards religion" as Shannon puts it.

While health care providers prioritize "being so protective of peoples' faith journey" as Petra refers to it, Carol reveals that there are a number of statements from patients that could be used as signals that spiritual or psychosocial care is desired or needed without an explicit ask.

> *[Clients will] say they just don't know what they believe. Sometimes they don't know what they believe. They were Catholic when they were a child and they've gotten away from the church. And you know, they don't know about God, or they don't know about what's going to happen to them when they die, they might be afraid. They might be afraid of what's going to happen. Will they be in pain? A lot of people are afraid of the pain. They are going to be in pain. So they say those kinds of things. They feel empty.*

81

Estranged from their families. They worry they didn't do enough with their life. Yeah. There's no point. Every day is the same. Things like that. (Carol)

In an effort to determine whether or not a patient has a specific need that could benefit from spiritual or psychosocial palliative care, health care providers could watch for some of these statements presented by Carol. Many of these have nothing to do with religion and could be met by religious or non-religious means depending on the preference of the patient. Petra gives some examples of services that could provide spiritual care without including a religious aspect.

There are different groups coming up now that offer sound therapy and bereavement sound therapy. I've noticed more and more things coming up in the community by individuals who realize there's an emptiness for people who aren't connected to specific [religious communities]. I'd love to see a community of threshold singers in this area…they come and sing to the dying. And it's all a cappella. They're volunteers, again, but they just come in and they sing. And it's beautiful, and it's therapeutic for everyone. (Petra)

Petra also shares that, in her view, patients' family members receive a substantial amount of spiritual care from bereavement groups. She expresses a challenge that arises in these groups, however, "when someone feels that there are black and white answers," usually based in a religious faith.

Some faith-based responses to death are so black and white for some people that they think, "This is the answer." And yet, underneath it they haven't really come to terms. And so they manipulate the gathering, they talk about the same things over and over again because they're stuck. And so you never want to discourage anybody's faith journey or question it, but sometimes when they have been given the black and white answers, it's hard for them to just sit in the questions and ponder them themselves, and try to come to terms with what's happened, you know? I loved somebody, and they were in my life, and they're gone, and my faith tells me I'm supposed to be happy 'cause they're gone to a specific afterlife after, but gee, I can't quit talking about it. And he's just stuck. Just stuck in a place that black and white doesn't go. (Petra)

While patients may initially prefer to leave religion out of their discussions of spirituality, Barbara points out that the spiritual needs of a person, or their perspectives of how their spirituality can be enacted, might change over time.

> *The truth of it is that the closer someone is to death, the more open they are to going, "You know..." and this is where sometimes spiritual care turns into religious care, they might say, "I used to go to church. That was a big part of my life when I was little. I got away from it. I never really got away from my faith, though. I still believe in God. But now that I'm dying, I'm really kind of wondering if I'm even ready to see God. I don't know if he's ready for me." So then we talk about what would it look like for you to have peace to know that it's okay to die? That doesn't happen all the time, but it happens frequently enough. Especially in this particular region which is... the population in this region has typically trended towards being a church-going region. I would say that's probably more, though, for the elderly population than it is for any other at this point. (Barbara)*

Despite the fact that many patients prefer not to identify as religious, Barbara observes that those who attended a church earlier in life often choose to reconnect with it during their dying time, perhaps in an effort to reconnect with their history. In light of this possibility, health professionals should continuously assess the spiritual and psychosocial needs of patients. Just as changes in physical symptoms may be observed, spiritual and psychosocial needs are dynamic, and can change over time.

6.4 Chapter Summary

In this chapter, it is revealed that a tension exists between the words "religious" and "spiritual" in this rural Ontario context. While "spiritual" care is heavily associated with religion in this context, discussing religion or receiving "religious" care is not always desired, posing a challenge to health care providers looking to discuss spiritual and psychosocial aspects of palliative care. In order to navigate these conversations, participants suggest that clarifying the definition of these terms, that is, you can be spiritual but not religious, could ease some of this tension. Alternatively, the use of open questions that avoid using these terms allows for patients

to bring them up in their own time, effectively defining these terms for themselves, and allowing

palliative care providers to work within these definitions. This chapter serves to highlight the

importance of attending to charged language in rural contexts like Duffy's Hill; by being aware

of how these two terms are perceived, health care providers can better tailor their care strategies

to serve spiritual and psychosocial palliative care needs.

Chapter 7: Sense of Place

In rereading transcripts, I was struck by recurring emphasis on the significance of a

patient's landscape and place in response to questions about what defines the provision of quality

palliative care in "Duffy's Hill." In this chapter, I present both literal and metaphorical usages of

land- and location-referencing language by participants and explore the potential significance of

such language to the particularity of palliative care provision in this small Ontario town. I

propose that, based on participant responses, a patient's sense of place plays a large role in their

spiritual and psychosocial well-being, and that attending to a patient's sense of place in this

context is part of providing good spiritual and psychosocial palliative care.

7.1 "You have to meet people where they're at"

We start to see the importance of an individual's sense of place, as well as others'

perceptions of their sense of place, in this simple statement. The phrase "meet[ing] people where

they're at," offered by Natalie in explanation for how a provider in her assessment can offer

good spiritual or psychosocial care, and again by Petra in illustration of how a person thinks

about death and grief, implies that individuals exist in a figurative "place" in life, that this place

impacts their expectations for care, and that it is the role of a palliative care provider to seek out

that place and meet their patient in it. In describing how a provider can begin to offer quality

spiritual or psychosocial care to patients, Barbara, for example, describes this as involving a sort

of mapping out of their biographically specific "landscape":

> *I want to see in what context has this cancer or this terminal diagnosis landed in. What's the context of this person's immediate life, and what has been the landscape of their entire life into which this cancer or palliative illness has landed. (Barbara)*

Barbara's description of the "landscape" of a person's life does not refer only to their

physical location nor solely their perceived identity in relation to their geography, though these

factors may contribute to their "landscape." Rather, factors that contribute to the "landscape of [a

patient's] entire life" include family connections and history, how individuals choose to spend

their time, what their favourite activities are, and ultimately, what gives that person "meaning,

value, or purpose" in Barbara's words.

Shannon likewise draws on a place-referencing metaphor, "understanding where a person

is at", in describing what she regards as the core point of departure for any quality provision of

palliative care. Asked to elaborate, Shannon clarified this "where the patient is at" is composed

of such things as their interests, hobbies or career pursuits "helps me to understand where

everybody is, find out who they were, you know, that he liked to play hockey and things like

that. What kind of work he did." Evidently, for these rural Ontario palliative care providers, a

sense person's landscape is not only or primarily even about their physical position in the region.

It is about where an individual's heart lies, in addition to their feet.

While a person's "landscape" encompasses more than their physical location, providers

view their patients' choice to live in rural Ontario as a major indicator for their care preferences.

Audrey, for example, comments,

> *It's certainly challenging for my patients that specialty centres are in [the city]. So they have to travel. And when they get to—and I mean even for palliative treatments, usually it comes to a point where they're making a decision between travelling and continuing treatment or not. And the travelling can become difficult because of the time and, and*

people live in rural areas because they don't want to live in cities. They don't like going there. (Audrey)

Individuals in rural Ontario live there because they want to. In Shannon's view, this choice to live rurally stems from a desire for a specific lifestyle and a deep connection to the area that transcends individual histories. A sense of pride exists for those whose families have made the region home for a long time.

There are still people that have been here their whole lives, and families and generations. It's such an old town in Canada. It's one of the older ones…people have been here a long time. (Shannon)

Given the historical and familial connections to the area that exist for many residents, participants regularly tie the importance of receiving care in the home region as an important aspect of psychosocial care in the area. In recalling a patient whom she found so "had it all together," Shannon notes,

He had a psychosocial part. Big stuff. He wasn't going to the city anymore. He wanted to be up there in the rural area so that he could be near his family so that his parents wouldn't have to travel back and forth. He was fantastic. (Shannon)

In Shannon's view, this individual understood the "psychosocial part" of palliative care in part because he understood the value of place in his care. Not only was his choice to remain rural for his dying journey convenient for the sake of family, but there was value in receiving care in a familiar region as opposed to a city hospital.

7.2 Spiritual Connections Between Person and Place

Participants frequently referred to place as having connection with a person's spirituality. Whether this meant that simply being in a certain environment was "spiritually healthy," or understanding the spiritual significance of a certain place or environment to a person, it is clear

from participant narratives that understanding of place plays a large role in providing good

spiritual and psychosocial palliative care to rural individuals.

Audrey suggests that a person's spiritual and psychosocial health is reflected in their

coping strategies, and that these coping strategies may have connection to person's sense of

place.

> *Some people feel that their coping and energy and their support comes from being in nature. So just being able to look out and see the birds or enjoy the fresh air or that sort of thing is very calming to them. (Audrey)*

In Audrey's observation, a person's environment, or access to that environment, impacts

on their spiritual or psychosocial well-being. In a palliative care context, a person's "energy," at

least in the physical sense, may pose a challenge; those who are experiencing life-limiting illness

often become themselves fatigued as their illness progresses. Being unable to eat or having

limited mobility are contributing factors to this. In this case, however, the "energy" Audrey

refers to is not a physical one, but a spiritual or psychosocial one. Just as pain and fatigue can be

treated with medications and physical treatment, so too can spiritual, social, and mental pain or

fatigue be treated with access to supportive, energy-promoting environments. Access to nature is

cited as particularly important for rural residents, as many spend their lives living in areas where

nature is immediately accessible. On way this might be achieved in a hospice setting is by

building a "healing space." Healing spaces are those that promote health by considering the

aesthetics of space (Shweitzer et al., 2004; Sternberg, 2009). Healing spaces are created by

establishing a calm, welcoming and homey ambiance (Schweitzer et al., 2004; Sternberg, 2009).

This space, therefore, can act as a soothing entity in a person's care, tending to spiritual and

psychosocial elements of their health. Shannon shared a story that describes an example of what

might be called a healing space, and highlights the significance of rural-living patients'

connection with nature:

> *We had one person, she'd been in the bush her whole life, and for her to come to*
> *this brand-new hospice, it was like purpose-built. It was a beautiful*
> *bungalow, beautiful atmosphere. And for her to be in a hospice when she's been in*
> *the woods all her life was a big change for her. And we didn't know how she was going to*
> *adapt to that. And we had low windows there so that you could always see out, so you*
> *can see down the grass into a ravine, basically. But it was something to look at; there*
> *were lots of trees. And as she was dying that morning, we couldn't believe it, there were*
> *six deer that suddenly came out and stood outside her window. And they weren't eating or*
> *anything, they just stood, six deer, outside her window. And we were all just blown away*
> *by this, we thought, well there! The Woods have come back to her, you know. It was—that*
> *was amazing. (Shannon)*

While concern existed over the fact that this patient might have challenges adapting to a

new environment, Shannon, as her health provider, felt that simply having a peaceful and

familiar scene to gaze upon made a difference in her care. While the hospice remained a different

atmosphere, the view from the window provided a touch of home, in Shannon's view, allowing

this patient to maintain her sense of place – featuring strong connection to the woods - even in a

new atmosphere.

We can also see significance in the view that a person's sense of place can "come back,"

or return to a person as "the Woods have come back" to this patient, in Shannon's words.

Undergoing palliative care treatment and accepting one's mortality can often be a identity-

shifting experience for individuals (Murray et al., 2004). Being unable to do the things they want

to do when they want to do them, or in some cases, receive care where they want to, can person

feel like they are losing control of themselves (Murray et al., 2004). In the case of this patient,

however, her sense of place was able to return to her in the eyes of the provider – she was able to

live as her healthy self might have in the last hours of her life, enjoying the view she might have

had on any normal day looking out the window of her home.

Allowing patients to live their last days, and die, in environments that align with their sense of place is part of good spiritual and psychosocial care palliative care. The importance of place, it emerged in some of the interviews with providers, remains significant after death also for some patients in Duffy's Hill, with implications for the provision of palliative care in this place. Shannon tells a story that illustrates this well:

> *There was one patient and he had nobody to speak for him, and so he was going to be a patient of a public guardian and trustee. So that person was on the end of a phone, never having met him before, so as soon as he couldn't speak for himself that person was speaking for him. But it was really important for him to be buried next to his mom in the cemetery on the other side of Ontario. So to him, that was his spirituality. He had definite ideas about what his body needed to do after he died. So when he died, they said, "You know what? That's going to be too expensive to ship across Ontario. We're going to cremate him here and then we'll transfer over." So I had to fight with them to make sure that they didn't do that, 'cause that was not his wish, right? I mean, that was important to him. And some people would say, "Well, he's dead. What does it matter now?" But it's all about getting trusting people, right, and just maintaining that and just honouring their life, you know?" (Shannon)*

For Shannon, offering good spiritual care meant honouring the patient's wishes beyond death as well as leading up to it. In recognizing the importance of these wishes, the significance of place to both the patient and provider is highlighted. It is clear that Shannon feels that if people maintain a spiritual sense of place preceding death, it is important to attend to how they might wish to maintain that sense of place even after death. While their spirit may no longer remain to hold that sense, their body can honour their life by maintaining it in their place.

All these examples point to the importance of recognizing the role of a person's sense of place in their spiritual and psychosocial health. Where individuals tie place to their identity, it is critical for providers in rural Ontario to recognize where patients might attribute meaning or associate parts of their own self and seek opportunities to engage this aspect as a part of a person's care.

7.3 Familiar Surroundings and a Sense of Safety

In discussions of offering spiritual and psychosocial support, one participant commented

that the act of moving to hospital could be very distressing for palliative patients. In describing

the process of care, Barbara outlines:

> *I might be asking questions of, "So, you know it's not uncommon when people have had…you know, they're brought to the hospital, it's kind of a scary experience. Is that what your experience has been? Has this been scary for you?" "Oh, goodness, yes, it's been terrifying. I've never been in the hospital in my whole life, and now look at me. I'm hooked up to all these wires and look at the machines they've for going around me." (Barbara)*

In Barbara's view, this fear becomes a barrier for palliative patients in receiving spiritual

or psychosocial care.

> *We can't begin to meet spiritual needs if the social needs are not met first. Especially, you know, we think about issues of safety. So, what I think of that from somebody in the hospital, I might be there to create a sense of safety for the patient. So that they can then receive other care that is going to be needed. But until they have a sense of safety, they are not going to have any of their needs met. (Barbara)*

The concept of safety Barbara refers to is not necessarily a physical one; where patients

may physically be the safest they've been in some time with round-the-clock care, security and

immediate access to medication and treatment, spiritually or psychosocially they may be feeling

lost, fearful or in danger of losing their sense of place (Castleden et al., 2010; Lloyd-Williams et

al., 2007). While they may be physically safe in a hospital, spiritually and psychosocially they

may feel unsafe because they are separated from their home.

Shannon suggests that patients may be wishing to spend their last days in a more familiar

place, their home. In fact, this desire to remain at home for the end of life is one aspect of care

that drew Shannon to work in palliative care.

> *Very quickly I learned that I really wanted to help people die at home and be in their own surrounding if that was their choice. And I didn't like to see barriers put up that would prevent them from staying at home to die – that they'd have to go to the hospital. (Shannon)*

Carol's view aligns with Shannon's. For her, creating a safe space for people to live out

their illness experience means allowing them to choose where to spend the end of their life.

Many times, this means remaining home in a familiar space.

