WHAT CONSTITUTES A GOOD DEATH? IMPLICATIONS FOR FAMILY NURSE PRACTITIONERS IN RURAL BRITISH COLUMBIA

by

Cindy Allison Fehr

BSN, University of British Columbia, 1994
MEd, University of Calgary, 2004

PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING: FAMILY NURSE PRACTITIONER

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

April 2013

Abstract

Death is an inevitable part of each individual's life. It is how that final event occurs and the time prior to and during one's last phase of life that greatly influence the dying experience for everyone involved. This project aimed to methodically and critically review research evidence to identify key elements necessary for a good death from patients' perspectives. The final number of articles totaled 35, with a dimensional analysis technique used to review and theme data. A key message following data analysis was that there is a diversity of perspectives and subjective characterizations of what constitutes a good death within and across sociocultural groups. Contributions to a good death involved four overarching domains: 1) preparation for death, 2) sources of support, 3) communication, 4) quality of life issues. The rural family nurse practitioner (FNP) role in supporting a good death needs to be based on working to full scope; engaging in end-of-life (EOL) care planning and anticipating life expectancy; providing holistic and consistent care; engaging in multidisciplinary collaboration and effective communication; providing caregiver support and education; engaging in continuing competence; and providing leadership to ensure the best EOL care is available for all patients wishing to remain in their rural home community to die.

Acknowledgements

Many people are to be thanked for the culmination of this project and degree; alone I could not have succeeded. Thank you to my professors and each of my committee members for your confidence in me. Specifically, for the reading, critiquing, and constructive feedback my committee devoted to make this project the best it could be.

Thank you to my peers for your dedication to nursing and inspiration to keep plugging along with a topic many consider morbid; nurses have a unique understanding of the reward felt in helping someone live their best while dying.

Thank you for the endless prayers and positive well wishes from friends and co-workers. Lastly, thank you to my ever present family for lifting me up when I was down and encouraging me to keep putting one foot in front of the other. The light at the end of our tunnel has finally arrived. Words alone cannot express my sincere gratitude to everyone involved in this journey…THANK YOU!

> "Death is the wish of some, the relief of many, and the end of all"
> Lucius Annaeu Seneca - *Roman philosopher and playwright.*

Table of Contents

Chapter One

Chapter Two

Chapter Three

Chapter Four

Chapter Five

Appendices

Table of Figures

CHAPTER ONE

Introduction

Death is an inevitable part of each individual's life. It is how that final event occurs and the difficult decisions that transpire prior to and during one's last phase of life that greatly influence the dying experience for everyone involved. However pessimistic and morbid it sounds, the reality is that 90 percent of Canadians are unlikely to experience a quick and painless death, instead dying from the consequences of chronic degenerative or life-limiting conditions (Carstairs, 2010). Objectively we know that approximately 30,000 British Columbians die annually (British Columbia Vital Statistics Agency, 2011), but what makes one death better than another? More precisely, what constitutes a good death, especially from the perspective of the dying person? Understanding what constitutes a good death will thereby inform the role of Family Nurse Practitioners (FNP) in providing end-of-life (EOL) care to support a quality dying experience in rural British Columbia (BC).

Family Nurse Practitioners are Master's prepared advanced practice nurses who possess the knowledge, skills, and experience to independently or collaboratively diagnose and treat common acute and chronic health conditions of patients across the lifespan, including care for those at EOL (British Columbia Nurse Practitioner Association [BCNPA], 2011; Canadian Nurses Association [CNA], 2009; College of Registered Nurses of British Columbia [CRNBC], 2010b; Weiland, 2008). They uniquely combine the holistic, comprehensive, and person-centered approach of nursing, with a biomedical focus on diagnostics and therapeutics (BCNPA; CRNBC, 2007; Weiland, 2008). FNPs are increasing in number and taking on more significant roles in rural primary care settings within BC, settings where consistent physician presence may be limited. Therefore, they have been introduced into BC's health care system with a goal of helping to improve access to primary care services while supporting holistic and comprehensive care (BCNPA).

Within the last decade there has been a swell of evidence-based best practice resources aimed at clinicians caring for individuals during the terminal phase of life (Marshall et al., 2008; Melvin, 2001; Shipman et al., 2008). Additionally, there are numerous resources reviewing the role of primary health practitioners in rural practice (Canadian Association for Rural and Remote Nursing, 2008; MacLeod et al., 2008; Misener et al., 2008; Pong & Pitblado, 2005; Romanow, 2002), along with articles reviewing palliative care needs in rural settings (Crooks, Castleden, Schuurman, & Hanlon, 2009; Downing & Jack, 2012; Evans, Stone, & Elwyn, 2003; Robinson et al., 2009). What has been less apparent is guidance for the unique role that FNPs have in facilitating a good death, particularly within rural settings. As FNPs continue to take on greater responsibilities within rural primary care in BC, it is important to understand how they can best support a good death through quality EOL care for those residents wishing to remain in their home community to die.

Project Aim

This project aims to systematically and critically review research evidence to identify key elements necessary for a good death from patients' perspectives. A critical analysis of these key elements, along with how a rural context may impact these goals will inform recommendations for FNPs working in rural BC. The specific questions asked in this project include: 1) What influences or shapes our good death ideal? 2) What do patients identify as necessary for achieving a good death? 3) How might a rural context of care impact a good death? 4) What are the key implications for FNPs working in rural BC? The target audience for this review includes FNPs currently working in or considering employment in rural BC communities with an anticipated patient population inclusive of those living with chronic and terminal illness.

In order to guide the integrative review process and apply findings to the context of FNP practice in rural BC, it is important to first understand background issues, perspectives, and questions informing the problem formulation and boundaries of the review itself. Therefore, the remainder of this chapter will summarize pertinent background information that serves as the foundation for initiating the integrative review and applying the findings of this project.

Good Death

For those not having been exposed to death in their personal or professional lives, conceptualizing what a death experience involves may be a mystery or constructed merely from media portrayals. The terms 'good' and 'death' may therefore seem contradictory, but what really determines whether a death is good or bad? If we could describe what an ideal death entailed, what would that look like? Is it based on the experience of the person dying or those witnessing the dying process and death event? Is it the physical experience of being with or without pain and other intolerable symptoms that influences our appraisal of death? Is it based on the age or stage of life at when death occurs? Are there universal elements of a good or bad death? While there is an abundance of literature mentioning good or bad death, there are fewer sources that define what these terms mean and how this then impacts health practitioners caring for those facing death. The fact is that everyone eventually dies: this is inescapable. Where health care practitioners can make a significant impact is in helping to facilitate a quality EOL process for patients and families alike.

End-of-Life Care

End-of-life care is both a philosophical and clinical approach to treating, comforting, and supporting individuals living with or dying from progressive or chronic life-limiting conditions while being sensitive to personal, cultural and spiritual values, beliefs and practices (University of Toronto and University of Ottawa, 2000; World Health Organization, 2012). A chronic degenerative, terminal, or life-limiting condition is one that is considered progressive in nature, either malignant or non-malignant, has no cure, and is expected to cause the death of that person within the foreseeable future (Palliative Care Australia, 2008). Common examples within the Canadian population include metastatic cancer; end-stage heart failure, liver, lung, or kidney disease; and degenerative neurological conditions such as amyotrophic lateral sclerosis. EOL care in the context of chronic degenerative disease therefore refers to the care that is provided at a time when progressive or rapid decline toward death is physically evident (Canadian Cancer Research Alliance, 2011). However, the focus of EOL care is supporting the patient in living well during their dying phase of life. This includes supporting the best possible quality of life (QOL) and relief of suffering. Other terms used interchangeably or in combination with EOL care include palliative care, hospice care, and terminal care (Health Canada, 2009).

Improving EOL care in Canada has been a well-recognized need, with greater appreciation for adequate resource allocation and patient choice (Carstairs, 2010; Heyland et al., 2010; Romanow, 2002). This is repeatedly correlated with an aging population of baby-boomers, prolongation of life-expectancy through enhanced chronic disease management, and a paradigm shift that regards 'comfort care only' as an appropriate therapeutic choice for those experiencing end-stage terminal conditions (British Columbia Ministry of Health [BCMOH], 2010a; Carstairs; Romanow; Wilson, Truman et al., 2009). The majority of Canadians are not expected to die suddenly, therefore many of them may benefit from EOL care to support a quality dying experience (Carstairs). With the understanding that death trajectories from terminal illnesses are somewhat predictable (Carstairs), that peak health service usage occurs within one's last 3-6 months of life (Kuropatwa, 2008), and 90 per cent of Canadians would prefer to die at home (BCMOH, 2010a), EOL care will need additional attention from primary care providers.

Canadians continue to be ill-prepared for EOL. In a recent national poll it was identified that despite increasing numbers of resources to support advance care planning, the vast majority of Canadians do not have a designated substitute decision maker, have not spoken to others about their wishes for future health care treatment, or have a written plan (Canadian Hospice Palliative Care Association, 2012). A lack of an advance care plan may complicate EOL care decision making for primary care practitioners.

Family Nurse Practitioners

Nurse practitioners (NPs) have been introduced into the Canadian health care system with an aim of improving the "timely access to individualized, high-quality, cost-effective care" (CNA, 2009, p. 1). While NPs are qualified to work as independent and autonomous practitioners, their role is not intended to be a substitute for physicians (BCNPA, 2011; Weiland, 2008) but instead complement their efforts to improve the health and wellbeing of all individuals through involvement with multidisciplinary health care teams. NPs use evidence-informed practice as the backbone to facilitating quality health promotion; disease and injury prevention; and management of common acute and chronic health conditions (CRNBC, 2007).

BC first began registering NPs in 2005 under BC Health Professions Act legislation (CRNBC, 2007). This allowed CRNBC to define and regulate the scope, competencies, limits, and conditions of NPs through a self-regulation model that ensures public safety (CRNBC). Within BC there are three NP streams. Pediatric NPs provide care for infants, children, and adolescents; adult NPs care for adolescents through older adults; and family NPs provide care for individuals across the lifespan with the exception of women during labor and delivery (CRNBC). Despite regulatory opportunity for pediatric, adult, and family NPs, the only stream currently educated within BC is the family practice stream.

There are currently 217 NPs registered in BC, with approximately 88 % working within the family practice stream (Roots, 2011). The vast majority are employed by regional health authorities within primary care clinics, community based specialty service clinics and hospital based specialty services, or clinics (Roots). While the majority of NPs are employed within the greater Vancouver/Abbotsford area, 22 % have been hired within smaller BC communities to provide rural residents with better access to primary care services (Roots). This is set to increase with the recent provincial government commitment to an additional 190 NP positions across BC over the next three years (Province of BC, 2011). With a holistic, comprehensive, and health promoting approach to care for persons of all ages, FNPs are well suited to work within rural communities where physician presence may be limited (BCNPA, 2011; CRNBC, 2010a).

Primary Care

Primary care is one service within the broader concept of primary health care, which reflects the principles of access, social justice and equity, appropriate technology, multi-sectoral collaboration, community participation, and self-determination for holistic health (University of Saskatchewan College of Medicine, 2011; World Health Organization, 1978). Primary health care is vital to improving the health of Canadians and developing a sustainable health care system for current and future generations. Primary care, historically delivered by physicians, has seen a shift to increasing demands for multidisciplinary management, including the integration of FNPs. This shift, along with other sociopolitical, cultural, scientific, philosophical, and theoretical influences has transformed practitioner-patient relationships. Traditionally cure-focused paternalistic decision making is being replaced with care planning that involves the patient in goal setting, identifying therapeutic preferences, and exploring the impact of the patient's illness experience on all aspects of life (Health Canada, 2012a, 2009). This holistic, comprehensive, and inclusive approach is particularly important when facilitating EOL care with patients and families. FNPs are well suited for this role by effectively blending medical therapeutics with nursing care principles.

Population Context

The aim of this project is to identify key elements necessary for a good death from patients' perspectives in order to inform role considerations for FNPs working in rural BC. To adequately understand the impact of this project's findings it is important to first understand the population context in which these findings can be applied. The following discussion includes an introduction to BC population demographics, an overview of aging, chronicity, and death statistics; and reflections on the impact of rurality on care delivery in BC. It is important to note that unless otherwise specified the subsequent statistics reflect data from the Canadian 2006 census.

British Columbia is an expansive and diverse province. The total population of BC was recently counted at just over 4.6 million individuals, an increase of approximately 11 % from 2006 statistics (Statistics Canada, 2009a, 2011). While BC's population is primarily concentrated around the major municipalities of Vancouver, Victoria, Kelowna, Abbotsford, Kamloops, Prince George, and Nanaimo, to name a few (McGillivray, 2005), approximately 15 % of British Columbians reside in rural communities (Statistics Canada, 2009a).

Residents of BC make up a pluralistic society; diverse in ethnicity, culture, language, and spiritual beliefs. Approximately 25 % of BC's population identified themselves as a visible minority (Statistics Canada, 2009b), and roughly 52 % identified as having one or more ethnic origins, including British, European, Dutch, Italian, Russian, East Indian and several others (Statistics Canada, 2009c). An additional 5 % of BC's 2006 population identified themselves as having Aboriginal identity (Statistics Canada, 2009d). Distribution of residence varies, with some regions such as the North Coast (35%) and Nechako (19.5%) having significantly higher concentrations of Aboriginal groups (BC Multiculturalism and Immigration Branch, 2008). It is important to remember that even within BC's Aboriginal population there exist distinct subgroups, each with their own cultural identity and traditions.

Beyond ethnic affiliation, 18 % of British Columbians in 2006 identified speaking one or more languages other than English (Statistics Canada, 2009e) and 28 % identified having a non-English mother tongue (Statistics Canada, 2007a). Unfortunately, 2006 statistics are not available for religious affiliation as this data is only collected every 10 years. According to 2001 census statistics, 64 % of BC residents indicated a religious affiliation. While the majority identified with Christianity (55%), other affiliations included Muslim, Jewish, Buddhist, Hindu, Sikh, Eastern religions, and other faiths. Another 36 % identified no religious affiliation at all (Statistics Canada, 2005).

Aging, Chronicity, and Death Demographics

In 2010, the median age of British Columbians was 40.8 years (Statistics Canada, 2010), with the largest age cohort between 15-64 years (70%) and the smallest age cohorts divided between 0-14 years and greater than or equal to 65 years (15% each) (Statistics Canada, 2011). This is consistent with other reports of BC's aging demographic, a trend that is predicted to continue with increasing life expectancy and death rates while birth rates remain in a decline (O'Neil, 2007). In fact, by 2026 it is projected that seniors will make up 20 % of the BC population (Statistics Canada, 2007b).

With an aging demographic comes an increased frequency of chronic disease, disability, and early death (Carstairs, 2010). In 2010, BC saw a total of 29,470 deaths, the majority being the result of chronic or malignant disease in the older adult population (BC Vital Statistics Agency, 2011). Historically, dying individuals were cared for at home by family and community (Jacques & Hasselkus, 2004). Today within BC, the bulk of deaths from natural causes occurs in hospital (50.6%), followed by extended care facilities (32.5%), and then home (15.2%) (BC Vital Statistics Agency, 2011).

Impact of Rurality on Care Delivery in British Columbia

Based on 2006 census statistics, rural residents make up approximately 15 % of the BC's population (Statistics Canada, 2009a). While it is recognized that there are differences between the definitions of rural and remote, for the purpose of this project, rural and remote are considered as one in terms of the impact on FNPs working in primary care (Pitblado, 2005; Wakerman, 2004; Williams & Cutchin, 2002). Together, rural and remote are captured under the concept of rurality.

Rurality is a geographical and socially constructed concept without a universally accepted standardized definition (Kulig et al., 2008; Minore, Hill, Pugliese, & Gauld, 2008; Pitblado, 2005; Romanow, 2002; Wilson et al., 2009a). Rurality reflects communities with sparse population density whereby restricted infrastructure and economic resources limit the ability to recruit and retain the desired level of services (Kulig et al.; Minore et al.; Romanow). Specialized health services, economic revenue, and human resource supply are often negatively impacted by geographic isolation (Bushy, 2002; Kulig & Williams, 2011; Romanow; Wilson et al.). Further disparity results when weather conditions negatively impact transportation access to regional centres and health economic policies favor urban acute care services (Romanow).

It is well recognized that provision of health care services to rural is more costly than to urban communities, in part by limited economies of scale and travel time between service delivery sites (Bushy, 2002; Minore et al., 2008; Romanow, 2002). Resource inequalities, along with increased prevalence of lower income families, less formal education, along with poorer lifestyle behaviours and higher occurrence of chronic disease compared with urban counterparts contributes to greater comparative vulnerability in terms of population health determinants for those residing in rural Canada (DesMeules et al., 2006; Kulig & Williams, 2011; Romanow). Adding to the rural service gap is the unique nature of EOL care provision and lack of associated service resources within these rural communities (Carstairs, 2010; Romanow).

The positive side of rurality is the tendency for small communities to be well connected and during times of crisis, surround those in need with cooperative group endeavors (Parliamentary Committee on Palliative and Compassionate Care [PCPCC], 2011; Wilson et al., 2009b). This positivity is likely influenced by the diverse and distinct culture and demographic characteristics common in rural communities (Kulig & Williams, 2011; Romanow, 2002; Wilson et al.). According to Wilson et al. (2009b) because formal health services may be limited in rural communities, informal volunteer caregivers may help bridge the gap in supporting patients wanting to remain in their home community to die.

