Abstract

This descriptive phenomenological research study invited Registered Nurses to describe their perceptions and insights of the experience of spirituality in palliative home care. Semi-structured interviews with guided questions were the means by which these eight clinically experienced palliative care nurses described the essence of spirituality in palliative home care. Colaizzi's (1978) method of phenomenological data analysis was used to identify the structure or essence of spirituality in this practice environment. The three major themes that emerged from this research study: spirituality and health, nurses engagement in relational practice and holistic care of the dying demonstrate the importance of being attentive to one's own spiritual health and wellbeing in the holistic care of the dying. This study offers suggestions for palliative care nursing practice, education and research and uncovers the importance of providing opportunities for nurses reflective practice in regard to spirituality and health as well as the importance of attending to one's own spiritual health through personal reflection.
Acknowledgements

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Also, I want to express sincere appreciation to my thesis advisory committee, Dr. Carol Ewashen and Dr. Shane Sinclair, for their invaluable contribution to the creation of this thesis through their gifts of time, words of wisdom and insightful comments they have shared with me.

To the eight Registered Nurses in palliative home care who participated in this descriptive phenomenological research study in the midst of health care restructuring and the worst flood ever experienced in Calgary's history, words cannot express my heartfelt gratitude for sharing your stories, insights and practical wisdom you have gained along the way in your experience as health care professionals.

Finally, to the countless individuals and families who are anonymously represented in the stories that nurses shared with me during the interviews, infinite thanks for allowing us as Registered Nurses into your homes and lives and for the opportunity to walk beside you in that final journey home.
Dedication

First and foremost I want to express my undying love and gratitude to my Lord and Savior Jesus Christ for sustaining me through this research project and for helping me to fulfill my lifelong dream of becoming a writer. You are the dream maker, the hope creator, and my beautiful, beautiful friend.

I am also deeply grateful to all my sisters who were my earliest teachers and mentors in life. Lois, you were the first nurse to ever take care of me and you have been my role model ever since. Dianne, you taught me a lot about love, compassion and caring. Barb, thank you for taking me everywhere with you when I was younger and for stirring up a love of creativity in my life. Nancy thank you for taking such good care of Mom and Dad while they were alive and for all the sacrifices you made in your life. Thanks for teaching me how to ride horses, laugh at life, and to fight for what I believe in. Margie thank you so much for encouraging me to pursue my Master of Nursing Degree, for your many words of wisdom and the many prayers you have sent up to the throne room of heaven on my behalf over the years. You are more than a sister - you are my spiritual mother and best friend. An extra-special thank you to my niece Angela for your gift of friendship and for being my guardian angel in life. To my two little dogs Cupie and Elsa, thank you for being so patient with "momma" during the many long months it took to complete this thesis - you are long overdue for a summer of unlimited play at the park. Finally, this thesis is dedicated in loving memory of my mother and father, Lewis and Alma Herbert, for giving me roots and then giving me wings.
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Definition of Terms

A priori: Knowledge that is “prior to, or independent of experience…” (Audi, 1999, p. 35).

Bracketing (also referred to as epoch by Husserl or decentering): a process whereby the researcher identifies and sets aside his/her a priori knowledge and beliefs about a phenomenon in order to unfetter the mind from preconceived ideas, beliefs and assumptions (Munhall, 2010).

Essences: “… those ineffable qualities that cannot be expressed with numbers” (Dombro as cited in Munhall 2007, p. 101).

Existential Suffering: “Existential anguish is described as the fear of facing death, the fear when faced with the possibility that human existence will cease abruptly after life has ended and the agony and distress arising from an unbearable state of existence” (Boston, Bruce & Schreiber, 2011, p. 606).

Healing: “The ability of a person to find solace, comfort, connection, meaning, and purpose in the midst of suffering, disarray, and pain. The care is rooted in spirituality using compassion, hopefulness and the recognition that, although a person’s life may be limited or no longer socially productive, it remains full of possibility” (Puchalski, Ferrell, Virani, Otis-Green, Baird, Bull, Chochinov, Handzo, Nelson-Becker, Prince-Paul, Pugliese & Sulmasy, 2009, p. 890).

Health: “… a state of wholeness which excludes nothing. It is lodged ‘in’ spirit; it is subsumed ‘by’ spirit; and the knowledge of health is made possible by spiritual awareness” (Nagai-Jacobson & Burkhardt, 1989, p. 18).

Holistic Care: In the context of this research study holistic care will be positioned with the ‘lived experience’ as a way of “thinking and being phenomenological” (Munhall, 2010, p. 114-115). Thus reductionist categories which tend to create an artificial separation of the individual’s being (i.e. mind, body, soul and spirit) will be rejected in favor of regarding the individual as being an integrated whole.

Lived experience: “The reciprocal relationship between the respondent and the environment as he or she sees it” (Dombro as cited in P. Munhall 2007, p. 102).

Palliative Care: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization (WHO), 2015).
**Phenomenology:** is both a philosophical approach with many different traditions and a methodological approach to qualitative research which seeks a deeper understanding of what it means to be human by exploring the essence or structure of the everyday lived experience as the individual perceives and interprets it (Munhall, 2010).

**Reductionism:** “Phenomena can be analyzed and understood by reducing them to their component parts…” (Dombro as cited in Munhall 2007, p. 102).

**Spiritual Distress:** The Nursing Diagnosis of Spiritual Distress as defined by the North American Nursing Diagnosis Association (NANDA) is a "disruption in the life principle which pervades a person's entire being and which integrates and transcends one's biological and psychological nature" (2001).

**Spiritual Pain:** “the spiritual manifestations of pain include: anxiety, anger, denial, depression, fear, guilt, suicidal or homicidal ideation, grief, suffering, distress, loss of meaning and purpose in life” (Canadian Nurses Association (CNA), 2009, p. 18).

**Spiritual Suffering:** “meaninglessness in past or present life, loss of social role functioning, feeling emotionally irrelevant, dependency, fear of being a burden on others, hopelessness, grief over imminent separation, guilt, “why me” questions, unfinished business, life after death, and loss of faith” (Morita, Tsunoda, Satoshi & Chihara, 2000, p. 190)

**Spirituality:** “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al. 2009, p. 887).

**Total Pain (also known as Total Suffering):** Total Pain is a concept that captures the multi-dimensional nature of the pain experience for terminally ill individuals (i.e. pain arising from one or more aspects of the individual’s biopsychosocial/spiritual being). It has also been used to convey the understanding that pain which is difficult to control is likely to involve spiritual pain/suffering (Baines, Dunlop & Saunders, 1983; Mehta & Chan, 2008).

**Transcendentalism:** “Any of several doctrines holding that reality is essentially mental or spiritual in nature, and that knowledge of it can be attained by intuitive or a priori, rather than empirical principles” (Funk & Wagnall, 1976/1979, p. 719).

**Universal:** 5. applicable to all situations or purposes (Encarta Dictionary: English (North America))
Epigraph

“The greatest disease in the West today is not TB or leprosy; it is being unwanted, unloved, and uncared for. We can cure physical diseases with medicine, but the only cure for loneliness, despair, and hopelessness is love. There are many in the world who are dying for a piece of bread but there are many more dying for a little love. The poverty in the West is a different kind of poverty -- it is not only a poverty of loneliness but also of spirituality. There’s a hunger for love, as there is a hunger for God.” (Mother Teresa, A Simple Path)
CHAPTER 1

Introduction

The essence of spiritual care within Alberta’s palliative home care program is under researched and therefore not well understood. Spirituality is intrinsic to all human life and all of humanity cries out with longing for meaning, purpose, and relationship with "self, others, nature, and the significant or sacred" (Puchalski et al., 2009). Research has shown that individuals at the end of life desire spiritual care (Puchalski et al., 2009; Puchalski, 2007; Sulmasy, 2002). As a palliative care nurse I began to wonder about the current structure of spiritual care in palliative home care and if our current health care system is adequately addressing this important need. In this research study I seek to understand this phenomenon, the essence of spirituality as it currently exists, from the perspectives of Registered Nurses in palliative home care.

Phenomenology, as a philosophy and as the chosen research methodology, offered the potential to enrich and deepen palliative nurses’ understanding of the essence of spirituality as well as contribute to a higher standard of compassionate spiritual care for individuals with a life-limiting illness and their families being cared for in the home (Munhall, 2010). As participants consciously reflected on their experiences of spirituality in palliative home care through the sharing of thoughts, feelings, insights, and genuine self their stories demonstrated an "openness to mutual, meaningful interactions with others" (Carper, 1978, p. 148). In this way my co-researchers have contributed to the development of 'personal knowing' in the pre-existing body of spirituality and healthcare literature (Carper, 1978). The palliative home care nurses interviewed were able to provide rich data on the phenomenon as they are a group of healthcare providers who have the most frequent and direct contact with individuals and families in the final months to days of life. Personal reflection, dialogue, and sharing of insights, gained from caring
for the dying also helped these nurses to identify challenges to providing spiritual care as well as those experiences that have made them feel spiritually enriched (Rose & Glass, 2009). Through the process of this study I sought to understand where spirituality and spiritual caring exist in palliative home care using the lens of descriptive phenomenology guided by the philosophical teachings of the German philosopher Edmund Husserl.

**Background of the Question**

Early identification and assessment of a client’s spiritual needs is imperative in order to reduce suffering and improve quality of life for individuals and families coping with a life-limiting illness (WHO, 2015). Initial and ongoing assessment of client needs should include identifying spiritual needs and their root cause (if applicable) and using validated assessment tools (CNA, 2009). Nurses have both a moral imperative and an ethical obligation to screen for signs and symptoms of spiritual distress in dying individuals and families and to address spiritual needs as they arise. However, there is a lack of research about how palliative home care nurses perceive spirituality in their every day practice or the types of challenges they may encounter in attempting to assess and care for the spiritual needs of clients and families. Exploring questions of meaning is at the core of ethical nursing care (Sommerville, 2004) while imagining, exploring shared "values", "stories, myths, poetry", self-reflection, "moral intuition, and "the human spirit" play an important part in its development" (Sommerville, 2006, p. 2). Each palliative care nurse had a unique perspective on the phenomenon of spirituality as lived in their practice every day. As nurses opened up and shared their stories of spirituality within their practice, an essence of the nature of spirituality as lived began to emerge. While there are shared theoretical definitions of spirituality as suggested by Puchalski (2009) Registered Nurses struggle with assessing spiritual care needs because in clinical practice a multitude of perspectives are employed. In
fact, limited knowledge, guidelines, and policies exist in home care to guide nurses when engaging in therapeutic conversations with individuals and families at home. If nurses do not possess the knowledge and guidance needed in providing spiritual care, then they are not fulfilling the holistic mandate of the philosophy of palliative care, or meeting professional practice standards set by the College and Association of Registered Nurses of Alberta (CARNA, 2011).

**Statement of Purpose**

The lived experience of spirituality in the context of palliative home care service delivery is under researched and therefore not well understood. A deeper understanding of the phenomenon of spirituality from the perspective of palliative home care nurses is necessary in order to build capacity into the health care system for spiritual care. On a daily basis palliative home care nurses through their relationships with patients and families have a unique understanding of the spiritual needs of dying individuals and their families. Nurses' perspectives, meaning, and lived experience of spirituality and spiritual caring in the home is an important and vital phenomenon that needs immediate attention to ensure that holistic palliative care is provided (Munhall, 2010).

**Research Question**

The research question that guided my study was “*what is the essence of spirituality in palliative home care as revealed through insights shared by palliative care nurses?*”

Much of health research literature in relation to spirituality has been written by nurses over several decades yet this literature reveals a general lack of conceptual clarity when it comes to understanding “spirituality” (McGrath, 2003; Sinclair, Pereira & Raffin, 2006b). In recent years nurse researchers have veered away from religious or faith based conceptualizations of
spirituality toward a more post-modernist view of spirituality as having multiple and different interpretations. Therefore, as an advanced practice nurse and nurse researcher I have endeavoured to take an approach that is honouring of multiple perspectives. Research has shown that palliative nursing is emotionally challenging work (Bruce & Boston, 2008; Rose & Glass, 2009) yet meaningful, fulfilling and mutually beneficial to both nurse and client (Desbiens & Fillion, 2007; McGrath, 2003; Sinclair, 2011). Spirituality is an integrative factor that connects all aspects of a person's life (Sinclair, 2009) thus palliative nursing care will be the most effective when it acknowledges this integration.

Assumptions Embedded in the Research Question

The assumptions of this research proposal are as follows:

1. The meaning of spirituality in everyday life is transcendent to the individual.
2. All human beings are inherently spiritual beings.
3. The structure or essence of spirituality within the context of palliative home care is under researched and therefore not well understood.
4. Palliative Home Care nurses would be able to describe the experience of spirituality as it exists in their practice.

Summary

Palliative care aspires to total, or 'whole person' care including body, mind, and spirit. In giving 'whole person' care to dying individuals and their families nurses do not simply care for dying individuals' physical bodies, but "tend their spirit, gently, respectfully, and knowingly" (Moules, 2000, p. 4). In practice nurses live out their beliefs, values, theories, knowledge, and experience in their actions. Actions of spiritual caring, compassion, and presence are integrally a part of who they are as persons and as palliative care nurses. Studying the essence of spirituality
in palliative home care is an important and vital phenomenon to understand, if we are committed to developing meaningful relationships as a way to know and understand the patient’s experience, and provide informed and compassionate spiritual care.

This chapter has revealed the background to my research question, assumptions, and purpose of this study. In chapter two, I investigate the relevant literature, to affirm the importance of asking the question. In chapter three, I present my method of inquiry, and discuss how phenomenology allowed me to explore the phenomenon of spirituality. In chapter four I present my findings by allowing the data to speak for itself. In the fifth and final chapter I expand upon and further discuss the findings of this research study.
CHAPTER TWO

Literature Review

The research method for this study was chosen prior to conducting a formal literature review since the choice of method would influence the type of and manner in which literature would be reviewed. A cursory literature review was conducted prior to focusing on the phenomenon of spirituality in palliative home care from the nurses' perspective. I discovered very little health care research on this phenomenon in the home care setting. I began my quest for a deeper, richer, fuller understanding of this phenomenon in order to contribute to nursing's body of knowledge about the structure of spirituality in palliative home care. In coming to the research question a qualitative descriptive phenomenological research methodology was chosen as the best means of addressing the phenomenon of spirituality in palliative home care from the nurses' perspective.