> *I want people to be able to choose, you know. I really like having the right to choose how*
> *I want to live my life and how I want to end my life. And to have that freedom. But let's*
> *face it, there are a lot of places that are very isolated rurally. So if we can help people*
> *stay home… and that's what the whole organization here is about, is helping people stay*
> *home and out of hospital if the can. (Carol)*

Shannon's and Carol's statements indicate that in attending to sense of place in the

Duffy's Hill context, patients should be cared for with the goal of returning them to their place of

safety, even at end-of-life. This is an important part of respecting the patient's wishes, in

Shannon's view:

> *They're trying to encourage them out of bed, but like why? Why are they doing that? So*
> *then we say, "You know, they really want to get home one more time. Can you please*
> *help them get stronger so that their mobility is good on the day so that they can get to*
> *their own bathroom?" (Shannon)*

Past literature (Burge et al., 2005; Howell et al., 2011; Wilson et al., 2009) has revealed

that dying at home is particularly desired by those living in rural areas, including rural Ontario.

While this may be the preference of many, it may not be feasible given the logistical challenges

of caring in sparsely populated areas. While it may not be possible for all patients to spend their

last days at home, there are other ways to allow patients the "safety" that comes with maintaining

sense of place. Shannon offers an example of one way this can be done.

> *We had a street guy once, and he couldn't go to the mission 'cause the mission was full in*
> *[the city]. So he came to our hospice and he did not want to be there. But he was dying,*
> *and he needed somebody to be looking after him. So he slept on the floor for the first two*
> *days. Then he finally accepted a pillow and blanket, and then he finally got into bed. And*
> *just before he died he agreed to a shower. And he said he'd never been looked after so*
> *well in his whole life as he did in that last week of life. And I thought, wow, that's…but it*
> *took time to adjust to him and what he wanted to have, you know. We really let him call*
> *the shots. (Shannon)*

In Shannon's view, letting this patient "call the shots" meant allowing him to do what he could to maintain an environment of familiarity, even if this preferred environment defied what was commonly considered a safe or functional care setting. Shannon's story holds important implications for offering good palliative care where attentiveness to the spiritual and psychosocial health of a patient has connection to sense of place. Where offering "good care" may, at face-value, mean providing comfort in the traditional sense, Shannon recognized that caring well for this patient meant forgoing traditional comforts like a bed or shower until he decided he wanted them himself. Carol shares a similar story about a client who died in the hospital, and what "calling the shots" looked like for him.

> *We did what we could, and in the end he died in the hospital with caring people who worked out of the hospital there, too. Bringing him what he wanted, like [his favourite soda] for his last weekend and stuff like that. (Carol)*

In Carol's view, part of what made this individual's care team so attentive to his spiritual and psychosocial well-being was their efforts to ensure sure he could enjoy his favourite drink despite his move to the hospital, adding a sense of familiarity to this new setting.

Whether maintaining a patient's sense of place, or their sense of safety through their connection with place, looks like sending them home one last time or simulating an environment of familiarity, allowing them to "call the shots" about their care puts power back in the hands of a patient regarding their life where otherwise have very little, allowing them to establish themselves as safe even at the end of life.

7.4 Chapter Summary

This chapter serves to demonstrate why attending to sense of place in caring for patients' spiritual and psychosocial palliative care needs is significant. Not only do participants discuss a

patient's "landscape," or the context in of their lives in relation to their hobbies, interests, and everyday activities, in their initial assessment, suggesting there exists an implicit "place" occupied by each individual in Duffy's Hill, and that in order to care for spiritual and psychosocial palliative needs, health care providers must "meet patients where they're at." Additionally, participants identify that the environment in which a patient receives care an contribute to spiritual and psychosocial aspects of their health, and that in maintaining familiar environments that remind patients of home and maintain their sense of place, patients can achieve some perceptions of spiritual and psychosocial safety. These observations demonstrate that place, and patients' relationships to it, constitute a major consideration in designing palliative and hospice care services, particularly those related to spiritual and psychosocial care.

Chapter 8: Relationships

The CIT informing the design of the interview guide for this study asked participants to recall end-of-life stories that went well, and less well. This question was sometimes rephrased in the interview as an invitation for participants to describe an experience in which they found they were able to do a good job providing for a patient's spiritual and psychosocial needs, and another where they had found that goal "difficult." The resulting narratives shed light on what spiritual and psychosocial needs exist in providers' eyes from their experience with patients in Duffy's Hill. A key theme that emerged in these narratives, alongside the importance of a patient's connection to place(s), was the importance of patient's connection to other humans. All participants described understanding a patient's relationships to other individuals as core to understanding palliative care patients and providing for their spiritual and psychosocial needs. Understanding those connections, as will become clear in this chapter, is key to providing for the spiritual care of palliative patients in Duffy's Hill. This understanding is essential when

providing for a palliative patient's well-being and often dictates their preferences for palliative

care.

8.1 "Spiritual needs are about connection"

"Spiritual needs are about connection," Barbara tells me as she sits across from me in her

office, walls lined with bookshelves filled to the top with books on spiritual and psychosocial

care theory from various disciplines. She continues:

> *I have connection with my loved ones. I feel an emotional bond with the people in my history. People who may believe life continues after death in some form will say, "I feel the connection of my ancestors." Or, "I feel the connection of that person who just recently died. They haven't really gone. They're still here with me." (Barbara)*

All six participants emphasized that a patient's connections to those they define as

important to them, whether those people are family or friends, living or dead, contributes to a

patient's understanding of who and where they are at the end of life. Listening to Barbara, family

is foremost in her mind as she references the spiritual dimensions of connections.

> *[O]nce I hear that they weren't really wanting religion, I will then assess and say, okay…is this about some of the family stuff that is going on? (Barbara)*

This view of family relationships as key to the spiritual health and needs of palliative

patients comes across in other providers' narratives as well. In her initial assessment of palliative

patients' needs, Shannon makes a point to ask questions about patients' family connections and

history.

> *[It] addresses their family support system as well, which is so important to understand. And it helps them to think about who is around for them, you know? Who is involved in their circle of care. And then I put them in the center and then if there is a brother, sister, mother, son, anybody that's important to them goes in those circles [around them]. And they can have as many circles as they like. Yeah, so it helps me to understand who they are. (Shannon)*

Audrey stresses her observed connections between family, spiritual health, and patients' abilities to cope with dying:

> *Family, another huge support for folks, and what helps them cope is knowing they've got family around they can talk to and come see them, that sort of thing. (Audrey)*

Relationships with family is an immediate element influencing the spiritual health of a palliative patient. Participants provided several examples of the significance of involving family in the spiritual and psychosocial healing process. Given the importance of these relationships in a person's life, it is intuitive that they would also play a large role in the person's death, or end-of-life.

In order to adequately attend to the spiritual and psychosocial needs of a patient in this context, providers described trying to uncover how interpersonal relationships play a role in a patient's sense of self and spiritual and psychosocial well-being, but also efforts to support healing of relationships for patients facing end of life. The following section explores in greater detail providers' framing of relationships as sites of pain and healing for patients, as well as providers' accounts of attempting to alleviate or transform relationship-based pain faced by their patients.

8.2 Healed Relationships

When discussing spiritual and psychosocial pain or distress, a major contributor that emerges from all participant interviews is pain caused by an estranged relationship with family.

> *Often if their symptoms are really difficult to manage, if they have a lot of pain, the idea of total pain…if there are things within their family dynamics like a strained relationship or estranged relationship. (Natalie)*

Providers in this context recognize that a patient's "total pain" includes a combination of physical, psychological, social, emotional, and spiritual elements, and that this combination is

unique to each patient's circumstances (Saunders, 1967). Along with this understanding among

providers emerges a shared perspective on which aspects of a patient's life contribute most

significantly to the spiritual and psychosocial levels of total pain. In this setting, addressing total

pain overwhelmingly means addressing strained interpersonal relationships that may exist in a

person's life. Addressing and ideally bringing some resolution to any strained interpersonal

relationships is key to patients achieving some level of spiritual or psychosocial healing.

"We can't take sides in family struggles," states Carol,

> *but meetings can be arranged where people can get to talk about their…like, everyone gets a say. This happened with one client who hadn't spoken to his brother in probably ten years, and then trying to track the person down. Everybody does that, really. They've done it at the hospital. And volunteers have done it. (Carol)*

Shannon affirms that this reconciliation is an important part of a patient's spiritual and

psychosocial palliative care.

> *It can be such a healing time, because they're wrapping things up. They're making amends with family that they've fallen out with, which is huge. And I've seen that time and time again. And that is such a good thing for a person to do. Be able to have those healing times—it's a real healing time for sure, when they're dying. Sounds weird, but they heal their spiritual side. (Shannon)*

In this view offered by Shannon, there is a positive association between reconciliation

and personal responsibility in this setting. In Shannon's view, resolving conflict with family or

friends is "such a good thing for a person to do" that it brings its own form of "healing." Here, a

different perspective, perhaps a culturally significant one, can be seen of what it means to be

healed. Despite the fact that an individual's body cannot be healed of its ailment, true spiritual

healing in this context can occur in the form of a healed relationship. While a person's body

cannot be preserved, their sense of self and place can be reaffirmed in reconciling with those

immediately surrounding them—with those who will remember them.

This statement about "[healing a patient's spiritual side" reveals a critical perspective regarding what good palliative care means in Duffy's Hill. While palliative care as a branch of health care continues to struggle with the public perception that its employment means no "curative" or "healing" treatment can be offered, and that a patient labelled "palliative" has been given up on (Hawley, 2014), palliative care providers do not see it that way. It is clear from these interviews that palliative care providers view their work as more than just "keeping patients comfortable" until the end of life. Rather, providers in this setting believe it is, in fact, possible to bring healing to palliative patients. There seems to be a cultural tension at play; in the Canadian normative biomedical context, patient outcome improvement is normally discussed as the absence of disease, manifested through a physical reduction of symptoms (Dudgeon, 1992; Engel, 1977), but the palliative care providers in this rural setting believe improvement comes in many forms. Even if there cannot be physical curing of the body, spiritual or psychosocial healing of the mind or soul can be achieved. The healing of the spiritual or psychosocial side is important, and can be facilitated by the healing of relationships.

Providers in this context describe how a person's physical pain can be exacerbated by psychosocial or spiritual pain, and connects the cause of this pain to conflict with loved ones:

> With a lot of the psychosocial-spiritual piece, you can't sometimes deal with someone's existential pain without dealing with the physical manifestation of that which is causing relationship dynamics between them and their loved ones. (Barbara)

One story offered by Shannon highlights the significance of spiritual pain related to interpersonal relationships and a physical manifestation of that pain that may occur in the total pain concept:

> I think of [one] patient that we had, and his pain was 10 out of 10 all the time. He was dying and we could not get this pain under control. It was 10 out of 10 all the time. We tried different pain medications, we got the pain and symptom management specialist team from [the city] involved, we had different doctors come in and look at

97

him. We could not get this pain under control. And then one day one of our volunteers who happened to be a minister was in, and I said, "Can you… go in and talk to that guy and just see if you can get anything." So he came out 45 minutes later and he said the man had cheated on his wife earlier in life and they had split up. But his wife had forgiven him. They got back together, and they had [many more] years of marriage, and he was dying now. And he's Catholic, so he's convinced that he's going to Hell. And he's just living in turmoil with this secret. So this minister said, "You know what? Your wife forgave you. God forgave you. Now you have to forgive yourself." So he got him to forgive himself, and that man died two days later, 0 out of 10 pain. As soon as he left the room even, his pain went right down to nothing. He didn't have one painkiller when he died. We'd forgotten about the psychosocial part. And like that man, maybe there's something in their past that they've never resolved, you know, got good resolution with. (Shannon)

Shannon's story provides a powerful example about how spiritual healing can ease physical pain. Guilt can be a highly debilitating and painful emotion (Boston et al., 2011; Stroebe et al., 2014). In the case of this patient, his existential turmoil began with interpersonal conflict, extended to become emotional pain (guilt), causing him to believe he must endure a punishment (Hell), and resulted in maximal amounts of physical pain. Such layered and interconnecting negative emotions create a complex total pain experience for the providers to navigate.

Another important note about Shannon's story was that what mattered in this case and what contributed to the patient's total pain was his perception of his own guilt. Despite the fact that his wife had offered forgiveness and that they had been able to rebuild their marriage of 20 years before his hospitalization, the guilt of his deeds festered like a wound in his mind. The guilt he felt had not been put on him by his wife, but was self-inflicted. What might seem to an outsider a "good resolution," as Shannon calls it, such as a renewed dedication to a marriage as in the case of this individual, might not be enough to reconcile things that have happened in an individual's history in their own heart and mind. When seeking to facilitate reconciliation for patients with estranged or distant loved ones, then, providers should consider what a "good resolution" looks like from the patient's perspective. True reconciliation might not look like only

forgiveness from another person; it might involve more, such as forgiveness from God or self-

forgiveness, as in the case of this man.

Barbara shares another example of an estranged relationship that caused physical pain in

a patient:

> *I remember back a few years ago having a palliative care patient in our unit who would come in for pain and symptom management, so pain was really high. Once we got pain under control, I was able to come in and go, "Okay something else is going on, here." Everybody had that sense that something else was going on. So in my assessment I learned that he had a daughter who he had been somewhat estranged from, and as I'm assessing I'm learning the story. I learn that he had been unfaithful to his wife, and that this had actually contributed to the estrangement with his daughter, because he had years ago been unfaithful to his wife, whom they had later divorced and separated. The daughter grows up really angry and hating her dad. And he desperately had a need, "I need to tell her I'm sorry. I need her forgiveness so that I can die." So through the wonders of making contact outside of the hospital, having his permission, figuring out, "Where is this loved one?" I got ahold of them. They came. Which surprised everyone, I think. But the daughter came. She was eager to come. "Of course I want to be with my dad! Of course!" So she came. And he didn't want to meet with her alone because he was afraid of maybe what she might say and how she might react, and so I had prepped her a little bit about, "Your dad just really wants to ask for your forgiveness for something." And I didn't even know what that something was at the time, because he had kept that piece of it really close to his chest. He hadn't told me about being unfaithful to his wife, he hadn't told me any of that. But he said, "I've got a daughter, and I really need to ask her forgiveness for something." I didn't know what I was heading into. I could have been heading into an incest situation, I didn't know, right? And so I'm with fear and trepidation making these phone calls to his daughter and speaking with her and just kind of getting a sense from her of her willingness to come, and she came. So guess what happened? When she came, his pain went down. He didn't have the same level of pain. Somebody who was, for all intents and purposes, imminently dying, ended up living at least another two months because he was able to get something off of his chest that was weighing him down in that total pain concept. His physical pain was being aggravated by this emotional, psychosocial-spiritual pain that he was in. That he needed to have forgiveness from his daughter. And the beautiful thing was she gave it. Which is why he was able to cope better with his illness. And she stayed. She took a leave of absence from her job, and she stayed in the area till he died. They had so many opportunities to rekindle their relationship and to rework their relationship. So that just didn't help him, that then helped her for her grief experience. No regrets. Right? So it brought healing, not just to him, but to her as well. That's why psychosocial/spiritual care is important in palliative care, right there. (Barbara)*

The first insight that can be recognized from Barbara's story is the tension that exists for palliative care providers as they are treating patients' interpersonal spiritual and psychosocial needs. Barbara knew that some form of reconciliation was required for this patient to achieve spiritual or psychosocial healing; however, she did not know the nature of the conflict that had strained the relationship and could only work with the information volunteered by the patient. Barbara trusted that the patient understood his needs better than she did, and to do all in her power to facilitate that healing without knowing the specifics of the situation. This trust stems from the importance of "caring about what the patient cares about." Although Barbara did not understand the significance or the context of what this patient needed to achieve through contacting his daughter, she recognized the importance it held to him, and in doing so was able to facilitate not only the healing of that relationship, but the lessening of physical pain. Recognizing that what is important to patients, even in cases where providers do not understand the significance of these things, facilitates good spiritual, psychosocial, and in this case, even physical care.