The project synthesized good death literature to capture themes influencing good death ideals and patient-identified essential elements for a good death. This data then informed implications for FNP practice within rural BC. The next chapter (Chapter Two) provides an overview of the research methods for this project, including search strategy and process of data refinement in preparation for data analysis. Chapter Two also overviews the literature sources chosen for review and analysis technique used to theme data. Themed literature findings and how a rural context of care may impact achieving a good death are presented in Chapter Three, while Chapter Four discusses role considerations for FNPs in facilitating a good death in rural BC. The final chapter (Chapter Five) presents the project summary, potential limitations of this research, and future considerations toward supporting good deaths for all.

CHAPTER TWO

Research Methods

The purpose of this project is to examine existing published literature on what individuals consider important for a good death. Cursory exploration revealed overwhelming results when patient, family and practitioner perspectives were considered. It was therefore decided to narrow the review focus to studies reflecting patients' perspectives only. While it is recognized that family and practitioner perspectives provide valuable insights into what is considered a good death and necessary for quality EOL care, each also has their own individual viewpoints and diverse roles in care which may be dissimilar from the priorities and concerns of those facing death (Hauser et al., 2006; Hendrickson & McCorkle, 2008; Heyland et al., 2006; Masson, 2002; Steinhauser et al., 2000a). Studies using general population surveys were also included with the belief that results might reinforce the insights drawn from patient studies.

Good death literature and EOL programs historically focused on individuals dying from malignancy, partly because illness symptoms and life trajectories with cancer are more predictable (Carstairs, 2010). With advances in medical technology and pharmaceuticals, conditions that would once quickly end the individual's life such as cardiovascular, pulmonary, and cerebrovascular disease, are now considered chronic conditions that lead to progressive decline in health and physical function (Carstairs). Caring for those facing death is now more broadly focused to include those experiencing chronic-progressive and life-limiting conditions. This broader focus on death, inclusive of chronic and cancer-related disease, was another lens through which the literature searches and review was completed.

As described in Chapter One, BC is a province with a diverse population and as such it is important to explore good death literature through a lens of diversity and cultural inclusiveness. While English language publication was an inclusion criterion, literature searches were not limited to Eurocentric North American Christian perspectives but instead sought out to capture articles from diverse countries, cultures, spiritual persuasions, life stages, and genders. This diversity is captured within Appendix A (Table of Evidence) which outlines the final list of articles retrieved for review.

Search Strategy

The overall search strategy and refinement of data sources for critical appraisal entailed three stages and therefore will be outlined according to each stage as reflected in Figure 1.

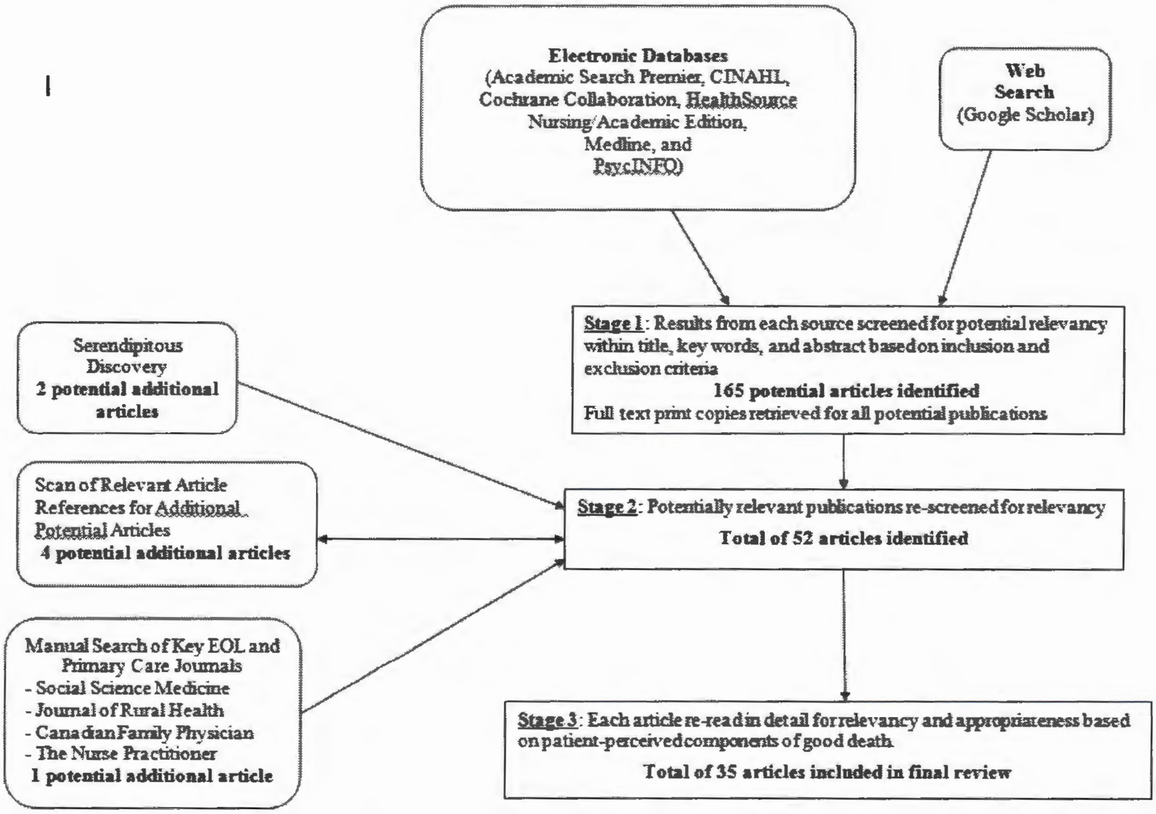

Figure 1: Overall Search Strategy

Stage One: Gathering Potential Relevant Resources

Credible integrative literature reviews need to be comprehensive (Bryman, 2008; Torraco, 2005; Whittemore & Knafl, 2005); therefore, the first stage of the search strategy consisted of gathering all potentially relevant electronic and print resources. To accomplish this, six electronic databases relevant to nursing, medicine, and allied health (CINAHL, Medline, Academic Search Premier, PsycINFO, HealthSource: Nursing/Academic Editions, and Cochrane Collaboration) were searched with a limit to articles written in English and published between January 2000 and December 2011. To help keep the literature search focused and relevant the following terms were used in combination: “good death”, “terminal illness”, “terminal care”, end-of-life, death, “death and dying”, wishes, and preferences. While euthanasia and assisted suicide may reflect a good death for some, this practice is not legally sanctioned in BC and was therefore excluded as part of this review. Google Scholar web search engine was also accessed to seek potentially relevant articles using the same inclusion and exclusion criteria as used during database searches.

Beyea and Nicoll (1998), along with Wittemore and Knafl (2005) recommend not limiting preliminary searches only to research articles as “clinical writings, reviews, and other documents, such as editorials and letters to the editor…can be helpful in identifying and organizing your topic around key issues that need to be addressed” (Beyea & Nicoll, p. 879). As such, a variety of article types were included during the first phase of resource retrieval. During stage one database searches, dissertations and theses were also included for review. Appendix B (Stage One Search Results) outlines the combined search terms and document results for stage one of the search strategy. Among these articles was a representation of varied methodology, location of study, and population characteristics including diversity of health status and prognostic stage, ethnicity, cultural affiliation, gender, age, sociocultural, geographic, and professional worldviews. Recognizing the potential for publication bias from using English-based sources, a demographically diverse sample was thought to help prevent Eurocentric and Western biomedical biasing of findings, conclusions, and recommendations. Stage one resulted in a total of 165 potential articles for review based on previously identified search terms within title, key words, and/or abstracts. Full text prints were obtained for all potential publications. When publications were not available online or in print at Vancouver Island University or the University of Northern British Columbia, copies were ordered using interlibrary loan.

Stage Two: Re-screening Potential Relevant Resources

Stage two of the search strategy involved re-screening initially sanctioned articles for potential relevancy based on inclusion and exclusion criteria. As discussed in the introductory section of this chapter, articles solely reflecting the views of family or health care practitioners were excluded from review while those that reflecting multiple viewpoints were included with the idea these perspectives would be dissected during thematic review. Due to the number and quality of primary and secondary research articles located during stage one database search, editorials, commentaries, book reviews and conference proceeding abstracts were excluded during the second stage of potential article appraisal. Several of these excluded articles, while not appropriate for this integrative review, were useful as background information in providing greater understanding of the topic.

To confirm saturation of the electronic literature search, a bibliographic scan of relevant publications and a manual search of key EOL and primary care journals was completed using the same search terms and inclusion criteria in stage one and is captured in Appendix C (Manual Journal Search Results). This process resulted in the addition of five potential articles for review. During background exploration of websites related to EOL care, an additional two articles were serendipitously identified for potential inclusion. Overall, stage two narrowed the articles for review down to an *n* of 52.

Stage Three: Reviewing for Relevancy and Appropriateness

In keeping with the integrative review framework recommended by Whittemore and Knafl (2005), stage three of the search strategy involved re-examining each resource for relevancy and appropriateness related to patient-perceived characteristics and components of a good death. To support research transparency, integrity, and future review, a literature table of evidence (Appendix A) was created to collate standard and comparable information from each resource. Of the original 172 potential publications identified in stages one and two, 35 articles were selected for review and thematic analysis. Several excluded articles, while not specific to the main topic, were used to better understand the breadth of EOL literature and as supporting documents for discussion of implications to FNP practice in rural BC.

Literature Reviewed

The review sample consisted of studies from the United States of America (14), Canada (5), the United Kingdom (4), Japan (3), Italy (2), the Netherlands (2), China (2), Australia (2), and Saudi Arabia (1). Most studies focused on patients with advanced disease or terminal illness (15). Others focused on age cohorts (7), sociocultural or religious affiliation (10), geographic residence (6), or general public perceptions (4). Six articles were literature reviews, nine studies were strictly quantitative, seventeen studies were qualitative in nature, and three studies were of mixed-method. No randomized controlled studies or cohort studies were identified for inclusion. Studies are excerpted in a Table of Evidence (Appendix A).

Characteristic of qualitative studies, patient sample size ranged from 3 to 180 participants and typically employed interviews and focus group discussions. Quantitative studies contained between 100 participants (cross-sectional and convenience samples) to 3061 participants (general public questionnaire). Literature reviews typically contained between 21 and 44 literature sources for analysis; within recognizable standards (Khan, Kunz, Kleijnen, & Antes, 2003). Further breakdown of study characteristics are included throughout the discussion of themed data within Chapter Three.

Analysis Technique

Methodical and thorough analysis is integral to scientific integrity and credibility of integrative reviews (Bryman, 2008; Torraco, 2005; Whittemore & Knafl, 2005). A meta-analysis was not possible as many reports were qualitative in nature. Instead, using a dimensional analysis technique, each report was appraised on its own and in light of the complete body of developing evidence (Hendrickson & McCorkle, 2008; Kools, McCarthy, Durham, & Robrecht, 1996; Whittemore & Knafl). This approach to comparing data from each study and across studies offered the opportunity to identify and synthesize main themes and essential attributes characterizing a good death as they emerged (Trochim, 2006; Torraco; Whittemore & Knafl). Themed literature findings are presented in the next chapter (Chapter Three) according to identified contributors that assist in shaping one's vision of a good death, along with corresponding domains and associated attributes described as important for achieving a good death. The impact that a rural context of care might have on realizing a good death is also explored.

CHAPTER THREE

Literature Findings

The term *good death* is commonly cited in EOL literature; however there remains no consensus definition or formula for approaching the care of individuals facing death. The current chapter provides a synthesis of the analyzed good death literature reviewed for this project by answering the following questions: 1) What influences or shapes our good death ideal, 2) What do patients identify as necessary for achieving a good death, and 3) How might a rural context of care impact a good death? It is from understanding what contributes to one's good death ideals by which practitioners can then identify how to best support those facing EOL.

What Influences or Shapes our Good Death Ideal?

Throughout the literature, several frameworks were used when discussing good death values and preferences; some authors arranged findings using a model of holistic care while others focused on particular care elements voiced by research participants. Despite the diversity of frameworks and thematic arrangements, what consistently appeared across participant groups and studies was that one's good death ideals are unique to each individual, subjective in nature, and shaped by a multitude of interconnected sociocultural and personal factors.

Likewise, our expectations for EOL are values-based and modifiable over time. They are dependent on our personal experience with illness and the health care system, as well as changes in health status and life context (Borreani & Miccinesi, 2008; Goldsteen et al., 2006; Hattori, McCubbin, & Ishida, 2006; Heyland et al., 2006; Hughes, Schumacher, Jacobs-Lawson, & Arnold, 2008; Jacques & Hasselkus, 2004; Kehl, 2006; Kelly & Minty, 2007; Masson, 2002; Miyashita, Sanjo, Morita, Hirai, & Uchitomi, 2007; Pierson, Curtis, & Patrick, 2002; Steinhauser et al., 2000b; Tong et al., 2003; Veillette, Fillion, Wilson, Thomas, & Dumont, 2010; Vig, Davenport, & Pearlman, 2002; Wilson et al., 2009a). Due to globalization and the diversity associated with multicultural societies, the concept of a good death and the factors influencing individual wishes related to a good death experience are becoming more complex and variable (Hattori et al.).

Variability in good death ideals was reinforced in Vig et al.'s (2002) study of geriatric outpatients with heart disease and cancer in which the depictions of a good death by some participants were reflected as a bad death by others. For example, having family members present at EOL was seen as contributing to both a good and bad death. Those seeing family presence as a positive did so because of the love and support family provide. Those seeing family presence as a negative did so because they perceived the request for family presence to be a burden on their family members. Additionally, Masson (2002), in his study of hospice day patients and relatives of previous hospice patients, noted the possibility for conflicting ideals and tension between what patients' identify as EOL preferences, and what family members would prefer during EOL with their loved one. Two clear examples involved the timing of one's death (sudden versus extended) and the request for specific individuals to be present or not present at EOL. Each of these aforementioned examples reinforces the diversity of good death preferences which are dependent on one's values, experience, and personal context at EOL. Interconnected influences contributing to an individual's good death ideal include: 1) one's philosophical views on life and death; 2) one's belief in individualism versus collectivism; and 3) one's personal context. Each of these influences will be further described below.

Philosophical Views on Life and Death

A clear theme through good death literature was that each individual's philosophical approach to life, illness, and death inherently influences the preferences for when, how, and where an individual wishes to die. One's belief or disbelief in an afterlife following death therefore seems to influence an individual's view of death as a process versus death as a product or event. Some view death as a process between earthly being and eternal/spiritual afterlife, while others view death as an event finalizing one's life cycle (Toscani, Borreani, Boeri, & Miccinesi, 2003). Both views deeply impact one's anticipated EOL experience and the resultant expectations for EOL care. In their study of Christian believers and non-believers in Italy, Toscani et al. (2003) found that an individual's beliefs influenced his/her preference for control in the timing of death, desire for awareness during the moments before death, and aesthetics of physical death. An example included how one's spiritual conviction was seen to help some find meaning in life and suffering while providing hope during the dying process. For others, a conscious awareness of how life is ending was important for coping with death and closure of one's life lived.

Likewise, Bullock, McGraw, Blank, and Bradley (2005) found that older African American adults with strong Christian beliefs viewed death as a transition which lessened their fears and provided hope for them in the dying process. Hattori et al. (2006), in their concept analysis of a good Japanese death noted death as a process connecting past, present and future but within a Japanese cohort. Likewise, Mjelde-Mossey and Chan (2007) found in their survey research of Hong Kong citizens the belief that current life experiences and death experience influence one's afterlife and ancestral linkage to future generations. This translated into high regard for death ceremonies and rituals.

Several authors address philosophical views about death in regards to beliefs and attitudes surrounding the timing of death. Views on timing of death and beliefs around naturalization versus medicalization are strong influencers for acceptance of impending death as well as medical therapeutics expected during EOL. In her literature review on the concept of a good death, Kehl (2006) discusses the general view that death involving an aged person with terminal illness is seen as more natural than the impending death of a child. Masson (2002), in his qualitative study of hospice patients, adds that death can in fact be a welcome release from prolonged hardships, declining health and function, or poor symptom control. Similarly, in their study of the general population in Japan, Miyashita et al. (2007) identify less attachment to duration of living during the dying process and greater focus on the perception of a good fight against disease along with physical and psychological comfort.

Linked to timing of death is the fear of inappropriate prolongation of life and the competing philosophies of medicalization versus naturalization of life and death. Several studies with diverse participant demographics revealed a natural acceptance of death and preference for comfort interventions versus life-prolonging medicalization when a cure was not expected for a disease or when participants perceived that quality of life would be negatively affected (Heyland et al., 2006; Jacques & Hasselkus, 2004; Kelly & Minty, 2007; Masson, 2002; Matsui & Braun 2009; Pierson et al., 2002; Smith-Stoner, 2007; Tayeb, Al-Zamel, Fareed, & Abouellail, 2010; Tong et al., 2003; Wilson et al., 2009b). Other studies concluded a preference for continuation of life-sustaining interventions, and reflected an active fighting spirit, effective coping mechanisms, and not giving up hope despite a grim prognosis (Bullock et al., 2005; Hirai, Miyashita, Morita, Sanjo, & Uchitomi, 2006). In their public survey of Chinese citizens, Mjelde-Mossey and Chan (2007) found that while a fatalistic life cycle belief permeated their results, men and women differed slightly in their preference for life extension. Whereas men preferred life-sustaining treatment despite the increased pain this might cause, women preferred pain relief over life extension. Whether this difference is strictly a sociocultural influence is not clear, given that other researchers also found similar findings but with different populations. For instance, despite differing spiritual belief systems among elder Japanese Americans in Hawaii, Matsui and Braun (2009) noted a fear of death yet a preference for not extending the dying process. Similarly, in studying EOL issues among Canadian Aboriginals Kelly and Minty (2007) found competing views on treatment support. Some participants preferred an exclusive pursuit for cure while others favoured maintenance of interventions until their death, a time they believed to be externally controlled by their creator. Despite these differences, a consistent message across studies was that attitudes toward death influence good death ideals and priorities during the dying experience.