Research studies that are descriptive in nature were reviewed with the intent of identifying themes relevant to the research topic. Three electronic reference databases (i.e. CINAHL, Medline (OVID) and PubMed) were searched for relevant research literature using the keywords “palliative care”, “nursing” and “spirituality.” I originally found 28 journal articles using the key terms palliative care, nursing and spirituality of which 8 articles were considered germane to this study. I then extended my search criteria to include an additional 34 articles were found by searching the reference list of the original 8 articles and by substituting the word “existential” for “spirituality” in the keyword search of the three electronic reference databases. A total of 42 nursing and medical research articles were reviewed with the majority of those articles being published after 1999. All 42 journal articles combined included qualitative, quantitative and mixed-method research studies. I also used the thesis portal on the University of Calgary
website to review relevant thesis material (1 thesis). Three general themes were identified in the literature including: spirituality and health, holistic care of the dying and palliative nursing. The following seven subthemes identified under these general headings include: conceptual issues in defining spirituality; spirituality and religion; existential/spiritual pain and suffering; spiritual care needs at the end of life; spiritual assessment tools used in palliative care settings; challenges to nursing care of spiritual needs of the dying, and nurses’ spiritual perspectives. The literature reveals that there are gaps in nursing knowledge about the structure/essence of spirituality in palliative home care and the impact this has on nurses both personally and professionally (Sinclair, 2011). These research studies also indicate there is a need to design studies in the future that will be inclusive of participants of other faiths and cultures outside the westernized Judeo-Christian tradition.

**Spirituality and Health**

The English word “spirit” is derived from the Latin word “spiritus” which has its roots in the ancient Greek word “pneuma” literally meaning “a gentle blast,” “breath” or “wind” and speaks to an animating life force as vital to human existence as oxygen is to our lungs (Online Etymology Dictionary, 2015). It is the spirit within which imbues the inner being with all its richness and gives light for our spiritual journey (Nagai-Jacobson & Burkhardt, 1989). Spirituality is forged in the fires of youth as we begin to form our world views and values (Rose & Glass, 2009) and continues to develop throughout our lifetime. It is “a way of being in the world” (Rose & Glass, 2009, p. 189). Historically nurses have long been interested in matters pertaining to spirituality with the majority of research literature related to spirituality, nursing and palliative care having been written over the past 25 years (Sinclair et al., 2006b). There is an
ever increasing amount of empiric evidence demonstrating the significance of spirituality to the health and well-being of the terminally ill (Sinclair, 2011).

Conceptual Issues in Defining Spirituality

Conceptual difficulties with defining spirituality have made research in this area problematic in the past (Berlinger, 2007; Sinclair et al., 2006b). Sellers & Haag (1998) identified difficulties with the conceptualization, definition, and measurement of spirituality resulting in a lack of theoretical and clinical knowledge to guide nurses in caring practices of individuals living with a terminal illness and families. Sinclair et al. (2006b) identified a number of approaches that have been used to define spirituality including treating it contextually; using a broad definition that is too vague; or using a narrow definition that is too restrictive. Nagai-Jacobson and Burkhardt (1989) conceptualized spirituality as the inner integrating essence of a person which seeks for meaning, purpose and connection with self, others, nature and The Other. For the purposes of this research study a broad definition of spirituality which captures the salient aspects of the phenomenon under study was chosen. “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al. 2009, p. 887).

Spirituality and Religion

While an individual’s spirituality may or may not include religion and religious practices it does involve a pilgrimage or journey to an unseen destination and those relationships made along the way which give life meaning and purpose (Boston et al., 2011; Penman, Oliver & Harrington, 2009; Puchalski et al., 2009; Sinclair et al., 2006b; Sulmasy, 2002). Spirituality in health care research in recent year reflects a postmodern approach with a multitude of
perspectives being valued as equally important (Rodgers, 2009). In the past the focus of most research was on the “self,” “quality of life,” and “improving or maintaining health” (Sinclair et al., 2006b, p. 464). More recently health care research is emerging that seeks to understand the lived experience of spirituality that is shared between health care professionals, patients and families (Sinclair, 2009, 2011; Sinclair, Raffin, Pereira & Guebert, 2006a).

**Holistic Care of Individuals at the End-of-Life**

In the past research has tended to create boundaries between the biological, physical, mental, social, and spiritual domains of an individual’s being. In phenomenological reality, it is assumed no such boundaries exist as all these domains are intricately interwoven in a “living nexus” (Bush & Bruni, 2008, p. 539). Approaching spirituality and end-of-life care from a holistic perspective is both ethical (Sommerville, 2006) and honoring of the humanity of all involved whether caregiver, care recipient, or researcher (Hayden, 2011; Ronaldson, Hayes, Aggar, Green & Carey, 2012; Tiffen & Bentley, 2009; Sinclair et al., 2006b; Sulmasy, 2002). In attending to the whole person throughout their journey, from diagnosis of a life-limiting illness to death, palliative nurse clinicians demonstrate a deep respect for the inherent dignity and worth of the individual. In this way palliative nurses are supportive of the individual's integrity as a human being, their capacity to self-heal, and their ability to transcend their current sufferings into a new way of being (Puchalski, 2007). Nursing practice guidelines must include spiritual care in order for nursing care at the end of life to be truly holistic (Bush & Bruni, 2008; Tiffen & Bentley, 2009).

**Existential/Spiritual Pain and Suffering**

Conversations about spirituality in palliative care often include discussions about pain and suffering. Quite often the concepts of spiritual pain/suffering are used interchangeably with the
concepts existential pain/suffering in research literature. Boston et al. (2011) reviewed 64 articles relating to existential and spiritual suffering at the end of life and found 56 definitions linking the two concepts together. However, Bolmsjo (2001) argues that these are two distinctly different concepts especially when spirituality is coupled with religion. This research study helps illuminate how palliative home care nurses perceive spirituality and suffering in caring for individuals at the end-of-life. Nurses’ understanding of the phenomenon of spirituality in palliative home care was demonstrated as they reflected upon the experiences they related to me as participants and co-researchers in this research study.

Suffering at the end of life, spiritual or existential, seems to be connected to a sense of past, present and/or future loss(es) and the fear of dying (Arman & Rehnsfelt, 2003; Berlinger, 2007; Bolmsjo, 2001; Boston et al., 2011; Bruce & Boston, 2008; Mako, Galek, & Poppito, 2006; Sinclair, 2009, 2011). Nagai-Jacobson & Burkhardt (1989) conceptualize pain and suffering as a part of the “larger life experience” which offers opportunities for “growth and transformation” (p. 26). Gudmannsdottir and Haldorsdottir (2009) interpretive phenomenological study interviewed 12 nursing home residents suffering with chronic pain (mean age 86) wherein the participants recounted experiences of loss (i.e. loved ones, home, health, independence and connectedness) thereby demonstrating that without the systematic assessment of spiritual pain many elderly residents would suffer in silence which in turn intensified their pain. Fagerstrom, Eriksson & Engberg (1998) argue that greater knowledge and understanding of the meaning of spirituality [in palliative home care] will enable nurses to understand and interpret the spiritual care needs of individuals and families more consistently.
Spiritual Care Needs at the End of Life

In a cross-sectional national survey conducted by Steinhauser, Christakis, Clipp, McNeilly, McIntyre and Tulsky (2000) more than 70% of respondents (i.e. physicians, nurses, patients and families) reported that “pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences and being treated as a ‘whole person’ were most important to them” (p. 2476). Also of great importance were “being mentally aware, having funeral arrangements planned, not being a burden, helping others and coming to peace with God” (Steinhauser et al., 2000, p. 2476). Of the 95 spiritual nursing interventions identified by nurses in this research study frequently identified were referral, prayer, active listening, validation of thoughts/feelings, conveying acceptance, and instilling hope while the most frequently implemented interventions were communication and religious nursing interventions (Steinhauser et al., 2000). In a separate study "...hospice nurses’ commitment to the delivery of spiritual caring was associated highly with their patients’ spiritual needs, the need for meaning and purpose in life, the need to give and to receive love and the need for hope and for creativity” (Ronaldson et al., 2012, p. 2127).

Spiritual Assessment Tools Used In Palliative Care Settings

Sulmasy (2002) reviewed and critiqued available spiritual assessment tools that measured religiosity, religious coping and support, spiritual well-being, and spiritual need presenting a framework for understanding these domains. Some of the more well-known clinical spiritual assessment tools currently in use include: FICA (Faith/Beliefs, Importance, Community, Address in care or action) (Borneman, Ferrell & Puchalski, 2010; Sulmasy, 2002); FACIT-sp (Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing Scale) (Desbiens & Fillion, 2007); SPIRIT (Spiritual belief system, Personal spirituality, Integration,
Rituals/restrictions, Implications and Terminal Events) (Borneman et al., 2010); and HOPE (Hope, Organized religion, Personal spirituality, Effects of care and decisions) (Borneman et al, 2010; Gowri & Hight, 2001; Selman, Young, Vermandere, Stirling, & Leget, 2014). However, most spiritual assessment tools have been written for and researched with terminally ill cancer inpatients of Euro-American, Judeo-Christian background and therefore have limited usefulness in guiding palliative nurses in the ongoing screening and assessment of spiritual care needs for those in the home care setting, with other types of terminal diagnoses, and from other cultures, backgrounds or faith traditions (Edwards, Pang, Shiu & Chan, 2010).

**Challenges to Nursing Care of the Spiritual Health of Individuals Living With Dying**

Empirical evidence clearly demonstrates the importance of attending to spiritual care needs at the end-of-life (Ehman, Ott, Short, Ciampa & Hansen-Flaschen, 1999; Flannelly, Weaver & Costa, 2004; McClain, Rosenfeld, & Breitbart, 2003; Reed, 1997; Smith, Stefanek, Joseph, Verdieck, Zabora & Fetting, 1993; Yates, Chalmer, St. James, Follansbee & McKegney, 1981) as a means of improving patient care outcomes (Griggs, 2010; Puchalski et al., 2009). Despite overwhelming empiric evidence that many individuals living with a terminal illness would like their spiritual needs addressed this is often not the case (Puchalski, 2007; Sulmasy, 2002). The Rose and Glass (2009) study of Australian urban and rural community nurses noted that challenges to engaging in spiritual care included “… opposing social forces, an inner dialectical tension between the nurses’ expectations of their professional practice and what is valued in their practice settings” (p. 185). Nurse Practitioners identified a need to manage barriers to spiritual care at the end-of-life (Tanyi, Mckenzie & Chapek, 2009, p. 690). Research indicates nurses may or may not believe they have a moral duty to engage in spiritual care, may not recognize spiritual issues when they arise or may struggle ethically with knowing the right thing to say or
do (Sulmasy, 2002). “Conceptual difficulties in defining spirituality for clinical and research purposes” (Puchalski, 2007), time constraints, financial burden to the health care system and the lack of uniformity in educating health care professionals (Edwards et al., 2010) are additional challenges to addressing spiritual care needs (Puchalski, 2007). Edwards et al. (2010) identify personal, cultural or institutional factors as barriers to spiritual care in nursing. Many researchers argue that a spiritual needs assessment should be included in a comprehensive patient care assessment (Ferrell, Levy & Paice, 2008; Hayden, 2011) however quite often there is a lack of clear practice guidelines and assessment tools to help nurses do so (Hayden, 2011). Normalizing spiritual care in nursing practice requires a process of self-reflection and open dialogue about spirituality. Hegarty, Hammond, Parish, Glaetzer, McHugh & Grbich (2005) retrospective case note audit observed that nurses rarely document spiritual care which leads them to conclude there is a need for education and better documentation tools to support nurses in this practice.

Community nurses’ engagement in activities that invite self-reflection, self-awareness and open dialogue in issues pertaining to spirituality have the potential to enhance confidence and skill when engaging in spiritual care practices (Hayden, 2011). Tiffen and Bentley (2009) add that professional nursing education in spiritual care of the dying, effective therapeutic communication skills, self-confidence and having role-models to emulate also help to normalize spiritual care in daily nursing practice. Other researchers argue that it is more important to focus on broader spiritual issues in helping others to find peacefulness, comfort and meaning at end-of-life” (Kruse, Ruder & Martin, 2007). Ronaldson et al. (2012) identified ‘insufficient time’ as the most common barrier to spiritual caring practice; lack of ‘patient privacy’ was also common for acute care RNs” (p. 2126). In any event palliative nurses often find creative ways to attend to the
spiritual care needs of terminally ill individuals and families being cared for at home (Puchalski, 2007).

Palliative Care

The word palliate was "first used in the 15th century" and comes from the Latin word *palliatus* which means "to cloak, conceal" (Merriam-Webster's Collegiate Dictionary, 11th ed.). To palliate means “…to ease (symptoms) without curing the underlying disease...." (Merriam-Webster's Collegiate Dictionary, n.d.). The modern palliative care movement began in the 1940’s with the work of British physician, nurse and social worker Dame Cicely Saunders and has spread across the globe since then. Today palliative care has become a specialized area of health care for individuals with a life-limiting illness and their families. Palliative care acts as “a catalyst for embarking on one’s own spiritual journey” as well as contributes to a culture of spiritual reflection among team members (Sinclair et al., 2006a).

Community/Parish Nursing

Over the past several decades nurses have made some of the most substantial and significant contributions to the health care system’s knowledge about spirituality, nursing, and palliative care (Sinclair et al., 2006b). While the importance of spiritual care at the end of life is valued by the nursing profession it continues to occupy the margins of patient care according to Carr (2010). Since palliative care (PC) has spirituality embedded in its' very definition and empirical evidence has demonstrated that spiritual issues will arise at the end of life much can be learned from talking with home care nurses. Some researchers have suggested that nurses who engage in spiritual care possess certain qualities such as competency (i.e. ability to create safety) and courage (i.e. ability to show empathy) (Fagerstrom et al., 1998), and that spiritual care begins
with a caring attitude (Tanyi et al., 2009). Carr (2008) identified an additional quality nurses who engage in spiritual care possess which she refers to as the X Factor described as

the essence of who we are, our spirit or soul. It is our uniqueness—
the total combination of our individual human qualities — which is
intuitively known to us and others but remains something of a mystery.
Expressing our X factor thus involves a process of nurturing our special
qualities and making it known that we are willing and able to share our
unique self — our spirit — with another. (p. 692)

Contributing to knowledge about where spirituality exists in palliative home care serves as a starting point from which future studies can be designed that will help to improve the quality of care for individuals with a life-limiting illness being cared for at home. Clearly, there is a need for research to occur at multiple levels of the health care system in order for spiritual care to move from the periphery of nursing care to the center of caring practice in palliative home care (Carr, 2010; Sinclair, 2011). This is the challenge facing nurses in the days ahead in order to achieve the best patient care outcomes possible.