A second notable element of Barbara's story is her perception that this man lived for another two months because he was able to achieve that reconciliation. That spiritual and psychosocial healing added time onto his life, in her view. This perspective provides further evidence that there may exist a cultural view that physical healing is not the only form of healing. Rather, spiritual and psychosocial healing is not only possible, but a major goal of palliative care. In Barbara's view, this form of healing is so powerful that it can actually extend the life of an imminently dying individual. Perhaps extending life *can* be a goal of palliative care in this context, depending on the method of doing so. While invasive physical treatments are discouraged at this stage in order to adequately manage pain, suffering, and maintain quality of

life, "invasive" spiritual or psychosocial treatments, such as engaging with a deeply painful

interpersonal conflict, may be warranted and necessary to achieve those very same objectives.

The need to seek forgiveness and conflict resolution with family may feel like an urgent

spiritual and psychosocial need to patients in Duffy's Hill. The urgency does not, however,

necessarily facilitate the work needed for such resolution. Working through painful feelings

often involves the participation of individuals other than the patient. Resolution of conflict is not

always possible within the timespan remaining for a palliative patient's life. "Not every life,"

comments Natalie, "is going to end with a pretty ribbon on top of the bow, and everything

packed up and finished exactly as we had planned it to be." It is important to recognize that this

is at no fault of the palliative care providers; circumstances may simply not allow for every

spiritual or psychosocial challenge to be addressed before death.

In cases where healing is not accepted on the part of an estranged family member, there

are still options palliative care providers can do to help patients achieve spiritual healing through

reconciliation on their own. Barbara explains her strategy for working through conflict resolution

with rapidly declining patients:

> *I've been with people on the last few days of their life where they are needing to ask for forgiveness, but the people won't come. So I've taken my pen in hand and I've let them dictate the letter and then I give the pen to them and I say, "This is what the letter says, these are your words." I get them to sign it. And I go into my office afterwards and I type up a letter to the loved one saying who I am, what I was doing. I've just spent the last hour with your father, mother, brother, sister, whoever who is, who has given me permission to tell you that they're dying. They would love for you to come but understand that you might not be able to come because of all the past history between you. But they have given me a letter, and I'm enclosing that in a sealed envelope for you to do whatever you need to do with. That's spiritual care. Caring about what your patient cares about. (Barbara)*

Even in cases where reconciliation with family is not possible before the point of death,

health providers can play a role in facilitating that resolution for patients leading up to, and even

after, death. This observation further emphasizes the point that, in this context, a person's sense of self extends beyond death, beyond even their own identity and into the identities of others. It involves a sense of belonging to place and to people, and that the "self" they want to leave behind is one who has sought peace with the individuals in their lives. This insight is what Barbara is alluding to when she says, "Caring about what your patient cares about." And often, in the cases of patients in rural Ontario, the people they will leave behind, no matter the history between them, is what they care about. Despite differences or bitter conflict, their sense of self and belonging is tied to the people around them; their identity continues to exist through them after they have left, and righting the wrongs tied to the people in their life who will represent and remember them after their death makes a difference in their spiritual and psychosocial well-being.

8.3 Fear of Missing Out

Providers spoke often of patients who "held out," or prolonged their life in anticipation of events looming in the future. Shannon shares a story of a patient who continued to live, in her view, out of sheer will to do so:

> *We have a patient and he should have died a couple of months ago, and every day he just lies there still and stoic like he's waiting for something. And he has his milk [with] every meal and that's all he's living on, and he's just rotting away and there's nothing we can do about it. And he won't get out of bed, and all he wants to do is lie there. And he's waiting for his granddaughter to be born. She's due [soon], so he decided that he was just going to keep going until she gets here. And he will. He's going to make it. So it's unbelievable what the mind can do for these patients. (Shannon)*

In Shannon's view, waiting for his granddaughter to be born is what gives this patient purpose. He had something to look forward to, or something to keep living for despite his illness. Shannon believed this man would live to his goal, simply because he had decided to. The expectation of meeting his granddaughter gave him the willpower to go on.

In Shannon's story, the patient in question has a sense of certainty that he would make it to his goal. What happens, though, in cases where certainty is absent? Natalie shares a story of a patient who was afraid of missing out on future events:

> *So I took her on when she was quite high-functioning thinking that likely her decline would be precipitous, not wanting to miss the boat and being able to get involved with her. And she's had very few physical symptoms. Like almost nothing. The only reason that you could tell that she [is dying is] she's just lost an incredible amount of body mass. And so my role in seeing her has really been in providing her supportive counseling and an opportunity to talk and share. Talk about and share the feelings that she's having as she's journeying through this part of her life. And in alongside her daughter who had a stillborn birth right before her [cancer] diagnosis, and then became pregnant [again] later, and then the worries of that pregnancy, and then the birth of her grandchild. And they lived in the same house together. And so, all the worries of would she be around for the birth? And now that she is, you know, how long is she going to be here? Is she going to be alive for her daughter's wedding? And what kind of legacy can she leave for her daughter as a mother and for her grandchild as a grandmother? It's still unfolding, but I really feel like my involvement there has helped this lady to cope better than had I not been involved especially because her illness trajectory has taken such a long time. (Natalie)*

In Natalie's view, the largest part of her role in this patient's care was not managing physical symptoms, but helping her to manage her fears about whether she would be able to meet her grandson, be there for her daughter at his birth, or even engage in some way in his life. And as these events come to pass and the patient is able to meet her grandson, there comes another new event in the future that she could miss, such as the wedding of her daughter. These fears of missing out on major events or milestones in her relationship with her daughter are significant to the patient, and therefore significant to Natalie. Natalie sees her role as a provider to be one of conversation. Her role in caring for this individual is allowing the "opportunity to talk and share." In other words, lending a listening ear to these fears helps her patient to cope better, especially in the case of a long illness trajectory.

In Natalie's story, she brings up the idea of "leaving legacy." For patients who feel this fear of missing out in the days leading up to the end of their life, providers believe that leaving

legacy can help ease the spiritual or psychosocial pain that may come with the fear of having to

say goodbye. Barbara shares an example of what leaving legacy might look like in this setting:

> *This particular patient that I'm thinking of had had a sibling die a few years before. And the sibling had done a lot of projects for children and grandchildren to be remembered by. This patient didn't have any idea how they could leave legacy and wanted to be remembered by their children and family, but knew that it was going to have to look very different. And so [they] wanted to explore "what do I even have to offer," right? And so, as I explored with this patient, I'm literally exploring with them them telling me their life story in a way that says, "so how did you spend your time? What does your leisure time look like? What was your favorite activities to do? Were you ever involved in any creative activities?" "I did this, this, and this." So those are the things then that are going to have to inform the legacy that you choose to leave for your family…If it's early in the journey, we still have some months or at least good quality weeks. The patient is going to have some ability to engage in the process of maybe, for example, writing a letter to a grandchild saying, "I'm so sad that I had to die when you were still so little, 'cause I had hopes and dreams about what we might have been able to do together." And so these are... I throw ideas out at clients. I'll say to them, "You know what about... is there a piece of family jewelry that would be something that maybe came from your grandparent to you, or to your parent to you that you would want them to know the story of?" (Barbara)*

In Barbara's examples, many of the options for leaving legacy involve what a patient

leaves with individuals the patient will be leaving behind. In this way, leaving legacy acts as a

method of continuing a relationship after death. It allows patients to leave a part of themselves

with the people they love, so that they may know what that relationship had meant to them while

they were living. Even the anticipation of a relationship, as in the case when a grandchild is too

young to get to know their grandparent, leaving legacy allows them to engage in that relationship

even beyond death, so that their grandchild may know how important looking forward to that

relationship had been during that lifetime.

This desire to leave some legacy of a relationship is consistent with what is culturally

important in this setting. Not only will a letter or gift from a loved one who has passed on allow

their relationship to transcend death, but it allows the recipient to understand their connection to

the people in their history and to the place those people lived. It acts as a way for individuals to

share with their loved ones who they were and, as a result, reveal to the recipient a piece of who they now currently are in the context of that rural setting. Who are they connected to? Where are they connected to? What kinds of activities might they be connected to? Or, are there certain objects that hold significance and can inform where a person comes from?

> *The beauty of having voice-recording, telling your story, telling where you came from, why you came from where you came from, talking about your career and why you chose that career, why were you so passionate to become an architect? What drove that for you? That's leaving legacy. 'Cause you're leaving pieces of yourself behind in the minds and hearts of the people that you've left behind. You're saying, "I'm going to be remembered. I won't be forgotten."* (Barbara)

The significance of leaving legacy, therefore, lies not only in allowing palliative patients to engage with those they are afraid to leave behind about who they were, but it allows them the room to have influence on the people they are leaving behind, and to take control of what people will remember of them. Even if they are not able to personally meet those they leave legacy for, their legacy describes who they were as a part of the recipient's history, embedding themselves in their loved one's sense of self even after death.

8.4 Those Left Behind

While leaving legacy may help a patient to preserve relationships and their sense of self in those they leave behind, it may not stop them from worrying, or even feeling guilty, about unfulfilled duties owed to loved ones.

> *[Y]ou do get folks who are more worried about how their family is coping than their own physical pain, so I think all of it needs to be considered. (Audrey)*

Even the act of being ill can be guilt-inducing. Not wanting family members to worry or grieve can manifest as spiritual or psychosocial pain. Barbara describes common worries patients discuss when entering the hospital for palliative care:

This is almost always [what they say], especially in the elderly: "I'm worried about my spouse." Or, "my cat who's at home, and I don't know how they're coping there without me." So that tells me that there's some connections of... they're trying to make meaning and sense of their illness. Their purpose has changed because they're in the hospital now, and there's still needs that need to be met that they were meeting for someone else, probably. And their beliefs are in there somewhere too. And their values. They're valuing their family connection that they can't have right now. And a lot of times it is – they value their relationships with their animals and their pets. (Barbara)

In Barbara's view, the value of these relationships is part of what causes this worry for palliative patients. Not being able to complete their duties as a parent, sibling, child, or pet owner can put strain on their view of their own role in relationships. In Barbara's observation, "making meaning and sense of their illness" means considering the changing nature of their relationships and finding ways to cope with this change. Palliative care providers can assist with this change in assuring patients that their relationships still hold value and helping patients see ways in which they hold value as they approach death.

Natalie shares an example of one father whose dying experience allowed for him not only to maintain his own relationships in a new way, but to facilitate the building of new relationships for his family through his dying journey:

He had a son who really hadn't been in his life very much, and he and his wife had been married before, and had been widowed. And she had children from the previous marriage, and they were sort of supportive of the mom but not overly involved in their life. And they seemed sort of at a loss as to, you know, do we call the family? Do we get them involved? How much do we tell them? Not really sure because of the timeline what to do. And so I saw him. I did my initial visit. It was pretty typical…[o]n the first visit it's pretty hard to tell how quickly someone's going to decline after only seeing them once. And then two days later I got a frantic call from his wife saying he was calling his son to take him to the emergency room 'cause he needed to go to the hospital. And I happened to be close by, which is odd, so I went over to see him. I said, "Don't let him leave until I come and see." And when I got there, his son was there with his wife. The son had said, "My dad has never called me before to ask me for help." I said, "You know, this this is pretty significant. He's declining very quickly." And you could tell he was confused and restless. And he said, "Yeah, I know." And I think, the dad had told me in my initial visit, you know, "I don't want to burden my son." Was telling him about, "we don't know what's going to happen so like, I'm worried about telling him how serious or how soon things might happen." But his son knew. I

think just knowing, just having me there to reiterate to him that this is happening and providing that reassurance that, yes, he should be here now. And from that moment on until the gentleman died four days later, it was an incredibly quick decline, he was there, his wife was there, the patient's grandson was there, the wife's sister came, her children came, they rallied together as a family and said to me things like, "You know, I've never been this close to my stepson. You know, this is the most that we've ever talked. We've shared some really good memories." I think all of the beautiful things that can come out of an end of life journey happened for this family. And really, not so much because of my involvement at all, because they recognized that this was their dad's dying time and that this was where they should be. And I think perhaps my recognition and my encouragement of, you know, it is time to rally the troops and it's time to be here together, allowed them to recognize that yeah, we shouldn't wait and see how things go. We should really be here for however long this is going to take. And I shared that with the patient the last time I saw him. The gifts that he was giving his family in allowing them to bear witness to his journey, however hard it was for them and for him was something that they would recall when it was their dying time. That they would benefit from having gone through this, even though it was something difficult for them to go through. And I think he took a lot of solace and comfort in knowing that he was giving this gift and leaving this legacy for his family. (Natalie)

In Natalie's view, spiritual or psychosocial healing for this patient meant overcoming a

view that he would burden his family with worry, and instead accepting that allowing his family

to be a part of his dying journey was an unexpected a gift. Independence is of high importance

for many individuals in this context. Never having to ask for help from his son was part of what

established this patient as self-sufficient, and the desire to remain self-sufficient would continue

to exist at the end of life. In the case of Natalie's story, however, she was able to help this

patient, who wanted to prevent burden from falling on his son or worry his family, to realize that

this was the time to "gather the troops." That this was the time to allow others to be involved in

his illness, instead of seeking to protect them from the emotional burden of grief. In this way,

Natalie's primary role was one of assurance, but also in helping the patient to shift his

perspective of his role as protector of the family as his circumstances shifted. The significance of

this perspective change is nontrivial. Not only did this successful shift allow for the patient to

spend time with his family at the end of his life, but his family members who did not have

significant relationships with each other were able to build those during his "dying time."

Natalie's role in caring for this patient's spiritual and psychosocial needs involved helping him to

see that he could act as protector in a new way: that he could use this time to help his family

learn what it is to die, to "bear witness to his journey," and leave them with a final gift of

emotional preparedness and new, deeper connections with one another.

This preparing of families through "bearing witness" to dying journeys is revealed again

in a story offered by Shannon:

> *[O]ne family in particular, I remember they had [many] children and they were all [a]
> really educated bunch, from all over the world, that came from all these different areas to
> look after their [parent]. And they wanted an IV running, they wanted everything, so that
> took a lot of work. And they didn't want their [parent] to have a painkiller unless all of
> them had been phoned, first of all, and I said "Do you realize how much pain your
> [parent] is in waiting for all of you to get contacted so that [they] could have something
> for pain?" So it took a lot of work. It was weeks of really hard work. But then the year
> after, one of the [children] sadly got really sick and died at the hospice, and it was a
> completely different family. They were so on board with everything and trusting of the
> nurses, but it took that first experience for the second one to be better for them.
> (Shannon)*

It is clear that involvement of family in the dying process, while often emotionally trying,

can be beneficial for those left behind in the long run. Considering this, palliative care providers

can help reassure patients that in leaving loved ones behind, they are not abandoning them or

shirking their duties in the relationship. Rather, they are teaching them a new lesson, and leaving

them with a final loving gift in allowing them to be a part of their dying process. It is good for

families to witness the dying journey of a loved one. This helps them cope better in the future. In

this way, palliative patients can contribute to the future of their loved ones emotionally, even

knowing that they will no longer be with them physically. The spiritual and psychosocial health

of bereaved family members also plays a significant role in spiritual and psychosocial care of

patients in this rural context.