Individualism versus Collectivism

An interesting dualism discussed in several cross-cultural studies was the influence that sociocultural views of individualism versus collectivism have on the information that is conveyed to individuals with terminal status, individuals responsible for making medical decisions and the focus of medical interventions that are agreed upon. Predominant Western European and North American views within good death literature tend to favour individualism whereby personal control, self-determination, autonomy, and independence are highly valued in health care decision making at one's EOL (Gott, Small, Barnes, Payne, & Seamark, 2008; Jacques & Hasselkus, 2004; Tang, 2003; Terry, Olson, Wilss, & Boulton-Lewis, 2006). Conversely, many non-Caucasian ethnic groups place higher value on collectivism and socially derived normative expectations where self is defined through interconnected personal relations; thereby medical decisions reflect what is best for the group rather than the individual (Borreani & Miccinesi, 2008; Goldsteen et al., 2006; Hattori et al., 2006; Hirai et al., 2006; Leung, Liu, Cheng, Chiu, & Chen, 2009; Miyashita et al., 2007; Mjelde-Mossey & Chan, 2007; Tong et al., 2003). For instance, while Westerners may negatively view collectivism with a perceived loss of control and self-determination, personal control may be less an issue for traditional Japanese patients who value cohesiveness; instead placing high value on family members' opinions and preferences regarding medical decision making (Hirai et al.; Matsui & Braun, 2009). Bullock et al. (2005) also found that historically, African Americans have valued collectivism and extended family involvement, adding a sense of trust and security felt by older African Americans in knowing their final wishes would be respected when family took on the care coordinator role. Several research studies also highlighted the inclusion of family and/or community elders within discussion of EOL expectations and preferences (Goldsteen et al., 2006; Hendrickson & McCorkle, 2008; Hirai et al., 2006; Kelly & Minty, 2007; Matsui & Braun, 2009).

Hattori et al. (2006) bring attention to anticipated shifting attitudes as globalization exposes more traditional collectivism-focused societies to contemporary Western beliefs that favor individualism and autonomy (Hattori et al.). As internet access to global perspectives expands and immigration continues to diversify Canadian demographics, health practitioners will increasingly need to explore patients' beliefs and preferences around EOL decision making control.

Personal Context

Personal context reflects one's unique attributes, relationships, conditions, experiences, and situatedness (SAFE Aging, 2003; Vining Radomski, 2007). Good death literature speaks to personal context in relation to differences of 1) sociocultural influences, 2) gender, 3) geographical residence, and 4) age and chronicity.

Sociocultural influences. Connectedness to others is an inherent human quality that can significantly influence one's worldviews and how the individual experiences events within their life (Tracey, 2009). Sociocultural connectedness reflects more than ethnicity, race, or language affiliation. It includes historical understandings; political, social, and religious affiliations; one's life experiences and relationships; along with the meaning and importance individuals' assign to these attributes (Hattori et al., 2006; Wilson et al., 2009a; Veillette et al., 2010). How a person views social connectedness and culture therefore influences how sensitive he/she is to these influences on others' EOL experiences and preferences when supporting a good death.

The literature provides numerous references to culturally derived preferences and the importance of sensitivity to these needs (Borreani & Miccinesi, 2008; Bullock et al., 2005; Hattori et al., 2006; Kelly & Minty, 2007; Tayeb et al., 2010; Tong et al., 2003). While many studies referred to cultural groups based on race, ethnicity, or spiritual affiliation (Hirai et al., 2006; Kelly & Minty; Leung et al., 2009; Matsui & Braun, 2009; Miyashita et al., 2007; Smith-Stoner, 2007; Toscani et al., 2003), several also presented culture from the experiential paradigm of age, diagnosis, or place of residence (Gott et al., 2008; Hendrickson & McCorkle, 2008; Hirai et al. 2006; Hughes et al., 2008; McGrath, 2007; Mjelde-Mossey & Chan, 2007; Pierson et al., 2002; Tang, 2003; Thomas, Morris, & Clark, 2004; Veillette et al., 2010; Vig et al., 2002; Vig & Pearlman, 2004; Wilson et al., 2009a). Hattori et al. (2006) added the dimension of sociocultural norms to highlight the need for considering how one's cultural, historical, political, and religious influences shape good death ideals and subsequent expectations for EOL care. Despite commonalities identified within and between cultural groups, it is important to remember that these studies only provide a snapshot of particular cultures within specified contexts and therefore should not be interpreted as indicative of generalized cultural beliefs.

A clear theme concerning cultural sensitivity and good death emphasized the need for health professionals to be respectful and open to diverse culturally-based preferences for environment, bedside presence, and terminal care activities. Bullock et al. (2005) identified African American beliefs around terminal nutrition and hydration, along with a preference for extended family member presence and inclusion in the dying person's care. McGrath (2007) similarly highlighted the need for health practitioners to be cognizant of traditional Indigenous people's strong spiritual connection with traditional land and how this influences desired location for death. He also spoke about the role community plays in one's family network for Indigenous peoples.

Changing immigration patterns within industrialized societies, along with blending of families through inter-racial marriage and post-divorce re-marriage are also impacting the diverse family relationships that health practitioners are engaged with in expanding North American multi-ethnic society (Jordan, 2012). In their study of community-dwelling minority and non-minority perspectives of a good death in the state of Connecticut, Tong et al. (2003) recognized similarities and differences for good death preferences across multiethnic groups. Similarities across minority and non-minority groups included location and environment of dying, presence of others, fear of burdening family, and communication styles. Minority groups identified the importance of cultural sensitivity in defining a good death and respecting cultural traditions, specifically related to food choices, involvement of extended family in care of dying, and rules around care for the body. In their study of older African American facing EOL decisions, Bullock et al. (2005) spoke to a fear of racial discrimination related to early treatment withdrawal, ignoring patient-identified requests, or inadequate pain control measures. These fears subsequently influenced EOL care behaviours and decision making. While not all cultural affiliations were identified within the studies reviewed, and assuming there is a continuum of connectedness to traditional culture-based good death preferences, a cultural needs assessment may help identify specific EOL care considerations. It is also important to remember that while core values may be shared within sociocultural worldviews, good death ideals also reflect other individualized aspects of one's personal context and past experiences (Gott et al., 2008; Hattori et al., 2006; Pierson et al., 2002; Vig & Pearlman, 2004). The diversity of sociocultural affiliation discussed within the literature reinforces the need for health care practitioners to explore each patient's definition of culture, social connectedness, and associated expectations or preferences that need particular consideration when planning EOL care.

Gender. The vast majority of studies (n=23) identified participant inclusion of both males and females, with only one study specifically identifying gender differences related to good death preferences (Mjelde-Mossey & Chan, 2007). Among literature sources reviewed, there were minimal gender differences related to EOL values and preferences. Where differences did appear, they were related to gendered roles, opportunities, and available choices based on sociocultural normative expectations rather than specific value differences between genders. Sociocultural gender values may play a role in EOL opportunities and choices but this was not clearly identified within the literature reviewed. In fact, gendered preferences varied only slightly regarding life-sustaining treatment. There were no studies that focused specifically on females' perspectives of good death and only one study, by Vig and Pearlman (2004), that focused on terminally ill male participants' views of good and bad dying. Consistent with good death preferences among the numerous gender inclusive studies, male participants in Vig and Pearlman's study preferred to die peacefully without pain and suffering, quickly or in their sleep, without knowledge of impending death, and having made peace with God. It is uncertain if a similar study of female patients with terminal disease would also reflect these preferences for a good death.

Geographical residence. Where one chooses to live and die can act as a social determinant of health by contributing to health inequity through resource availability and accessibility, particularly when rural residence results in isolation from health and social resources (Brennan Ramirez, Baker, & Metzler, 2008; Romanow, 2002). Several authors identified the unique rural challenges (e.g. geographic isolation, health practitioner turnover, financial barriers, and lack of inpatient facilities) influencing the availability and accessibility to specialized EOL services necessary to support a rural good death. (Kelly & Minty, 2007; Veillette et al., 2010; Wilson et al., 2009b). Wilson et al. (2009a) and Veillette et al. (2010), in discussing their ethnographic studies of a good rural death in the Canadian provinces of Alberta and Quebec, identified a strong preference for rural residents to remain in their home community to die. The authors also identified a rural sub-culture of solidarity and mutual support that stemmed from interdependence and inherent expectations of neighbourly support during difficult times which helped residents overcome geographic barriers to service access. This often translated into a deep commitment to ensuring dying community members were able to remain in close proximity to family, friends, and a place they feel secure. So while rurality can negatively influence formal EOL care resource availability, there may be informal resources that can be tapped to support a good death for those wishing to remain in their rural home community to die.

Age and chronicity. There are two major groups facing EOL experience in North America: the aged with progressive co-morbid conditions and those with terminal, life-limiting illnesses (Vig et al., 2002). While about half of studies (n=18) identified adults as the population of focus, five studies specifically targeted older adults, one included children and adults, one focused exclusively on children, and seven did not specify population age at all. There were no age-specific good death preferences identified within the literature. This seems to reinforce the complexity of interrelated factors that contribute to the individuality of good death ideals regardless of age, gender, or ethnic background.

Interestingly, the findings from the sole literature review on the concept of a good death in children (with cancer) noted that children with life-limiting illness often have an understanding of death far beyond their years, and like those of other age groups, children also experience the stages of grief and loss during preparation for death (Hendrickson & McCorkle, 2008). Consistent with perspectives of adults and older adults, Hendrickson and McCorkle concluded that each child is unique in their needs for a good death and should therefore be offered developmentally appropriate opportunities to participate in good death planning.

Although not specifically noted in the literature, one might also presume that developmentally appropriate engagement would be prudent with other age cohorts given the likelihood of shared beliefs, memories, and experiences within generational subcultures such as baby boomers, generations X, Y, and Z (Markert, 2004; Moss, 2010).

While an aging population is commonly cited as a major factor contributing to the increasing death rates in Canada, life-limiting chronic illness and comorbid disease also have a role to play (Carstairs, 2010). While the bulk of good death studies focused primarily on populations with unspecified or mixed diagnoses of terminal or life-limiting chronic illness (n=10), other studies focused specifically on individuals with cancer (n= 6) or non-cancer (n=2) diagnoses. As the population continues to age and greater numbers of older adults die from chronic progressive disease (Carstairs), it will be important for health care practitioners to recognize how this older age cohort, along with how their particular sociocultural and life experiences with death and dying, will impact attitudes and preferences for EOL care.

Notwithstanding age demographics or condition the patient is dying from, a clear theme across studies was that within the last phase of life, a number of holistic care resources are often needed as the one's physical body is debilitated, caregiver resources become depleted, and everyone processes the terminal nature of the patient's condition. The health professional's challenge thereby becomes provision of holistic care and resources that reflect the individual's good death ideals.

What do Patients Identify as Necessary for Achieving a Good Death?

This section presents a discussion on the fundamental components of a good death as derived from thematic analysis of the literature, resulting in four overarching domains, each having their own defining attributes. Specific domains include: 1) preparation, 2) sources of support, 3) communication, and 4) quality of life issues. It is important to remember that individual attributes do not stand alone but instead are interconnected and overlapping within and across domains. While there are similarities that cross cultural, spiritual, and geographical boundaries, these attributes are also heavily influenced by personal and sociocultural contexts.

Preparation

The first domain necessary for achieving a good death is the opportunity to prepare for one's own demise; a major activity of those approaching EOL (De Jong & Clarke, 2009; Jacques & Hasselkus, 2004). Preparing for one's death is not a discrete event but a process that includes several individualized components. Death preparation involves both a solitary reflective process of life review and meaning making, along with time to engage with others in the form of life closure, reconciliation, and generativity activities (Byock, 1996). According to several authors who have written about good death, EOL preparation begins with a cognitive awareness and acceptance that one is going to die (Goldsteen et al., 2006; Gott et al., 2008; Hattori et al., 2006; Jacques & Hasselkus; Kehl, 2006; Pierson et al., 2002; Steinhauser et al., 2000a). Once the individual acknowledges terminality he/she can move on to reflective and interactive activities of closure and generativity and/or decisions related to the logistics of dying and death.

Closure and generativity activities. Although the process of closure and generativity was defined differently across studies, several authors identified the need for dying individuals to view their life as full and complete, without regrets, guilt, or worry (De Jong & Clarke, 2009; Hattori et al., 2006; Heyland et al., 2006; Leung et al., 2009; Masson, 2002; Miyashita et al., 2007; Steinhauser et al., 2000a). In fact, this theme crossed generational and culture boundaries. Goldsteen et al. (2006), Jacques and Hasselkus (2004), and Steinhauser (2000a) describe the importance of reminiscing life experiences and accomplishments as part of reconciling emotions of fear and anxiety around death with affirmation of past life, goals reached, and providing a sense of meaning to one's life. Hendrickson and McCorkle (2008) recommended the use of a memory box to identifying what is meaningful and serve as legacy for family after one dies. Other authors also identified the importance of the dying individual feeling he/she will be remembered after death and the opportunity to reciprocate through the sharing of time, gifts or knowledge (Hattori et al., 2006; Jacques & Hasselkus, 2004; Kehl, 2006; Steinhauser et al., 2000a, 2000b). McGrath (2007) identified leaving a legacy as particularly important for Indigenous Australians, illustrated by passing on sacred information to descendants, a component directly tied to the preference for dying in one's hereditary homeland surrounded by family.

Resolving conflicts, seeking forgiveness, and reconciliation were additional closure activities identified as important to a good death that crossed generations and cultures (Jacques & Hasselkus, 2004; Kehl, 2006; Pierson et al., 2002; Steinhauser et al., 2000b). In their ethnography of those at an urban residential hospice, Jacques and Hasselkus (2004) relate reconciliation with the opportunity to make peace with self, others, and God. Mjelde-Mossey and Chan (2007), in their general population study added that forgiveness is significant because it is thought to be important for a peaceful death.

Linked to the concept of reconciliation and completion of final tasks is the opportunity to spend time with important people and say good-bye. While this was a consistent theme across several studies, saying good-bye took on many forms including email, cards, letters, phone calls, personal interactions, and special gatherings (Jacques & Hasselkus, 2004; Kehl, 2006; Pierson et al., 2002; Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2006; Steinhauser et al., 2000a; Tayeb et al., 2010). From a generational perspective, De Jong and Clarke (2009) noted that the older adults with terminal illness in their study related a good death with opportunities to have an open dialogue about dying with loved ones, along with an opportunity to say good-bye. Jacques and Hasselkus (2004) and Pierson et al. (2002) added the inclusion of pets as significant visitors within their American based research studies. This may simply reflect a Western sociocultural perspective but may also be relevant in other cultures as well.

Logistical decisions and arrangements. Once an individual has come to terms with their forthcoming death they may then begin to make decisions about practical matters related to closure and generativity. Often this included finalizing funeral arrangements, obituary writing, arranging support for bereaved family members, bequeathing of one's estate, and attending to financial and legal affairs surrounding death (Goldsteen et al., 2006; Gott et al., 2008; Hattori et al., 2006; Jacques & Hasselkus, 2004; Kehl, 2006; Pierson et al., 2002; Steinhauser et al., 2000a). In particular, Bullock et al. (2005), Kehl (2006), and Rietjens et al. (2006) highlighted the concern for grief and distress that medical decision making, financial costs, and caregiving responsibilities added to the dying individual's family. Many of these EOL decisions relate to a common fear of becoming a burden on family and ensuring loved ones will be provided for following the individual's death (Bullock et al., 2005; Hattori et al., 2006; Kehl; Miyashita et al., 2007; Steinhauser et al.; Thomas et al., 2004; Tong et al., 2003).

Similar to a Western desire for family security following death, Tayeb et al. (2010) also noted a consistent Muslim desire for economic and social security for family members left behind. Other non-Western cultural perspectives from Hattori et al. (2006), Mjelde-Mossey and Chan (2007), Tayeb et al. (2010), and Toscani et al. (2003) commented on the role of family in planning and executing sociocultural and spiritual practices expected during and after death. Mjelde-Mossey and Chan (2007) specifically addressed the traditional Chinese perspective of respecting cultural ceremonies, rituals, superstitions, rules, and dying tasks to support a smooth and peaceful transition to afterlife.

Linked to a need for control over self and circumstance, several studies noted a preference for control over death location, whether that be home, hospice, hospital, residential care facility, or other setting (De Jong & Clarke, 2009; Gott et al., 2008; Kehl, 2006; Tayeb et al., 2010). While there has been a small decline in the number of hospital-based deaths within Canada and abroad, it remains a common experience despite the preferred location of dying and death being in one's home environment with family (Hattori et al., 2006; Heyland et al., 2006; Kelly & Minty, 2007; Matsui & Braun, 2009; Rietjens et al., 2006; Tang, 2003; Tong et al., 2003). For many, a hospital death was likened with sterility, lacking warmth or safety, removal of dignity, and a place associated with alienation (Masson, 2002; McGrath, 2007; Pierson et al., 2002; Tong et al.). For others, the hospital or other non-home environment provided security in symptom control while limiting any perceived burden on family (Gott et al.; Masson; Pierson et al.; Steinhauser et al., 2000a; Tang; Thomas et al., 2004; Toscani et al., 2003; Vig & Pearlman, 2004). An important component for those dying away for a home environment was a long-standing trusting relationship with consistent care providers (Steinhauser et al.; Tang; Toscani et al.). To compensate for deviation from their idealized home death, many patients would make the new location as home-like as possible (Hirai et al., 2006; Masson; Miyashita et al., 2007).