Nurses’ Spiritual Perspectives

Palliative home care nurses perspectives on spirituality are invaluable as they are “eyewitnesses” and therefore “key informants” to the “ultimate meaning and mystery” that surrounds life and death (Sinclair, 2009, 2011). Palliative care nurses in the acute care setting tend to be older, more career advanced, have stronger spiritual perspectives and more fully developed spiritual caring practices than non-palliative nurses in the same setting (Ronaldson et
al., 2012). It is also known that palliative nurses spiritual perspectives influence their spiritual caring practice (Ronaldson et al., 2012). It is known that the spirituality of palliative health care professionals (PHCPs) in acute care and hospice settings is “experiential in nature” (Sinclair, 2009, p. iii) and that “clinical exposure to death and dying taught participants to live in the present, cultivate a spiritual life, reflect on their own mortality, and reflect deeply on the continuity of life” (Sinclair, 2011, p. 180). Palliative home care nurses may share some of the same perspectives about spirituality as PHCPs in the acute care and hospice settings but their lived experience of spirituality may have some important differences as well. Carr’s (2008) phenomenological inquiry of health care professionals (HCPs) in a tertiary acute care centre in Atlantic Canada concludes that “the meaning of spiritual nursing care is highly individualized and is experienced differently from person to person” (p. 696). Sinclair (2009), noted that “nurses are privy to insights that benefit the dying” (p. iii). PHCPs in hospice and acute care settings tend to view the lived experience of spirituality in palliative care as a positive one which imparts many benefits both personally and professionally (Sinclair, 2009, 2011). Other benefits included invaluable life lessons such as “to live in the present; and to discover meaning in life through life experiences of others” (Sinclair, 2011, p. 180). Research has also demonstrated that the culture of the palliative care team fosters a collective spirituality which will emerge as HCPs share their perspectives about spirituality and palliative care (Sinclair et al., 2006a).

**Summary**

Current research literature recognizes the importance that spiritual care has to improve health care outcomes for individuals and families being cared for at home. However health care providers are challenged in meeting these needs because this field of research is nascent,
including the impact on health care outcomes. In addition to this research points to the many benefits health care professionals experience in attending to their own spiritual self-care both personally and professionally. Consistent screening and assessment of spiritual care needs can help nurses to identify and support those who might otherwise suffer in silence. Still, much work needs to be done to help nurses incorporate spiritual caring in daily clinical practice. Self-reflection and dialoguing with Registered Nurses is essential to help normalize spiritual care in everyday clinical practice. A collective spirituality will be revealed as health care professionals open up and share their perspectives about spirituality and palliative care (Sinclair et al., 2006a).

In the next chapter I will describe in detail how I arrived at the locus of my study as the best approach in answering the research question and as guided by the methodology's basic tenets. I will also describe in greater depth how the chosen philosophical approach was structured in relation to my life-world, my intuition, my evolution during this study, and research literature.
CHAPTER THREE

Methodology

Selection of the Research Design

In coming to the research question it became evident to me that a qualitative research approach as modus operandi was congruent with my own ontological commitments. It was actually somewhat difficult deciding upon a specific methodology to answer the research question as each potential qualitative method had its own merits and limitations. However, when I did my initial literature search I discovered that few studies actually tried to understand and describe the structure or essence of spirituality from the perspective of those who are most closely associated with and living it in their daily practice. I believe that a basic understanding of the structure or essence of spirituality in palliative home care is needed before further studies can be designed to meet the specific needs of this population. A couple of studies have been done, one in Australia and one in Quebec, looking at the experience of community nurses in providing palliative care but none looked at this experience in western Canada. Adding to this dilemma is that the concept of spirituality itself is poorly defined and understood in research literature.

It would be impossible to design further inquires of a particular phenomenon without first identifying it and defining it (Polit & Beck, 2004). Considerable soul-searching took place before determining that a descriptive phenomenological approach would be the best research methodology to identify and define more precisely the essence of spirituality in palliative home care through insights and subjective experiences shared by those who live it. Concomitantly, I began to seek out a greater understanding of phenomenological philosophy.
Phenomenological Philosophy

Philosophy can be defined as "a search for a general understanding of values and reality by chiefly speculative rather than observational means" (Merriam-Webster's Online Dictionary, n.d.). Phenomenology is both a philosophical school of thought and an approach to qualitative research design. Phenomenological philosophy is a "movement that describes the formal structure of the objects of awareness and of awareness itself in abstraction from any claims concerning existence" (Merriam-Webster's Online Dictionary, n.d.). The concept of the “lived experience” originated with Wilhelm Dilthey (1833-1911) a German Hermeneutic philosopher from the University of Berlin (Dombro as cited in Munhall, 2007, p. 111).

Phenomenology as a qualitative research method invites rich description and careful analysis to understand how meaning is created through embodied perception (Sokolowski, 2000; Stewart & Mickunas, 1974). The phenomenon is described by the individual precisely as they experience it reflectively. In this way taken-for-granted assumptions about these ways of knowing are exposed (Starks & Brown Trinidad, 2007, p. 1373). Phenomenology’s central concepts include intentionality, essences, intuiting, reduction, bracketing, embodiment, and being-in-the-world (Husserl, 1964).

In phenomenological research the individual’s unique perspective provides a way into a deeper understanding of the meaning or structure of a universal phenomenon such as spirituality without the use of theories, conceptualizations, or categories (Munhall, 2010). Giorgi (1975) identified eight characteristics of phenomenological research which include: fidelity to the phenomena as it is lived”; “primacy of life-world”; descriptive approach; expression is from the viewpoint of the participant; lived experience as the basic unit of research; “a biographical emphasis since all human phenomena are temporal, historical, and personal”; “presuppositionless
description” and “a search for meaning” (Knaack, 1984, p. 109). In fostering a richer and fuller understanding of the phenomenon of spirituality of palliative home care nurses moral knowledge and ethical action will be fostered that will guide nurses in nurturing the highest and most humanistic standards of care (Munhall, 2010).

Phenomenological Research

In learning how to "think and be phenomenological" (Munhall, 2010, p. 115) the potential exists to not only "[be] a great researcher but also... a very understanding person" (Munhall, 2010, p. 116). Phenomenology is a way into understanding subjective human experience objectively, without preconceived notions. Paradoxically "...objectivity is itself a subjective concept. For the researcher and the participant create an "intersubjective space" that arises from "...different social constructions of reality... using language differently..." and in fact "have two different experiences during the encounter" (Munhall, 2010, p. 115-116). "For the researcher "...hearing language and believing something is being revealed that might be valid, but it is hearing and also contemplating what might be concealed in responses" (Munhall, 2010, p. 117). Munhall states that "phenomenological research could be problem solving and illuminate needed changes in many areas, whether policy or practice" (Munhall, 2010, p. 117). Through engaging in a phenomenological approach in this research study I strove to understand the essence of spirituality in palliative home care from the Registered Nurses' perspectives.

The human experience of a phenomenon is made up of "objects of perception... memory, imagination, and feeling" (Polkinghorne, 1989, p. 41). Phenomenological research is concerned with the structure or essence of a particular phenomenon, in this study that phenomenon is spirituality in palliative home care, and is described from the perspectives of Registered Nurses' as they reflect on their personal experience of this phenomenon. "The purpose of
phenomenological research is to produce clear, precise, and systematic descriptions of the meaning that constitutes the activity of consciousness” (Polkinghorne, 1989, p. 45).

Phenomenology's philosophical underpinnings and methodology created an opportunity for me to develop a clearer, deeper, and more concise understanding of the essence of spirituality in palliative home care, which is something I have long desired to do. A phenomenological approach to research was consistent with the objectives of this study and the best approach to answer the research question.

**Descriptive versus Interpretive Phenomenology**

Since there are a variety of phenomenological methods it was necessary for me to further explore my values in relation to the various approaches and their philosophical underpinnings in order to decide which method would be a good fit for the study. This began with investigating the two major phenomenological schools of thought which are descriptive or eidetic (Husserlian) and interpretive (Heideggerian) (Cohen & Omery, 1993). Both approaches are often used in nursing research (Cohen & Omery, 1993) because they explore questions of meaning in the human experience and provide a "thematic description of the pre-given "essences" and structures of lived experiences" (Starks & Brown Trinidad, 2007, p. 1373). The two methods diverge in relation to their respective findings.

Husserlian descriptive phenomenology generates its' findings through rich descriptive analysis of the pure data generated from each individual's narrative of their real/perceived world and experienced meaning. In Heidegger's interpretive approach findings are generated through the researcher's interpretation of the meanings of the person's context, and how those meanings influence the choices the person makes. Findings of Husserlian research can be used to help further the health professional's knowledge of the structure or essence of the phenomenon to
those experiencing it. In coming to a richer understanding of what motivates human behavior in relation to a particular phenomenon the foundation is laid for future research or from which relevant nursing interventions can be designed. In interpretive phenomenology the findings add to the health professional’s knowledge of the context of the experience which may be relevant to providing care to the individual (Lopez & Willis, 2004).

I determined that an interpretive approach, while revealing potential contextual influences related to spirituality in palliative home care, would not achieve the objectives of this study. Husserl's descriptive method was the best approach to helping me identify the essential structure of the meaning of the lived experience of spirituality in palliative home care. Husserl's (1964) phenomenological approach met the intended objectives of this study and fit with my own philosophical beliefs in two ways. First, the research question is consistent with Husserl's (1964) philosophy which emphasizes the description of the human lived experience. The question seeks to learn what Registered Nurses as individuals know about the meaning of spirituality in palliative home care. Husserl's approach assumes that there is an essence or basic structure of spirituality in palliative home care will emerge as individuals experience the phenomenon reflectively. Husserl (1964) assumes that by identifying the universal essences experienced by all participants who have lived the experience being studied, the identity of the investigated phenomenon is revealed.

Husserl (1964) believed that human actions are influenced by what they perceive to be real, which is congruent with the objectives of this study - that palliative nurses who engage in spiritual care of the dying are influenced by their perceptions. Therefore, the essence of spirituality is revealed within the context of palliative home care through the lives of those who have lived the experience (i.e. Registered Nurses).
Husserl's Descriptive Phenomenology

As a philosophy phenomenology has been greatly influenced by the work of Edmund Husserl (1859-1938) (Dombro as cited in P. Munhall, 2007). Husserl was a Jewish born philosopher from the Frankfurt School of Philosophical Thought in Germany. He is considered the founder of phenomenological research and it is his body of work that serves as the “gold standard” by which all other phenomenological research methods are compared. Husserl believed in the concept of intentionality (i.e. that consciousness is always directed toward an object). An individual’s perception of truth or reality is experienced through the physical senses (i.e. embodiment) and to some extent passed down from previous generations through language, culture and traditions (Rodgers, 2009). Husserl believed that the purest meaning of a lived experience for an individual can only be understood by the researcher first bracketing (i.e. identifying and setting aside) the “natural attitude” or in other words previously held beliefs or “assumptions” about a phenomenon. In this research study bracketing was achieved through self-reflection prior to interviewing the participants. These reflections were documented in a journal for easier reference during data analysis in order to identify presuppositions and biases (Polkinghorne, 1989). Phenomenology’s philosophical underpinnings lend to a holistic approach in researching human experience. It represents a shift away from empiricism and the natural sciences with its search for a single truth or explanations of reality toward a human science approach in understanding what it means to be human (Munhall, 2010; Rodgers, 2009).

Colaizzi’s (1978) Method of Interpretation and Data Analysis

Creating an “audit trail” is essential in establishing rigor in qualitative research as it allows the reader to follow the thought processes of the researcher in data analysis and is essential to establishing authenticity and trustworthiness (Streubert & Rinaldi Carpenter, 2011). Both
description (Husserl) and interpretation (Colaizzi) have been included in the final analysis of data. Analysis of data was achieved through coding, categorizing, decontextualizing, and recontextualizing the data (Starks & Brown Trinidad, 2007). Decontextualization involved isolating data from each interview and assigning codes to units of meaning (Starks & Brown Trinidad, 2007). During recontextualization codes were examined for patterns and these were organized into central themes that were common across all narratives (Starks & Brown Trinidad, 2007). The phenomenon of spirituality in palliative home care from the nurses’ perspective has then been described in detail as well as its fundamental structure. Validity of findings was supported by the inclusion of low-inference descriptors (i.e. examples taken from participant’s verbatim accounts) that helped to justify my interpretations (Johnson, 1997; Priest, 2002).

Keeping an open mind prior to data analysis was achieved through reflexive practices such as bracketing a priori knowledge by journaling my own thoughts, feelings, beliefs, perspectives, and developing hypothesis about the phenomenon under investigation (Gearing, 2004; Sokolowski, 2000; van Manen, 1997) and by consulting with my doctoral supervisor and my thesis advisory committee (Finlay, 2002). Bracketing was used to set the context for describing the pure essence or structure of the phenomenon of spirituality in palliative home care.

Data analysis occurred simultaneously during data collection (Morse and Richards, 2002). Thematic analysis was used to organize the data and explore “meaning” with themes and sub-themes identified (Van Manen, 1997). Themes and patterns emerged during interviews that were further explored in the follow-up telephone call with each participant. New ideas, themes and concepts were described as they emerged. Descriptions of the phenomenon were clustered together to describe the “essence” or core commonality and structure of the experience (Starks & Brown Trinidad, 2007, p. 1373). The researcher (RH) listened to the tapes, read and reread the
transcripts, identified significant statements, determined themes, prepared an exhaustive
description of the phenomena and the relationship among the themes and synthesized the themes
into a consistent description or statement of the phenomenon studied. All interviews, field notes
and observations were transcribed as they are collected. Analysis of the data included seven
steps of Colaizzi’s (1978) method which are:

1. “Acquiring a sense of meaning for each transcript” (Colaizzi, 1978)
2. “Extracting significant statements” (Colaizzi, 1978)
3. “Formulation of Meanings” (Colaizzi, 1978)
4. “Organize formulated meanings into clusters of themes” (Colaizzi, 1978)
5. “Describing in detail the investigated phenomenon” (Colaizzi, 1978)
6. “Describing the fundamental structure of the phenomenon” (Colaizzi, 1978)
7. “Returning to the participants to validate findings” (Colaizzi, 1978)

Data Generation

Interviews

The phenomenological interview is conceived of as a discourse or conversation (Mischler, 1986). Each interview involved all interpersonal engagement in which the participants were encouraged to share their experience fully with the researcher. The focus of the interview was on the life-world or experience of the participant. The intent of the interview was for the participant to share their stories and uncover common meanings in their experiences. Open-ended conversations facilitated the collection of rich data by providing the participants with the opportunity to describe their experience without interruption. The interviewer took care to
remain open to the presence of natural responses of individual participants day-to-day lived experiences.