While the presence of family members and connection with loved ones can impact patients' spiritual and psychosocial health during their dying time, Carol explains that the converse can also occur; she has observed how the dying person can greatly affect the spiritual and psychosocial health of a hospice volunteer for the better.

> *The person that comes in to look after you, you have an effect on them, you know? And so they'll often tell the patient things and the patient gets concerned about them. 'Cause they care about them. And they care about the young people, you know? They care about these people coming in, and are they overtired? Overworked? And are they going to hurt their back helping them into the bathtub? And things like that. (Carol)*

In Carol's view, a patient's illness and dying time allows them opportunity to make a final impact on the people surrounding them, including the volunteers offering them care during this time. In her experience, the impact of the relationships is mutual. Not only do volunteers reassure patients that they are "not alone" as Carol puts it, but patients can leave volunteers with a lasting remembrance of them. While volunteers care for patients, patients also care for volunteers, leaving them with the memory of that special relationship, a final legacy that they can be proud of.

8.5 "[They're] waiting for me"

In some cases, participants indicated that connection to those who had already passed away played a role in the spiritual and psychosocial health of patients nearing the end of life. Shannon shares a story of a young boy whose relationship with someone they had lost played a role in his own understanding of his death:

> *This little girl…got hit [by a disease] at the same time. So they went through [treatment] together… and then they both got sick again, and then [she] died [a few] weeks before him, and he said, "You know, she showed me how to die. And he said, "I know she's waiting for me. (Shannon)*

Carol shares a similar story in which an understanding of a person's spiritual and psychosocial care needs was linked with connections to his deceased parents.

> He divulged to me one day, his father was Indigenous. I found out very late, this must have been near the end where he started talking about his family and his father, and how his father died, and died when he was young. He didn't really get to know him. I just thought maybe something more could have been done to support that person. From maybe their roots, you know, they didn't know a lot about their roots. But maybe someone coming in that had known their father. And the roots, the [Indigenous] roots that were there. And this person, too, hadn't cut their hair in 25 years. Their mother died, and as a sign of respect for their mother who liked their hair long, they just didn't cut their hair in 25 years. I just thought that was pretty special. So this was a very spiritual person, really. (Carol)

Two insights emerge from Carol's story. First, Carol's perception of this individual as a "spiritual person" is partially drawn from her observation of the connection he felt to his deceased mother. This relationship manifested physically in a desire to honour his mother by maintaining the length of his hair. Carol's perception demonstrates that providers in the Duffy's Hill context view relationships with those who have passed away as valid and important connections in a person's life, and that patients should be given room to honour these relationships in the ways they see fit as a part of their spiritual and psychosocial care.

Second, Carol believes that this person's spiritual and psychosocial well-being could have been better attended if he was given more opportunity to connect with his "roots," or his history. Connecting with this history would have meant learning more about his father: who he had been as a man, as well as what his Indigenous heritage meant to him. Carol's reflection demonstrates that health care providers in Duffy's Hill understand personal history to be connected with the histories of those who came before them. Connecting with one's history and forming connections with loved ones, even those who have passed away, can contribute to one's sense of self and spiritual and psychosocial well-being.

These stories from Shannon and Carol reveal the importance of understanding who in a patient's life has passed away. In her initial assessment, Shannon suggests that,

> *It's good to know if anybody close to them has died because they often talk to those people at the end of life, so I always put a little sidebar if they just lost a son or daughter or parent or partner. (Shannon)*

For those in rural Ontario who believe in a life after death, this connection to people who have already passed on gives them something to look forward to in death. While they may be leaving precious relationships behind, they have other relationships to rediscover on "the other side." When asked if she had any additional comments on anything related to spiritual and psychosocial palliative care at the end of her interview, Shannon felt it was important to share her experience in witnessing the dying experience of patients in hospice:

> *There is a common activity going on and that's that they're looking around the room, it's as if they're looking at different faces. And I see it time and time again and. We saw lots of different cultures in the hospice in [the city], and it doesn't matter what religion they are or no religion, they're looking around the room and they're acknowledging these, you can imagine, different faces all the way around the room, but it's never frightening. And they're having really good conversations. One time I walked in on a lady and she put up her hand. 'Cause she wanted to finish the conversation. And she said, "Yes?" and I'm like, "I just wanted to see if you need anything." "No, I'm fine." And then she wanted me out of the room so she could continue talking. And she wasn't confused or anything, she was absolutely crystal clear. But she was obviously having a conversation with somebody in the room. (Shannon)*

Regardless of who, or what, these patients were talking to near the end of life, Shannon views patients' acknowledgement of something, or someone, unseen as a significant indicator of the spiritual and psychosocial aspects of being. In Duffy's Hill, the need to live in relationship with others is an important aspect of patients' well-being palliative care providers take into account when supporting their patients. If people must live in relationship, they must also die in relationship, whether that be with a present individual or one unseen. People can be at peace, can be "absolutely crystal clear" as long as they have significant relationships to engage in. In

recognizing this need to converse and engage with people, providers can make sense of the work they do, and walk patients through the spiritual and psychosocial aspects of the dying process with attention to that which really matters in this context.

8.6 Therapeutic Relationships

In Barbara's view, attending to the spiritual and psychosocial aspects of a person's health has implications for the approach to care. Namely, the relationship between provider and patient plays a large role in how they accept care. "That person-to-person, intimate kind of way: I want to learn about you through conversation."

In this setting, caring for the spiritual and psychosocial needs of a patient involves getting to know them on a personal level. Genuinely caring for a person means understanding their context, where they come from, who they know, and what is of value to them. Learning these things involves conversations that often delve into deeply personal topics. This responsibility can create a difficult balance between maintaining professionalism and creating a "solid therapeutic relationship," as Natalie refers to it. Despite the challenges that may come with connecting with patients on a spiritual or psychosocial level, Natalie explains why genuine connections between health care providers and patients are significant in Duffy's Hill:

> *If a patient and family really feel like we have a connection and my availability or discussion of existential distress, distressing issues, and psychologically distressing issues helps them to cope, then my services may be the only one they need. It's not really explicitly like, "I will do this for you." But the relationship evolves to that. (Natalie)*

In Natalie's view, good spiritual and psychosocial care can only be provided if the therapeutic relationship has evolved to a point where enough trust exists that those conversations can take place. "The spiritual aspect for some is very private," comments Audrey. "Some folks don't want, don't share that kind of information."

In discussing who should be involved in having those conversations about spiritual and psychosocial aspects of health, Natalie offers:

> *I think it's really whoever in their care team has that connection and that relationship with that patient and family should be able to provide psychosocial care for the patient and family. (Natalie)*

Natalie continues this sentiment in her explanation of why forming these relationships might be difficult for health care providers:

> *Sometimes [providers] have patients on their caseloads for years, and they are exactly the person that should be having these types of conversations 'cause they have that built-up, solid therapeutic relationship, but yet they don't have a comfort level with it. And I think that again comes back to our society and our discomfort and inability to have these difficult conversations on a personal side. I don't think it's necessarily from a professional side of things, although it clearly bleeds into that. But I think there's a lot of work that we need to do in helping everybody in health care to be even more comfortable with having these types of conversations and providing this type of care and support for patients. (Natalie)*

While establishing that therapeutic relationship between provider and patient is important, it is also critical that providers understand that that relationship should be led by the patient and should resemble what the patient wishes it to look like. Shannon offers a good example of this:

> *We had one [client] with social anxiety and [they] did not like to see people. So suddenly [they've] got different nurses every shift, [they've] got a different doctor every week. So I asked [them] how [they] were doing with all this. We managed to get [them] into a private room. And [they] said, "You know, I've tried to avoid people all my life," [they] said, "but I really get a lot of comfort in the nurses coming in to see me." So I thought, this is fantastic. (Shannon)*

For this patient, simply having the nurses be present was enough of a therapeutic relationship for them to receive comfort. This demonstrates that establishing a therapeutic relationship does not mean providers need to become "friends" with patients. It is possible for a level of professionality to exist between patient and provider, even in instances where a more personal connection is formed to address spiritual and psychosocial health. In most cases, it is

ideal for providers to take the patient's lead, build trust, and slowly work towards a relationship

that will promote the spiritual and psychosocial well-being of both parties.

In cases where health care professionals have concerns that a professional relationship is

compromised by more personal connections with patients, Carol suggests that volunteers could

help to fill this therapeutic relationship role.

> *A lot of us in our professional roles, there's a reason why we have those boundaries, and it's better in a lot of ways, it's better on both sides, right? But a volunteer can be a bit more real with someone. (Carol)*

Carol continues that volunteers play a unique and important role in caring specifically for

patients' spiritual and psychosocial health.

> *The volunteer relationship, for a lot of people, it's just that acceptance. That listening. That non-judgement. The dependability. The caring of that consistent person visiting them over time that really helps with that need, you know? (Carol)*

Carol explains that the role of a volunteer is to provide companionship and connection to

patients who desire it. Her role, as a volunteer coordinator, is to match up volunteers with

patients based on who she thinks would be a good fit.

> *I'm there too to find out, you know, who they are and then who they might have a good conversation with. 'Cause a lot of people, conversing and having someone there, that's where they're getting their enjoyment out of life. They're not able to do things, but even what they did enjoy, they might like to talk about the gardening they did or the farm life they had. And, you know, if they are interested in making things, making furniture, doing crafts, or whatever it is. (Carol)*

Carol's efforts to match patients with volunteers who share their interests further reveals

the importance of deep, real relationships in Duffy's Hill. Although it would be easy for Carol to

match patients with whichever volunteers are available, she understands that the relationship

forged between patient and volunteer during a patient's dying time is a part of what treats their

spiritual and psychosocial needs. In matching volunteers with patients who have shared interests,

Carol helps to ensure that that deep therapeutic relationship is formed. Carol also mentions the

importance of maintaining this relationship throughout the patient's illness experience. In order

to ensure some semblance of constancy and maintain the therapeutic relationship between patient

and volunteer until the end of life, volunteers will "follow" patients and volunteer with them

regardless of where they receive care.

> *If a volunteer is matched with somebody in the home and they end up in long-term care for lack of a residential hospice in the area, they don't want to cut off that relationship. They want to see it through. (Carol)*

Carol's statement implies that "cut[ting] off" a relationship like this is a negative thing.

Conversely, "seeing a relationship through" means that a volunteer will continue to engage with

that patient until the end, ensuring them that "they're not going to be alone," and combatting a

fear of loneliness that impacts spiritual and psychosocial well-being, in Carol's view. It also

allows for a sense of closure on the part of a volunteer. Following a patient to the hospital allows

them to "wrap up," in Shannon's words, that relationship they have formed with a client, and

"see it through" to the end.

In supporting bereaved family members following the deaths of loved ones, Petra

similarly expresses the massive role played by volunteer facilitators in providing this care. Petra

shared that in many cases, the volunteer facilitators have experienced loss in a similar way and

can provide support through affirmation and validation of family members' thoughts and feelings

based on their shared experience.

> *Someone who's had someone at home for a long time in palliative care can really speak to someone who has just gone through that, is exhausted from it, and wondering "Did I do everything? Should I have done more?" Questioning medical advice. And just being able to say, "I hear you. This is my experience. And I'm here now. You know, there's movement. You're always going to be sad when you think about that, that's not…I mean if you love somebody, you'll grieve them." But yeah, the personal experience is the best textbook. (Petra)*

These observations by Petra and Carol demonstrate that therapeutic relationships do not necessarily require special training related to the provision of medical care. Rather, a listening ear and personal touch to care can assist in creating this relationship. "[Clients] need…someone to listen to them and be part of something," states Carol. Volunteers and health care providers alike can work together to provide this care in a way that respects and attends personal needs and boundaries.

8.7 Chapter Summary

In this chapter, it has been demonstrated from participant responses that attending interpersonal relationships play a large role in meeting the spiritual and psychosocial palliative care needs of patients in Duffy's Hill. Practically, this involves assisting patients in spending time with their loved ones in the ways they feel to be significant; this may involve facilitating time and space for patients to reconcile with estranged family members in an effort to heal broken relationships. It involves providing patients with opportunities to leave legacy for their loved ones, including those they may not be able to meet, and coming to terms with what and who they will be leaving behind. It also involves establishing robust therapeutic relationships with patients built on genuine and supportive connection to help them through their dying time.

Having provided detail on a number of elements that hold implications for spiritual and psychosocial palliative care, in Chapter 9 I turn to challenges related to this care and how they are managed in the Duffy's Hill context according to participants. These challenges will further demonstrate how Duffy's Hill presents a unique context that requires equally unique solutions to address these challenges.

Chapter 9: Challenges

In their interviews, health care providers highlighted a number of challenges that arise in offering spiritual and psychosocial care to residents of Duffy's Hill. Among these was a lack of time and space available to health care providers to doing this work "well" in their view, a lack of consensus on who should be involved in offering spiritual and psychosocial care, a loss of what to do for patients who refuse spiritual and psychosocial care, and unique challenges that arise from treating non-local patients in "cottage-country." In this chapter, I describe each of these challenges from the perspectives of health care providers, along with providers' proposals for their mitigation.

9.1 Time and space to do the work

One major barrier to offering spiritual and psychosocial care in the views of health providers was a lack of time and space to do the work "well." Natalie highlights that her patient load is akin to that observed in urban settings. While she values her rural, home-based care role because it can allow for more time to be spent with patients, she notes that many palliative care providers in the area don't have that luxury of time to spend with patients, and that this can make providing quality care challenging.

> *I can't just prescribe a drug to help you accept what your purpose was in life, right? Like these are challenging, often time-consuming conversations to have. And the reality of health care these days is that, in many settings, that is not reasonable. And it's really unfortunate, because we miss out on the humanity with which medicine should be provided. (Natalie)*

Natalie adds that while she does her best to work with other health care professionals to share spiritual and psychosocial care provision for patients, she recognizes that all are busy and trying to make the best of their time with every patient. She notes that "although it would be ideal for them to have enough time to apply a palliative approach to care for all of their patients,

the reality is they don't." Shannon also shared insights along this line of thought, commenting

that the system is not set up to encourage health care providers to take the time required to offer

palliative care fully.

> *Palliative patients take up a lot of your time in a work day, and in community it's all about getting your patients not... you know, you get paid by the patient rather than the hour so they didn't like to slow down for two hours at one place. So, I just started picking up all the palliative patients 'cause I loved it so much. (Shannon)*

Shannon's comment implies that those who desire to do palliative care, especially those

who wish to put time and effort into spiritual and psychosocial aspects of care, cannot be in it for

the money. While this reality is likely to attract people like Shannon who "[love] it so much" to

do the work, and likely excel in it due to this passion, it presents a challenge for health care

organizations to attract the personnel to provide these services.

Barbara points to another barrier to spiritual and psychosocial care, especially in

hospitals. In her view, quality provision of these aspects of care requires private space where

patients can feel safe to explore and discuss these aspects of their care.