Cultural influences also contribute heavily to preferred location of death. Just as no two individuals or groups are completely alike, neither are the specific expectations for dying and death. Therefore it is important to separate the cultural themes identified within good death literature from what individuals may specifically interpret as important for their own dying and death experience. However, good death literature did identify themes within and across cultural groups that are important to consider when conceptualizing a good death. In their literature review to describe the meaning of a good death in the Japanese community, Hattori et al. (2006) noted that traditional Japanese cultural expectations often included the responsibility of family to prepare a place for the ill family member to die, including a traditional tatami mat (death mat) for a home death. In their study to identify and describe components of the Muslim good death perspective among multi-national Muslims in Saudi Arabia, Tayeb et al. (2010) found that when possible, relocation to a holy place such as Madinah, Makkah (the holiest places for Muslims), or a local mosque for those living away from these holy places, was seen as supportive for a quality death. Similarly McGrath's (2007) research found that northern Australian Indigenous peoples, especially elders, saw dying in one's homeland surrounded by family was not only a place of comfort and familiarity but helped ensure their spirit was able to return to the land for transcendent connection with future generations.

While the majority of research participants articulated a particular location for death, others were more abstract in reflecting location as a place that provided a sense of safety, security, comfort, and familiarity of important people, cultural practices, religious beliefs, and surroundings (Hirai et al., 2006; Miyashita et al., 2007; Wilson et al., 2009a). This reinforces the idea that individual studies only provide contextualized views but should not be seen as providing complete understanding of cultural beliefs and preferences across contexts. Despite mixed opinion on best location of death, preference factors commonly included familiarity, privacy, autonomy, companionship, and environmental comfort (Miyashita et al.; Steinhauser et al., 2000a; Tang, 2003; Toscani et al., 2003). EOL experience is also heavily impacted by the supportive relationships each patient experiences.

Sources of Support

The second domain identified as necessary for achieving a good death focuses on the dying individual's sources of support. The importance of family relationships and presence during EOL was a theme cited across the majority of literature sources and likely reflects the centrality of family for many cultural groups (Hattori et al., 2006; Hirai et al., 2006; Kelly & Minty, 2007; Miyashita et al., 2007). What differed among studies was the definition of family. The North American health care system often narrowly defines family (Bullock et al., 2005) but many sociocultural and religious groups see extended family relations, community members, informal helpers, and pets as critical to the caring process (Jacques & Hasselkus, 2004; Kelly & Minty; Pierson et al, 2002).

Although Vig and Pearlman (2004) found mixed opinions on the presence of family during one's dying phase, several other authors noted a desire for support, compassion, comfort, and sympathetic human contact from friends and family (Bullock et al., 2005; Hattori et al., 2006; Kehl, 2006; Pierson et al., 2002; Tong et al., 2003). In some instances support referred to the caregiving role, while other times the focus was simply being present; a time to informally visit or sit with the dying individual as they rested (Bullock et al.; Jacques & Hasselkus 2004). In studying the views of older adults, both Bullock et al. (2005) and Steinhuser et al. (2000a) noted physical touch, interaction, and presencing – focused attention and receptivity (Zerwekh, 1997) - helped to reinforce the humanness of the dying experience rather than purely focusing on the physical dying shell. Participants described a desire for being treated genuinely, with empathy, and inclusivity (Bullock et al.). This humanness perspective is consistent with views of positivity, maintaining hope, normalization, and focusing on living despite a terminal status (Goldsteen et al., 2006; Kehl; Miyashita et al., 2007; Steinhauser et al.). Hirai et al. (2006) also found maintaining hope and a fighting spirit to be effective coping strategies that are positively regarded within Japanese culture. This is possibly due to the culture's high regard for pride, dignity, collectivism, and reincarnation. This outlook may partially explain why many Japanese see maintaining treatment through to death as part of a good fight.

Health care professionals were another identified source of support but with particular restrictions. Patients voiced expectations for health professionals to be nonjudgmental, collaborative, respectful, trusting, reliable, advocative, confident, and genuine (Bullock et al., 2005; Hirai et al., 2006; Kehl, 2006; Miyashita et al., 2007; Pierson et al., 2002; Steinhauser et al., 2000a; Thomas et al., 2004; Tong et al., 2003). Steinhauser et al. (2000a) and Thomas et al. (2004) suggested a care approach that established professional boundaries yet allowed for a supportive personal relationship with patients and families. While some cultures expect medical paternalism because of their inherent trust in authority, many Euro-centric cultures voiced a greater desire for autonomy and shared decision making (Hirai et al.; Miyashita et al.; Thomas et al.). Kelly and Minty (2007) add that building trust can take significant time, especially for those with historical trauma such as Canadian Aboriginal peoples. Balancing the need for paternalism and shared decision making requires understanding of the patient's beliefs and values. Regardless of the approach taken, effective therapeutic communication will be required.

Communication

The third good death domain centres on communication; a consistent and important theme throughout good death literature. Several studies reported the significance of active listening along with open and truthful dialogue in order to build trust, empower patients, and provide opportunities to discuss questions, fears, desires, and available options (Hattori et al., 2006; Heyland et al., 2006; Kehl, 2006; Kelly & Minty, 2007; Steinhauser et al., 2000a; Tong et al., 2003). Other researchers addressed the need to provide anticipatory guidance about the likely sequence of events and physical signs characterizing key transition points signaling impending death (Gott et al., 2008; Jacques & Hasselkus, 2004; Steinhauser et al.; Tayeb et al., 2010; Terry et al., 2006; Thomas et al., 2004). Having someone to facilitate understanding of information, address myths or unrealistic expectations surrounding the dying process, and affirm treatment choices helped patients mentally prepare for dying and relieve fears (Bullock et al., 2005).

When language barriers are an issue, Kelly and Minty (2007) recommend the use of interpreters but caution that their use needs to be done with foresight such that interpreters not only have good understanding of the language but also of the patient's culture. They also warn against the use of family members as interpreters given the potential for breach of privacy and potential undeclared value conflicts between parties. Mjelde-Mossey and Chan (2007) add the importance of health providers having cursory understanding of cultural rules and superstitions to prevent unintentional over-disclosure or discussion of taboo subjects.

In their work with terminal patients, family, and care providers in the Netherlands, Goldsteen et al. (2006) found that many patients were supportive of open acknowledgment and communication with family about their impending death but others were more reserved. Terry et al. (2006), in their ethnography of hospice patients, also found that not all patients desired complete transparency. Some patients even voiced fear for their decisional autonomy if family were made fully aware of their EOL preferences and thus requested the opportunity to censor information that was to be shared with family members.

Similar to information censoring is the concept of truth-telling in which some cultures believe it is customary to hide serious diagnoses from loved ones in order to protect them from harm. While truth-telling may be seen to some as a barrier for patients in accepting one's nearness to death, it is often steeped in traditional cultural beliefs around death and dying with an intention of support or protection, not maliciousness. Hattori et al. (2006) stressed that in traditional Japanese culture bad news is considered cruel and since the family's role is to protect loved ones from potential harm, many families may only agree to partial disclosure. Kelly and Minty (2007) similarly found that relatives of ill Aboriginal patients may not want to disclose the seriousness of their loved one's illness trajectory because of a belief that positive thoughts help promote health and that discussing terminality may hasten death.

Mjelde-Mossey and Chan (2007), in their general population survey in China, found that discussing death was thought to bring bad luck or early death for ill individuals within traditional

Chinese culture; consequently care planning decisions may be left to health professionals or implied through nebulous discussions. Contrary to support for non-disclosure, Leung et al. (2009) in their Chinese study of lay persons, found that the majority of their respondents supported full disclosure so that individuals could develop an understanding of the terminal nature of their condition before moving on to acceptance of death within the context of one's life journey and eternal afterlife. These variances within and across cultural groups again reinforces the need for individualized assessment when working with clients experiencing terminal conditions.

Only one study specifically focused on pediatric terminal care but did speak to the importance of an appropriate communication approach with this population (Hendrickson & McCorkle, 2008). The authors asserted that children with life-threatening conditions often acquire an adult-like understanding of death beyond their years regardless of whether death is spoken about or not. Many are perceptive enough to inherently know something is wrong but may not be able to grasp the significance in relation to impending death. The authors therefore advocated preparing children for death by involving them in discussions about EOL care preferences, but at an age appropriate level. While not specifically mentioned by the authors in this study, developmentally appropriate communication that considers life stage and context may be prudent for all patients facing EOL decisions.

Quality of Life Issues

The final good death domain focuses on the importance of maintaining quality of life (QOL). While QOL is a complex and subjective concept, it was consistently identified throughout the literature as an important component of a good death (Veillette et al., 2010). Elements characterizing QOL include providing integrated holistic care; maintenance of dignity, respect, and personhood; and sense of control.

Providing integrated holistic care. Several authors noted the importance of patients feeling affirmed as unique wholly integrated individuals within their holistic relational existence (Kehl, 2006; Pierson et al., 2002; Steinhauser et al., 2000b; Veillette et al., 2010). While physical comfort was of significant importance toward relief of suffering, QOL also included other holistic dimensions such as attending to the physical, psychological, social, emotional, and spiritual well-being within the context of that individual's life and values (Tracey, 2009). This was a particularly important perspective for Aboriginal peoples who viewed ill health as reflecting imbalance within these interdependent dimensions (Kelly & Minty, 2007). Since each culture views health, illness, and holism differently, a thorough assessment with clear communication and cultural sensitivity would be prudent.

Faith and spiritual beliefs influence one's view on death and the process of dying. While the theme of faith and spirituality appeared across several studies, they were most prominent among minority groups, with some using it as a positive coping mechanism during times of vulnerability and uncertainty (Bullock et al., 2005; Steinhauser et al., 2000a, 2000b; Tong et al., 2003). In their study of older African Americans, Bullock et al. (2005) found that death was seen as a process of transition, not a final stage in their life cycle, and that spiritual customs (e.g. reading scripture, prayer, last rites) were an important part of this transition from life, to death, to spiritual afterlife. Spiritual conviction helped participants find meaning in life and suffering while providing hope during the dying process (Bullock et al.). Likewise, Tayeb et al. (2010) noted that their Muslim participants found spiritual and emotional support was greatly valued. They also discovered that death and the dying experience were believed to be closely linked to faith. For instance, suffering was seen as atonement for one's sins and religious rituals or ceremonies such as reciting Qur'an verses, death position, place, and timing of death in relation to a holy time were important for a good death.

In contrast to viewing faith and spirituality as important and supportive, Hirai et al. (2006) and Miyashita et al. (2007) found spiritual beliefs were less important for participants in their respective Japanese studies. Similarly, in their study of Americans dying of acquired immunodeficiency syndrome (AIDS), Pierson et al. (2002) found mixed views about the role of spiritual traditions. Some participants found religious traditions to be important, while others were indifferent, and still other participants feared having the beliefs of family, hospice volunteers, or health practitioners imposed on them. From the diversity of views identified about faith and spirituality, the importance of effective communication and individualized assessment is once again reinforced.

Maintenance of dignity, respect, and personhood. For many, QOL meant preservation of personal dignity, respect for individual style, and maintenance of personhood (Hendrickson & McCorkle, 2008; Kehl, 2006; Miyashita et al., 2007; Pierson et al., 2002; Rietjens et al., 2006; Steinhauser et al., 2000a; Tayeb et al., 2010; Thomas et al., 2004). Loss of control over physical and cognitive self was seen to contribute to loss of dignity. For many participants this translated into a preference for one's final living moments to be peaceful, painless, unknowing, and in the presence of important people (De Jong & Clarke, 2009; Gott et al., 2008; Hughes et al., 2008; Kehl; Kellly & Minty, 2007; Miyashita et al.; Pierson et al.; Steinhauser et al.; Vig et al., 2002; Vig & Pearlman, 2004). For other participants, dignity was correlated with self-image, intact bodily functions, maintaining appearance, mental alertness, and not exposing feebleness (Hirai et al., 2006; Miyashita et al.; Pierson et al.; Rietjens et al.; Steinhauser et al.). Loss of dignity was therefore seen as a contributor to a bad death and associated with debilitation, loss of personhood, and objectification. This was particularly important for Muslims in Saudi Arabia who identified body image, cleanliness, and appearance as very important for a good death (e.g., no distortions, deformities, or bad odors); not only for self-dignity but for how others experience their body (Tayeb et al., 2010). Terry et al. (2006) found similar sentiments from hospice patients with a fear that the dying process would cause their behaviour to become incongruent with their long-held character.

Toscani et al. (2003) added the importance of death atmosphere aesthetics, in that one's death scene determines the quality of memory for those left living and reinforced the need for visions of peace, tranquility, and rituals. When patients feared their dying process would negatively affect loved ones, De Jong and Clarke (2009) found these patients would subsequently prefer to die alone. Diversity again became the reinforced theme where some participants voiced a clear preference for a soft, quiet atmosphere while others envisioned solace with open mourning (Pierson et al., 2002; Toscani et al.).

Sense of control. Linked to maintenance of dignity and respect for individual choice is the desire for autonomy, self-determination, and personal control over self, dying process, and EOL care decisions (Gott et al., 2008; Hattori et al., 2006; Heyland et al., 2006; Jacques & Hasselkus, 2004; Kehl, 2006; Leung et al., 2009; Pierson et al., 2002; Steinhauser et al., 2000a; Tang, 2003; Tayeb et al., 2010; Terry et al., 2006; Tong et al., 2003). Like other good death elements there was variability in viewpoints and preferences related to autonomy and control. Leung et al. (2009), Matsui et al. (2009), Miyashita et al. (2007) and Rietjens et al. (2006) found a propensity for independent decision making among the Chinese, Japanese Americans, Japanese, and Dutch groups they respectively studied. Kelly and Minty (2007) also identified Aboriginals valuing personal independence in decision making but retaining tremendous respect for the wisdom, experiential, and spiritual insights that elders could add to the decision making process. Familiarity with cultural beliefs, personal values, and preferences was also appreciated by minority groups, likely related to fear of racism and medical paternalism contradicting their personal values and preferences (Bullock et al., 2005). A clear message was the expectation for care team members to respect patient wishes (De Jong & Clarke, 2009).

Other studies focused on personal control through regulation of who is involved with caregiving and present during EOL (Kehl, 2006; Tayeb et al., 2010). Several studies highlighted the need for consistent, accessible, responsive, and affordable resources for around-the-clock symptom control; providing a sense of safety and security during a most vulnerable time (Bullock et al., 2005; Gott et al., 2008; Heyland et al., 2006; Terry et al., 2006; Thomas et al., 2004; Veillette et al., 2010). Control over physical comfort at EOL was consistent across the majority of studies; crossing cultures, generations, belief systems, and disease experiences (De Jong & Clarke, 2009; Gott et al.; Hattori et al., 2006; Hirai et al., 2006; Hughes et al., 2008; Kehl; Kelly & Minty, 2007; Leung et al., 2009; Miyashita et al., 2007; Pierson et al., 2002; Rietjens et al., 2006; Smith-Stoner, 2007; Steinhauser et al., 2000a, 2000b; Tayeb et al.; Tong et al., 2003; Vig et al., 2002; Vig & Pearlman, 2004). Some participants related suffering to loss of personal integrity while others related pain and symptom crisis to increased anxiety and distress thereby resulting in loss of dignity and control (De Jong & Clarke; Gott et al.; Hendrickson & McCorkle, 2008).

Kehl (2006), Masson (2002), and Steinhauser et al. (2000a) found that while symptom management is important, sometimes it competes with other preferences such as mental alertness and ability to communicate; important contributors to personal autonomy and control. Unlike pain and symptom management, preference for remaining conscious at EOL differed among study groups. In their survey of Dutch general public, Rietjens et al. (2006) found that younger and lower educated respondents voiced greater preference than older and better-educated respondents for a conscious state until death. Whether this reflects generational comfort with death and afterlife is unclear. Toscani et al. (2003) also found differences for alertness at EOL between non-believers and believers. While believers were comfortable with a non-awake state during one's final moments, non-believers wanted to protect their self-identity and saw a conscious death as one last opportunity to fully experience life in totality.

Irrespective of disease state, age, or worldview it seems that patients want at least some sense of control during the dying process. Whether this sense of personal control can be achieved through advanced care planning decisions was not fully explored within the studies reviewed. It would be advantageous to explore what determines personal control at EOL given the push for increased advanced care planning and that individual EOL care preferences can change as one's dying context changes.

How Might a Rural Context of Care Impact a Good Death?

The literature was sparse regarding a good death within a rural context of care. In fact, only three studies, all Canadian and from the same authors, touched on rural good death implications. Consequently, some of the following arguments are supported with rural-focused literature drawn from outside this project's literature search.

Choosing to remain in one's rural community to die does not automatically translate into a bad death. It may however mean that care providers and family members must work harder to ensure resources are available to support EOL care preferences, especially services that are typically located within more urban centres. Due to limited specialist providers in rural communities, the vast majority of dying patients are cared for by generalist practitioners who may not have formalized EOL care training (Kelley, Sletmoen, Williams, Nadin, & Puiras, 2012; Wilson et al., 2009a). While there is an increasing need for rural EOL care services, access to these resources remain greater in urban centres where specialist practitioners and programs are located.

When urban specialized services are necessary the patient must either go to where the services are provided, or have the services come to them. More commonly, patients are required to travel in order to minimize health system costs (Wilson et al., 2009b). Fortunately the electronic age is bridging some of this burden by providing avenues for patients and practitioners to consult with specialists for care planning without having to leave the comfort and security of their home community. This not only decreases the physical burden of travel, but can help minimize other negative impacts such as risks associated with travel during adverse weather conditions, costs of temporary relocation and absence from work, along with separation from emotional supports.