Prior to beginning each participant interview a letter explaining information about the study was provided to each participant. Sufficient time was allowed for each participant to review the contents of the letter and to ask questions before providing the researcher (RH) with written informed consent. Each participant was asked for permission to audio tape the interview prior to turning on the tape recorder. Guided questions (see Appendix D) were used for each interview to help assess the impact of palliative home care nurses perceptions of spirituality in caring for dying individuals and families. Questions were used for consistency of data collection but were meant as a guide only in order to keep the interview process open-ended and flexible. In this way participants were provided with the opportunity to explore their lived experience of spirituality in-depth as well as to reflect on those experiences which have informed their spiritual care practices (Swanson-Kauffman, 1986). Each interview was approximately one hour in length.

The interviewer responded to verbal/non-verbal cues of participants and asked clarifying questions as themes begin to emerge (Sorrell & Redmond, 1995). I (RH) reviewed the interview format with my Advisory Committee prior to engaging in actual research in order to reduce any long silences, confusion, or unnecessary data collection (Sorrell & Redmond, 1995). Each interview began with the open-ended question “what is your lived experience of spirituality?” Interviews ended when each participant felt they had exhausted their description(s) or the researcher felt that data saturation had been reached and no new information was emerging from the data (Streubert & Rinaldi Carpenter, 2011). The researcher paid special attention to establishing and maintaining an atmosphere of trust and confidentiality throughout the interview
process so that participants would feel safe in sharing memories, feelings and emotions that surfaced (Sorrell & Redmond, 1995). Each individual interview varied with regard to the time needed for each interview and answering questions related to the research study (Sorrell & Redmond, 1995).

Information was shared and created during the interview through “freely exchanging ideas, impressions and opinions” (Sorrell & Redmond, 1995, p. 1118). The researcher was cognizant to ensure strategies such as "remaining attentive, providing non-verbal nods, moving closer to the respondent, and maintaining eye contact communicated interest in the participant's response” (Sorrell & Redmond, 1995, p. 1118).

Field notes were recorded during or immediately after each interview either at the interview location or at my home. These notes included unspoken expressions as well as my immediate thoughts. I made notes of my biases, my thoughts, and noted the non-verbal communication the subject had used to contribute to her story. Field notes created during times of quiet, personal reflection were vital in order to elucidate the meaning of the experience to each participant.

**Research Sample**

The research sample consisted of 8 experienced Registered Nurses who were recruited from an urban palliative home care program in Alberta, Canada. After approval for the study was received from the Department Manager recruitment posters were posted at the four main sites where nurses are employed (see Appendix C). The recruitment poster and a brief explanation of the research study were also sent out by email to all potential participants via group emailing. A total of 70 potential participants received this email. Potential participants were invited to contact me either by email or by phone to volunteer for the study and to answer any questions they may have about the study.
Sample sizes in qualitative research are typically small because of the large volume of verbal data that must be analyzed and because qualitative research tends to emphasize intensive and prolonged contacts with subjects (Sandelowski, 1986). Purposeful (or theoretical) sampling was used to recruit participants from the entire population of 70 palliative home care nurses working at or out of four palliative homecare worksites located within the Calgary Zone of AHS. Two Registered Nurses with the Palliative Home Care Team were interviewed for a prior paper that was written course work for the Master of Nursing program. Ethics consent was granted as part of the course work and these nurses consented to have their interviews included in this research study. An additional 6 participants were recruited as a result of posters placed in a strategic location at each of the four home care work sites. Participants self-selected based on their expert knowledge (i.e. Registered Nurses with at least 3 years of palliative nursing experience) and their ability to generate information rich cases for in-depth analysis (Sandelowski, 1986; Streubert et al., 2011). Participation was completely voluntary and participants were fully informed about the study before providing us with written consent. Each participant spoke English fluently. All of the interested participants were invited to contact the writer by telephone for further explanation of the study. This research study was conducted between June 23, 2013 to August 24, 2013.

Respect for Persons

The sensitive nature of the topic of this study and the vulnerability of the participants was taken very seriously in the design of this study. The potential risks of participation in the study were discussed with each individual participant as part of the informed consent process. Participants were not coerced into participating in this study. Informed consent was voluntary and ongoing allowing the individual participant to withdraw at any time from the study. However, due to the nature of phenomenological research participants were made aware that the
ability of the researcher to partially or totally remove the interview data or the resulting different understanding that the researcher gained, would be impossible. An area of particular difficulty in this research study was sample size and anonymity. As the study was relatively small and drawn from one geographical area, participants could be identifiable through their articulated experiences, even though pseudonyms are used therefore a promise of strict anonymity was not guaranteed to the participants. Due to the highly personal nature of the data and the central focus of articulating each individual nurse’s experience attempts to remove any possibility of recognizing an experience or event from the reported data could have resulted in weak data. Therefore, participants who required a promise of complete anonymity were not included in this study. Participants were assured that all information would be kept confidential. No medical chart review was necessary. All data was collected directly from the participants in the interviews.

**Data Protection**

All data obtained was handled consistent with the Health Information Act (Office of the Information and Privacy Commissioner, Alberta, 2012). Only my supervisor, my committee, and I had access to the data.

Audio recordings, transcripts and research notes have been stored in a locked file within an office at the University of Calgary and will be destroyed in five years. All data was kept on a password protected computer during the study and all digital data has been transferred onto an external memory device which was stored in a locked cabinet and will be destroyed after five years. All files will be erased from the researcher’s computer upon completion of the study.
Concern for Welfare

The self-reflective/introspection that occurred during the interviews necessitated a concern for the welfare of the participants. Sharing spirituality narratives did, on occasion, bring forth painful memories for some of the participants. During the initial telephone conversation between the researcher and each participant and during all interviews the researcher reminded each nurse that they have access via self-referral to support from the Employee and Family Assistance Program at no expense. Those who found the interview process too emotionally painful, were offered the opportunity to take a moment to compose themselves. The researcher followed up with the participants one week after the interview to inquire if there are any concerns regarding the interview process and again to offer support from the Employee and Family Assistance Program.

Allowing the participants to select the location of the interview was intended to minimize the effort necessary for participation. Although this research was not intended to be therapeutic, there may have been some benefits to participation for the nurse. The resulting reflection on spirituality by the nurse may in fact have offered her a new understanding of the mutually beneficial role that spirituality plays in their personal and professional lives as well as the impact it has in the care provided to clients and families in the community.

Justice

This research represents a much needed opportunity to articulate palliative home care nurses’ experience of spirituality in caring for dying individuals and their families in order to enable nurses to better meet the needs of this population. This research study attended to the vulnerability of the participants by clearly identifying the eligibility criteria for participating in the study. Justice was integrated into this study through the concern and respect that participants...
received. The open and unstructured interview was a respectful approach to capturing the experience of nurses. “Narrative responses can be suppressed if the listener attempts to control the interaction by pursuing a particular line of inquiry or if specific questions are used that reflect the listener’s interests rather than the narrator’s priorities” (Romanoff & Thompson, 2006, p. 311). Attention was paid to not interrupting or redirecting the narrative as it unfolded, or hurrying the responses or attempting to elicit the facts instead of experiences. Participants guided the discussion, opening discussions on topics that were important to them. The researcher did not force the discussion of topics that participants were not ready to articulate. Nurses were interviewed individually and every effort was made to provide a safe environment for the conversations.

Throughout this study, attention was given to minimizing harm at all times to the participants of this study. Although the main risk of emotional distress could not be entirely avoided, attention was given to supporting individuals who experienced distress. In designing this study, a fine balance was negotiated to minimize harm and maximize benefits and at all times respect the participant’s human dignity. Asking nurses to share their spirituality narratives in this study was closely aligned with the cardinal value of the Tri-Council policy statement of respecting human dignity (TCPS, 2010).

**Ethical Considerations**

Ethical considerations were adhered to according to the Tri-Council Policy Statement with attention given to the principles of research ethics which include autonomy, informed consent, privacy and confidentiality (TCPS, 2010). Ethics approval was obtained from Conjoint Health Research Ethics Board (CHREB) prior to initiating the study. Participation in this study is
completely voluntary and participants were aware they were free to exit the study at any time without prejudice.

**Rigor: Establishing Trustworthiness**

“In considering rigor in phenomenological research, as with any qualitative research, there is a need to determine whether the study is believable, accurate, and right, and whether it is useful to people beyond those who have participated in the study” (Saunders, 2003, p. 293). Rigor was maintained by establishing credibility, auditability, and fittingness of the research findings (Guba, 1990).

**Credibility**

Credibility involved reviewing interpretation of the research findings with each of the participants to verify the accuracy of the findings. In an effort to enhance credibility, direct quotes have been used in the body of the research report so that the reader can follow that the interpretations as drawn in the report are firmly grounded in the data. Finally, journaling decisions, “thoughts, feelings, and reflections” throughout the research process (which was reviewed by my supervisor) was done in order to establish credibility (Saunders, 2003, p. 293).

**Dependability**

Dependability is the ability of the reader to audit the process of understanding as it evolves throughout the research process (Koch, 2006). An audit trail was established throughout this study using careful documentation and reflective writing in my research journal. Self-awareness of the researcher is vital (Koch, 2006). In the final written thesis supporting literature has been used to strengthen my analysis so that the reader can follow how my understanding of the phenomenon under study has changed. Quotes from the original transcripts and reflective
thinking from my journal provided an auditable decision trail with intention to be presented in person during my final oral dissertation, to establish dependability. This carefully conducted research study is submitted as further evidence of dependability (Maggs-Rapport, 2001).

**Transferability**

Streubert & Rinaldi Carpenter (2011) defined transferability as “the probability that the study findings have meaning to others in similar situations” (p. 39). It is important to note that it ultimately is the reader who decides if the findings are transferable (Streubert & Rinaldi Carpenter, 2011). Sandelowski (1986) reported that a study meets the criterion of transferability when “its findings can ‘fit’ into contexts outside of the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (p. 27). In order for the reader to accurately assess the degree of similarity between this research study and their own particular setting sufficient contextual information has been provided within the written report (Koch, 1998).

**Benefits and Limitations**

Benefits that may be derived from my study include:

a) contribution of evidence-informed knowledge to the current knowledge base regarding palliative home care nurses perceptions of spirituality in caring for dying individuals and their families.

b) generation of evidence-based research which may assist in the development of practice guidelines supporting community based palliative care nurses in the routine assessment of the spiritual care needs of dying individuals and their families.
c) enhancement of the quality of work life for community based palliative care nurses by giving them an opportunity to reflect upon and dialogue about how they experience spirituality in practice.

d) potential impact to improve individual wellbeing by utilizing the findings of this study in the development of a holistic model of care which includes routine screening for spiritual distress in homecare.

Potential limitations inherent in this study include its' relatively small sample size being drawn from only one population of home care nurses. The participants in this study included (6) individuals of the Judeo-Christian faith tradition, (1) Buddhist and (1) "Buddhist-like" however a more diverse sample reflective of other belief systems may have provided greater insight into the phenomenon of spirituality. Another limitation of this research study is that the participants were drawn from one population of urban nurses whereas a sampling of rural nurses may have yielded a richer understanding of this phenomenon. My relative inexperience as a novice researcher may have impacted data collection (i.e. interviewing skills) as well as my analysis of the raw data despite the supervision of a thesis committee.

**Summary**

In summary, phenomenology is both a philosophical approach and a research methodology, which seeks to understand the meaning of the lived experience through bracketing a priori knowledge of a phenomenon (Giorgi, 2000b; Sandelowski & Barroso, 2002). Colaizzi's (1978) descriptive phenomenological method of data analysis guided by the philosophical underpinnings of Husserl have made it possible to answer the research question in a meaningful way.
In this chapter the process of generating data through audio-taped interviews, journaling, observations, and field notes were described. Colaizzi's (1978) method for data analysis of the data collected from experienced Registered Nurses regarding the phenomenon of spirituality in palliative home care was outlined, and the procedure for recruitment and the setting were described. The process of assuring rigor of the study, generating an identifiable audit trail, and the process for protecting the rights of the participants was presented. In chapter four the descriptive profiles of the participants and the findings as revealed through the data analysis phase of the study will be described.
CHAPTER FOUR

Findings

Colaizzi (1978) asserted that having individuals describe their experience of a phenomenon is the best way into understanding the essence of that phenomenon, and the findings of this research study testify to that. I will begin with a brief descriptive profile of each individual participant interviewed, my co-researchers, who provided the rich description for this project. A pseudonym was assigned to each participant by RH and this name is used throughout the study. The descriptive profiles will then be followed by a description of the findings based on the stories and insights shared by the participants and my journaling detailing the essence of spirituality in palliative home care. I endeavoured to set aside my natural attitude (i.e. my personal beliefs, values, assumptions and perceptions) about the phenomenon under study throughout the interviews through the process of bracketing. Bracketing was accomplished through self-reflection and journaling both prior to beginning this study and periodically throughout data collection and data analysis. Bracketing was also achieved by incorporating excerpts directly from the participants words in order to allow the data to speak for itself. Participants described the data as they experienced it reflexively through the stories and insights they shared with me. Three major themes with its' thirteen related sub-themes emerged from the data and will be presented herein. Finally, a summary of the findings will be presented bringing this chapter to conclusion.

Descriptive Participant Profiles

Jenny

On the day of our interview Jenny, a Registered Nurse in her mid-40's, had been working as a nurse since she graduated from high school except for time taken off to raise a family.
Jenny has her Master of Nursing Degree and has worked in various health care settings before coming to palliative care. Jenny was recruited to do an interview as part of previous coursework in partial fulfillment of requirements for the Master of Nursing Degree and was aware the results of that interview would be included in this present research study.

Donna

On the day of our interview Donna, an RN in her 50's, had been working as a Registered Nurse for many years in various roles in both rural and urban settings before being employed in palliative care. Donna was recruited to do an interview as part of previous coursework in partial fulfillment of requirements for the Master of Nursing Degree and was aware the results of that interview would be included in this present research study. Donna is a wife, mother and grandmother.

Astrid

At the time of our interview Astrid, a Registered Nurse who has worked in diverse settings, had spent more than a decade of her career in palliative home care. She described herself as being an "up" person and very "passionate about palliative care." My interview with Astrid took place in the aftermath of the worst flood in Alberta history so we spent about 45 minutes talking about the impact the flooding had on people being cared for at home. Astrid's faith-based perspective on the essence of spirituality in palliative home care offered not only insights of the phenomenon under study but also practical suggestions for spiritual care nursing interventions.

Nancy

At the time of our interview Nancy had been practicing as a Registered for 40 years with many of those years being spent in palliative home care. She is a wife, mother and grandmother.
Her main objective in participating in the interview was to advocate for a chaplain for the palliative team.

**Rosa**

On the day of our interview Rosa, a Registered Nurse in her 50’s, had been working in Palliative Home Care for over 20 years. Rosa’s spouse, children, and faith are an important source of support for her. Rosa was looking forward to moving on to a different area of nursing and expressed the hope that it would be a "life-affirming" experience for her.