> *They need the privacy to be able to have those open conversations. So that would be a limitation in the hospital setting. They don't always have that privacy. And if they've come into hospital for pain and symptom management, we have to consider that we have to meet that need first. We have to get that stabilized before we can actually do some of this deeper work. (Barbara)*

Often patients need to have their pain addressed, and this aspect of palliative care is

conventionally provided in hospital in Duffy's Hill. Barbara's statement highlights an important

consideration for providers hoping to balance physical aspects of care, with the spiritual-

psychosocial need for space. Finding a balance between these often-competing interests in

necessary for organizations looking to address the spiritual and psychosocial aspects of care in

Duffy's Hill, and should be taken into account in the designing of palliative care programs.

9.2 Who should be involved in offering spiritual and psychosocial care?

Implicit in Natalie's above highlighted statement that not all health care providers have the time and space to apply a palliative approach to care is the question: who should be involved in offering spiritual and psychosocial aspects of palliative care?

"My personal belief is that anyone who says they provide palliative care should be able to provide a spiritual component to palliative care," posits Natalie. She continues:

> *But I think it is an expectation from me that a part of their visits when they are going to do a review of medications or going to complete an [assessment], that they're really delving into those mood, anxiety, coping specifics. (Natalie)*

Natalie specifies that those who have the aforementioned "robust, therapeutic relationships" with a patient should play a role in offering these aspects of care.

> *I think family doctors in in a rural setting who have traditionally done home visits and who have been very available and who have a really robust therapeutic relationship with their clients and their families have a really big part to play in providing psychosocial and spiritual care for these patients. And so that's one of the things that I recognize is when I have patients. Usually the family doctors that are willing to partner with me are the kind of family doctors that have this relationship and recognize being a part of this patient's journey, even if not in person, is really important. (Natalie)*

In examining her own role in partnership with other health care providers addressing spiritual and psychosocial aspects of care, Natalie gives an example of a patient for whom most of her role is sitting in conversation and listening to their experiences.

> *I know that [this person] really treasures my visits and really is able to take that one hour or whatever to really let go and to share [their] emotions. And then that frees [them] up to be able to go back to being an active participant in [their] life, and not having to worry or not having to be consumed by those thoughts because [they've] had an opportunity to circumvent them when I'm there. So, I think that's where I see the usefulness of psychosocial care in addition to, or in a situation where even physical care is very minimal. This could be very easily done by someone not in the medical profession, but because I happen to be the person there and happened to form this relationship with [them], I'm the one doing it. So, I think it's a case in point. It doesn't need to be somebody who is trained or typically the one who does the psychosocial support, but it can still be done really well if you have the time and ability to sit and bear witness to someone's difficult thoughts and emotions. (Natalie)*

While Natalie suggests that these conversations do not necessarily require specialized training in order to take place, Barbara proposes that having a specialized spiritual and psychosocial care provider is beneficial for patients' health.

> *Just like you wouldn't want just anybody off the street giving you good medical advice, you're going to want [spiritual and psychosocial care] to come from a professional. I think that that is where a little bit more confidence can come in, if we can say we actually have somebody who's trained and equipped in this area, and this is their specialization. This is what they do. Can we call them in? 'Cause yes, the nurse at the bedside in the middle of the night, or the housekeeper in the hospital room in the middle of the night can offer good, personal, one-on-one support for somebody. That emotional support, or the person is crying and—because I've heard these stories from staff—"They were crying when I went in, so I just held their hand." And I'll say to them, "Good for you! 'Cause that was really good spiritual care. Thank you for doing that. Thank you for seeing at the need and then meeting the need." But would I want my person who is [not as experienced or skilled] going in and providing spiritual care every day? No, I don't. 'Cause they don't know what they don't know, right? Whereas I've got training that I draw from every day when I'm having my interactions with people. So that I don't re-traumatize a traumatized person, right? 'Cause that's important, and that's why I think the trauma-informed lens is so critical. And we need more of that in our healthcare. (Barbara)*

Barbara's reflection that health care professionals should approach spiritual and psychosocial palliative care from a trauma-informed perspective is key to understanding who should provide this care, and what kind of special training might be required in order to do it. In many cases, confronting one's spiritual and psychosocial ideas, feelings, and experiences involves revisiting potentially traumatic events or memories that can cause harm if not properly anticipated (Crunkilton & Rubins, 2009; Ganzel, 2018; Gwyther et al., 2005). In this sense, having trauma-informed care practices will improve care quality and minimize harm. Special training on trauma- and violence-informed care (TVIC) is increasingly available and encouraged for Canadian healthcare providers (Browne et al., 2015; Green et al., 2015; Levine et al., 2020). This approach attempts to create an "emotionally safe" (Browne et al., 2015, p.3) environment that is aware of potential past traumas that patients may have experienced and keeps this

awareness in mind while providing care (Browne et al., 2015). Learning to approach care in this

way often requires special training—training that Barbara has.

Petra agrees with Barbara's assertion that some formal training is required to do this work

well, particularly for volunteers. This being said, this training must be paired with a personal

quality that may include experience with the topic.

> *I think some training has to be given because people need to know where to draw the line. I think that's extremely important. Who to call, when to call. To redirect people if their needs are bigger than what the volunteer has to offer. Nobody is an expert in grief. When you live through grief, I think that's your best resume. (Petra)*

Audrey, Carol, and Petra agree that a specialist trained to address these aspects of care

would indeed improve quality of palliative care for patients who are "really suffering." "It is a

gap," Audrey comments, when asked what she thought could be done to improve spiritual and

psychosocial palliative care in the area.

> *What would be amazing would be non-denominational…I want to say healers, but I'm not sure that's their term. But it's like this little niche of people who would be willing to come and talk to people who are struggling. In their homes. And be willing to be open to whatever their belief system was. (Audrey)*

In Audrey's view, the need for spiritual and psychosocial palliative care in the area paired

with the shortage of medical personnel available to address these aspects of care calls for a

specialist with the time and training to address these aspects specifically. She suggests that as

separate aspects of care, a specialist is warranted to help individuals access this less-attended

area of their health.

> *I mean the fact that we all cope means that we've got some sort of belief system in place. Some people don't realize that it's there or how to access it. So it's a separate category of counselor, in my mind, that would be able to connect with people and help them with that. (Audrey)*

Carol agrees with Audrey's suggestion, commenting that a non-denominational spiritual

and psychosocial care provider could ease the burden on health care providers and volunteers,

though volunteers are largely already filling this role in the local palliative care landscape.

> *On an informal basis, everybody should be concerned about that and do their little 10-minute whatever they can do. Whether it's comfort, or just keeping… even if like a nurse goes in and thinks "This would be something a volunteer could do with the patient," or whatever, they could tell us. But if we had a spiritual care advisor, or somebody that was more formally part of the team, then when you saw the person you could explain what that role would be. You could say, "You don't have to tell me right now. Would this be something you'd be interested in?" Not to force it on them. 'Cause sometimes even with a volunteer visitor, [they ask], "Well what are they going to do? Am I going to have to entertain them?" And then you're like, "No, no. You're not here to entertain the volunteer. If you need to sleep you can. They're going to give you some companionship and support. Maybe water your plants, get you a cup of tea, you know, give your caregiver a break." You know? So you just reassure them. (Carol)*

While Carol agrees that having a "spiritual care person" available to address spiritual and

psychosocial needs specifically would be helpful, she also suggests that the informality with

which this care is usually currently offered is valuable in its own way.

> *I just don't know how clinical you want to get in offering [spiritual and psychosocial care] to a person. I like a gentler approach, and I just like to see how things evolve. I don't like to come in there with my clipboard and my questionnaire. And questions can be slipped in. I like subtle. And I don't like to take notes that much when I'm with people, unless you have to. I know when you've got a document and doing medical history and all that kind of stuff, but if I'm just going to sit and have a chat with you when I come in, sit down, you might offer me a glass of water or coffee, and we just sit and chat. And you could ask some probing questions in just a subtle way as you're going through. And that might be that she's missing her sister. They had a falling out ten years ago. Maybe there's a way to contact her. But you're just kind of listening for those hints of where you might go with it. Because a lot of people have been assessed so much, and they're kind of tired of it at this point, when you have like a hospice service going in. And they feel too, I think, the briskness and the time constraints of a lot of health professionals. So they don't feel like they're really listening. And if they're not really listening, I'm not going to tell you. That's kind of how they feel, you know? And do they really care, or is this a sterile, institutional environment? (Carol)*

Carol suggests that true caring involves real listening. While completing an assessment

does not necessarily imply that a provider is not truly listening to a patient, she points out that in

some cases, it could be perceived that way, and cautions against the "clinical-ization" of spiritual and psychosocial care, areas of care that really cannot be quantified or measured. According to Carol, providing good spiritual and psychosocial care sometimes means putting aside assessments or procedures, and simply sitting and talking with the patient, accepting that cup of water of coffee, and using probing questions to get to the heart of what troubles them. Carol suggests that volunteers can fill this role well, since they do not need to complete any aforementioned assessments, avoiding a "clinical" or routine feel that could accompany these.

Petra suggests that spiritual and psychosocial care providers should be involved with bereavement care for families as well. She suggests that these providers "could be a social worker or a chaplain, but volunteers, volunteers, volunteers." In Petra's view, volunteer bereavement group facilitators best fill this role by "provid[ing] a presence…just a kind and loving presence to the family of the dying." "Volunteers are the backbone of the bereavement program," she emphasizes. "Their only focus is on: who are you? How are you? Where are you? I'm with you. You know? They're just being present."

Shannon offers a final thought on her own experience regarding offering spiritual and psychosocial aspects of palliative care to residents of Duffy's Hill. She reflects that her own experiences can contribute to her capacity in offering these elements of care, and that the ability to do so grows with experience and increased self-awareness.

> *I think that comes from where are [we] at in [our] own psychosocial/spiritual*
> *issues? Because we're all learning as we're going along, right? So every day you're*
> *learning about yourself a little bit more, and if you're not in a good headspace, how are*
> *you going to help somebody else be a good headspace, you know? (Shannon)*

By being "in a good headspace," Shannon believes that her ability to assist someone else along in their health journey, at least spiritually and psychosocially, is optimized. This reflexive

state of mind is crucial, in her view, for a palliative care professional working to address spiritual and psychosocial elements of care.

Petra suggests that a similar point of reflection is required of volunteer bereavement group facilitators.

> *The facilitators join the group, and they're there to support others, but they're also journeying with their grief. And whether it's five, or ten years, or two. These spaces are so needed. People never tire of speaking about their loss. (Petra)*

The perspectives offered by participants on this question present two ideal requirements for those who provide spiritual and psychosocial palliative care in Duffy's Hill: first, a reflexive frame of mind that understands the value of time and simple conversation with patients is necessary to achieve desired outcomes; second, training on the subject optimizes care quality, best observed when a trauma-informed approach is applied along with a broad, if not non-denominational, understanding of spirituality.

9.3 "You can't force spiritual care on anyone"

In discussing barriers to spiritual and psychosocial care for palliative patients, all participants mentioned the necessity of patient willingness to receive care before it can be offered. "You can't force good spiritual care on anybody just like you can't force good medical care on people," explains Barbara. "If they don't want it, they don't want it."

While this is an accepted reality by health care providers, it is a frustrating and sometimes discouraging barrier for health care providers who desperately want to help. Barbara shares the following illustrative story:

> *"I had an example of somebody who was actually on our palliative care service that I can speak to about that. I know that for this individual there is so much going on, but for them, their defense is up and they use humor to mask their incredibly strong, powerful anger. And I see through that. I say to them, "so I hear you say it this way, and the disconnect for me is that you're laughing about something that you're actually*

grinding your teeth about. That's not really... you know, there's incongruency here between what you're saying and what you're physically experiencing." And the person got very angry with me. To the point that they just berated me from one end of the street the other. And I could not continue to offer them any spiritual care because their anger would not allow anything in. Like there was no crack that they were going to allow to open up to the point that I sat there, and I said to the person, I said, "Sounds to me like you really don't even want me to be here." And they said, "Well I'm going to let you stay." And I said, "Why would I, why would I stay if you don't really want me here?" And then the person just continued to berate me and berate palliative care. And when I reflected back was, that sounds like a lot of pain speaking. And then the person would say, "You don't even know whether or not there's pain in me! You have no concept! You have no idea what I'm going through!" And I'd say, "Yes, you're right, I don't. But just the way you're speaking tells me that there's a lot of emotional pain." And I said, "It makes me sad that you are so closed off to any support for that." So, I couldn't give [them] any spiritual care because [they were] completely closed. It's very, very sad. (Barbara)

Audrey agrees with Barbara's postulation that provision of spiritual and psychosocial care, like biomedical care, begins with consent to receive it. "It starts with people being willing to consider it as an option that might help them," she explains. In discussing those for whom spiritual and psychosocial care are difficult to offer, Audrey indicates "the individuals who don't have family support of have had very dysfunctional families. And had never really learned good coping skills, so yeah, they're the hard ones."

I have this one person I'm thinking of who came from a chaotic life, struggled with addictions and was in a certain amount of denial about what was happening, and I think, again, it shouldn't be that... just that never really developed good coping strategies. Which again, personally, I think comes from some sort of spiritual belief in something. And when a person's feeling less and less well and dealing with pain or loss of energy or isolation 'cause they can't get out and the fear of what is happening just increases. And, I... you can offer for someone to come talk to them and they tend to not want that. (Audrey)

Natalie shares a similar story about a time when she found it challenging to offer spiritual and psychosocial care to a patient who did not want it.

[I saw] a young man who had [cancer]. And he did not want to talk about dying. He did not want to talk about the fact that this was, he was going to die from this cancer. He and his wife, they clearly had a strained relationship. He had a history of alcohol use, and she was willing to care for him at home but very worried about his

inability to open up… he would just push down all of his emotions and it would all of a sudden burst out in a huge rant, or yelling at her and snapping. So, she was very reluctant to keep him at home and having a lot of guilt about the idea of sending him somewhere for the end of his life because she couldn't cope. And I tried many, many times with this guy to sit with him and ask some hard questions, and he just had no ability to open up to me. To acknowledge the things that I was trying to get him to recognize. I know deep down he knew but could not come to terms with acknowledging them. And he was one that... he did die at home, his wife cared for him at the end, but it was a horrible last 12 hours. He was... we were trying every type of anti-anxiety medication, pain medication, trying to get him settled. And he went kicking and screaming. And his wife was traumatized by that. I mean, it... he comes to mind whenever I think about a situation [in which] I could have been better. But, I mean, it was not for lack of trying on anybody's part: it was him. He just was not there. You can't... not every death is going to be, not every life, I should say, is going to be, is going to end with a pretty ribbon on top of the bow, and everything packed up and finished exactly as we had planned it to be. (Natalie)

In their stories, Natalie and Barbara both note that while situations like this are disappointing and can feel disempowering, it is important for health providers to not take on blame or responsibility for a frustrating outcome, just like in cases where biomedical treatment might not work. "We have to be able to meet our patients and families where they're at and not force the issue and not take it personally," comments Natalie. It is only fair to expect from patients that which they are willing to give; if they do not wish to engage in spiritual or psychosocial care options, their decision must be respected.