With fewer formal care services available in rural communities, the burden of care lands on the shoulders of family and other informal community supports (Donovan & Williams, 2012; Wilson et al., 2009a). Access to adequate respite and home support services may not be available in rural centres and if family support persons also reside outside the patient's community, further dependency and potential burnout may result (Wilson et al.; Wilson, Truman et al., 2009). With difficulties in recruiting and retaining appropriate health professionals with EOL care experience, care consistency and quality can be at risk (Wilson et al.). This then can negatively affect a patient's sense of safety, trust, and security in EOL care reflecting their values and preferences.

While there are several challenges to residing and spending one's final days within a rural community, there are also benefits. There exists a subculture of social connectedness and mutual respect, even among residents who do not directly know each other. This was evidenced by funeral attendance for long-time residents and family members of friends (Wilson et al., 2009b). Long-standing relational approaches, comradeship, and interconnected communication patterns among residents helps spread important information and messages faster within informal circles and thereby adds to the sense of community connectedness (Wilson et al., 2009a).

This chapter has reviewed themed good death ideals that are individually unique and shaped by interconnected sociocultural and personal influences: philosophical views on life and death; decision making based on individualism versus collectivism; and personal context. Following this discussion was an examination of thematically derived elements of a good death, comprised of four overarching domains: preparation, sources of support, communication, and QOL issues. Each of these domains included overlapping and interconnected attributes that are heavily influenced by each individual's personal and sociocultural context. Chapter Four will expand on this discussion by posing several rural FNP considerations for supporting a good death within BC.

CHAPTER FOUR

Role of Family Nurse Practitioners in Facilitating a Good Rural Death

Death does not discriminate based on geographic residence or individual demographic differences. Due to their role as primary care generalist practitioners and their relative proximity away from specialist health care services, rural FNPs should expect to take primary responsibility for the organization and collaborative delivery of EOL care services for those wishing to remain in their rural home community to die. This will require knowledge and skill associated with comprehensive EOL care for a diversity of clients across the lifespan. With an absence of literature specifically addressing the unique FNP role in supporting a good death in rural settings, many of the following considerations involve inference and deduction from this project's thematic synthesis. Practice considerations will be reviewed within the following nine areas inherent within FNP clinical practice: 1) advanced scope of FNPs, 2) holistic care, 3) EOL care planning and life expectancy, 4) consistency of care, 5) multidisciplinary collaboration, 6) effective communication, 7) caregiver support and education, 8) continuing competence, and 9) leadership.

Advanced Scope of Family Nurse Practitioners

At the core of nursing practice, regardless of regulatory level, is provision of compassionate, comprehensive, ethical, and evidence-informed quality care that is unique to an individual's needs for holistic wellness, and built on the concepts of relational practice, health promotion, collaboration, partnership, and cultural sensitivity (CNA, 2008, 2010). As advanced practice nurses, FNPs have been permitted additional regulatory authority to provide services that go beyond the RN scope of practice (CNA, 2009). This includes the ability to complete advanced physical and health assessments; diagnose and manage common diseases, disorders, and conditions; order, conduct, supervise, and interpret diagnostic tests; prescribe pharmacologic agents and non-pharmacologic therapies; perform advanced interventions for patients across the lifespan; and admit or discharge patients from health facilities (CNA, 2010; CRNBC, 2012b). This expanded scope allows FNPs working in rural settings greater ability to provide appropriate and comprehensive EOL care for patient's within their home community, where access to physicians and specialist services may be limited.

Holistic Care

People with persistent and life-limiting illnesses are motivating a shift in the primary health care approach from one that is practitioner and disease centered to one that acknowledges a relational and life-oriented perspective (Heyland et al., 2006; Masson, 2002). When engaging with clients in primary care, particularly those from diverse backgrounds and experiencing life-limiting conditions, it is important for FNPs to remember that one size does not fit all; different patients need different approaches. While the biomedical model is helpful in understanding the physical experience of illness and dying, it alone is incomplete and could lead to a depersonalized interventional approach to care. A holistic and personalized care approach attends to the physical, emotional, spiritual, psychological, and social domains; incorporating personhood and humanness during the dying experience rather than purely focusing on the physical aspects of dying.

While a holistic and personalized approach can be found across multiple disciplines, what differentiates the FNP advance practice role is how FNPs combine the best of nursing's holistic approach with the advanced depth and scope of medicine in order to provide comprehensive patient care that honors a multidimensional view of health and wellbeing (CNA, 2010). For instance, an inclusive and nonjudgmental presence is important when discussing medical care options, particularly exploration of traditional, complimentary, and alternative therapeutics that patients may be reluctant to self-disclose (Kelly & Minty, 2007; Roy & Jones, 2007).

End-of-Life Care Planning and Life Expectancy

Given that the majority of patients will die from chronic or life-limiting disease, rural FNPs must develop competence in not only diagnosing acute and chronic conditions, but also delivering bad news, recognizing when illness trajectory becomes terminal, determining best timing for EOL discussions, and actively engaging in secondary and tertiary prevention to avoid adverse events before they reach an intensity requiring emergency treatment or hospitalization. In focusing on the individual's life left to live, along with wellbeing while dying, FNPs need to then balance the maintenance of hope and positivity with grounded reality. This requires ongoing dialogue and anticipatory counseling with patient, family, and allied health team members about the patient's anticipated life expectancy; potential disease-related challenges and associated care options; expected changes as death approaches; and realistic goal setting based on the patient's individualized good death ideals and accessible EOL care resources.

Ideally, FNPs would begin advance care planning discussions with every new client in their practice while encouraging patients to complete an advance directive (AD). Realistically this may not always be possible and thus the FNP needs to be a skilled communicator in anticipatory health counseling and exploration of medical care preferences to guide clinical decision making. Also referred to as advance care plans or EOL directives, ADs are written instructions made by a capable adult to provide specific examples of health care interventions that the individual gives or refuses consent for in times when they are incapable of providing such direction themselves (BCMOH, 2012a; CRNBC, 2013). Resulting from legislation amendments to the Health Care (Consent) and Care Facility (Admission) Act [HCCFA] (1988), ADs became recognized as legal documents in British Columbia in September 2011 (BC Ministry of Justice, 2011). This means that FNPs are legally bound to follow the directions for care conveyed within these documents. While FNPs can and should help patients with advance care planning by means of ongoing dialogue and AD guides (BCMOH, 2012a), it is important to note that they are not legally permitted to witness the signing of these documents if providing care to that patient (HCCFA). Like other health professionals, rural FNPs must honor the ADs of patients or consult substitute decision makers when no ADs are known.

According to Old and Swagerty (2007), a common question asked by patients at EOL is "*How long do I have?*" [emphasis in the original] (p. 89). Being able to anticipate life expectancy is an inexact science that can be stressful and complex, but can positively support anticipatory bereavement and allow for arrangement of appropriate resources before crises occur. Prognostication is an expected health assessment and diagnostic competency for FNPs in BC (CRNBC, 2010b). A good starting point for estimating life expectancy might include the FNP asking himself/herself "*Would I be surprised if this patient died within the next 6 months?*" [emphasis in the original] (Old & Swagerty, p. 93). When communicating estimated life expectancy to patients and family, Old & Swagerty suggest reinforcing the difficulty in its determination and using general time frames of 'months to years', 'weeks to months', 'days to weeks', and 'hours to days'. This approach honors the need for those seeking timelines while recognizing the individuality and unpredictable nature of dying and death.

It is well known that limited life expectancy for terminally ill patients is associated with functional decline. As such, rural FNPs should gain an understanding of any change in the patient's level of function in the areas of cognition and mental clarity; activities of daily living (e.g., dressing, eating, ambulation, toileting, and hygiene); continence, nutrition, and weight; mobility; social engagement; and changing hematology values (Old & Swagerty, 2007; Province of BC Guidelines and Protocols Advisory Committee, 2010). Because FNPs may not see patients as frequently as family caregivers or home care support workers, and given that some patients may be too frail to attend the FNP's clinic, it is vital that FNPs are able to glean information on the patient's status from the patient's family and collaborative care partners. This may be accomplished through regular phone follow-up between clinic or home visits. The Palliative Performance Scale (PPS) (Victoria Hospice Society, 2006) may also serve well as a tool for consistent assessment communication between health care colleagues and family caregivers. The PPS is a framework to measure physical performance based on one's degree of ambulation, activity level or extent of disease, self-care ability, nutritional intake, and level of consciousness. The PPS scale uses 10% decrements, with 100% representing full activity and health, 70-100% signifying a stable palliative state, 40-60% reflecting a transitional EOL state, 10-30% signaling an active dying state, and 0% indicating death (Victoria Hospice Society). While based on subjective judgment of an individual's level of function, the PPS is a tool with demonstrated good overall reliability and ease of use that can support assessment consistency when estimating terminal decline (Campos et al., 2009; Lau et al., 2009).

Another resource for rural FNPs to consider is the BC clinical practice guideline titled "Palliative Care for the Patient with Incurable Cancer or Advanced Disease Part 1: Approach to Care" (Province of BC Guidelines and Protocols Advisory Committee, 2010). Not only does this document provide assessment tools to identify functional decline and symptom burden, it also identifies signs indicating imminent death, and outlines numerous recommendations for comprehensive care planning actions from the time of palliative diagnosis through active dying and bereavement care.

Multidisciplinary Collaboration

Ideally, EOL care delivery is a multidisciplinary collaboration with overlapping roles amongst team members, yet maximizing each individual's scope of practice to ensure comprehensive, streamlined, and well-coordinated care. EOL care coordination, particularly in rural settings, is a complex and time intensive role that often falls to disciplines consistently present within the rural community. Often adding to the complexity of rural EOL care is the relative distance from specialist practitioners and health care resources, thereby necessitating the FNP within rural communities to take on activities they might normally entrust to others when practicing within an urban context.

While FNPs are legally permitted to perform activities within the RN scope; efficient practice encourages rural FNPs to work collaboratively with other team members involved in the patient's care, thereby allowing time for rural FNPs to focus on activities within their expanded scope. This expanded scope often includes advanced level assessments; ordering, interpreting, and acting on diagnostic tests; identifying treatment plan options; prescribing a variety of medications and other therapeutic interventions to prevent and manage EOL symptoms; and completing home visits for house-bound patients. Within the multidisciplinary team the FNP may also play a significant leadership role in facilitating linkages to regional and local palliative care and hospice resource programs.

Despite the fact that rural FNPs in BC primarily function as expert generalists in primary care settings and that their legislated scope of practice continues to expand, statutory barriers continue to hamper FNPs in delivering full scope EOL care. As such, rural FNPs need to be fully versed in the legislated scope and restrictions governing care commonly provided at EOL (CNA, 2010; CRNBC, 2012 a). Although recent federal legislation changes allow for FNPs to prescribe, administer, and provide legal controlled substances (e.g., narcotics, benzodiazepines, and methadone), provincial legislation and organizational guidelines still require amendment before rural FNPs can incorporate this into their clinical practice (CRNBC, 2013; Health Canada, 2012b). Other examples of restricted FNP abilities common to comprehensive EOL care include the inability to complete: 1) a *No Cardiopulmonary Resuscitation* form for those wishing not to have cardiopulmonary resuscitation performed in the event of respiratory and/or cardiac arrest

(BCMOH, n.d.); 2) *Notification of Expected Death in the Home* form (BCMOH, 2010b); and 3) a *Medical Certificate of Death*, even if this death is expected and the FNP has been the primary care provider for this patient (College of Physicians and Surgeons of British Columbia, 2009; CRNBC, 2013). Completion of the aforementioned forms remains under the physician-only scope of practice. Until statutory amendments expand NP authority to include these provisions, rural FNPs need to engage in collaborative patient management with physician colleagues for those interventions and decision making that fall outside their professional scope of practice or area of expertise (CRNBC, 2012 a; Steinhauser et al., 2000 b).

Consistency of Care

An essential element in facilitating a good death that was consistently highlighted within good death literature was around-the-clock access to professional care providers familiar with the patient's personal context and EOL care preferences. Research participants stressed that care consistency helps limit the burden on patient and family from having to repeat their story over and over and rearticulating goals as team members change (Bullock et al., 2005; Hendrickson & McCorkle, 2008; Heyland et al., 2006; Hirai et al., 2006; Thomas et al., 2004; Veillette et al., 2010). Consistency of team members also supports an environment of care continuity, where practitioners develop understanding of an individual's preferences for holistic EOL care through genuine long term relationship and not simply from prescriptive written advance directives. Having FNPs in salaried positions within BC affords the flexibility to visit patients across a variety of settings, be that in local hospital, hospice, the patient's own home, retirement residence/assisted living, complex care facility, or primary care clinic. With the FNP as central care coordinator, along with having advance assessment skills, home visits can help improve continuity of care while also helping to recognize emerging problems which can be caught early and proactively managed to prevent crises, distress, and suffering.

According to CRNBC (2012b) FNPs “have an ethical obligation to be available to provide care for their established patients on a 24-hour basis either personally or through ongoing call schedules” (p. 14). It therefore makes sense that the rural FNP would play an important role in care coordination and provision so that care consistency can be maximized. Unfortunately, current FNP remuneration in BC is primarily based on a standard work-week salary model with no ‘on call’ financial provisions having yet been made available. This structure thereby becomes a barrier to around-the-clock care consistency by primary care practitioners familiar with the patient’s EOL goals and preferences. In rural communities this could potentially result in burnout for physicians taking call for FNP colleagues, or displacement of patients out of their home community to receive necessary care. On-call remuneration is likely an area for ongoing contract negotiation and in future may result in ‘in lieu’ days or consolidated time away to pursue professional development.

Effective Communication

Given the economic environment of declining resources and the fact that rural communities are less likely to attract and retain specialist practitioners (Romanow, 2002), FNPs need to develop competence with electronic and other technology tools to ensure effective and timely communication, consultation, and referrals for patient health and social resource needs. Alternative methods of communication are especially important for times when the patient and/or his/her caregiver are unable to physically travel to medical specialists and other resource supports yet require their insights and management recommendations. As effective interdisciplinary team members, rural FNPs need to develop proficiency in clearly and concisely communicating the patient’s condition to others while also developing a sense of comfort and competency when carrying out recommendations of specialists; one of the greatest differences between rural and urban primary care FNPs. In urban practice, patients can see the specialists face-to-face but in rural practice this may not be realistic. Therefore, FNPs become the intermediary and generalist action professional. He/she also becomes an expert among informal caregivers and is seen as the health care leader, resource person, educator, and role model in the eyes of formal and informal caregivers (CNA, 2010; CRNBC, 2010b; CRNBC, 2012 a). Being able to collect important information from family and collaborative care partners, while also effectively communicating EOL care plan directions, both verbally and in writing, become essential to providing comprehensive and consistent EOL care.

Caregiver Support and Education

Care within one's home at EOL is often a 24/7 commitment that can be physically, emotionally, and socially draining; factors that weigh heavily on patients' considerations for place of death. The potential for burnout among EOL caregivers is high when time and care intensity increase during extended terminal trajectories typical of chronic progressive illnesses. Although health and human resources tend to be scarcer in smaller and more isolated communities, rural communities are known for their resiliency and communal nature, especially during times of stress and strain (Kulig & Williams, 2011). This can be capitalized on by rural FNPs in helping patients and collaborative partners identify and recruit informal resources, including family, friends, neighbours, religious group members, home and community care workers, private skilled care services, and trained hospice volunteers (Castleden et al., 2009; Kulig & Williams). While assessing and helping with the arrangement of financial and social supports (e.g., federal employment insurance compassionate care benefits program) (Service Canada, 2012) is often completed by social workers in urban centres, this role may fall to the FNP in rural communities that do not have social work positions. Likewise, provision of respite through admission privileges, and providing counselling to individuals, families, and groups fits within the advance scope of FNP practice.

A significant education function for FNPs is providing anticipatory guidance and teaching to patients, family members, and community supports for such topics as illness trajectory, symptom management, red flags with follow-up plans, crisis prevention, and signs of impending death. Information allows individuals to prepare physically, psychologically, and socially for what is to come. Families may not have personal experience with dying or death and therefore will need education on what to expect as the patient transitions through the terminal stages of their disease and physical signs cue key transition points signaling impending death. Knowing what to expect can facilitate a sense of control and help reduce anxiety. Sometimes patients and family may just not know what questions to ask but in regular follow-up meetings, with replication of key messages, the probability of addressing important questions and concerns is greater. An additional resource for ongoing family support may include the development of an EOL care 'toolkit' that provides general information on EOL principles, answers to frequently asked questions, lists of appropriate community resources, and provision of checklists to support decision making around final arrangements commonly encountered at EOL (Castleden et al., 2009).

Continuing Competence

Rural FNPs must not only possess a baseline understanding of palliative care philosophy but also a working knowledge of EOL interventions to support physical symptom management (e.g., pain, dyspnea, anxiety, and confusion) and crisis prevention. Therefore, FNPs must possess the ability to interpret and critically appraise evidence to inform clinical decision making. Fitting with CNA's (2010) expectation for ongoing self-evaluation of practice competence and continuing professional development, rural FNPs may need to engage in theoretical and practical continuing education to enhance their ability to provide appropriate

EOL care, especially if the FNP's educational preparation did not provide sufficient theoretical or practical experience with EOL care provision.