**Melissa**

At the time of the interview Melissa, a very articulate, well-spoken, married woman in her 30’s, had been working as a Registered Nurse for over a decade. The past four years of Melissa's nursing practice have been in palliative home care and she describes feeling "called to this work." Melissa asks the question "what is your personal heaven?"

**Kay**

At the time of our interview Kay, a nurse in her 50s, had been working in palliative home care for many years. "Fascinating job, fascinating! ...you know you are making a difference for people" Kay declared emphatically. Kay described spirituality as that aspect of life that is elusive and often the last thing to be addressed in nursing care if it is addressed at all.

**Lee**

At the time of our interview Lee, a Registered Nurse in her 30s, had been working in palliative care for over a decade. Lee is a practicing Buddhist and expressed a belief that the purpose of spirituality involves a lot of soul searching throughout life, exploring the meaning of life, which may lead to change in how you live in the now. Lee has observed that individuals in
western society are often spiritually starved for lack of nurturing of the spirit and thus described spirituality as "food for the soul".

**Themes**

In this section I will describe the findings that emerged from interviews with the nurses introduced above. "Codes" or "units of meaning" are ascribed to each subject's significant statements in keeping with Colaizzi's (1978) method of data analysis (see Table 1) and these are then organized them into thirteen categories. From these thirteen sub-theme categories, three major theme clusters emerged. The major themes and sub-themes are presented in Table 1.

Through intuiting, analyzing, describing, and reflecting on the descriptions of the structure of spirituality in palliative home care, from the perspective of Registered Nurses, the following three major themes emerged:

1. Spirituality and Health (Inner Self - Coping - Resiliency)
2. Spirituality: Nurses Engaging in Relational Practice
3. Holistic Care of the Dying

The participants chose to make statements that were significant to them, and in listening to their words and observing their non-verbal language I was able to orientate the themes to their stories. Significant statements were identified through the number of times their meaning was repeated in the stories shared, through my intuiting and reflecting on these statements, and in the way in which palliative nurses emphasized what they were saying through their speech tones and/or body language. Giorgi (2000a) states "a purely linguistic examination of the texts in question would yield no proof.... It is less a question of counting up quotations than of determining and expressing in concrete form this phenomenology for ourselves" (p. 12). Attention was given to all statements made by participants at first review - even those that did
not seem at first to fit - because a meaningful connection might become evident as the data analysis phase progressed (Colaizzi, 1978). With three major themes and thirteen subthemes emerging from the research data it becomes evident that the palliative nurses interviewed for this study considered it important to include multiple topics of importance in their stories about the essence of spirituality in palliative home care.

**Reflections and Assumptions on Preparing for Data Analysis: A Naive Reading**

Dialogue is central to the phenomenon investigated in this research study. Significant statements were extracted from the dialogue used by each participant, which form the structure of the essence of spirituality in palliative home care and are presented in the themes and sub-themes of this study. Meanings of significant statements were synthesized and validated according to protocol. My goal in this phenomenological research study was to give voice to the experience of spirituality in palliative home care from the Registered Nurses' perspective as it is an important aspect of nursing care that often is the least understood but is deserving of more attention in order to achieve the best possible patient care outcomes. The participants shared insights into the lived experience of spirituality in palliative home care are invaluable, as they help to shed light on an otherwise poorly understood phenomenon. In sharing their stories the participants of this research study have contributed to the capacity of the health care system to support the spiritual care needs of this population.

There was a comfort level and familiarity with the participants’ ways of speaking and non-verbal communication due to my many years of clinical nursing experience in palliative home care, however, I was careful not to make assumptions, and considered the meaning of the words themselves carefully. For example, I was aware of the high frequency of the word "um," and the
words "suffer(ing), "struggle," "scared," "comfort," "support," "peace," and "connect(ed)" by the participants. This helped to confirm my understanding of the participants' words.

The participants contextualized their stories in the past, present and future of their personal lives and professional practice. Hopes were expressed for the future of palliative home care - specifically that a chaplain or spiritual care coordinator would become a part of the home care team to provide support to both palliative and generalist teams as well as to dying individuals and their families in home care. They situated their stories mainly in their adult life and in their recent or current nursing practice at the time of the interviews.

In order to place the conversation in the context of the experience of spirituality in palliative home care I asked the participants to talk about their lived experience of spirituality inside their practice and how it has impacted nursing care of dying individuals and their families. From the initial interview, as illustrated by the research questions, I was aware that the lived experience of spirituality in palliative home care may be a lived experience that occurred as they admitted, permitted, and incorporated spirituality into their life world. Colaizzi (1978) states that "the return to things themselves" (p. 56) is necessary "to descriptively identify what each phenomenon is" (p. 56). As nurses returned to their world of spiritual experiences inside their practice each of the participants spoke to me of those experiences that were part of their personal growth even as they have become a part of the essence of spirituality in palliative home care.

From the beginning of the first interview I realized that my understanding of the meaning of participants' phrases might be different from theirs. In noting this I attempted to set aside any presuppositions and viewpoints I had about the experience to hear more clearly the meaning of the nurses' discourse. Colaizzi (1978, p. 59) states when "the same or nearly the same statements" are identified by the researcher, "repetitions can be eliminated." In all of the themes I eliminated
statements that had previously been stated thereby reducing the number of significant statements for each theme while maintaining the meanings provided by the subjects.

The following discussion and presentation of the themes and sub-themes, with rich, detailed description in the form of quotes taken from interviews with each nurse, will provide the reader a means to the dialogue shared with me during the interviews. These quotes are provided with each of the themes and sub-themes so the reader might experience "the rhythm and sound of the words and other features that make a quoted passage not only informative, but also an aesthetic experience" (Sandelowski, 1986, p. 481). The next section is intended to introduce and familiarize the reader with each participant, and their story as a way into understanding the structure or essence of spirituality in palliative home care.
Table 1: Themes and Sub-themes

**Spirituality and Health**
- 1. Inner Self
- 2. Resiliency
- 3. Coping

**Spirituality: Nurses Engaging in Relational Practices**
- 1. Benefits Experienced by the Registered Nurses in Caring for the Dying Individual at Home
- 2. Roles and Attitudes of the Registered Nurse
- 3. Exploring and Engaging in Therapeutic Conversations about Spiritual Care Needs
- 4. Challenges to Engaging in Therapeutic Conversations
- 5. Near Death Experiences
- 6. Spiritual Care Interventions

**Holistic Care of the Dying**
- 1. Suffering
- 2. Spiritual Care of the Dying is an Essential Service
- 3. Spiritual Needs of Individuals at the End of Life
- 4. Spiritual Needs of Families
**Theme One: Spirituality and Health**

**Inner Self**

What is spirituality? The participants identified conceptual challenges with defining spirituality. When asked this question Lee stated "that's a hard question to answer, it's a huge concept." However all of the nurses included one or more of the following elements in their definition of spirituality: unique to the individual, involves meaningful relationships with the self, others, nature, and that which is significant. One's spirituality may or may not involve an identifiable connection between the individual/family and an organized religion or faith community. The following questions often emerge: what can one hope for when cure is not possible? What is left when the human body is beyond repair and all treatment options have been exhausted? Lee answered this question rhetorically by stating "...that's where spirituality comes into play - right?"

The participants described the essence of spirituality in palliative home care as being mainly unstructured, client/family-centered care provided within the context of an established helping-trust relationship. Once the helping-trust relationship was established nurses' felt more comfortable engaging in therapeutic conversations with dying individuals and family members thereby providing an them with an opportunity to explore their own thoughts, feelings, and perceptions about life and death. Conversations with palliative nurses indicated there is a need for a shift in the "culture of care" to "open up more to the spiritual aspects of care" (Rosa). Many of the participants expressed a desire for more open, honest dialogue of spiritual care within the context of palliative home care provision itself. Palliative nurses' perceptions of this phenomenon were situated in their own cherished values, beliefs, world view, morality, ethical principles, and philosophical beliefs. It is these aspects of the inner life world that motivate us to
care for and serve others. Melissa says "I have personally found it a lot more helpful to be very grounded and very clear on what my own beliefs are, my own morality, ethics, philosophy - not necessarily religion 'cause I don't consider myself a particularly religious person - but it helps to give yourself that time so that you're pretty clear on what your own beliefs are." This clarity helps the nurse in her care to show respect for the individual's values, beliefs, and world view.

Christian and Buddhist traditions were the most easily identifiable philosophies revealed in interviews with the palliative nurses. Nurses' own spirituality gave them inner strength and increased their ability to cope with the demands of their work and resiliency against emotional distress and burnout. For example, Jenny's personal philosophy of spirituality demonstrates a belief that God's hand has always been on her life - teaching, guiding and preparing her to do the work she is now engaged in. "I feel as if I have been called to this job. I think God was making me... trying to show me patience even though I wasn't very patient." Jenny's words also reflect a belief that there is a loving creator who is willing and able to meet the deepest needs of individuals and families. "...I feel that when you have patients who have a faith... they don't seem to have that inner turmoil because they know where they're going and they know Who will be receiving them and they have a faith of what's going to happen next and they're not scared."

As a palliative home care nurse Jenny has faced some very challenging and complex client care situations in her practice. Through personal prayer Jenny partners with her loving Creator, trusting that He will work through her to help her meet the complex, challenging spiritual care needs of those at the end of life.

The nurses' personal beliefs, faith, and value system has also made them more aware of the spiritual needs of those in their care and for some it helped them to frame the experience of spirituality in palliative home care as one with divine purpose and intelligent design. Astrid said
"I feel like when you're connected with God... He can work through you and you're at your best...." The antithesis of being "connected" or in right relationship with others is to be "disconnected" which translates as being focused on one's self.

All health care professionals will at one time or another encounter complex issues that challenge them mentally, emotionally, physically or spiritually and sometimes those experiences can leave scars on our souls. The experience of spirituality involves having a place of refuge, a place of safety within one's self, where one can work through those things we don't understand and those painful experiences we sometimes encounter in our practice. Melissa says "...you have to find your own personal place to... to deal with things that you (hesitatingly) don't really know how to deal with."

**Resiliency**

Inevitably the conversations with the participants turned to the role of spirituality in relation to resiliency of the human spirit to not only withstand suffering but to transcend that suffering to experience spiritual growth, new ways of understanding, and as the pathway to finding inner peace. The American Psychological Association (APA, 2015) outlines the following steps to increasing resiliency in one's life: increase social support, accept change as inevitable; have courage to face your present challenge(s); trust in your ability to manage difficult situations; set realistic goals and take at least one small step every day toward achieving that goal; don't give up (i.e. perseverance); be kind to and seek to understand yourself better.

The experience of spirituality in palliative home care has enabled Registered Nurses like Astrid to be able to develop resiliency in the face of their frequent, ongoing contact with those who are nearing the end of life, death, and bearing witness to grief, sorrow, loss and suffering.
"...there seems to be a kind of lightness now with working with death and dying that I probably wouldn't have been aware of before...." (Astrid). The Registered Nurses interviewed also expressed an admiration for the courage and way in which individuals at the end of life and their loved ones cope with a life-limiting illness. As Nancy says "...I'm hoping that the things that I've learned from so many courageous people will help me get through that time myself."

Nurses' reasons for being a palliative care nurse are multifaceted - passion for the work, a culture of support among team members, and it is a good fit for the nurse. In contrast to this palliative home care nurses often work in isolation, deal with complex client needs and must cope with frequent exposure (often over many years) to suffering, grief, loss, death, and bereavement. The individual nurse's spirituality gives her a resiliency and ability to cope with these things.

Many of the Registered Nurses interviewed expressed an interest and curiosity about how individuals with different belief systems from their own cope with stressful life experiences such as living with a life-limiting illness. "I'm always curious about those folks and I think "so what happens when you're in trouble? Who do you turn to? Where do you go?" The nurses interviewed also expressed an interest and a desire to learn more about the belief systems of other health care professionals such as those of the Muslim faith and wondered if their perceptions and understanding of spirituality in palliative home care would be similar to their own with perhaps different language being used or if it would be significantly different from their own perceptions and understandings. Melissa, Rosa, and Astrid all expressed an interest in how palliative home care nurses of other faiths, beliefs, cultural backgrounds experience spirituality in their practice - if it is the same or different from their own - and how they cope with the ambiguity. This illustrates the importance of opening up the dialogue about spirituality
among health care professionals in order to expand nursing knowledge and to help build greater understanding about the experience of spirituality among team members.

The experience of spirituality in palliative home care is both comforting and discomforting. There is a comfort that comes from sharing in another's suffering but also a discomfort - a personal cost - that arises from investing one's self - one's time, energy, spirit, physical being and emotions in helping alleviate another's suffering. Therefore it is important to count the cost before engaging in caring for the spiritual needs of another making sure to invest in your own spiritual health and wellbeing. Melissa illustrates this when she says "...it was very comforting in many ways because to work so closely with somebody who has suffered and is essentially saying goodbye to their life one inch at a time... it's not only hard on the family it is hard on the nurse as well." All the participants emphasized the importance of spiritual self-care in enabling them to cope with the many stressors and demands placed on them in the workplace. Melissa said "...it has been a motivating factor in my own life to get a grip on my own... self-care, my own philosophical... place to stand on... my own firm ground to stand on." Spiritual self-care and self-reflection are an important part of palliative nursing practice. Rosa illustrates this when she says "...when we’re dealing with death and death and death and death in our jobs if that spiritual piece for us isn’t shared and talked about – just like it isn’t for the patient – we are carrying a lot of stuff that makes us emotionally and spiritually not well and just like I say the patient needs that opportunity to be able to share, to be connected, um to explore those issues, I think as a nurse because we are having to ask those questions they really need to be asked back to us and we need to have supports for that. I’m not saying that work has to supply that but what I’m saying is that nurses need an awareness that there is a need in their life... where are they at
with their spiritual [self] care." The participants also engaged in spiritual self-care by spending time with their family, communing with God, meditation, bible reading and prayer.

Coping

The human spirit not only has the ability to withstand suffering but also has the capacity to transcend suffering to experience spiritual growth, new ways of understanding, and inner peace. Jenny's experience with individuals and families is that they "suffer less" when their "life world" embraces a faith which gives them a framework to understand the experience of illness, loss, dying, death, and the transcendence of the human spirit. To "suffer less" means to "fear less" and is experienced by the client as inner peace, anticipatory joy and a positive outlook at the thought of meeting their creator. It is important to acknowledge the suffering of another as Melissa says "...it helps when you are trying to bear witness to their suffering...acknowledging that - I hear you."