At the same time, Natalie comments that a lack of enthusiasm or willingness on the part of the patient should not bar health care providers from attempting to offer the absolute best care they can in the ways allowable to them:

I think people who are uncomfortable with having those [spiritual/psychosocial care] types of conversations often fall back on the excuse of, well, they didn't seem like they wanted to talk about it, or they weren't really open. And I think I have the experience and the bravery, perhaps, to ask those hard questions even when I recognize that this person doesn't want me to ask this question. I know they don't. I know they don't want to talk about this. But if I don't ask the question, then I don't know if they would have taken that opportunity even if they don't want to talk about this, right? If I ask the question and they don't answer, or they tell me they don't want to talk about it, then that's fine. But at least I've given them an opportunity, where if I hadn't asked then they

wouldn't have had an opportunity, right? And perhaps they'll know that because I asked that question this time, then next time when they do feel like talking about it they'll know that I'm somebody who's willing to have these hard conversations with them. But that comes with experience. (Natalie)

For Natalie, offering good spiritual and psychosocial care means offering the opportunity for care, even if it is refused, throughout a patient's care journey. Just because a patient refuses spiritual or psychosocial care at one point, does not mean they will be closed to it for the duration of their illness journey. In Natalie's view, it is the responsibility of the health care provider to continue to provide opportunity for those types of care, even if its actual offering is refused. This constitutes an answer to what can be done for those who refuse spiritual and psychosocial care outright; respecting a patient's decision while leaving the opportunity open is a part of providing this care well.

9.4 "They just can't get there": Physical Isolation as a Rural Challenge

Consistent with what has been found in past literature (Brazil et al., 2015; Kaasalainen et al., 2011; Kaasalainen et al., 2014), health care providers in Duffy's Hill view physical isolation as a barrier to spiritual and psychosocial care accessibility. This challenge was particularly noted by Carol and Petra. Carol explains that patients who are immobile are often unable to make it into town to engage in the activities they enjoy.

If they end up in a wheelchair, then we don't have wheelchair transportation. So for our transportation service, people have to be able to transfer into a car and our of a car. So if they need a wheelchair, and say they don't have ODSP, it's expensive…there's no, like…a taxi, but that's even way more expensive than transportation service. So limited access to transportation (Carol)

Petra notes that access to bereavement groups is similarly limited if family members are unable to make it into town to join in the groups.

Travel, for some, if the bereavement…so [Duffy's Hill] is a wider community. And if somebody [out of town] is newly bereaved, they don't have a car, they don't drive, they

can't get to the groups that are being held in [town]. So you need that many more teams than we have currently to get out to the different areas and run programs. (Petra)

In an effort to reach physically isolated individuals, particularly during the COVID-19 pandemic, Petra organized an online bereavement group via Zoom for facilitators and family members who had recently lost a loved one, however, this also posed challenges with accessibility.

One thing this area struggles with, when we started [having Zoom bereavement groups], so many people said their Internet is so bad that they couldn't join in the online…Even one of our facilitators, she couldn't get online with us because the Internet sucked. So there is that challenge…which deters people from getting technological education, you know, because they don't, they don't have a tool to use it, so why would they bother? So it keeps them a bit secluded, and when you think of Facebook and all of those different programs that people could be using to break though that isolation. (Petra)

There are many areas in Duffy's Hill that remain without wireless internet access. Because of this, accessibility is not always improved by online meetings. Because of this, in-person meetings remain a preferred option for many individuals, assuming that a transportation service is available. In describing the needs that must be filled to overcome this challenge, Petra states,

We need more internet accessibility. We need more volunteer drivers to get people to these things. Yeah. There are people who can't join because they just can't get there. (Petra)

"And even stipends for the volunteers for their gas, even, would be nice," suggests Carol. If patients and family members are unable to travel, volunteer drivers could provide this service if funding was available to reimburse them. These insights reveal that in order to provide adequate spiritual and psychosocial care, practical needs such as transportation or internet accessibility must be met as a prerequisite to their accessibility.

9.5 The Challenges of Cottage Country

For many nearby city-dwellers, Duffy's Hill serves as "cottage country"—a place they choose to spend their summer holidays to escape the busyness of urban life. In Shannon's experience, working in cottage country presents a unique challenge for providing quality palliative care, especially to religious and cultural minorities.

> We can have people from anywhere at all. Like it's a cottage environment here, right? And people have often come to the cottage for one last summer, and they're not going to make it back home, you know, so they end up in here with us. So they could be from any walk of life. You know, city people hire from everywhere in the world, right? So then it's like, can we shift gears fast enough to accommodate this person? (Shannon)

In particular, Shannon worries that a lack in diversity of medical staff will affect the quality of care available to individuals from minority cultures. This concern stems from the fact that the majority of health care staff in Duffy's Hill originate from the area and belong to the majority white, Christian population.

> [T]hese nurses have all come back to their home, you know, so these people are all from here. So it's really difficult sometimes. I mean now and again will get a doctor from the city, maybe from another culture. That is like, okay, well good. At least we've got a little bit of a mix. At least we can understand a little bit of where this person is coming from. But we're really so very... I don't know, traditional, I guess you'd say for the area. (Shannon)

In order to address this challenge, Shannon suggests that there is a need for a diverse team of volunteers available to help with the provision of care from city-dwellers who retreat to the country during their dying time, as well as residents belonging to minority groups.

> [I]t would be good to have an arsenal of people on board. Like volunteers that are trained for palliative care and that have, you know, what can you offer? You know, can you speak another language? Can you speak sign language? You know, only anything at all. But, I mean, for the most part communication isn't a huge deal. There's usually somebody in the family that can... that can translate. (Shannon)

Particularly, Shannon believes having the capacity to communicate with an individual in their first language is a key aspect of providing good spiritual and psychosocial care. While this

is not always possible with limited staffing resources, Shannon shares that they do their best to find ways to communicate.

> *I just try and accommodate, by like that one volunteer being able to speak a language, you know? Like just to really communicate with somebody, genuinely communicate, like actually be able to speak their language is huge. (Shannon)*

It is clear from Shannon's experience that addressing the challenges posed by the limited resources and diverse clientele of "cottage country" requires resourcefulness and a highly collaborative community of care providers, both paid and volunteer. The remaining question is this: how can a small community with a largely homogenous population mobilize the volunteer-base needed to serve such a diverse clientele? As Duffy's Hill continues to diversify and more individuals from cultural and religious minorities choose to settle in the area, this vision will have increasing potential to become a reality. For now, Shannon and other health care providers like her continue to do their best to individually care for each patient they encounter and meet their specific spiritual and psychosocial needs in any way they can.

9.6 Chapter Summary

It is clear from the results presented in this chapter that Duffy's Hill is a unique context that experiences very particular challenges, and that these challenges require creative and resourceful solutions. Having outlined specific elements contributing the spiritual and psychosocial well-being in rural palliative patients located in Duffy's Hill and listed the challenges faced in offering this care, I now move into a discussion of what the implications of these results are, what recommendations can be made, as well as what implications exist for future research given the findings of this thesis.

Chapter 10: Discussion

As stated in earlier chapters, the results presented in this thesis constitute an exploratory study intended to examine the potential role of rural Ontario "culture," if such a thing exists, in caring for spiritual and psychosocial palliative needs in one rural town. Based on semi-structured interviews and drawing on Flanagan's (1954) CIT, the methods used aim to generate detailed insight into the practices and meanings for providers implied by the phrase "spiritual and psychosocial dimensions of palliative care" in Duffy's Hill. With such a small sample size, it is impossible to draw definitive conclusions about the cultural specificity of spiritual and psychosocial palliative care needs and provision in this Ontario town. That being said, there are similarities in values, norms, beliefs, and practices that appear across participant interviews. These suggest some level of shared understanding regarding what it means to offer good spiritual and psychosocial palliative care in this context. As noted in Chapter 1, Leininger (1997) defines culture as "the lifeways of an individual or group with reference to values, beliefs, norms, patterns, and practices that are learned, shared and transmitted intergenerationally" (pp. 38). In this chapter, I begin by reviewing these shared values, beliefs, norms, and practices and draw on these to make a number of recommendations for spiritual and psychosocial palliative care in the Duffy's Hill context. In the second part of the discussion, I consider the significance of the findings beyond Duffy's Hill. I explore what is similar and distinct about results from this context compared with knowledge from past research, highlight the advantages and limitations of applying a cultural lens to the analysis of palliative care practices in Canada, and propose future directions for research on palliative care in rural Ontario contexts.

10.1 Underlying Values That Give Meaning to Spiritual and Psychosocial Care

The results summarized above (Chapters 6–9) explore individual and shared meanings of spiritual and psychosocial palliative care, allowing for a broad understanding of what is important in offering these areas of care in this setting. In examining the themes that give meaning to these areas of care, one major value emerges that appears to underlie all spiritual and psychosocial palliative needs in the Duffy's Hill context and holds implications for practice. In this context, based on participant responses, high value in spiritual and psychosocial palliative care is placed upon caring for relationships: specifically, relationships with place, relationships with people, and relationships with individual and shared histories. Although possession of relationships is not unique to individuals in Duffy's Hill, there appears to be a shared understanding about how these relationships are experienced in Duffy's Hill that affects how health care providers approach spiritual and psychosocial care, how they get to know their patients, and ultimately how they perceive success or failure in offering this care.

Health care providers in Duffy's Hill understand that relationships with place, people, and history form a resident's social identity in this town. Because so many residents have "been here their whole lives, and families and generations" as Shannon puts it, not only do you "get to know everybody," but everyone also knows where each individual comes from: their family history, where in the area they have lived historically, what they do for a living or what their family has done, where they went to high school and whether or not they played hockey, football or both during that time, are common knowledge in this context. There are no strangers in Duffy's Hill; residents have connections to everyone in town, even those they have not yet personally met, through a thriving network of interpersonal relationships that extends beyond the individual to become shared. "They know that you're looking after them because you're so-and-so's daughter," shares Shannon, revealing the perception that interpersonal relationships can be

formed on the basis of an individual's history, and that this history is connected greatly to an individual's sense of place. An individual "belongs" in Duffy's Hill because they feel a shared connection to the rural, because they enjoy the small, intimate feel of knowing everyone in town, or at least knowing someone who knows someone, and because they understand the value of knowing where each individual comes from.

Given the shared understanding of these relationships and their importance in Duffy's Hill, recommendations for spiritual and psychosocial care can be summarized as opportunities to highlight these relationships, and center spiritual and psychosocial services around them. I propose that these three types of relationships could form the basis of any services developed in Duffy's Hill to address spiritual and psychosocial palliative care. In the following sections (10.1.1–10.1.3), I outline a number of recommendations drawn from participant responses that, at their core, address one or more of these relationships. An abbreviated list of these recommendations, along with relationships they have potential to address, is included in Table 2. It should be noted in reading the following sections that, while recommendations are sorted into the categorical relationship seems best to fit, many of these recommendations may actually address more than one area because of the overlapping nature of these relationships in the Duffy's Hill context.

Table 2: Recommendations for spiritual/psychosocial palliative care in Duffy's Hill

Recommendations	Relationships addressed		
	People	*Place*	*History*
Hospice layout/construction			
1) Build hospice in rural area	X	X	X
2) Build hospice in area where nature is easily accessible		X	X
3) Build with lots of windows so that residents can see the outside		X	X
4) Allow flexibility within hospice rooms for patients to "call the shots" and make the space familiar		X	X
The initial conversation/assessment			
1) Use non-leading questions to inquire about patient spirituality while avoiding use of terms "spiritual and "religious" until patients use them.			X
2) Ask about family and friends who have passed away	X		X
3) Pay attention to patient coping strategies as an indicator of psycho-spiritual health	X	X	X
Addressing interpersonal relationships			
1) Provide time and space for patients to reconcile with estranged family where possible	X	X	X
2) Have option to write letters or record messages for family who that not come	X		X
3) Provide services to help patients leave legacy	X		X
4) Brainstorm with patients to find ways to adjust relationships to match their new role (i.e. how can caregivers feel as though they are still providing that care?)	X		X
5) Provide privacy for patients wherever possible	X	X	
Recommendations for staff			
1) Pay staff by the hour, not by the patient	X		
2) Hold mandatory trauma-informed care training	X		X
3) Hire non-denominational spiritual care providers to address spiritual and psychosocial needs			X
4) Strive for a diverse team of volunteers with different linguistic abilities and from different backgrounds	X		X
5) Provide reflexive activities for staff to support their spiritual and psychosocial health while providing this care	X		X
Other			
1) Make arrangements to honour patients' wishes for after-death	X	X	X
2) Offer a transportation service, or offer stipends to volunteer drivers		X	

10.1.1 How to Care for Patients' Relationships with Place

While Chapter 7 discussed the in-depth the role of place in caring for spiritual and psychosocial elements of palliative care in Duffy's Hill, a number of recommendations emerge from this and other chapters that could be considered in the creation of these services to attend this sense of place. First, location of care should be considered. While receiving care at home has been shown to be preferred in many parts of Canada (Howell et al., 2011), there is little research examining this preference in rural Ontario, likely because most rural deaths occur in hospital (Conlon et al., 2019; Dumont et al., 2015). Despite this dearth in understanding, services do exist in Duffy's Hill that allow patients to receive palliative care at home, and broader access to these services and increased support to staff could better accommodate patient preference to die at home if it indeed exists. Simply having options for where one chooses to spend the end of their life attends to their sense of place and allows them autonomy over how it is expressed and experienced at the end of life.

In cases where it is not possible or desired for an individual to die at home, accommodations could be made in the construction of a rural hospice to account and care for a residents' sense of place. Most of these recommendations have to do with hospice location, layout and construction that facilitate the formation of a healing space (Sternberg, 2009). For example, in discussing a patient who "had it all together," Shannon explains that he "wasn't going to the city anymore. He wanted to be up there in the rural area so that he could be near his family." This story reveals that an ideal hospice location, therefore, would be one easily accessible by residents of Duffy's Hill so that family and friends could visit their loved ones without difficulty. The principal benefit of having a rural hospice available is that it is just that:

rural. It does not involve moving to a city; it keeps a palliative patient in their own community, connected to their home, to the people that are important to them, and to their history.

Audrey's observation that many individuals' "coping and energy…comes from being in nature" reveals the importance of landscape in caring for patients' sense of place. Audrey suggests that "being able to… look out and see the birds or…enjoy the fresh air or that sort of thing is very calming" for patients in this area. To facilitate a caring environment supportive of this common coping mechanism, a hospice could be built in an area with familiar surroundings. For many Duffy's Hill residents, this means somewhere accessible to "the bush" in Shannon's words, or nature. The building could be designed with large windows so that clients who are unable to go outside are able to enjoy the sunshine and view of the woods, reminding them of home.

Barbara and Shannon both stress the importance of a sense of safety and autonomy for patients that supports their sense of place. Barbara states that for patients in the hospital, her role is "there to create a sense of safety for the patient," and that patients' fears can stem from unfamiliarity and lack of autonomy in the hospital space when patients are "hooked up to all these wires." Shannon's story of the client who chose to sleep on the ground after experiencing homelessness shows a contrasting experience to that of Barbara's patients in the hospital; while Shannon's client did not seem "safe" in the literal sense, spiritually, the familiarity of sleeping on the ground allowed him to claim the hospice space as his own. He was the one "calling the shots" in Shannon's words. In light of these observations, hospice programs could aim to allowing flexibility for patients to move around furniture in rooms where possible, creating a familiar pattern and some semblance of the feeling of home. This allowance will add to a sense of familiarity and control that can help them feel as though they are "calling the shots."