Fortunately, there are several provincial and national initiatives to support professional development in EOL care, along with access to specialist support services for decision making about therapeutic interventions and ethical issues. For example, there is a 24/7 accessible palliative care consultation line aimed at health care practitioners (BCMOH, 2012b). Each provincial health authority has hospice palliative care online resources for family and practitioners, and the Province of BC Guidelines and Protocols Advisory Committee (2010, 2011a, 2011b) has several online palliative care clinical practice guidelines to support clinical decision making by primary care providers. Additionally, the Faculty of Medicine at the University of British Columbia (UBC) offers a three day theory and practice module on palliative and EOL care (UBC, 2012). Victoria Hospice, which is a provincial charitable organization in BC, offers a variety of continuing education resources and electronically accessible clinical tools for health professionals (Victoria Hospice Society, 2012). Similarly, the Canadian Virtual Hospice, through their electronic website, offers information and support links aimed at both the general public and health professionals regarding palliative and EOL care education, symptom management, and bereavement (Canadian Virtual Hospice, 2012). The Australian Medical Association also offers a clinical practice guideline that FNPs may find supportive when preparing to discuss prognosis and EOL issues with patients and their caregivers (Clayton, Hancock, Butow, Tattersall, & Currow, 2007). When rural FNPs gain appropriate knowledge and clinical competence with EOL symptom control measures, they can become more proactive in therapeutic management while confidently reassuring patients and family that physical comfort can be attained and suffering minimized.

Leadership

As identified by CRNBC (2010b), all FNPs are responsible for guiding, initiating, and providing leadership "in the development and implementation of standards, practice guidelines, quality assurance, and education and research initiatives" (p. 11). While not all rural FNPs will be experts in EOL care, those that are can promote evidence-informed practice decisions as a component of EOL leadership. Rural FNPs not only use research to guide their own clinical decision making but can role model the implementation of research findings (evidence-informed practice) as a way to counter hegemony and champion change in clinical practice. This may involve providing clinical leadership within multidisciplinary teams, providing mentorship for students and novice practitioners, and/or engaging in conference presentations and collaborative publications.

Community leadership involves engagement in community partnerships and capacity building with formal and informal support networks to facilitate the design, implementation, and enhancement of services to meet the current and ongoing needs of patients requiring EOL care in rural communities within BC (Bushy, 2002). With this goal in mind, rural FNPs may therefore need to engage in inter-sectoral collaboration for the purposes of coalition building, campaigning for sufficient resources from various levels of political, community, and non-governmental sectors, as well as lobbying for EOL care to be on the political, economic, and research agenda. As professionals in the regional health authority, rural FNPs can assist in health policy transformation by participating in the development and evaluation of innovative care approaches to meet the needs of the diverse community members they serve.

It is also important for FNPs to recognize that although they work within a health care system dominated by Western medical ideals, they can contribute to new normative expectations within this paradigm (Goldsteen et al., 2006). In doing so, rural FNPs play an important role in social transformation and political activism as a form of advocacy, empowerment, and societal altruism (CNA, 2010; Roy & Jones, 2007). Rural FNPs may also choose to become involved in organizational policy, procedure, and guideline development groups; participate in primary and secondary research to identify clinical and organizational EOL needs; or seek out opportunities to collaborate with administrators toward wider organizational change supportive of holistic and person-focused quality EOL care for all.

CHAPTER FIVE

Conclusion

This integrative literature review of good death research sought out to identify influences that shape good death ideals and specific elements necessary for supporting a good death, specifically with those choosing to die within their rural home communities. A key message was the diversity of perspectives and subjective characterizations of what constitutes a good death within and across sociocultural groups. Factors influencing one's beliefs and values about dying and death included philosophical views on life and death, one's sociocultural beliefs about individualism versus collectivism, and one's personal context, including sociocultural normative expectations, geographical context, and illness considerations.

Specific elements contributing to a good death identified in the research literature involved four overarching domains, each with their own overlapping and interconnected attributes, again heavily influenced by each individual's personal and sociocultural context. The first domain was preparation for death, which included a solitary reflective process and time to engage with others around life closure, reconciliation, and generativity activities. For some, preparation also included decision making and arrangements regarding the practicalities of death and posthumous plans for significant others. The second domain focused on sources of support, including family, health care professionals, and community relations. Again, this domain was heavily influenced by sociocultural expectations and varied definitions of what constitutes family. Key themes in the evidence on sources of support included the importance of genuineness, companionship, emotion support, consistency, and understanding of patient preferences.

Communication was the third domain and research highlighted the importance of openness and honesty in building a trusting therapeutic relationship. Communication was also identified as important in supporting caregivers prepare for upcoming EOL experiences by demystifying the dying process, relieving fears, and providing reassurance of ongoing care provision to relieve their loved one's suffering. The final good death domain focused on maintaining QOL through provision of care with the goal of maintaining dignity, respect, and personhood, while also attending to holistic dimensions of wellbeing (psychical, psychological, social, emotional, and spiritual needs). Linked with QOL and maintenance of dignity was supporting a sense of control and choice over as many aspects of EOL as possible.

Given the increasing presence of FNPs in rural primary care settings in BC, it was important to identify the role of FNPs in facilitating a good death for those wishing to remain in their rural home community to die. Based on this project's findings, nine areas of consideration for FNPs role in supporting a good rural death were discussed including: advanced scope of FNP practice; EOL care planning and life expectancy; holistic care; consistency of care provision; multidisciplinary collaboration; effective communication skills; caregiver support and education; continuing competence; and leadership. This discussion focused on the advanced practice scope of FNPs, beyond that of RNs and other health team members who might also be involved in supporting rural EOL care. Working collaboratively with multidisciplinary team members, each maximizing their own professional scope of practice, will help ensure comprehensive, streamlined, consistent, and well-coordinated care in a setting where physical physician and specialist presence is likely to be limited.

Potential Limitations and Future Considerations

The findings of this project may be limited by the numerous surrogate and overlapping terms related to concept of good death (e.g., peaceful, natural, appropriate, desirable, decent, healthy, beautiful, or correct death; dying well; good ending, close, or completion; best death; dignified death; socially approved death; and resigned death) that were not included in the search terms for literature retrieval. It is therefore a risk that key articles informing a good death were inadvertently omitted using the chosen search terms for this project. Likewise, there are other related concepts to a good death, such as quality of life, quality of care, and quality of dying that may have informed FNP practice considerations when facilitating a good death in rural BC. While a manual search of specific palliative care journals in stage two of the search strategy may have provided additional studies to inform rural and EOL care implications for FNPs, time limitations prevented this. Future expansions on this project would likely benefit from such breadth of literature exploration.

This project reviewed studies of varying participant demographics and sample size. While EOL subject matter does not lend well to double blind control studies, clinical trials and population surveys involving larger samples of multiethnic and multigenerational groups may provide additional insights into the contributors to the diversity of good death ideals. As the population continues to age and greater numbers of elders die from chronic progressive disease, it will be important for health care practitioners to recognize how this older age cohort, along with their particular sociocultural and life experiences with dying and death, will impact attitudes and preferences for EOL care. While there are significant ethical considerations for primary research with those at EOL, there is much to be learned about how to support EOL care toward a goal of an individualized good death for all. Future research on generational, ethnic, spirituality, and gender differences would further inform practitioners on contextual factors to consider when asking about good death preferences and the resources necessary to ensure these wishes are met.

A significant portion of reviewed studies included participants with terminal physical illness conditions such as cancer, AIDS, and heart failure. While these conditions characterize common terminal conditions, there was a lack of research involving those with comorbid mental illness. Considering 20 percent of Canadians will experience mental illness in their lifetime, affecting one's cognition, mood, and behaviour (Centre for Addiction and Mental Health, 2012), EOL research involving participants with comorbid mental illness would be informative for additional considerations with this population. Additionally, while this project focused on *patient* preferences for a good death, there is also much to be gleaned from the voices of family members, informal caregivers, community, and cultural groups, along with health care practitioners. It is important to consider the impact of death environments across each of these groups given the intertwined nature of dying and death on all parties involved. Research-based insights are also important for informing future enhancements to health practitioner curriculums, professional development resources, and clinical practice guidelines with the goal of preparing health practitioners to facilitate a good death for all.

While there are currently relatively few non-Aboriginal visible minority groups in rural BC, immigrant and minority migration patterns are changing such that greater numbers of immigrants and ethnically mixed families are relocating to rural communities. Findings from this project that highlight good death considerations for minority groups may prove supportive for future rural FNP practice. It may also provide health administrators rationale for improving resource allocation to rural communities for those facing terminal illness and wishing to remain in their rural home community to die.

While it is not expected that each rural FNP will specialize in EOL care, it is this practitioner's hope that findings of this project provide insight into what patients find most important and supportive in preparing for and experiencing a good death. FNPs combine the best of nursing and medicine in order to provide holistic and comprehensive patient care that honors a multidimensional view of health and wellbeing. The next step is for each rural FNP to consciously consider how prepared the community they work in is to meet the needs of a community members who may wish to die in their rural home community, and what he/she as a community health leader can do to advocate for and organize appropriate care resources to support such a wish.

References

Beyea, S., & Nicoll, L. (1998). Writing an integrative review. *AORN Journal, 67*(4), 877-880. doi:10.1016/S0001-2092(06)62653-7

Borreani, C., & Miccinesi, G. (2008). End of life care preferences. *Current Opinion In Supportive and Palliative Care, 2* (1), 54-59. doi:10.1097/SPC.0b013e3282f4cb27

Brennan Ramirez, L. K., Baker, E. A., Metzler, M. (2008). *Promoting health equity: A resource to help communities address social determinants of health.* Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/nccdphp/dach/chhep/pdf/sdohworkbook.pdf

British Columbia Ministry of Health (BCMOH). (n.d.). *No cardiopulmonary resuscitation.* Medical Services Plan (MSP) forms for medical and health care practitioners. Retrieved from https://www.health.gov.bc.ca/exforms/practitioner.html#3021

British Columbia Ministry of Health (BCMOH). (2010a). *End of Life*. Retrieved from http://www.health.gov.bc.ca/hcc/endoflife.html

British Columbia Ministry of Health (BCMOH). (2010b). *Notification of expected death in the home.* Medical Services Plan (MSP) forms for medical and health care practitioners. Retrieved from https://www.health.gov.bc.ca/exforms/practitioner.html#3021

British Columbia Ministry of Health (BCMOH). (2012a). *My Voice: Expressing my wishes for future health care treatment. Advance care planning guide*. Retrieved from http://www.healthlinkbc.ca/kb/inc/custom/suppressed.asp?r=/kb/content/special/aa114595.html

British Columbia Ministry of Health (BCMOH). (2012b). *BC palliative care benefits program physician guide* (version 2.2). Retrieved from http://www.health.gov.bc.ca/pharmacare/outgoing/palliative-physguide.pdf

British Columbia Ministry of Justice. (2011). *Incapacity planning: Representation agreements and enduring powers of attorney*. Retrieved from www.ag.gov.bc.ca/incapacity-planning

British Columbia Multiculturalism and Immigration Branch. (2008). *The diversity of visible minorities and ethnic origins in BC*. Retrieved from http://www.welcomebc.ca/wbc/immigration/choose/people/multiculturalism.page?

British Columbia Nurse Practitioner Association. (2011). *Frequently Asked Questions about Nurse Practitioners*. Retrieved from http://www.bcnpa.org/_tiny_mce-plugins/filemanager/files/NPs_FAQs.pdf

British Columbia Vital Statistics Agency. (2011). *Selected vital statistics and health indicators:*

Annual report 2010 (139th ed.). Retrieved from http://www.vs.gov.bc.ca/stats/annual/2010/

Bryman, A. (2008). *Social research methods* (3 rd ed.) [electronic chapter]. New York, NY: Oxford University Press. Retrieved from http://www.oup.com/uk/orc/bin/9780199202959/bryman3e_ch04.pdf

Bullock, K., McGraw, S. A., Blank, K., & Bradley, E. H. (2005). What matters to older African Americans facing end-of-life decisions? A focus group study. *Journal of Social Work in End-of-Life & Palliative Care, 1*(3), 3-19. doi: 10.1300/J457v01n03_02

Bushy, A. (2002). International perspectives on rural nursing: Australia, Canada, USA. *Australian Journal of Rural Health, 10*, 104-111. doi:10.1046[sol]j.1038-5282.2002.00457.x.

Byock, I. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine, 12*(2), 237-252. Retrieved from http://www.dyingwell.org/suffopp.htm

Campos, S., Zhang, L., Sinclair, E., Tsao, M., Barnes, E. A., Danjoux, C., … Chow, E. (2009). The palliative performance scale: Examining its inter-rater reliability in an outpatient palliative radiation oncology clinic. *Supportive Care in Cancer: Official Journal of The Multinational Association of Supportive Care in Cancer, 17*(6), 685-90. doi:10.1007/s00520-008-0524-z

Canadian Association for Rural & Remote Nursing. (2008). *Rural and remote nursing practice parameters discussion document*. Retrieved from http://www.carrn.com

Canadian Cancer Research Alliance. (2011). *Investment in research on survivorship and palliative and end-of-life care, 2005–2008: A special report from the Canadian Cancer Research Alliance's survey of government voluntary sector investment in cancer research*. Toronto, ON: CCRA. Retrieved from http://www.ccra-acrc.ca

Canadian Hospice Palliative Care Association. (2012). *News release: National Ipsos-Reid poll indicates majority of Canadians haven't talked about their wishes for care*. Retrieved from http://www.advancecareplanning.ca/news-room

Canadian Nurses Association. (2008). *Code of ethics for registered nurses.* Retrieved from http://www2.cna-aiic.ca/cna/practice/ethics/code/default_e.aspx

Canadian Nurses Association. (2009). *Position statement: The nurse practitioner*. Retrieved from http://www.cna-aiic.ca/

Canadian Nurses Association. (2010). *Canadian nurse practitioner core competency framework.* Retrieved from http://www.cna-nurses.ca/

Canadian Virtual Hospice. (2012). *For professionals*. Retrieved from www.virtualhospice.ca

Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. The Senate of Canada. Retrieved from http://www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf

Castleden, H., Crooks, V. A., Morgan, V. S., Schuurman, N., Hanlon, N., & Inter Tribal Health Authority. (2009). *Dialogues on Aboriginal-focused hospice palliative care in rural and remote British Columbia, Canada*. School for Resource and Environmental Studies Dalhousie University. Retrieved from http://www.virtualhospice.ca

Centre for Addiction and Mental Health. (2012). *Mental health and addiction statistics*. Retrieved from http://www.camh.ca/en/hospital/about_camh/newsroom/for_reporters/Pages/addictionmentalhealthstatistics.aspx

Clayton, J. M., Hancock, K. M., Butow, P. N., Tattersall, M. H. N., & Currow, D. C. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia, 186*(12), S76-S108. Retrieved from https://www.mja.com.au/

College of Physicians and Surgeons of British Columbia. (2009). *Professional standards and guidelines: Medical certificate of death*. Retrieved from http://www.cpsbc.ca/files/u6/Medical-Certificate-of-Death.pdf

College of Registered Nurses of British Columbia. (2007). *A regulatory framework for nurse practitioners in British Columbia*. Retrieved from https://www.crnbc.ca/Registration/Lists/RegistrationResources/NPRegulatoryFramework.pdf

College of Registered Nurses of British Columbia. (2010a). *Nurse Practitioner streams of practice*. Retrieved from https://www.crnbc.c/Registration/Lists/RegistrationResources/680StreamsofNPPractice.pdf

College of Registered Nurses of British Columbia (CRNBC). (2010b). *Competencies required for nurse practitioners in British Columbia*. Retrieved from https://www.crnbc.ca

College of Registered Nurses of British Columbia (CRNBC). (2012a). *Applying the competencies required for nurse practitioners in British Columbia*. Retrieved from https://www.crnbc.ca

College of Registered Nurses of British Columbia (CRNBC). (2012b). *Scope of Practice for Nurse Practitioners (Family): Standards, Limits and Conditions*. Retrieved from https://www.crnbc.ca

College of Registered Nurses of British Columbia (CRNBC). (2013). *Legislation relevant to nurses' practice*. Retrieved from https://www.crnbc.ca

Crooks, V. A., Castleden, H., Schuurman, N., & Hanlon, N. (2009). Visioning for secondary palliative care service hubs in rural communities: A qualitative case study from British

Columbia's interior. *BMC Palliative Care, 8*(15), 1-11. doi:10.1186/1472-684X-8-15

De Jong, J. D., & Clarke, L. E. (2009). What is a good death? Stories from palliative care. *Journal of Palliative Care, 25* (1), 61-67. Retrieved from http://www.criugm.qc.ca /journalofpalliativecare/

DesMeules, M., Pong, R., Lagacé, C., Heng, D., Manuel, D., Pitblado,… Koren, I. (2006). *How healthy are rural Canadians? An assessment of their health status and health determinants*. Ottawa, ON: Canadian Institute for Health Information. Retrieved from http://www.phac-aspc.gc.ca/publicat/rural06/pdf/rural_canadians_2006_report_e.pdf

Donovan, R., & Williams, A. (2012). Shifting the burden: The effects of home-based palliative care on family caregivers in rural areas. In J. C. Kulig & A. M. Williams (Eds.) *Health in rural Canada,* (pp. 316-333). Vancouver, BC: UBC Press.