The significant statements that pertained to the subjects' descriptions of coping were used to identify the theme cluster "spirituality and health" and related sub-themes: inner self, resiliency, and coping. Within these three sub-themes, the palliative home care nurses described factors that contributed to their understanding of the structure of spirituality within their practice.

The participants described the lived experience of spirituality within palliative home care as experienced reflexively within the context of their nursing practice in palliative home care and related areas of nursing practice. The structure of this experience is non-linear with experiences with terminally ill individuals and their families occurring in order of significance to the participants and not in chronological order.
Theme Two: Spirituality: Nurses Engaging in Relational Practices

As the participants in this study described spirituality and health in palliative home care, they also described spirituality and their work with other team members involved in giving care. The second major theme emerged from six sub-themes: benefits experienced by Registered Nurses in caring for the dying at home; role and attitudes of the Registered Nurse; Exploring and engaging in therapeutic conversations about spiritual care needs; challenges to engaging in therapeutic conversations; near death experiences; and spiritual care interventions.

The participants described the structure of spirituality in palliative home care in the context of their experience as a Registered Nurse. The expertise demonstrated by these nurses in caring for the terminally ill is reflected in their spiritual care practices.

Benefits Experienced by the Registered Nurses in Palliative Home Care

The palliative nurses described many positive benefits to their spiritual well-being as a result of caring for individuals at the end of life and their families in the home care setting. Jenny experienced an environment filled with tension and hostility when she worked in acute care but feels valued by individuals and families whom she cares for in the home. Jenny has found that the life lessons she has learned has given her guidance for her own life as well as professional fulfillment and role satisfaction from knowing that you have made a difference in someone's life. In the initial interview with Jenny she discussed the insights that dying individuals shared with her. They are "very philosophical" and "brilliant," she says, "they teach me something every single day." Jenny values the practical wisdom she gleans from her interactions with terminally ill individuals and their families. Jenny reveals that her experience caring for individuals with a life-limiting illness has taught her the secret to living a richer, fuller life with fewer regrets. It is by putting her relationship with her family first over her commitment to work. During our
interview Jenny often expressed that she loves her work, and finds personal fulfillment in it. Beyond this Jenny expressed a feeling of personal pride that she would be leaving her children a legacy of helping people in the world.

Astrid expressed a deep gratitude for life and the importance of celebrating the gift of a day "...because I think you never know when it's going to be your time to go... every day is a gift...." She has also experienced the gift of a deeper, stronger personal faith as a result of caring for dying individuals and their families in the home. Astrid shared her faith as an awareness of the importance of life that is heightened from her work "...[when it's] time to go and you're going to have nothing to hold on to in a sense that your house won't matter, your car won't matter, your relationships won't matter, your materialism won't matter, your money in the bank won't matter. All that will matter is hanging on to Jesus...."

Many of the nurses interviewed voiced that their faith life was more vibrant as a result of caring for people who are at the end of life. "I start seeing things differently. I guess [I'm] looking for the spiritual piece in it all," (Astrid). The relatedness that occurs in caring for dying individuals brings an openness of sharing and creates a space that nurses' consider in the dying individuals expression of spirituality. Astrid recalls being at the home of individuals who listen to music with lyrics that are at times religious in nature and how she felt this touched both of their souls. Melissa has found that her experience of spirituality in palliative home care has enabled her to talk to her own family members about death and dying. She says "...it has helped me be a little bit more open and certainly a lot more articulate... with my family members."

The Registered Nurses interviewed also expressed a gratitude for the practical insights and life lessons they have gleaned from the caring for those at the end of life. For example, Astrid speaks of an experience she had where a woman who was a hoarder passed away and the
stress this created for the sister left behind as she struggled to sort through all her personal effects and paperwork. "...that was... a good learning lesson for me... just keep things light, don't be a hoarder...."

Roles and Attitudes of the Registered Nurse in Palliative Home Care

Registered Nurses such as Melissa choose to work in palliative home care because "it was a good fit" for them. Melissa says "...I just wanted to have the full continuum of a person's real life and my last 4 years in home care have really confirmed for me that real life doesn't happen in the hospital - it happens where the person's at...." Other nurses such as Jenny feel "called" to the work. Melissa says that nurses need to keep a proper perspective of the importance of their role in helping people with their spiritual needs by "not underestimating your effect on people but not over estimating your importance either." Palliative nurses and the individuals/families they care for may understand and experience spirituality differently but as Melissa says "I believe there's enough common ground between people of whatever faiths that we can help each other through the experience." Spirituality is unique to the individual nurse and for many is a source of support in coping with the duties entrusted to them. Each nurse has unique qualities and beliefs that enable him/her to relate to others in meaningful ways. Registered Nurses in palliative home care work very closely with individuals and families in the final months, weeks and days of life therefore they are in an ideal position to support spiritual needs through engaging in therapeutic conversations, providing information about community supports, and assisting the individual to facilitate meeting their own spiritual need. The nurses interviewed in this research study also spoke to the importance of assessment, planning, implementation, evaluation, and documentation of nursing care of dying individuals and their families in palliative home care in order to demonstrate to their managers and advocate for increased spiritual care resources in home care.
The Alberta Comprehensive End-Of-Life Assessment Tool (AHS, 2012) was introduced to the palliative home care team in November of 2014. However, at the time this research study was done in 2013 it is unclear if screening for spiritual distress was a routine part of palliative nurses' initial and ongoing assessment of terminally ill client's needs. At the time this study was done there appears to have been some inconsistency in screening for spiritual care needs of the dying depending on the individual nurse's perception of her role in relation to spiritual care. Kay is likely not alone in her belief that her role as a palliative home care nurse is to focus on physical symptom management. However, the majority of participants in this study perceived that caring for the spiritual needs of terminally ill individuals and their families was an important part of their role. Astrid stated "...I listen for the psychosocial spiritual pieces and if I think they need some extra support or help... I leave it with the case manager or I'll even phone a social worker or try to get them connected... although I don't know the spiritual support people in their community... I encourage them to connect with their own spiritual support." Rosa described a freedom when engaging in therapeutic conversations "...basically your avenue is wide open as a nurse in that area because people will share private moments of their life in palliative care...."

Most of the nurses I interviewed viewed their role as one of facilitating supportive care for individuals and their loved ones which included many possibilities such as: helping people to either reconnect or connect to a faith community of their choice, facilitating a home visit by an identifiable spiritual care leader in the community, engaging in therapeutic communications about spiritual concerns, journeying with the individual/family as they transition from this life to the next, helping individuals/families understand the meaning of their experience with death and dying, and bearing witness to the experience.
Western society has been said to be a death denying society but as Lee says "...death is inevitable..." Nurses attitudes toward death and dying influenced the importance they placed on caring for the spiritual needs of the dying. All of the nurses interviewed understood death and dying as a natural part of life - a transitional stage that is in large part shrouded in mystery. The participants also expressed either a curiosity about or a belief in life after death. Astrid says "...my belief is that we come from God and we go back to Him and going back to Him is going home." Fear of dying is one of the more frequent concerns individuals experience at the end of life. Some of the participants in this study perceived this fear as being more of the process of dying rather than the fear of death itself. "Will it hurt," "will I suffer," "will I be aware of what is happening to me?" are some of the questions asked of nurses. Most of the nurses interviewed expressed a belief that God can help the individual come to a place of peace and experience an assurance of eternal life. Astrid explains "...sometimes I just can't bring them to a peaceful place because they don't believe...." Melissa balances out this perspective when she says "...we can't always fix things but we will not abandon them, we will be there with them...."

Astrid revealed that she has been privileged to bear witness to the outward manifestation of an inward transformation when the dying individual's spiritual need is met (e.g. the individual moves from a 10/10 anxiety level to a 0/10 anxiety level). Moving people from fear to faith - that is the power of providing spiritual support to families identified as palliative. Astrid believes that the work of alleviating suffering is ultimately between the individual and God ("the Big Guy") but that God often chooses to partner with people in His work.

Role modeling acceptance of "what is" gives individuals and families permission to accept the reality of their situation according to Melissa. "I hear you saying "I wish it wasn't this way"...but let's see what we can do to put our heads together and deal with the reality as we find
it - and it's only the hardest thing in the whole world to accept what is but if the professional caregiver can model that it just seems to give permission to everybody else to do so as well. ...to just accept what is no matter how much it sucks."

**Exploring and Engaging: Therapeutic Conversations**

In phenomenology the use of symbols and environmental cues are referred to as "the language of semiotics" (Munhall, 2010, p. 152). They serve as a starting point for the nurse to explore the importance of spirituality with the individual and/or family in order to help them make meaning sense" out of their experience with terminal illness (Munhall, 2010, p. 152). For example, Jenny noticed one of her clients of South American origin was wearing a rosary around his neck, which spoke to her about his identification with the Roman Catholic faith. This cued Jenny to start exploring the meaning of spirituality with this gentleman and to assess if he had any unmet spiritual needs. It was an opportunity for this gentleman who was actively dying to seek out his faith before he passed away. Jenny astutely assessed that spiritual support from an identifiable leader of this man's faith community was a priority need for him and his family. Jenny then proceeded to help bridge a gap in client care by facilitating the man's need to speak with a priest and receive the sacrament of the sick before dying.

Engaging in therapeutic conversations about spirituality, suffering and illness with individuals and families is the portal to healing according to Wright (2005). The Palliative Home Care Nurses interviewed for this research study felt that it is both a privilege and an honor to be allowed into the individual's inner life (or inner sanctum) for a period of time. It is a powerful, potentially life-changing opportunity to make a difference in someone's life. The inner sanctum is that place of refuge for one's soul during times of distress and hardship. Kay says "I found deeper feelings of frustration, of unfairness, of how difficult this is." The reality of one's
own mortality and impending death can contribute to anxious feelings in individuals as they near the end of their life. It is also a cue for nurses to open up a dialogue with the individual about their concerns. Rosa relates the following experience "...I went to a patient in a night shift and she had tremendous anxiety - she felt her pleurex needed to be drained and I listened to her chest and it was good and she had just been drained like 5 hours previous and basically I said to her "I honestly don't think you need to be drained. I think this is an anxiety issue" and she said to me "you're right!" and I said "well can you share what your anxious feelings are about?" and she said "well I'm dying. Wouldn't that make you anxious?." An individual may experience fear of judgment for past misdeeds in the afterlife and need someone to help them work through those unresolved issues that are plaguing them and hopefully come to a place where they can receive forgiveness and inner peace. Through engaging in therapeutic communication nurses can give individuals an opportunity to voice those anxious thoughts and feelings so they can hopefully come to a resolution and find inner peace. Rosa described an encounter with a woman who expressed fear of facing judgment in the next life. "I basically was taking the role of a priest and listening to her confessions... and I explored 'well what do you believe?' and asked her what she found truthful about that and... basically in working through that she came to a place in her faith... and she said to me [on a subsequent visit a few weeks later] 'just having that conversation - I do not have the same level of anxiety anymore." Nurses who engage in these conversations have certain characteristics that enable them to engage in these healing conversations. For example, Jenny adopts a phenomenological stance of the novice learning from the experts with an open, non-judgmental, recursive (i.e. back-and-forth) conversation style when engaging in conversations about spirituality with individuals and families of other faiths. Statements made by the participant’s demonstrated courage and a strong confidence in their ability to support
terminally ill individuals or their loved ones when experiencing a disturbance in the inner sanctum. These same nurses also made statements that reflected a humble attitude and a teachable spirit when sharing their stories of spirituality within their practice. Silence was also seen as a very powerful communication tool when used within the framework of a helping-trust relationship. Lee described a comfort level in dwelling with the individual in the silences because she recognized this person needed time to process their thoughts and feelings about their situation.

Spirituality is a way into experiencing forgiveness. Lee recounts a powerful story from *The Tibetan Book of Living and Dying* about a Tibetan Monk who visits the home of a dying man only to discover that he is struggling with past misdeeds and in need of experiencing forgiveness. "...the dying person asks him 'do you think God will ever forgive me for my sins?' and the [Monk]...say[s] 'forgiveness already exists in the nature of God, it is already there, so God has already forgiven you for God is forgiveness itself...but can you truly forgive yourself?' and that's the real question."

In the interviews the nurses were asked how they might open a conversation that leads to a discussion of spirituality. Melissa stated "...I think it takes a bit of experience as a nurse to be able to um say in various ways...'I don't know but here's what we've experienced in the past; here's what people tell us; here's some of the things we might want to consider in the context of your beliefs/of your faith and your philosophy - how does that fit?' and that usually is enough of an answer for most people just to know that you're not afraid of the topic as a caregiver." Kay says "I might ask them leading questions in terms of "how are you coping? who is...your support network?" that would open up the possibility of talking about their...faith community."
Individuals may be curious about the nurse's personal faith/beliefs - Registered Nurses may self-disclose, if they feel comfortable doing so, as part of building a helping-trust relationship. Nancy says "I guess if people ask me about what I believe then I share my faith with them but I do try not to proselytize because I know that some um people don't appreciate that." In addition Kay described nurses' engagement in therapeutic conversations as "...a dance we nurses do - right? To build a trust allowing [the individual to]...manage the conversation as to where...they want to go and to follow [them]." Healing conversations involved getting "to the heart of the matter" (Kay) by using therapeutic communication techniques such as open-ended questions in such a way that it opens things up. Melissa emphasized the importance of "avoid[ing] getting anybody's defenses up by framing [dialogue] in a religious or spiritual context especially if we do not know that person or what their spiritual beliefs are. I don't want to, you know, 'step in it' unknowingly. Conversations with terminally ill individuals and/or their families involved discussions around end-of-life planning including determining the goals of care; encouraging venting/verbalization of feelings and validating those feelings. The participants identified limited time as the number one challenge to engaging in therapeutic conversations with individuals and families followed by systemic goals that either value or undervalue the importance of spiritual care of the dying.

The participants interviewed reflected a knowledge of and skill in applying therapeutic conversation techniques. Being fully present and active listening are, two very important communication techniques nurse’s use when engaging in healing conversations. Melissa concurred by saying "...personally I believe there is something very healing about having an individual story heard, really heard...and not flinching in the presence of someone else's suffering...it takes practice." Simple, open-ended questions are often all it takes to open up a
conversation about spiritual concerns with terminally ill individuals and families. It is important to use the language that the individual uses to frame the discussion around spirituality. For example some individuals may use more traditional, faith-based language in speaking about spiritual concerns while others may frame their experience more in terms of "values and beliefs." Giving space for the individual to share their story; being fully present in the moment; active listening; asking open-ended questions and making clarifying statements; demonstrating empathy; validation of the individual's feelings; focusing on and commendation of the individual and family strengths were some of the therapeutic communication techniques employed by the participants of this research study.