One final consideration when looking to care for patients' sense of place involves understanding what patients' wishes are for after their death; what do they want to happen to their remains? Shannon's story about the client who wanted their remains sent across the province to be buried with his mother demonstrates that an individual's perception of their sense of place extends beyond death, and that they wish for their living relationship with their sense of place be honoured in the laying to rest of their remains. For the individual in Shannon's story, his sense of place was connected to the location of his mother's remains; he wanted to be with her in death the way he once was in life. This fact further supports the suggestion that connections exist between interpersonal relationships and relationships with place. Extending the living wishes of an individual to their post-mortem remains is a part of providing good spiritual and psychosocial care, and where possible, services should be available for arrangements to be made by patients themselves if desired.

10.1.2 How to Care for Patients' Relationships with People

Similarly to relationships with place, this report features an entire chapter (Chapter 8) dedicated to unpacking the importance of interpersonal relationships in offering spiritual and psychosocial palliative care in Duffy's Hill. While addressing interpersonal relationships will look different for every patient, a few key considerations arise from participant perspectives that reveal general recommendations for how these relationships can be prioritized within care.

First, time and space is required for patients to reconcile with any family or friends from whom they have been estranged. Barbara expresses that patients "*need* the privacy to be able to have those open conversations." Health care providers can facilitate this by asking about family relationships and providing private space where possible for patients to meet their loved ones.

Having the option for patients to write letters or leave voice messages to loved ones who will not come constitutes a good alternative to meeting in person. Additionally, services could be developed to assist patients in leaving legacy, perhaps using the PDQ discussed in Chapter 2 (McDermott, 2019) or by brainstorming other methods for how this experience could be individualized for each patient.

One thing health care providers should consider in providing spiritual and psychosocial care to patients in Duffy's Hill is that there may have been a significant change in that patient's familial role with the onset of their condition, which could lead to a loss of identity or purpose for that individual. For those who are primary providers for their family, the transition from being healthy at home to very ill can be very distressing; being unable to fulfill their self-perceived duties as head of household can influence their view of their relationships with family, and skew the way they think of themselves in reference to family members. In failing to practically protect family with food or shelter, focus shifts instead to protecting them emotionally, and preventing them from feeling burden of the illness. Providers can help patients rethink their role in their family by acknowledging how their role has changed, and adapting to maintain some sense of that role in a different, more manageable way. Natalie's experience with the father who wasn't sure how to involve his family in his care exemplifies an instance of where and how this could happen.

> *I shared that with the patient when I, the last time I saw him… the gifts that he was giving his family in allowing them to bear witness to his journey, however hard it was for them and for him or something that they would recall when it was their dying time. That they would benefit from having gone through this, even though it was something difficult for them to go through. And I think he took a lot of solace and comfort in knowing that he was giving this gift and leaving this legacy for his family. (Natalie)*

Natalie was able to help this patient understand that his role, though changed, was not insignificant. On the contrary, in sharing his dying time with his family, this patient was able to

138

play a new caregiving role, preparing his family for the future and giving them one last "gift," in Natalie's words. There are multiple ways individuals can care for relationships. Helping patients see these different forms of caring is a meaningful way health care providers can support spiritual and psychosocial well-being related to interpersonal relationships.

10.1.3 How to Care for Patients' Relationships with their History

Of the three relational areas summarized in this chapter, relationships with history is the only area without a corresponding results chapter. However, in drawing from the results presented by health care providers in their interviews, three major aspects of an individual's history appear to have direct implications for spiritual and psychosocial palliative care: first, what their relationships with religion and spirituality have looked like in the past (this could include their own experiences with religion and spirituality or ideas about religion and spirituality that have been passed to them by friends and family), second, how they have historically coped with stress, difficult news, or illness, and third, events in their life that may have caused trauma.

For the health care providers in this research, learning about a person's history began with an initial conversation/assessment of their well-being. While many palliative care providers already have tools or questions available to them for assessment of a patient's spiritual needs, this study highlights one particular challenge that arises in this context regarding a patient's history that is likely to vary between patients: this is historical relationship with religion. What does the patient thin of religion as they understand it? Was it a part of their life at some point? Did they intentionally distance themselves from it? Do they prefer not to discuss it? And if so, how can a discussion of spirituality be initiated in a way that does to raise discomfort from one's

relationships with this part of their, or the town's, history? To avoid tension or misunderstanding when discussing this factor, providers should try to avoid the use of the terms "spirituality" or "religion" until they are used by the patient in order to keep the nature of this care as broad as possible for patients. Questions might ask along these lines, as suggested by Shannon and Barbara:

    1) What do you think happens after you take your last breath?

    2) Do you think there is more to life than this?

    3) What would it look like for you to have peace to know it's okay to die?

    These questions are non-leading one way or another, and allow patients to access their own history, values, and beliefs to recall terminology that makes the most sense to them regarding their spirituality. This way, patients are again "calling the shots," as Shannon puts it, of their own care. Patients lead the way into what spirituality means to them, allowing providers to come alongside them to support their own understanding of what spirituality and the role of religion, or lack thereof, implies for their care.

    Psychosocial or spiritual assessments might also seek to learn if patients have lost anyone important to them in their lives. Shannon believes that this is an important part of understanding patients' histories, as she has observed that it is "good to know if anybody close to them has died because they often talk to those people at the end of life." Learning about this loss of relationship may help providers understand patients' views about approaching death and how they view their illness journey in relation or comparison to their loved ones'.

    Audrey suggests that paying attention to patients' coping mechanisms, whether this be spending time with family or engaging with nature, will also assist care providers in understanding what is truly important to patients, and what kinds of services or opportunities can

be provided to them to care for spiritual and psychosocial aspects of their health. Audrey strongly believes that how people cope and their spiritual well-being are closely tied, and that understanding how a patient has historically coped with stress in their life can also help providers predict whether or not patients might be receptive to spiritual care; Audrey identifies that individuals that "never really learned good coping skills" are "the hard ones."

Additionally, requiring mandatory trauma- and violence-informed care trainings could help prepare staff to address spiritual and psychosocial issues as they arise in a sensitive and informed manner. Barbara believes this trauma-informed lens is particularly important for those offering spiritual and psychosocial care because they didn't always "know what [we are] heading into." Not only will this type of training better equip palliative care providers to better understand the significance of patients' history on their spiritual and psychosocial health needs, but it will also support their own professional practice, helping them to be more prepared to face difficult or potentially shocking circumstances so that they will not be caught off-guard or under-supported.

10.1.4 Caring for the Providers

In addition to the above summarized measures that support patient relationships with people, place, and history within spiritual and psychosocial services, a number of structural and practical matters can be employed to better support these aspects of care within hospice and palliative care staff. First, where possible, hospice programs (whether home or residential hospice) might consider paying nurses by the hour to encourage them to take the time necessary to provide palliative care well. Four participants in this study identified time as a barrier to providing this care well. By incentivizing staff to slow down and take the time necessary to

provide this care on a one-on-one basis, the quality of palliative care services, especially spiritual and psychosocial care, will improve.

Alternatively or additionally, hiring a non-denominational spiritual and psychosocial care provider to specifically address these aspects of care could further improve quality of these services for a diverse base of belief systems. Audrey suggests that this is her ideal concept of what spiritual and psychosocial care in the area should look like; in her view, spiritual and psychosocial care is important and distinct enough to warrant a professional specialized in this area. Barbara is one of these specialized professionals, and, in her opinion, her specific training in the area allows her to perform this type of care on a different level than could be achieved by other health professionals working within the shared care model. If a non-denominational spiritual healer is available, some of the burden to provide this care is lifted from nurses, physicians, and other health care providers who also must spend time attending to physical aspects of care.

Given the challenges of serving a diverse patient-base coming from the city to cottage country, building a roster of volunteers with experiences from many different backgrounds would be ideal to assist with culturally sensitive care for individuals who may not fit within the ethnocultural majority in Duffy's Hill. Use of a diverse team of volunteers in such a way has been suggested before by Jovanovic (2012) as a method of building cultural competence in health teams, however, this idea is simplistic in nature and holds danger to perpetuate assumptions and stereotypes about cultural experiences (Bothelo & Lima, 2020). Health teams should be cautioned, then, that recruitment of volunteers should occur openly, with opportunity for volunteers to reveal if they have skills that could assist with care for minority demographics while avoiding tokenism. Of foremost importance among these skills, perhaps, is languages

spoken; Shannon emphasizes that being able to communicate with a patient in their own language greatly improves their care and sense of home; even if they cannot be in their home environment during their dying time, at least someone is around who can communicate with them as if they were. Additionally, if volunteers are required to drive to attend patients, providing them with stipends to cover gas will support their ability to offer that care.

Finally, in order to support the spiritual and psychosocial health of those providing this care, hospice development teams might consider producing a number of reflexive activities for staff and volunteers to use to track their own thoughts and feelings around providing this care. Shannon stresses that while patients are exploring their spiritual and psychosocial needs at the end of life, health providers are doing the same thing, and must be in a "good headspace" to offer these types of care. All humans live their lives in synergy with spiritual and psychosocial experiences, however, whether or not they recognize or are aware of these experiences within themselves is a point of individual experience. Shannon emphasizes that "we're all learning as we're going along," and providing health care providers the optional activities to and space to do this learning could support both their personal and professional well-being while offering spiritual and psychosocial care to patients.

10.2 Implications Beyond Duffy's Hill and Future Research Directions

This exploratory study, while small in nature, reveals insights and implications for consideration in future research. Firstly, this study reveals advantages and limitations of considering potentially cultural values, norms, patterns or practices when examining palliative care needs in rural communities, as well as potential lessons that could be applied to future studies looking to apply a cultural lens to rural contexts. The following sections explore the

broader implications of this study, summarizing insights and recommendations for future research looking to continue the work begun by this exploratory study.

10.2.1 What can we learn from Duffy's Hill about culturally specific palliative care provision?

Despite the limited applications of results from such a small sample size, a number of observations can be derived from this study that contribute to the ongoing discussion about if and how a potentially rural "cultural" impacts care needs, and how systems can be set up to address these. From this study, we see a number of similarities to or distinctions from past research on culturally informed palliative care that allow us to learn more about this emerging idea and its applications.

First, it is revealed in this study that health care providers in Duffy's Hill hold the perspective that it is possible, and in fact is the goal of spiritual and psychosocial palliative care, to assist patients in "dying healed." We have seen value placed on the idea of "dying healed" in Hampton et al.'s (2010) study of palliative care in Indigenous communities, in which Hampton et al. (2010) emphasized that dying healed meant achieving a "good death" in the context of Indigenous Peoples' cultural experience. For health care providers in Duffy's Hill, a "good death" meant that the patient had come to terms with the end of their life. This definition of a "good death" seems to fall somewhere in the middle of Sinclair et al.'s (2011) two views of death; while health care providers did not explicitly discuss ideas related to a "continuum of life" beyond acknowledging that some patients believe in an afterlife, they also did not discuss death as unnatural. Rather, participants seemed to view a good death one that accepts that this is the end; it is finite, but it is not sinister. And in accepting the finite reality of life, patients could adequately "wrap up" their life's story, allowing them to die well.

Contrary to what has been discussed in literature exploring cultural elements of palliative care (Ebrahim et al., 2011; Weerasinghe & Maddalena, 2016; Donovan & Williams, 2016; Donovan et al., 2011), spiritual needs in the Duffy's Hill context do not necessarily map to religious needs. It was very important for participants in this study that they emphasize the difference between religiosity and spirituality; while spirituality may include religious participation in some form, these two concepts do not always go together in the Duffy's Hill context. While the Spiritual But Not Religious movement in Canada has been documented in past literature (Beyer, 2015), there have yet to be any Canada-focused studies examining the implications of this for palliative care, specifically spiritual and psychosocial palliative care. This study, therefore, reveals a new consideration for studies examining palliative care in rural Ontario; does this movement away from religion towards spirituality present in other rural communities? And if so, what are its implications for spiritual and psychosocial palliative care services?

Similar to what has been found in past research in the rural Ontario context (Johnston et al., 2013), family plays a large role in palliative care in the Duffy's Hill context. What appears to differ from other studies examining cultural particularities of palliative care is who is given decision-making power at end of life. In Duffy's Hill, patient autonomy is of high importance. While family plays a role in caring for the individual as death approaches, health care providers do not consider family members to have a say in how care is offered to patients; that is up to the patient. Even in cases where a substitute decision maker has been named, these individuals are not given authority until after a patient has stopped speaking. This observation is consistent with those others have made about the Canadian biomedical model for care; patient autonomy is considered of highest importance, and while it is important to include family in the care of

patients, this will not stop providers from sharing news about prognosis or treatment options with the patient directly, even against family wishes (Elliot, 2001).

This being said, while patients are given highest priority when it comes to decision making, it is clear from participant responses that it is important for patients in the Duffy's Hill context to feel surrounded and supported by family in their care. This finding is consistent with Veillette et al.'s (2010) conclusion of rural communities in Quebec. Additionally, it is important that patients maintain their connections to place, history, and people within the community. This finding is consistent with Pesut et al.'s (2011) observation that maintaining connections with neighbours and one's community is necessary for good care in rural Canadian contexts. These consistencies further emphasize the possible shared values among rural communities in Canada, pointing to the possibility of some leveled of shared culture.

Finally, this study continues to reveal the importance of language in offering culturally informed palliative care. Past research has revealed that the avoidance of using certain words is important in specific cultural contexts (Johnston et al., 2013; Hordyk et al., 2017; Kelly et al., 2009). Duffy's Hill is no exception to this. The tension that exists between the words "religion" and "spirituality" further reveals the significant impact language has on practice, as well as the how important it is to understand the context within which one is working in the health care field in general. In adapting practice to avoid, or at least to wait to use these words until they are first used by the patient, care becomes more attuned to the cultural particularities that may exist in the Duffy's Hill context. This lesson holds particular significance for future research; in any study using a cultural lens, particular attention should be lent to stigma surrounding language.

10.2.2 Advantages of Applying a Cultural Lens

A number of advantages can be observed from the use of a cultural lens in approaching study such as this. First, it allows for an understanding of the high specificity that accompanies care needs in specific rural contexts. Many studies have commented that the unique challenges faced by rural Canadian communities require solutions that could look quite different from urban areas (Klinger, 2013). What works in one part of Ontario might not work in another. Therefore, an advantage can be seen in looking at the needs of just one rural town and seeking to determine what the specific needs of that town is in light of observed cultural particularities. This high specificity lends itself beautifully to the establishment of culturally accessible services. In Chapter Two, it was concluded that a "culturally accessible" health care system is one that acts within the cultural norms of individuals it serves, making them more likely to access and understand it. In seeking to understand palliative care needs light of culture, these systems can be tailored to specifically serve the cultural needs of communities in which it is established.

In addition to this, a cultural lens lends itself well to a community-based participatory action approach, such as that employed in this study. In community-based participatory action research, the specific needs and priorities of communities in which researchers work are given primary attention. Researchers perform work dictated by the community, and work alongside community organizations and members to produce results that will directly affect them (Kidd & Kral, 2005). In applying a cultural lens to the results of this study, results obtained are tailored to meet the specific needs of Duffy's Hill. The results of this study are entirely situated within the Duffy's Hill context, allowing for community health authorities, in this case DHCHC, to use the results in their catchment area to improve tailored services for the patients under their care.