Downing, J., & Jack, B. A. (2012). End-of-life care in rural areas: what is different? *Current Opinion in Supportive and Palliative Care, 6*(3), 391-397. doi:10.1097/SPC.0b013e 328356ab1f

Evans, R., Stone, D., & Elwyn, G. (2003). Organizing palliative care for rural populations: A systematic review of the evidence. *Family Practice, 20*(3), 304-310. doi:10.1093/fampra /cmg312

Goldsteen, M., Houtepen, R., Proot, I. M., Abu-Saad, H. H., Spreeuwenberg, C., Widdershoven, G. (2006). What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Education & Counseling, 64* (1-3), 378-386. doi:10.1016/j.pec2006.04.008

Gott, M., Small, N., Barnes, S., Payne, S., & Seamark, D. (2008). Older people's views of a good death in heart failure: Implications for palliative care provision. *Social Science & Medicine, 67* (7), 1113-1121. doi:10.1016/j.socscimed.2008.05.024

Hattori, K., McCubbin, M. A., & Ishida, D. N. (2006). Concept analysis of good death in the Japanese community. *Journal of Nursing Scholarship, 38* (2), 165-170. doi:10.1111/j.1547-5069.2006.00095.x

Hauser, J. M., Chang, C., Alpert, H., Baldwin, D., Emanuel, E. J., & Emanuel, L. (2006). Who's caring for whom? Differing perspectives between seriously ill patients and their family caregivers. *American Journal of Hospice and Palliative Medicine, 23*(2), 108-112. doi: 10.1177/104990910602300207

Health Canada. (2009). *Palliative and end-of-life care*. Retrieved from http://www.hc-sc.gc.ca /hcs-sss/palliat/index-eng.php

Health Canada. (2012a). *Health care system: About primary health care.* Retrieved from http://www.hc-sc.gc.ca/hcs-sss/prim/about-apropos-eng.php

Health Canada. (2012b). *Factsheet: New classes of medical practitioners regulations*. Retrieved from http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2012/2012-71bk-eng.php

Health Care (Consent) and Care Facility (Admission) Act. (RSBC 1996). Chapter 181. Retrieved from www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96181_01

Hendrickson, K., & McCorkle, R. (2008). A dimensional analysis of the concept: Good death of a child with cancer. *Journal of Pediatric Oncology Nursing, 25*(3), 127-138 doi: 10.1177/1043454208317237

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., & Lam, M. for the Canadian Researchers, End-of-Life Network (CARENET). (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal, 174*(5), 627-633. doi:10.1503/cmaj.050626

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., Jiang, X., Day, A. G., & Cohen, R. for the Canadian Researchers at the End of Life Network. (2010). Defining priorities for improving end-of-life care in Canada. *Canadian Medical Association Journal, 182*(16), E747-E752. doi: 10.1503/cmaj.100131

Hirai, K., Miyashita, M., Morita, T., Sanjo, M., & Uchitomi, Y. (2006). Good death in Japanese cancer care: A qualitative study. *Journal of Pain and Symptom Management, 31*(2), 140-147. doi: 10.1016/j.jpainsymman.2005.06.012

Hughes, T., Schumacher, M., Jacobs-Lawson, J. M., & Arnold, S. (2008). Confronting death: Perceptions of a good death in adults with lung cancer. *The American Journal of Hospice & Palliative Care, 25*(1), 39-44. doi: 10.1177/1049909107307377

Jacques, N. D., & Hasselkus, B. R. (2004). The nature of occupation surrounding dying and death. *OTJR: Occupation, Participation & Health, 24*(2), 44-53. Retrieved from http://www.slackjournals.com/otjr

Jordan, M. (2012, February 17). More marriages cross race, ethnic lines. *The Wall Street Journal*. Retrieved from http://online.wsj.com/article /SB10001424052970204880404577226981780914906.html?mod=rss_US_News

Kehl, K. A. (2006). Moving toward peace: An analysis of the concept of a good death. *American Journal of Hospice & Palliative Medicine, 23*(4), 277-286. doi: 10.1177/ 1049909106290380

Kelley, M. L., Sletmoen, W., Williams, A. M., Nadin, S., & Puiras, T. (2012). Integrating policy, research, and community development: A case study of developing rural palliative care. In J. C. Kulig & A. M. Williams (Eds.) *Health in rural Canada,* (pp. 219-238). Vancouver, BC: UBC Press.

Kelly, L., & Minty, A. (2007). End-of-life issues for aboriginal patients. *Canadian Family*

Physician, 53, 1459-1465. Retrieved from http://www.cfp.ca/

Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *Journal of the Royal Society of Medicine, 96*(3), 118-121.

Kools, S., McCarthy, M., Durham, R., & Robrecht, L. (1996). Dimensional analysis: Broadening the conception of grounded theory. *Qualitative Health Research, 6*(3), 312-330. doi: 10.1177/104973239600600302

Kulig, J. C., Andrews, M. E., Stewart, N. J., Pitblado, R., MacLeod, M. L. P., Bentham, D., D'Arcy, C., Morgan, D., Forbes, D., Remus, G., & Smith, B. (2008). How do registered nurses define rurality? *Australian Journal of Rural Health, 16*(1), 28-32. doi:10.1111 /j.1440-1584.2007.00947.x

Kulig, J. C., & Williams, A. M. (2011). *Health in rural Canada*. Vancouver, BC: UBC Press.

Kuropatwa, R. (2008). *Health care use at the end of life in British Columbia.* Canadian Institute for Health Information. Retrieved from http://secure.cihi.ca/cihiweb/en/downloads/EOL _Report_BC.pdf

Lau, F., Downing, M., Lesperance, M., Karlson, N., Kuziemsky, C., Yang, J. (2009). Using the Palliative Performance Scale to provide meaningful survival estimates. *Journal of Pain and Symptom Management, 38*(1),134-44. doi:10.1016/j.jpainsymman.2009.08.003

Leung, K. K., Liu, W. J., Cheng, S. Y., Chiu, T. Y., & Chen, C. Y. (2009). What do laypersons consider a good death? *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer, 17*(6), 691-699. doi: 10.1007/s00520-008 -0530-1

MacLeod, M. L. P., Misener, R. M., Banks, K., Morton, A. M., Vogt, C., & Bentham, D. (2008). "I'm a different kind of nurse": Advice from nurses in rural and remote Canada. *Canadian Journal of Nursing Leadership, 21*(3), 40-53. Retrieved from http://www.longwoods.com/publications/nursing-leadership

Markert, J. (2004). Demographics of age: Generational and cohort confusion. *Journal of Current Issues and Research in Advertising, 26* (2), 11-25. doi:10.1080/10641734.2004.10505161

Marshall, D., Howell, D., Brazil, K., Howard, M., & Taniguchi, A. (2008). Enhancing family physician capacity to deliver quality palliative home care: An end-of-life, shared-care model. *Canadian Family Physician, 54*(12), 1703-1703.e7. Retrieved from http://www.cfp.ca/

Masson, J. D. (2002). Non-professional perceptions of 'good death': A study of the views of hospice care patient and relatives of deceased hospice care patients. *Mortality, 7*(2), 191-209. doi:10.1080/13576270220136294

Matsui, M., & Braun, K. L. (2009). Japanese Americans' death attitudes and preferences for end-of-life care. *Journal of Hospice & Palliative Nursing, 11*(6), 353-361. doi:10.1097/NJH .0b013e3181bd03f1

McGillivray, B. (2005). *Geography of British Columbia: people and landscapes in transition* [electronic version] (2nd ed.). Vancouver, BC: UBC Press. Retrieved from http://www.ubcpres.ca/books/pdf/chapters/mcgillvray.pdf

McGrath, P. (2007). 'I don't want to be in that big city; this is my country here': Research findings on Aboriginal peoples' preference to die at home. *Australian Journal of Rural Health, 15*(4), 264-268. Retrieved from http://ca.wiley.com/WileyCDA/WileyTitle /productCd-AJR.html

Melvin, T. A. (2001). The primary care physician and palliative care. *Primary Care: Clinics in Office Practice, 28*(2), 239-249. Retrieved from http://www.sciencedirect.com/science /journal/00954543

Minore, B., Hill, M. E., Pugliese, I., & Gauld, T. (2008). *Rurality literature review.* Centre for Rural and Northern Health Research, Lakehead University. Retrieved from http://www.cranhr.ca

Misener, R. M., MacLeod, M. L. P., Banks, K., Morton, A. M., Vogt, C., & Bentham, D. (2008). "There's rural, and then there's rural": Advice from nurses providing primary healthcare in northern remote communities. *Canadian Journal of Nursing Leadership, 21*(3), p. 54-63. Retrieved from http://www.longwoods.com/publications/nursing-leadership

Miyashita, M., Sanjo, M., Morita, T., Hirai, K., & Uchitomi, Y. (2007). Good death in cancer care: A nationwide quantitative study – Japan. *Annals of Oncology: Official Journal of the European Society for Medical Oncology, 18*(6), 1090-1097. doi:10.1093/annonc/ mdm068

Mjelde-Mossey, L. A., & Chan, C. L. (2007). Survey on death and dying in Hong Kong: Attitudes, beliefs, and preferred end-of-life care. *Social Work in Health Care, 45*(1), 49-65. doi: 10.1300/J010v45n01_04

Moss, S. (2010). *Generational cohort theory.* Retrieved from http://www.psych-it.com.au

Old, J. L., & Swagerty, D. L. (2007). *A practical guide to palliative care.* Philadelphia, PA: Lippincott Williams & Wilkins.

O'Neil, D. (2007). *Census fast facts: Ageing of British Columbia population.* BC Stats, Branch of Service BC, Ministry of Labour and Citizens' Services. Retrieved from http://www.bcstats.gov.bc.ca

Palliative Care Australia. (2008). *Palliative and end of life care glossary.* Retrieved from http://www.palliativecare.org.au/Portals/46/PCA%20glossary.pdf

Pierson, C. M., Curtis, J. R., & Patrick, D. L. (2002). A good death: A qualitative study of patients with advanced AIDS. *AIDS Care, 14*(5), 587-598. Retrieved from http://www.tandf.co.uk/journals/titles/09540121.asp

Pitblado, J. R. (2005). So, what do we mean by “rural,” ”remote,” and “northern”? *Canadian Journal of Nursing Research, 37*(1), 163-168. Retrieved from http://cjnr.mcgill.ca/

Pong, R., Pitblado, R. (2005). *Geographic distribution of physicians in Canada: Beyond how many and where*. Ottawa (ON): The Canadian Institute for Health Information. Retrieved from https://secure.cihi.ca/free_products/Geographic_Distribution_of_Physicians_FINAL_e.pdf

Province of British Columbia. (2011). *BC funds more nurse practitioner positions*. Newsroom: BC Government Online News Source. Retrieved from http://www.newsroom.gov.bc.ca/2012/05/bc-funds-more-nurse-practitioner-positions.html

Province of British Columbia, Guidelines and Protocols Advisory Committee. (2010). *Palliative care for the patient with incurable cancer or advanced disease - Part 1: Approach to care.* Retrieved from http://www.bcguidelines.ca

Province of British Columbia, Guidelines and Protocols Advisory Committee. (2011a). *Palliative care for the patient with incurable cancer or advanced disease - Part 2: Pain and symptom management.* Retrieved from http://www.bcguidelines.ca

Province of British Columbia, Guidelines and Protocols Advisory Committee. (2011b). *Palliative care for the patient with incurable cancer or advanced disease - Part 3: Grief and bereavement.* Retrieved from http://www.bcguidelines.ca

Rietjens, J. A., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2006). Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliative Medicine, 20*(7), 685-692. doi: 10.1177/0269216306070241

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), 253-258. doi:10.1089=jpm.2008.0228

Romanow, R. J. (2002). *Building on values: The future of health care in Canada – final report.* Commission on the Future of Health Care in Canada. Retrieved from http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf

Roots, A. (2011). *Nurse Practitioners in BC: Update on positions and roles*. Retrieved from www.bcnpa.org

Roy, C., & Jones, D. A. (Eds). (2007). *Nursing knowledge development and clinical practice* [electronic text]. New York, NY: Springer Publishing Company.

SAFE Aging, Inc. (2003). *Glossary: Personal context*. Retrieved from http://www.safeaging

.com/index.htm

Salmond, S. W. (2007). Advancing evidence-based practice: A primer. *Orthopaedic Nursing, 26*(2), 114-125. Retrieved from http://journals.lww.com/orthopaedicnursing/pages /default.aspx

Service Canada. (2012). *Employment insurance compassionate care benefits*. Retrieved from http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Definition

Shipman, C., Gysels, M., White, P., Worth, A., Murray, S. A., Barclay, S., … Higginson, I. J. (2008). Improving generalist end of life care: National consultation with practitioners, commissioners, academics, and service user groups. *British Medical Journal, 337*, 848-862. doi: 10.1136/bjm.a1720

Smith-Stoner, M. (2007). End-of-life preferences for atheists. *Journal of Palliative Medicine, 10*(4), 923-928. doi:10.1089/jpm.2006.0197

Statistics Canada. (2005). *Population by religion, by province and territory (2001 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/ demo30c-eng.htm

Statistics Canada. (2007a). *Population by mother tongue, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/101 /pro01/pro110-eng.htm

Statistics Canada. (2007b). *A portrait of seniors in Canada*. Retrieved from http://www.statcan .gc.ca/pub/89-519-x/89-519-x2006001-eng.htm

Statistics Canada. (2009a). *Population, urban and rural, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/101/pro01/pro110 -eng.htm

Statistics Canada. (2009b). *Visible minority population, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/101/pro01/pro110 -eng.htm

Statistics Canada. (2009c). *Population by selected ethnic origins, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaus/sum-som/101 /pro01/pro110-eng.htm

Statistics Canada. (2009d). *Aboriginal identity population, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/101/pro01 /pro110-eng.htm

Statistics Canada. (2009e). *Population by home language, by province and territory (2006 census).* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/101/pro01

/pro110-eng.htm

Statistics Canada. (2010, September 29). *The daily*. Retrieved from http://www.statcan.gc.ca daily-quotidien/100929/dq100929-end.pdf

Statistics Canada. (2011). *Population by sex and age group, by province and territory*. Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo31a-eng.htm

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000a). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association, 284*(19), 2476-2482. doi:10.1001/jama.284.19.2476

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000b). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine,* 132(10), 825-832. Retrieved from http://www.annals.org/

Stetler, C. B., Brunell, M., Giuliano, K. K., Morsi, D., Prince, L., & Newell-Stokes, V. (1998). Evidence-based practice and the role of nursing leadership. *The Journal of Nursing Administration, 28*(7/8), 45-53. Retrieved from http://journals.lww.com/jonajournal /pages/default.aspx

Tang, S. T. (2003). When death is imminent: Where terminally ill patients with cancer prefer to die and why. *Cancer Nursing, 26*(3), 245-251. Retrieved from http://journals.lww.com /cancernursingonline/pages/default.aspx

Tayeb, M. A., Al-Zamel, E., Fareed, M. M., Abouellail, H. A. (2010). A "good death": Perspectives of Muslim patients and health care providers. *Annals of Saudi Medicine, 30*(3), 215-221. doi: 10.4103/0256-4947.62836

Terry, W., Olson, L. G., Wilss, L., & Boulton-Lewis, G. (2006). Experience of dying: Concerns of dying patients and of carers. *Internal Medicine Journal, 36*(6), 338–346. doi:10.1111 /j.1445-5994.2006.01063.x

Thomas, C., Morris, S. M., & Clark, D. (2004). Place of death: Preferences among cancer patients and their carers. *Social Science & Medicine, 58*, 2431-2444. doi:10.1016 /j.socscimed.2003.09.005

Tong, E., McGraw, S. A., Dobihal, E., Baggish, R., Cherlin, E., & Bradley, E. H. (2003). What is a good death? Minority and non-minority perspectives. *Journal of Palliative Care, 19*(3), 168-175. Retrieved from http://www.criugm.qc.ca/journalofpalliativecare/

Torraco, R. J. (2005). Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review, 4*(3), 356-367. doi: 10.1177/1534484305278283

Toscani, F., Borreani, C., Boeri, P., Miccinesi, G. (2003). Life at the end of life: Beliefs about individual life after death and "good death" models – a qualitative study. *Health and*

Quality of Life Outcomes,1, 65. doi:10.1186/1477-7525-1-65

Tracey, M. F. (2009). Direct clinical practice. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed.) (pp. 123-158). St. Louis, MO: Saunders Elsevier.

Trochim, W. M. K. (2006). *Research methods knowledge base: Qualitative approaches*. Retrieved from http://www.socialresearchmethods.net/kb/qualapp.php

University of British Columbia. (2012). *Community & service: 3 day module on palliative/end of life care*. Retrieved from http://palliativecare.med.ubc.ca/community-service/

University of Saskatchewan College of Medicine. (2011). *Definition of primary health care*. Primary Health Care Research Group. Retrieved from http://www.medicine.usask.ca /research/health-research-groups/primary-health-care-research-group-1/definition-of -primary-health-care/index.html

University of Toronto & University of Ottawa. (2000). *A guide to end-of-life care for seniors*. Retrieved from http://rgp.toronto.on.ca/PDFfiles/eol-english.pdf

Veillette, A., Fillion, L., Wilson, D. M., Thomas, R., & Dumont, S. (2010). La belle mort en milieu rural: A report of an ethnographic study of the good death for Quebec rural francophones. *Journal of Palliative Care, 26*(3), 159-66. Retrieved from http://www.criugm.qc.ca/journalofpalliativecare/

Victoria Hospice Society. (2006). *Victoria Hospice Palliative Performance Scale version 2 (PPSv2)*. Retrieved from http://www.victoriahospice.org/health-professionals/clinical -tools

Victoria Hospice Society. (2012). *Health professionals*. Retrieved from www.victoriahospice.org

Vig, E. K., Davenport, N. A., & Pearlman, R. A. (2002). Good deaths, bad deaths, and preferences for the end of life: A qualitative study of geriatric outpatients. *Journal of the American Geriatrics Society, 50*(9), 1541-1548. Retrieved from http://onlinelibrary.wiley .com/journal/10.111/(ISSN)1532-5415

Vig, E. K., & Pearlman, R. A. (2004). Good and bad dying from the perspective of terminally ill men. *Archives of Internal Medicine, 164*(9), 977-981. Retrieved from http://archinte.ama -assn.org/

Vining Radomski, M. (2007). Assessing context: Personal, social, and cultural. In M. Vining Kadomski & C. A. Trombley (Eds.), *Occupational therapy for physical dysfunction* (6th ed) (pp. 284-309). Baltimore, MD: Lippincott Williams & Wilkins.