Melissa described feeling that it is easier to talk about spirituality in larger groups (i.e. among health care professionals) by framing the discussion in "neutral terms" such as "ethical/moral distress." Regardless, the one thing we all have in common is that Registered Nurses care for the whole person and as long as we keep that as our focus as health care professionals we can be tolerant of language, belief systems, and understandings that may differ from our own" …"the one commonality seems to be at the end of the day as long as we are supporting the client as best we can you just... you're just good with it you know." Helping people connect with a spiritual support person or encouraging them to engage in a conversation about spiritual concerns with someone they trust and feel comfortable with is one strategy in helping people to address their spiritual concerns. "...I think we go from the broader topic and then narrow it down to what exactly their need is" (Rosa).

**Challenges to Engaging in Therapeutic Conversations**

Individuals who are nearing the end of their life often have limited energy and nurses only have a limited amount of time with them to address their priority needs. Nurses can mitigate the
time constraints by assuring the individual they will be able to continue on that conversation in
the next visit or as Kay says "...the...impression you want to give is "that I'm going to be back." The individual's willingness to open up and engage in conversations about their spiritual needs is also a factor. Jenny relates the story of caring for a terminally ill young woman in her mid-40's with breast cancer that had metastasized to the lungs, liver and then leptomeningeal disease. This lady was married with two children and was "a lovely, lovely person" and Jenny felt very connected to this family. Jenny attempted to explore the meaning of spirituality with this couple however they put up a barrier to engaging in this conversation because their belief system was unable to reconcile the reality of this woman's diagnosis existence of a loving God. Jenny immediately recognized the family was not open to discussing matters of faith and respected those boundaries by not engaging in any further discussion on the topic. Registered Nurses' in palliative home care recognize that each individual in their care is unique and therefore have their own unique beliefs about life after death. Nancy expressed concern for those individuals she has encountered in her practice who are reluctant to express their spiritual concerns about their spirituality "...partly because of what I believe but largely because I'm concerned that they... don't have peace, or they're very afraid... of what's coming even though they don't necessarily believe that there is anything coming."

Melissa admits to sometimes having difficulty separating the threads between an individual's values, beliefs, cultural, and religious influences and the impact it has on health care decisions they make at the end of life. The Goals of Care Order is a tool used in the Alberta Health Care System, which enables members of the health care team to have a discussion with individuals and families about their treatment goals and to document that discussion to ensure that individual's choices are honored as well as ensure continuity of care. There are 3 main
categories and 7 sub-categories ranging anywhere from R1 (full medical treatment including CPR, resuscitation, intubation and ICU care) to C2 (comfort care, does not want transfer to hospital and no resuscitation). Quality of life is important at every level but some individuals may choose quality of life versus quantity of life and opt for conservative comfort care while others may want more medical interventions and life saving measures with the view of prolonging their life. Melissa says "I have a hard time teasing apart... the cultural versus the religious influences on... people who don't want to discuss Goals of Care because it would be construed as um... a lack of faith in God or something like that if they were anything less than an R1. "...okay, we want to respect your beliefs but... have you considered the effect of ongoing, aggressive treatment... versus... quality of life... and what does the individual want." Religion, values, beliefs, family dynamics, cultural influences, differing world views all influence an individual's goals of care at the end of life. It may be that what the individual chooses seems medically inappropriate or incongruent with the philosophy of palliative care, which emphasizes quality of life and comfort care. Situations like this can be difficult for health care professionals as individuals may experience a more difficult illness trajectory and a traumatic death. Nurses feel a responsibility to do their due diligence to engage families in discussions about their goals of care and to support individuals in their choices and most important to document those discussions and the choices that are made. Registered Nurses may experience moral and/or ethical distress when an individual's choices may go against what the nurse understands as "good palliative care." When life worlds collide Melissa says "I don't know that we make a lot of headway on those cases sometimes but we do our due diligence...." It is also important for the health care team to debrief and support one another through these complex challenging cases.
Near Death Experiences

Most people are curious about what lies beyond the veil that separates life and death. We see in part and we understand in part but one day all will be revealed. The recent proliferation of books about near-death experiences shows that there is a need for the comfort and reassurance that there is more to life than living and dying. Most of the nurses interviewed demonstrated an open-mindedness in entertaining the possibility that there are existential phenomenological realities experienced by others that are not congruent with the nurse's own life world. Dying individuals or their loved ones may have supernatural experiences such as visions, dreams, receive messages from angels, or have near death experiences that are very real to them and who is to say that it isn't real? Melissa says "...I have had co-workers who had other clients reporting things like visions or um what they thought were messages from angels, that sort of thing, and it doesn't matter what your personal spiritual beliefs are - I think that's what I would count as... as part of that ambiguity - you have to be open to the possibilities."

Rosa described a very meaningful encounter with an individual who had a near-death experience and how she helped him work through this experience. Kay admitted to a curiosity and fascination about near-death experiences and has read numerous books on the subject. She was able to use this knowledge to give comfort to a grieving daughter who was worried about where her mom would go after she died. Registered Nurses in palliative home care have had experience caring for people who have had near death experiences or have a certain fascination with this phenomenon and often have done a lot of reading on the subject. Registered Nurses in palliative home care have deeply held beliefs about the perpetuation of the spirit at the time of death. These deeply held beliefs about life after death enable the palliative nurse to cope with the duties expected of them. Rosa tells the story of an experience she had in the ICU where a
patient went into v-tachycardia and flat lined so they spent 4 minutes trying to revive him. When this gentleman revived he recounted his near-death experience to Rosa. "I turned around and I was going down a tunnel...I have not been right with God and I know I was going to hell - it was getting darker and darker and darker as I went down this tunnel and the fear coming upon me was incredibly troubling and I feel like God has given me a second chance." Thankfully Rosa was in a strong enough position spiritually to validate this individual's experience and help him work through the meaning of the experience to him. This was a moment of awakening for this gentleman to realize he had unresolved issues in his life that he needed to attend to. Melissa, in her conversation about life and death, asks the question "what is your personalized heaven?

**Spiritual Care Interventions**

In addition to engaging in therapeutic conversations the nurses I spoke with shared other strategies in supporting the spiritual care needs of the palliative population. For example, Astrid often suggests to individuals who express spiritual concerns that they go to a bookstore and look in the faith-based section to see if one of the books speaks to them. This is an easy, practical, non-threatening nursing intervention that can help people meet their own spiritual needs. Prayer was another nursing intervention nurses were willing to engage in either with or (privately) on behalf of individuals who were struggling with existential distress. Visualization or guided imagery were other therapeutic techniques the participants employed to help individuals connect with their ultimate source of support and to find inner peace. Melissa reports that her only "conscious spiritual therapeutic intervention...is try to consciously help them acknowledge what is and acknowledge what we wish was because what gets hidden takes energy to push down. So bringing it all into the light of day often helps [the individual] to move on...."
Theme Three:  Holistic Care of Individuals Nearing the End-of-Life

In order for nursing care to be truly holistic nurses must attend to the spiritual needs of dying individuals and families. As the participants in this study described the essence of spirituality in palliative home care, they also described holistic care of the dying as being important. The significant statements that pertained to the subjects' descriptions of the essence of spirituality in palliative home care were used to identify the theme cluster "holistic care of the dying" and its' related sub-themes. Within these 4 sub-themes, (Suffering, Spiritual Care of the Dying is an Essential Service, Spiritual Needs of Individuals at the End of Life, Spiritual Care Needs of Families) the palliative home care nurses described factors that contributed to their understanding of the essence of spirituality within palliative home care.

Suffering

The question about suffering is a philosophical one that must be asked and explored - not necessarily with the intent of finding "the answer" as there will be multiple perspectives on this question but to use this as a catalyst to develop a greater empathy for the suffering of others, to motivate us to love and serve others, and to transcend our present human condition. Suffering has been viewed as a threat to the individual's integrity (Chapman & Gavrin, 1993). Kay says "...we see so much suffering and it is really hard not to have that impact you personally at times and so...it really piques my interest...why some people cope better than others and just the big general question of why." Kay reflects on this question later on in our interview when she says "not that I think that I am going to find the answer because of course I realize that...there is no one answer...." Lee's perspective is that "...suffering is inevitable the minute you are born you are born into suffering...." All the nurses interviewed viewed suffering as a natural part of the human experience. Jenny uses the term "total suffering" to describe the devastating effect that
unmet spiritual needs can have in an individual who is nearing the end of life. "Total suffering" or "total pain" may be expressed verbally in expressions of fear or in physical symptoms such as pain or other troubling symptoms that are difficult to control. Jenny believes that the source of this pain comes from a belief system that leaves the client with unanswered questions about death, dying and life after death. "Total Pain" is a concept first coined in the 1960's by Dame Cicely Saunders (a pioneer of the modern hospice movement). Dame Saunders education in the disciplines of nursing, medicine and social work combined with a strong Christian faith were the impetus for her work with terminally ill cancer patients (Clark, 2009). It is a concept that captures the unique and multi-dimensional nature of pain related to any terminal illness to include the physical, spiritual, psychological, and social domains of the individual which are really not separate domains at all but intricately interwoven in the seamless fabric of their being.

As human beings we often struggle with our understanding of "why bad things happen to good people," (Astrid). Many of the nurses interviewed expressed a belief that natural disasters, illness, and suffering are to be expected in life and it is how we respond to these events that is important. Unexpected tragic events can happen to anyone, anytime, anywhere. God is not the author of tragedy, Astrid says, He is seen in mankind's compassionate response to these events. When we are confronted with a personal crisis do we choose to give up or become bitter, angry and blame God for our troubles or do we surrender to the process allowing ourselves to transcend our present circumstances? Astrid reflects on this question but cautions it can be tempting to want to "fix" things instead of allowing the person to struggle but in doing that we rob that person of the opportunity for personal growth and transformation. The Registered Nurses interviewed recognized that individuals and families will struggle with spiritual issues and that it is okay to struggle. In working through these issues individuals often gain a new perspective,
undergo a metamorphosis or inner transformation and become stronger individuals as a result of the struggle. Astrid makes the following analogy to illustrate this point "...that story about the... caterpillar... in the cocoon... trying to turn into a butterfly. ...if you cut the sac you actually kill the butterfly because in order to become a butterfly it has to struggle to build up its' strength so that when it does break open you know, the casing, it turns into a beautiful butterfly and flies."

Speaking from a Buddhist perspective Lee says the main point of being a palliative home care nurse is to help relieve suffering and to help people find Nirvana (i.e. inner peace, right here and right now). She says "as long as you're at peace with yourself..you are...in Nirvana." In order to understand the meaning of suffering on a personal level involves "...meditat[ion], contemplating on life itself - your own life and by observing others [lives] and how things happen in the world...and all the suffering may be meant for you to slow down and think about the whole point of your...suffering...and how do you get out of that and not having to come back to that, you know, suffer[ing in] life then that means...you've got to improve yourself and be nice to everyone and create... positive karma."

**Spiritual Care of the Dying is an Essential Service**

Dying can be a lonely, isolating experience and the participants in this study expressed strong beliefs that holistic nursing care includes the spiritual and it is therefore an essential service. The nurses' life world and belief system have empowered them to engage in healing conversations with individuals and families in alleviating their spiritual distress. "The nurses' approach is intentional but not "a planned approach" says Donna. In their conversations the participants revealed that conversations about spiritual needs are approached in a consultative, recursive, back and forth process between the nurse, individual and family in order to identify the priority needs of the individual or family member(s) which may include spiritual concerns.
Rosa tells the story of being called out to the home at 2 a.m. in the morning to visit a dying man of the Catholic faith who wanted to receive the sacrament of the sick but she didn't know who to call. She called this man's parish priest who refused to come to the home in the middle of the night and since there is no chaplain coverage in palliative home care she phoned the chaplain of a local hospice who drove an hour across town just to fulfill this man's final wish. "The family...absolutely thanked me for getting that in place for they said after the priest left [the patient] was absolutely at peace and he was able to [die] feeling that he had resolved what he needed to resolve so that was essential - to me that was an essential service and except that I had to find someone to offer that - I had no way to offer that because that hadn't been set up in my work place." Thanks to this Registered Nurse's perseverance she was able to facilitate a dying man's spiritual need at a critical time in his life. The outcome of this experience could have been very different if the nurse had not viewed spiritual care as an essential service and taken the initiative to help this individual to fulfill his spiritual need.

**Spiritual Needs of Individuals at the End of Life**

Individuals nearing the end of their life are usually "very clear" about their beliefs and what they are expecting according to Melissa. Therefore it is important for nurses to *listen, really listen* not only to what is being said but the manner in which individuals communicate their truth with us. Melissa feels it is important to reframe the persons experience in terms of their values in order for them to express what is most important to them. Melissa's words beautifully reflect the importance of nurses framing conversations about spiritual concerns in a language those in our care will understand. Individuals may feel isolated or alone in their experience of illness and in dying that may cause them to wonder if what they are thinking and feeling is normal. Melissa explains "...I believe part of my role as a palliative nurse is to open that [discussion] up for
whatever they feel comfortable [talking about] and helping them to normalize that experience because everybody thinks their anxiety is unique - they're alone in this experience." Most of the nurses interviewed for this research strongly believe that terminally ill individuals being cared for in the home desire spiritual support from a recognized spiritual care expert such as a member of the clergy or a spiritual care professional. However, the participants in this study also expressed a concern that individuals were falling through the cracks in terms of having their spiritual care needs met, as currently there is no process in place that enables nurses to make a timely referral to a member of the clergy or a spiritual counselor. The team social worker can provide supportive care and counseling in the home and have knowledge of where resources exist for support in the community. While there are a variety of psychosocial resources available on an outpatient basis in the community individuals nearing the end of life are often too frail to access these services on an outpatient basis.

Anxiety and agitated behavior were two of the common symptoms identified by the participants as symptoms of spiritual distress in people nearing the end of life. Nancy related the story of an individual who was verbally abusive toward his wife and she sensed that this was a sign that the individual was experiencing a spiritual crisis. Nancy believed that if there was a process in place whereby she could have referred this individual to a team chaplain or team counselor this may have helped to improve the outcome for this family – “he may have had some relief from his anxiety”.

Donna identified the importance of helping dying individuals reconnect with an identifiable leader of their faith community in order to "work through some things" or unresolved issues identified during their life review thereby helping them to find inner peace before they die. To illustrate this point Donna tells the story of when she facilitated an individual nearing the end of
life to connect with the Father of a Roman Catholic Church in the community who was willing to come to the home and meet with the individual. In addition to this Donna identified the team social worker as the spiritual support person for the individual/family when there is no pre-established connection to a spiritual support person in an identifiable faith community. Unconditional love, acceptance, support, non-judgment, and someone to walk alongside us in the journey are spiritual needs of individuals identified by most of the participants in this study. Donna says "...the main thing is just to let them feel there is somebody there to hear them and support their family."