Therefore, the priorities of Duffy's Hill are not only identified through efforts to understand cultural particularities but are also ensured to be applicable within this context.

10.2.3 Limitations of a Cultural Lens

While a number of advantages exist to applying a cultural lens in this research, it also presents a number of limitations. The very premise of using a cultural lens dictates that each population studied is distinct in some way, and because of this, results from other studies in other populations cannot be directly transferred for application in other contexts. In keeping with this reality, results from Duffy's Hill cannot be generalized to hold meaning for other rural Ontario contexts.

An additional limitation of using a cultural lens for a small interview-based study is that it is difficult to know which perspectives are individual beliefs and which are shared among the community being observed. As noted in the Preface, this study was initially designed to be comparative. The logic to that approach was to bring into clearer focus similarities as well as differences in providers' emphases on potentially culturally informed beliefs, values, and practices. This plan was interrupted by the COVID-19 pandemic, unfortunately, and suspension of research plans in a second rural Ontario context. The pandemic also made it unfeasible to adjust this study's design, to conduct ethnographic fieldwork to supplement interviews and in this way gain further insight into whether providers' perspectives and explanations of spiritual and psychosocial needs and care in Duffy's Hill reflected those of the town's wider population. At the close of this study, it is unclear to what extent perspectives shared by providers are shared by all members of that culture.

Finally, applying a cultural lens poses a problem in knowing what ideas "belong" to what culture, or, whether culture really exists at all. In Chapter 2 of this report, it was emphasized that it is unclear based on past literature whether rural Ontario towns "possess" culture. While many have noticed that there is something distinct going in rural areas compared to urban areas (Conlon et al., 2016; Dumont et al., 2015; Robinson et al., 2009; Klinger et al. 2013) and that rural residents believe themselves to be set apart from other towns, cities or regions (Veillette et al., 2010; Pesut et al., 2011), so many dynamics are at play that it is difficult to determine whether or not particularities observed are produced by the rural-ness of an area or exist for other reasons. It is impossible to know which ideas belong to "which culture;" it can only be observed that there are shared ideas that exist and hold implications for care. This study demonstrates that among the six participants included in this study, a shared understanding of what constitutes spiritual and psychosocial palliative care in Duffy's Hill exists. This is as far as we can conclude for now.

10.2.4 Remaining Questions and Implications for Future Research

Given the advantages and limitations of applying a cultural lens, a number of theoretical and practical questions remain. These merit further consideration and study. First, it remains unclear what qualifies a group as culturally distinct and, by extension, as necessitating culturally specific palliative care in the Canadian context. The point of departure of this study is that rural Ontario life in Duffy's Hill represents a setting distinct from nearby urban contexts. It reveals, amongst providers of palliative care at least, shared values, norms, patterns, and practices related to spiritual and psychosocial care needs in this town. Even if further research established that these ways of doing and thinking about spiritual and psychosocial palliative care are indeed

reflective and productive of a larger cultural way of life in this place, it is clear from the literature that what defines a group as culturally distinct and thus worthy of culturally-particular palliative care varies enormously. For the most part, however, "culturally distinct" is shorthand for non-white, racialized, non-Christian groups. Further theoretical discussion is needed to challenge what is essentially an 'othering' way of thinking about culturally relevant palliative care provision. This study can provide a starting point for that discussion.

Practically, there is no comparative evidence available to determine whether or not these shared values, norms, patterns, and practices are unique to the Duffy's Hill context or whether or not they are shared by all rural Ontario communities. In light of this, one direction for future research could be to examine spiritual and psychosocial palliative care needs in multiple rural Ontario communities in order to compare and contrast which needs are shared across the province and which are specifically experienced in particular contexts.

Additionally, in order to better understand what it means to provide and receive spiritual and psychosocial palliative care in Duffy's Hill, future studies might seek to explore the experiences of patients, their family members, and other community members involved in palliative care in Duffy's Hill. Determining whether the shared values observed among participant interviews in this study are echoed in participant experiences will further validate the results of this study, as well as contribute additional depth to the understanding of spiritual and psychosocial care and what it means in this area.

Chapter 11: Conclusion

In this exploratory qualitative study, two major research questions were answered:

1) In the views of palliative care providers, what does it mean to offer spiritual and psychosocial palliative care in one specific rural Ontario context?

2) Are there cultural particularities that underlie care needs (and corresponding responses to these needs) that should be considered when serving a rural population such as this?

This study found, from participant responses, that attending to spiritual and psychosocial palliative care needs in Duffy's Hill means providing opportunities for palliative patients to connect with their relationships with place, relationships with people, and relationships with their histories. Good spiritual and psychosocial service provision in this context is aware and acts in consideration of a tension that exists between the words "spiritual" and "religious." Offering good spiritual and psychosocial care in this context also means attending to the unique challenges faced in a rural context like Duffy's Hill, such as overcoming barriers to location of care, employing staffing practices that encourage health care providers to take the time needed to provide this care well, and employing volunteers who can help fill gaps in patient needs, such as communication services. In revealing this meaning behind spiritual and psychosocial care in Duffy's Hill, this thesis has created a starting point from which health care authorities in this context can begin building relevant palliative care programs.

In answering the second question, this thesis reveals that a number of particularities arise that could be cultural in Duffy's Hill. Ideas of what a "good death" means in a rural context like this differ from what has been found in past literature, suggesting that death is a finite, but not necessarily a negative part of life. It was discovered in this thesis that spiritual needs did not

151

necessarily map to religious needs, a phenomenon that has not yet been documented in rural Ontario palliative care literature. While patient autonomy is held in high importance and health providers view allowing patients to "call the shots" of their care a priority, the involvement of family and neighbours in care was still of high importance, consistent with past findings on the subject. Finally, the use of language in certain ways, for example use of the terms "spiritual" and "religious," was found to be a major consideration in offering spiritual and psychosocial palliative care. Cultural use of language has been observed in other rural contexts, suggesting that this community has some cultural particularities that distinguish it from others. While it is not possible to definitively determine whether or not Duffy's Hill is unique as a rural community compared to others, it can be concluded that health care providers in this context share values, beliefs, norms, and practices related to the provision of spiritual and psychosocial palliative care in this context, pointing to the possibility that something cultural is going on. Future research might explore this possibility further by comparing these values, beliefs, norms, and practices in a number of rural Ontario communities, and looking for similarities and differences between them that could reveal a shared "rural" culture or distinct town cultures.

The results presented in this thesis begin to fill a gap in Ontario palliative care literature, providing health professionals and policy makers the evidence required to build on and create effective, holistic palliative services. This research further contributes to Leininger's (1997) idea that care needs must be addressed within a specific context and that health professionals must pay attention to the differences in needs that exist between cultures in order to offer effective, relevant care. Finally, the results of this study can contribute to the improvement of care quality for palliative patients in Duffy's Hill, leading to an improved quality of life for those facing

terminal illness. In lending attention to *all* areas of health, a holistic health system can be created,

leading to a higher level of wellness among patients in spite of lingering illness.

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Curriculum Vitae

ERYNN MONETTE

Education

Master of Science (Health & Rehabilitation Sciences)   October 2020
Field Specialization in Health Promotion
Western University
Additional certificate in Business and Consulting

Honours Bachelor of Science (Life Science)   April 2018
Minor in Anthropology
McMaster University

Relevant Employment

Quality Improvement Advisor
South West LHIN | London, ON
September 2020–Present

- Led teams of health care stakeholders to undertake various quality improvement projects in the South West Local Health Integration Network (LHIN)
- Communicated regularly with local health care providers to provide up-to-date information regarding health care quality and improvement efforts

Research Coordinator
Western University | London, ON
September 2018–Present

- Coordinated monthly meetings for trans-national research team based in Canada and Rwanda
- Led development of a Global Health Research Equity Analysis Tool
- Presented team research at national and international conferences
- Wrote grant applications and research reports for publication
- Facilitated workshops in Canada and Rwanda

Publications

Monette, E. (2020). Cultural considerations for palliative care provision: A scoping review of Canadian literature. Manuscript submitted for publication.

Monette, E., McHugh, D., Smith, M., Canas, E., Jabo, N., Henley, P. & Nouvet, E. (2020). Informing "good" global health partnerships: A scoping review of principles to guide trans-national research relationships. Manuscript submitted for publication.

Monette, E., McKinley, G., Savundranayagam, M. & Nouvet, E. (in press). Spiritual and psychosocial palliative care in a rural Ontario town: An exploratory study of patient needs and provider experiences. *Electronic Thesis and Dissertation Repository*.

Canas, E., Smith, M., Gough, R., **Monette, E**., McHugh, D., Janzen Le Ber, M., Benjamin-Thomas, T. Kasine, Y., Utuza, A. & Nouvet, E. (2020). What do we mean by critical and ethical global engagement? Questions from a research partnership between universities in Canada and Rwanda. Manuscript submitted for publication.

Nouvet, E., Strachan, P., Luciani, M., de Laat, S., Conti, A., Oliphant, A., **Monette, E.**, Kapiriri, L. & Schwartz, L. (2020). Triaging critical care during COVID-19: global preparedness, socio-cultural considerations, and communication. Hamilton, Canada: Humanitarian Health Ethics Research Group. ISBN: 978-0-9938354- 5-2.

Monette, E. (2017). Reframing ABC prevention: the value of ethnographic research in creating culturally relevant HIV programs in Belize. *Nexus*, *25*, 13-22

Working Papers

Monette, E. (2020). Palliative care research efforts in Canada: An overview of the funding landscape. Manuscript in preparation.

Conference Presentations

Strachan, P., Luciani, M., Shwartz, L., Kapiriri, L., de Laat, S., Conti, A., Oliphant, A., **Monette, E.** & Nouvet, E. (2020, September). Transparency in the time of COVID-19. Presentation at the International Association for Communication in Healthcare (ICCH 2020 On-line).

Monette, E., McHugh, D., Jabo, N., Smith, M., Canas, E., Henley, P., Gough, R. & Nouvet, E. (2020, June). Realizing equity: Principles to inform a Global Health Equity Research Analysis Tool (GHREAT). Accepted for presentation at the Canadian Sociological Association Conference, London, ON.   *Cancelled due to COVID-19 Pandemic.*

Nouvet, E. & **Monette, E.** (2019, September). The Global Health Equity Analysis Tool. Presentation at the NextGen Symposium, Ottawa, ON.

Monette, E., McKinley, G., Savundranayagam, M. & Nouvet, E. (2019, September). Palliative Care in Rural Ontario: Cultural Considerations for Spiritual and Psychosocial Services. Presentation at the Canadian Hospice Palliative Care Conference, Ottawa, ON.
> *Winner: Best Trainee Poster Award*

Monette, E., Nouvet, E., Henley, P., Iyakaremye, I., Janzen Le Ber, M., Smith, M., Canas, E., Lawson, E., McHugh, D., Gough, R. & Kasine, Y. (2019, February). Prioritizing equity: Developing a self-assessment tool for global health research partnerships. Accepted for presentation at the Health & Rehabilitation Sciences Graduate Research Conference, London, ON.   *Cancelled due to inclement weather.*

Monette, E., Nouvet, E., Lawson, E., Smith, M., Iyakaremye, I., Canas, E., McHugh, D., Henley, P., Janzen le Ber, M. & Gough, R. (2018, November). Power, practice, and ethics in context: Assessing equity in international collaborations. Presented at the Global Health Students and Young Professionals Summit, Toronto, ON.

Monette, E., de Laat, S. & Schwartz, L. (2018, April). The need for palliative care in Rwandan refugee camps. Presentation at the McMaster Life Sciences Symposium, Hamilton, ON.

Monette, E. & Nouvet, E. (2017, October). Refugee Healthcare in Lebanon: Palliative Care Efforts and Access. Presentation at the CSIR Canadian Conference on Global Health, Ottawa, ON.

Research Experience

Critical Care Triage & COVID-19 Humanitarian Health Ethics Research Group *March 2020–Present*	• A qualitative study understanding the cultural and social factors impacting triage decisions globally during the COVID-19 pandemic. *Duties: Interviewed participants, analyzed interviews for relevant data*
Palliative Care in Rural Ontario Master's Thesis *September 2018–Present*	• A qualitative study exploring culturally specific spiritual and psychosocial needs in two rural Ontario communities. *Duties: Study design, conducted interviews, analyzed results, disseminated results.*
Health Equity in Context: Local Solutions to Global Problems Health Equity Interdisciplinary Development Initiative *September 2018–Present*	• An interdisciplinary development initiative exploring the challenges of maintaining equity in global health contexts. *Duties: Perform literature reviews, coordinate team meetings, facilitate workshops, design Global Health Research Equity Analysis Tool*

Palliative Care in Humanitarian Emergencies Humanitarian Health Ethics Research Group *January 2017–April 2018*	• A qualitative study exploring the need for palliative care in humanitarian settings. *Duties: Performed literature reviews and presented results at international conferences.*
Refugee Palliative Care in Rwanda Undergraduate Thesis *September 2017–April 2018*	• A literature review examining palliative care needs in Rwandan refugee camps. *Duties: Performed literature review and presented results at institutional symposia*
Animal-Assisted Reading in Hamilton Public Libraries Undergraduate Senior Project *September 2017–April 2018*	• A community-based participatory qualitative study examining the effectiveness of animal-assisted reading programs in the Hamilton Public Library. *Duties: Performed literature reviews, designed project, conducted qualitative interviews, wrote report*

Teaching Experience

Teaching Assistant (Undergraduate) Western University	London, ON *January 2019–April 2019*	• HEALTH SCI 2610: Introduction to Health Ethics • Graded course assignments and met one-on-one with students to discuss course content
Teaching Assistant (Graduate) Western University	London, ON *September 2019–December 2019*	• APPL HEALTH SCI 9003: Introduction to Global Health • Designed course content and assignments • Graded assignments and met one-on-one with students to discuss course content

Awards & Honours

Best Trainee Poster Award   September 21, 2019
Canadian Hospice Palliative Care Conference | Ottawa, ON

Western Graduate Scholarship   September 2018, 2019
Western University | London, ON

Dean's Honour List   April 2017, 2018
McMaster University | Hamilton, ON

McMaster Entrance Scholarship   September 2014
McMaster University | Hamilton, ON

Grants & Fellowships

Africa Institute Graduate Student Research Fund   February 26, 2020
Western University | London, ON

Academic Societies

President. Health & Rehabilitation Sciences Graduate Student Society. Western University. London, ON. *June 2019–May 2020.*

Executive Director. Global Health Equity Collective. Western University. London, ON. *February 2019–January 2020.*

Conference Planning

Approaching Global Health Equity. March 28th, 2020. Western University. London, ON. *Cancelled due to COVID-19.*

Health and Rehabilitation Sciences Graduate Research Conference. February 4th–5th, 2020. Western University, London, ON.

A Journey to Mino Bimaadiziiwin: A critical analysis and interdisciplinary perspective on Indigenous Health on Turtle Island. January 28th–29[th,] 2020. Western University, London, ON.

Power and Global Health Day. November 14th, 2019. Western University, London, ON.

Workshop Facilitation

Enacting Equity in Global Health Research. (December 17, 2019). Presented at Western University, London, ON.

Defining Critical and Ethical Global Engagement. (November 14, 2019). Presented at Western's Power and Global Health Day, London, ON.