Wakerman, J. (2004). Defining remote health. *Australian Journal of Rural Health, 12*(5), 210-214. doi:10.1111/j.1440-1854.2004.00607.x

Weiland, S. A. (2008). Reflections on independence in nurse practitioner practice. *Journal of the American Academy of Nurse Practitioners, 20*(7), 345-352.

Whittemore, R., & Knafl, K. (2005). The integrative review: Update methodology. *Journal of Advanced Nursing,* 52(5), 546-553. doi:10.1111/j.1365-2648.2005.03621.x

Williams, A., & Cutchin, M. (2002). The rural context of health care provision. *Journal of Interprofessional Care, 16*(2), 107-115. doi:10.1080/13561820220124120

Wilson, D. M., Fillion, L., Thomas, R., Justice, C., Bhardwaj, P. P., & Veillette, A. (2009a). The "good" rural death: A report of an ethnographic study in Alberta, Canada. *Journal of Palliative Care, 25*(1), 21-9. Retrieved from http://www.criugm.qc.ca/ journalofpalliativecare/

Wilson, D. M., Fillion, L., Thomas, R., Justice, C., Veillette, A. M., & Bhardwaj, P. (2009b). Planning and providing for a good death using French-Canadian and English-Canadian insights. *Reviews in the Neurosciences, 20*(3-4), 313-320. doi:10.1212/REVNEURO .2009.20.3-4.312

Wilson, D. M., Truman, C. D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, K., & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine, 68(10)*, 1752-1758. doi:10.1016/j.socscimed.2009.03.006

World Health Organization. (2012). *WHO definition of palliative care*. Retrieved from http://www.who.int/cancer/palliative/definition/en/

World Health Organization. (1978). *Primary Health Care*. Retrieved from http://whqlibdoc.who .int/publications/9241800011.pdf

Zerwekh, J. V. (1997). The practice of presencing. *Seminars in Oncology Nursing, 13*(4), 260-262. Retrieved from http://www.journals.elsevierhealth.com/periodicals/ysonu

Appendix A: Table of Evidence

The following table of evidence uses Levels 1-6 to identify type and rigor of completed research as recommended by Salmond (2007) and Stetler et al. (1998). Levels of evidence are outlined as following:

Level 1: Guidelines; Meta-analysis of multiple randomized controlled trials; Systematic literature reviews
Level 2: Individual studies with experimental design; RCTs
Level 3: Quasi-experimental studies; Cohort studies
Level 4: Descriptive non-experimental studies (opinion surveys) or qualitative approach;
Level 5: Case reports or from experience;
Level 6: Opinions of specialists

Author & Date	Location of Study	Level of Evidence	Population	Study Focus	N
Borreani & Miccinesi (2008)	Italy	4 Literature search and review for themes	Medline literature search from October 2006 to October 2007	Literature grouped into categories: (a) EOL preferences in patients with advanced stages of terminal illness; (b) contextual factors influencing preferences; (c) guidelines & tools to support practitioners	21 articles
Bullock et al (2005)	USA	4 Qualitative - Focus groups; NUD-IST 4 support and constant comparative method analysis	Older African American adults	To better understand what matters for African American elders faced with death, dying and EOL care; Part of larger study conducted to improve EOL care in one state	22 adults
De Jong & Clarke (2009)	Canada	4 Qualitative - Individual interviews; narrative approach	3 palliative care patients aged 60-80; Also interviewed primary caregivers (3), physicians (3), nurses (6)	To understand components of good and bad deaths	3 patients
Goldsteen et al (2006)	Netherlands	4 Qualitative - Individual interviews;	Terminally ill patients with life expectancy less than 3 months	To seek insight into how terminally ill patients talk about dying and death;	13 patients

		hermeneutic approach	living at home - patients (13); Also family caregivers (13), professional caregivers (13), bereaved carers (14)	current Western normative expectations about a good death	
Gott et al (2008)	United Kingdom	4 Qualitative - Semi-structured interviews; themed by 2 independent researchers with aid of NUD-IST coding	People with advanced heart failure and poor prognosis, living in own homes - male (21), female (19); median age 77 years	To explore the thoughts about, and concerns for, dying and death	40 patients
Hattori et al (2006)	Japan	1 Literature review; concept analysis using Rogers' evolutionary method	Literature search using 5 academic databases; no time limitation	To clarify the meaning of a good death in the Japanese community	44 articles
Hendrickson & McCorkle (2008)	USA	1 Literature review; dimensional analysis technique	Literature search using 3 academic databases and review of bibliographies	To clarify the dimensions involved in a good death of a child with cancer; examine perspectives of dying child, child's family, and health care providers	43 articles
Heyland et al (2006)	Canada	3 Quantitative – face-to-face questionnaire interviews with patients & family members	Patients with advanced disease greater than 55 years old; Convenience sample at 5 hospitals across Canada	What seriously ill patients in hospital and their family members consider key elements of quality EOL care	434 patients & 160 family members
Hirai et al (2006)	Japan	4 Qualitative - Semi-structured interviews;	Patients with advanced cancer (age 20-80); family members (10), physicians	To identify components of a Japanese good death	13 patients

		content analysis for categories of attributes and concepts; descriptive analysis on frequency of attributes	(20), nurses (20) from regional cancer institutions in Japan		
Hughes et al (2008)	USA	3 Quantitative - Cross-sectional design; individual interviews; content analysis	Adults with primary lung cancer attending a multi-disciplinary treatment clinic	Perceptions of a good death among patients with lung cancer	100 patients
Jacques & Hasselkus (2004)	USA	4 Qualitative – 6 month ethnographic study	Patients in urban residential hospice; patients (5), staff (22), volunteers (3)	To explore the occupation surrounding dying & death at a small residential hospice in the midwestern United States	5 patients
Kehl (2006)	USA	1 Literature review – Rogers' evolutionary method of concept analysis	Literature search using 3 academic databases; 1995-2004; English only; concerning adults (age 18 and older); pertaining to Western culture	Western (North American, European, Australian) perspectives of the concept of a good death	42 articles
Kelly & Minty (2007)	Canada	1 Literature review	Literature search using 4 academic databases; 1966-2005	To understand cross-cultural issues in providing palliative care to Aboriginal patients, especially EOL decision making and treatment	40 articles
Leung et al (2009)	China	4 Quantitative - Survey questionnaire SPSS statistical analysis, Cronbach's	Lay persons – adult age range 20-77; female predominance	To understand laypersons' attitude regarding good death	184 adults

		alpha coefficients, ANOVA			
Masson (2002)	United Kingdom	4 Qualitative - narratives during taped interview or written contribution	Hospice care patients (10) and relatives of individuals who had died in hospice (10)	Explore non-professional perceptions of good death	10 patients
Matsui & Braun (2009)	USA	4 Quantitative – Cross-sectional design; survey questionnaire SPSS, Cronbach's alpha, t-test, Pearson r, Spearman R, ANOVA	Community dwelling Japanese Americans greater than or equal to 60 years of age	To explore death attitudes among Japanese American elders and examine associations between death attitudes and EOL preferences	123 Adults
McGrath (2007)	Australia	4 Qualitative - Phenomenology, iterative, open-ended data collection interviews; thematic analysis with aid of NUD-IST coding	Indigenous patients (10), Indigenous caregivers (19), Indigenous and non-Indigenous health care workers (41), interpreters (2)	To explore and document wishes in relation to place of death for rural and remote Aboriginal people	10 patients
Miyashita et al (2007)	Japan	4 Quantitative - Cross-sectional questionnaire Exploratory factor analysis and Cronbach's alpha coefficients	General population (2548) and bereaved family members (513)	To explore dimensions of a good death in Japanese cancer care; clarify relative importance of each component; explore factors related to an individual's perception of domains of a good death	2548 adults
Mjelde-Mossey & Chan (2007)	China	4 Quantitative - Telephone interview	General public - adults equal or greater than 18 years of age	To explore the attitudes, beliefs, preferences for EOL care, death & dying	430 adults

		survey; SPSS t-test, chi-square test			
Pierson et al (2002)	USA	4 Qualitative – Interviews; grounded theory analysis	Patients with advanced AIDS	Exploration of what constitutes a good versus bad death	35 patients
Rietjens et al (2006)	Netherlands	4 Quantitative - Mailed questionnaire Chi-square tests using SPSS	Dutch general public between ages of 20 & 93 years	To gain insight into the characteristics of a good death for the Dutch general population	1388 adults
Smith-Stoner (2007)	USA	4 Quantitative and Qualitative Online/paper survey of open-ended & closed questions; content analysis, descriptive statistics and thematic coding	Atheists ages 18 years and up; had been atheists for at least 10 years	Explore EOL preferences among Atheists and apply threefold model of spiritual care to assess appropriateness of potential interventions	88 adults
Steinhauser et al (2000a)	USA	4 Quantitative - Cross-sectional stratified random national survey questionnaire Chi-square tests, Fisher exact tests of independence, Friedman tests, Wilcoxon tests, multivariate exploratory analysis, logic regression	Patients from Veterans affairs and treatment database with advanced chronic illness - seriously ill patients (340); recently bereaved family (332); physicians (361); non-physician care providers (429)	To determine the factors considered important at EOL by patients, their families, physicians, and other care providers	340 patients
Steinhauser	USA	4	Full spectrum	To gather descriptions	17 patients

(2000b)		Qualitative - Focus groups & in-depth interviews; grounded theory approach with aid of NUD-IST coding	persons involved in EOL care stratified by role & randomly sampled from possible participants – Oncology & HIV patients (17); Nurses (30); social workers (12); Chaplains (7); hospice volunteers (8); physicians (7); bereaved family members (5)	of the components of a good death from patients, families, and providers	
Tang (2003)	USA	4 Qualitative - Semi-structured interviews; exploratory and descriptive study	Terminally ill patients with cancer recruited from four tertiary care hospitals and two home care programs in Conneticut	To explore the preferences for the place of death among terminally ill patients with cancer, to identify the reasons for selecting a preferred place of death, and to examine the importance of dying at one's preferred place of death	180 patients
Tayeb et al (2010)	Saudi Arabia	4 Quantitative & Qualitative - Questionnaire and interviews and focus groups; Content analysis for interviews and focus groups; univariate descriptive statistics for questionnaire	Muslims aged 18-71 years; recruited by random sampling from one military hospital (oncology, hematology, palliative care) and one rehabilitation center, and one long-stay nursing unit	To review the TFHCOP good death perception to determine its validity for Muslim patients and health care providers; to identify and describe other components of the Muslim good death perspective	26 adults
Terry et al (2006)	Australia	4 Qualitative -	Hospice patients with advanced	To describe the concerns of dying	36 patients

		Patient interviews; constant comparative analysis	malignant disease aged 44-92 years (36); carers of deceased patients of the palliative care service (18)	patients about the problems they would face as death approached	
Thomas et al (2004)	United Kingdom	4 Qualitative – Interviews; grounded theory approach with aid of Atlas.ti analysis programme coding	Terminally ill patients with cancer with estimated 3 months of life remaining (41) and informal carers (18) living in Morecambe Bay area of north-west England	To examine preferences for place of death	41 patients
Tong et al (2003)	USA	4 Qualitative - Focus groups; independent and then joint sessions of coding using QRS NUD-IST software; constant comparative analysis	Community dwelling population of minority and non-minority individuals	To identify common domains that characterize a good death in a diverse range of community-dwelling individuals; describe differences that might exist between minority and non-minority individuals' views	95 subjects
Toscani et al (2003)	Italy	4 Qualitative - Semi-structured interviews; individual and group analysis	Believers (4) and non-believers (4) from the general Italian population	To identify the influence of believing in individual life after death on good death models	8 adults
Veillette et al (2010)	Canada	4 Qualitative - Ethnography inclusive of interviews and focus groups; constant comparative analysis	Two rural communities in Quebec; one close and one some distance from Quebec City; people having experience with death and dying in rural community;	To explore what constitutes a good death from persons living in rural Quebec	46 Individuals

			staff at health and non-governmental organizations, local health care providers and policy-makers		
Vig et al (2002)	USA	4 Qualitative - Interviews using open and close-ended questions; constant comparative analysis	Geriatric outpatients with non-terminal heart disease or cancer	To explore the attitudes of older adults with medical illness about EOL and if EOL preferences could be inferred from current values	16 patients
Vig & Pearlman (2004)	USA	4 Qualitative - Interviews; grounded theory methods	Adult men terminally ill with heart disease or cancer	To learn how terminally ill men conceptualize good and bad deaths	26 patients
Wilson, … Veillette (2009)	Canada	4 Qualitative - Ethnography; participant observation, formal interviews and focus groups; constant comparative analysis	Two rural communities in Alberta; broad selection of participants	To establish a conceptual understanding of the good death from a rural-Canadian perspective	34 participants
Wilson, … Bhardwaj (2009)	Canada	4 Qualitative - Ethnography	Document analysis within rural Alberta and rural Quebec	To explore and define the good death; to develop a baseline understanding about death and dying in rural communities that were close or distant from large cities in Alberta and Quebec; to help select two rural communities in Alberta and two communities in Quebec for focus groups	Not defined

Appendix B: Stage One Search Results

Terms	Academic Search Premier	CINAHL with Full Text	Medline with Full Text	HealthSource: Nursing/Academic Edition	PsycINFO	Cochrane Collaboration	Google Scholar	Hand Search “Social Science & Medicine”	Hand Search “journal of rural health” (potential)	Hand Search “Canadian Family Physician” (potential)	Hand Search “Nurse Practitioner”
“good death”	368	272	280	177	203	0	433	54	0	5 (1)	0
“good death” **NOT** euthanasia	332	251	227	164	194	0	405	52	n/a	n/a	n/a
“good death” **AND** wishes	5	10	10	3	11	0	1	34	n/a	n/a	n/a
“good death” **AND** wishes **NOT** euthanasia	5	10	8	3	11	0	1	32	n/a	n/a	n/a
“good death” **AND** preferences	21	15	15	10	16	0	2	21	n/a	n/a	n/a

“good death” **AND** preferences **NOT** euthanasia	19	14	11	9	16	0	2	20	n/a	n/a	n/a
“terminal illness” **AND** preferences	30	29	38	14	36	1	4	48	3 (1)	2	0
“terminal illness” **AND** wishes	12	11	16	6	16	0	1	26	3 (1)	1	0
End-of-life **AND** wishes	264	228	311	108	187	3	32	846	11	10	3
End-of-life **AND** wishes **NOT** euthanasia	238	209	238	103	180	0	32	n/a	n/a	8	n/a
End-of-life **AND** preferences	491	377	531	214	373	4	163	352	5	15	3
end-of-life **AND** preferences **NOT** euthanasia	472	357	432	208	366	0	163	n/a	n/a	12	n/a
Death **AND** preferences	882	305	567	222	514	0	51	5	29	24	0

NOT euthanasia										
Death **AND** wishes **NOT** euthanasia	294	159	249	108	226	0	23	7	39 (1)	1	0
Terminal care **AND** preferences	303	287	444	123	80	0	2	27	1	5	0
Terminal care **AND** preferences **NOT** euthanasia	289	265	325	120	78	0	2	23	n/a	4	n/a
Terminal care **AND** wishes	150	179	259	68	41	0	1	19	2	3	0
Terminal care **AND** wishes **NOT** euthanasia	136	154	189	67	39	0	1	16	n/a	3	n/a
Death and dying **AND** preferences **NOT** euthanasia	190	91	107	57	246	0	0	38	1	2	1
Death and dying **AND** wishes	88	39	50	28	119	0	0	46	1	1	1

NOT euthanasia											

Appendix C: Manual Journal Search Results

Terms	Social Science & Medicine	Journal of Rural Health (potential for review)	Canadian Family Physician (potential for review)	Nurse Practitioner
"good death"	54	0	5 (1)	0
"good death" NOT euthanasia	52	n/a	n/a	n/a
"good death" AND wishes	34	n/a	n/a	n/a
"good death" AND wishes NOT euthanasia	32	n/a	n/a	n/a
"good death" AND preferences	21	n/a	n/a	n/a
"good death" AND preferences NOT euthanasia	20	n/a	n/a	n/a
"terminal illness" AND preferences	48	3 (1)	2	0
"terminal illness" AND wishes	26	3 (1)	1	0
End-of-life AND wishes	846	11	10	3
End-of-life AND wishes NOT euthanasia	n/a	n/a	8	n/a
End-of-life AND preferences	352	5	15	3
end-of-life AND preferences NOT euthanasia	n/a	n/a	12	n/a
Death AND preferences NOT euthanasia	5	29	24	0
Death AND wishes NOT euthanasia	7	39 (1)	1	0
Terminal care AND preferences	27	1	5	0
Terminal care AND preferences NOT euthanasia	23	n/a	4	n/a
Terminal care AND wishes	19	2	3	0
Terminal care AND wishes NOT euthanasia	16	n/a	3	n/a
Death and dying AND preferences NOT euthanasia	38	1	2	1
Death and dying AND wishes NOT euthanasia	46	1	1	1