Dying individuals often experience anxiety over how their loved ones will cope when they are gone. Coming to terms with one's own mortality also produces a certain amount of anxiety and uncertainty. Participants shared stories of witnessing the benefits experienced by dying individuals and their families who received timely and ongoing support from spiritual care coordinators in the home. Dying individuals were able to move from a place of fear, anxiety, and uncertainty to a peaceful, comforted, certain place (Astrid). Participants identified therapeutic conversations, guided imagery (i.e. visualization), and prayer as some of the interventions they used to help individuals connect to their source of spiritual strength and find inner peace. Dying individuals need reassurance that their family will continue to be cared for after they are gone.

Spiritual Needs of Family Caregivers

Family members need spiritual support as well not only during their loved ones illness but also throughout the grief, loss, and bereavement process. The participants in this study provided support to families through engaging in therapeutic conversations (i.e. being fully present, active listening, validating feelings). Kay explained that it is very normal for family caregivers to
struggle with issues related to loss, grief, and bereavement throughout the illness trajectory and [nurses are here] to support the [caregivers] and validate that how very difficult this is and how that it is so important that they take care of themselves...whatever that means to them...."

Registered Nurses in palliative care often help families to make meaning/sense of the experience of grief, loss, and death through bereavement support. Donna tells a story of helping a grieving family cope with the death of their 15-year old daughter by helping them to visualize the beautiful light and peace their daughter experienced before she passed. Rosa tells the story of a woman who saw an angel on her porch the day her husband passed away. "...I feel as a nurse it was so important that she felt she could share that because I was arriving at a very private time and a time that's critical in her faith of thinking of where her husband is at and she felt the freedom to share that and so as nurses I feel it is so very, very important that we can be that sounding board." Rosa shared the example of how individuals who are at the end of life often will see and/or talk with a loved one who has already passed away. These experiences often serve as source of comfort to families as it reassures them that there is life after death.

**Exhaustive Description and Statement of Identification**

The final step in Colaizzi's (1978) method of data analysis is combining themes and sub-themes into a thorough description of the phenomenon under study. Thus I as the Researcher integrated the statements of meaning, themes, and sub-themes into a comprehensive description of the results of my analysis. This has allowed me to combine the findings of each participants' story into a description that reflects the purest essence or structure of spirituality in palliative home care from the nurses' perspective. This has been presented as eight subjects telling the essence of their stories to myself. Finally, Colaizzi (1978) suggests this comprehensive description be formulated into one "unequivocal statement of identification of [the
phenomenon's] fundamental structure...." (p. 61). Drawing upon an example of a statement of identification from Colaizzi's own research to guide me (1978, p. 65), I formulated a descriptive statement from the rich description provided by the participants of this study providing a clear, precise, and systematic description of the essence of spirituality in palliative home care from the nurses' perspective. This will be presented in Chapter 5, including discussion, and implications for practice and research.
CHAPTER FIVE

Coming to an Understanding

The essential structure or universal essence of a phenomenon will emerge from the common threads throughout each participant's narrative, according to Husserl (1964), and indeed this was the case in this research study. These universal essences represent the identity of the phenomenon of spirituality in palliative home care from the nurses' perspectives and are detailed in Table 1. The identifiable themes that emerged from the raw data reflected the spiritual caring practices of the nurses as they shared the truths experienced in their life world.

Despite my best efforts it was impossible to completely bracket my biases and preconceptions of the phenomenon under study and nowhere was this more evident than during the writing of my thesis when I reviewed the findings with my Advisor. This became an "aha" moment for me that helped me identify just how very difficult it really is to step outside one's life-world and set aside your preconceived notions of how things "ought to be" as opposed to how things "really are". This means that my approach and all that was involved in the research process, from the research question to intuiting meanings to moving to the language of the individual participant was unavoidably influenced by my participation in the study. I did have to go back and re-bracket my personal biases since I experienced a personal epiphany or "ah-ha moment" which helped me to see the essence of spirituality in palliative home care from the perspective of others which is really what I was hoping to achieve as a result of this research study. In qualitative research understanding "is a dialogue in which interpretation always occurs with reference to a personal, shared, and historical position" (Todres & Wheeler, 2001, p. 3). This experience caused me to re-examine my own biases and presuppositions and seek to be more objective in coming to an understanding of what it was like for palliative home care nurses
to care for the spiritual needs of individuals and their families at the end of life. This did not change the results of the data analysis or my findings except when it came to identifying the essential structure of spirituality in palliative home care. I identified compassionate care of the dying as the essence of spirituality in palliative home care because I saw nurses' going above and beyond the call of duty in terms of caring enough to take the time to talk about concerns with individuals and spending extra time above and beyond the call of duty in helping individuals find a chaplain or priest to come to the home to minister to that person's spiritual need in the midnight hour. Since I have witnessed with my own eyes the compassionate care palliative home care nurses provide in the line of duty I believed there was evidence of this in the raw data. However, in consultation with my supervisor I came to realize the data did not support this finding for this particular study.

Each participant shared insights that made the experience "real" for me as a researcher. In this way I have attempted to bring to life or "give voice" (Sandelowski & Barroso, 2002, p. 7) to the phenomenon under study as the participants experienced it reflexively as revealed through the insights and feelings they shared with me. Finally, it will be up to the reader to interpret the findings of this research study using a language that they understand. For it is with the individual reader that "understandings dwell" (Colaizzi, 1978, p. 66).

**The Essence of Spirituality in Palliative Home Care**

It is the individual nurse who draws upon her/his expert knowledge, clinical skill and cherished values and beliefs to provide a human response to the dying individual's experience.

*The essence of spirituality in palliative home care from the Registered Nurses' perspective is that the nurse must be attentive to one's inner self in the engagement of spiritual and relational nursing practices in the holistic care of the dying.*
This research study provides the essence of palliative nurses spiritual caring practices with the aim to offer supportive care to individuals and family caregivers in the home. It is difficult to represent this in a diagram because the threads of this caring process are interwoven in a whole rather than separate and distinct domains. However, for the sake of clarity, the findings of this study are illustrated in Figure 1 as a continuous, cyclical process. In the first major theme *Spirituality and Health*: nurses through the awareness of their inner self, are authentically present in caring interactions, creating a space where healing can occur. 'Authentic presence' involves self-reflecting on the nurses' own spirituality, values, fears, to become conscious of their own spirituality, and experiences with life, death, and dying. Desbiens et al. (2012) discussed that self-reflection may help nurses judge their self-competence and become more conscious of their role. Use of 'authentic presence' opens up a space where the dying individual feels free to discuss their concerns in relation to death and dying. Sharing self – is bringing a part of yourself to the relationship by sharing values, fears, and meanings with regard to life and death. Palliative care nurses must be aware of the implications of these interactions: they may prevent the nurse from focusing on and recognising that the individual experience of quality of life is dependent on meaning and personal context as defined by the patient and family, not the health professional (Desbiens et al., 2012; Reed, 2010). Existential growth—through nursing care in the journey to death, in relationship, is where the nurse and patient gain understanding of the illness and the dying experience. Moreover, while nurses guide the patient in the exploration of understanding his/ her dying process, nurses may expand their understanding of life and death and the meaning of their work, transforming themselves and gaining personal satisfaction (Desbiens et al, 2012; Reed, 2010). Realistic hope—in the therapeutic relationship, between nurse and dying individual may have an important role in
reframing patient and families’ hopes by helping them move the goal from cure to a realistic idea of prognosis and treatment (Reed, 2010). This process helps to give patients and families the opportunity to work through significant issues, improving their ability to cope with a life-threatening illness and their quality of life. The palliative nurses use of authentic presence, openness, willingness, and a non-judgmental attitude all the while bearing witness to the changing/evolving journey of dying individuals over time are reflected in the narratives of the participants of my research study. The following is a descriptive statement of the essence of spirituality in palliative home care from the nurses' perspective.

**Exhaustive Description**

The participants began their stories with the cues they observed as motivating factors for self-care which acted as a catalyst to caring for the spiritual needs of individuals and families. These cues were described as their knowledge of the importance of spiritual self-care in themselves, in their colleagues, and in those they care for. For example, if one factor such as the individual's expression of anxiety served as a cue for the nurse to respond to the suffering of the individual this cue would be sufficient to cause movement towards assisting the individual in meeting their spiritual need. First, the individual nurse would process the cue through her understanding of the importance of providing for the spiritual care needs of individuals nearing the end of life and their families. Nurses would draw upon their life experience, their nursing knowledge and skill including their therapeutic communication skills, use of empathy and voice to engage in active listening, being fully present in the moment to support the individual or family member in need. If the individual in distress requested the nurse pray with him/her then this should evoke a caring response in the nurse by engaging in prayer as a therapeutic intervention to address the individual's anxiety.
If the individual's anxiety persisted this is not evidence of failure to provide good nursing care of spiritual needs. Nurses are responsible to engage in therapeutic conversations but cannot and should not try to "fix" the problem. So sometimes, despite nurses' best efforts to listen, to support and validate the individual's feelings and concerns the individual is not able to come to a place of peace regarding their issue(s). Ultimately it is the responsibility of the individual nurse to do the work involved in addressing their spiritual needs. For example, participants described an observable behavior such as anxiety serving as a cue for them to explore the meaning of this observed behavior with the person. The nurse may not have the answer but acts as a sounding board allowing the individual to express their spiritual concerns and to validate those feelings. It is in this interaction that a space for healing can be created. The individual expressing their need, the nurse actively listening, using her authentic self, to support the individual in their journey. Often the individual will tell you what they need if we listen closely. Kay puts it this way, "I found deeper feelings of frustration, of unfairness, of how difficult this is. I don't ever shy away from if they want to talk about [that]... so I validate those feelings and encourage um them to talk ... or the families.

If the client or family caregiver's anxiety persisted despite the nurse's best efforts he/she might then turn to the Clinical Nurse Specialist (CNS), the palliative physician consultant, or the Care Manager for guidance and support. In the absence of a chaplain to guide the spiritual care practices of the palliative team nurses will often make referrals to one of the team social workers. In their stories, some participants expressed confidence in their ability to identify spiritual care needs and support individuals and families during their time of need. However, there were others who emphasized the physical symptom management takes priority over spiritual care
needs and did not feel they were qualified nor did they have the time to provide this type of support.

Therapeutic conversation is a foundational relational practice that foster nurses attending to dying individuals spiritual care needs. Palliative nurses who are confident in entering into the spiritual domain with dying individuals might initiate a therapeutic conversation with them about their spiritual concern(s) as a caring response to the pain or suffering they are experiencing. However, the participants in this study reported that more often than not it is the family caregiver(s) who are in need of spiritual support as the dying individual is too exhausted and frail to engage in an in-depth conversation with the nurse. It is the family caregiver who then responds to the spiritual concerns of their loved one. Failing to initiate these conversations could result in the silent suffering of those who are nearing death or leave family members feeling unsupported in caring for their loved one at home. The essence of spirituality in palliative home care means supporting the individual to experience quality of life and comfort/inner peace as death approaches. It is also a way into providing a deeper level of support to family caregivers to connect with their source of inner peace, hope and strength. I believe that the participants of my study expressed a high degree of self-efficacy and resiliency in helping individuals face and master the challenges they were experiencing which made them more likely to engage in healing conversations.

If the individual continues to struggle despite the nurse's best efforts to provide spiritual caring this is not necessarily a sign of failure on their part. Astrid illustrates this point beautifully when she shares the analogy of the caterpillar in the cocoon. "…if you cut the sac you actually kill the butterfly because in order to become a butterfly it has to struggle to build up its' strength so that when it does break open you know, the casing, it turns into a beautiful butterfly and flies."
If individuals being cared for at home not have a pre-existing connection to a faith community or are too weak and frail to access spiritual care resources in the community they will often fall through the cracks in the system.

Spiritual care has taken on a more structured approach in the participants' practice environment in the past 6 months with the introduction of the Alberta Comprehensive End-of-Life Assessment Tool (AHS, 2012). This assessment tool includes a spiritual needs assessment which invites questions "regarding the beliefs and practices that involve faith, religion, values, the spirit, and/or the soul" (AHS, 2012, p. 11). Nevertheless, it is still incumbent upon the individual nurse to draw upon his/her personal and professional values and beliefs, clinical knowledge and skill, and their capacity to persevere and be creative in the face of limited resources to provide a caring response to the deepest, most visceral needs of the human spirit.

Discussion of Findings

In this study, nurses' perspectives of their lived experience of spirituality in palliative home care were similar and different from those of their colleagues. The findings in this study reveal that attentiveness to one's inner self was the central motivating factor for palliative home care nurses engagement in spiritual and relational nursing practices in the holistic care of the dying.

Palliative care nurses described living in a world of ambiguity. They described many tensions when bearing witness and walking alongside individuals in their experience of pain/suffering or fear/anxiety toward a place of inner peace. The nurses' also revealed a dialectical tension in addressing spiritual care needs in the home especially in trying to communicate with individuals who were in denial and in engaging in conversations about unmet spiritual needs when individuals put up roadblocks to do so. Spirituality was viewed by experienced palliative care nurses as a part of their life-world of nursing practice, described by
nurses as part of the construction of their personal life and professional nursing practice. As a result, the RNs' who participated in this study viewed the experience of spirituality in palliative home care as an opportunity to support the individual in their life journey learning "life lessons" along the way while moving through it into new ways of understanding and being.

The participants embodied spirituality did not seem to view spirituality as a means to escape the reality of suffering but felt it was an important way to ease the pain and suffering of those in their care. They viewed spiritual care as a part of their role as Registered Nurses and an opportunity not only to have a therapeutic effect on those in their care but an opportunity for them to learn and grow as individuals. Indeed, the palliative home care nurses in this study demonstrated competency and courage (empathy) (Fagerstrom et al., 1998) and a caring attitude (Tanyi et al., 2009) in their openness and willingness to engage in therapeutic conversations with individuals and families about their spiritual concerns. In being willing and able to share their "unique self - [their] spirit - with another" the nurses in this study certainly possess the X Factor which Carr (2008) identified in nurses who engage in spiritual care. The participants in this study were very articulate in describing the lived experience of spirituality in palliative home care and demonstrated a high degree of confidence, knowledge, skill and efficacy in the engagement of healing conversations with individuals and family members.

**Nurses' Spirituality and Spiritual Self-Care**

The three major themes, revealed that the nurses' own spirituality and spiritual self-care was an integral part of palliative nurses' lived experience of spirituality and spiritual care of those at the end of life. Palliative home care nurses are at high risk for caregiver burnout due to their frequent exposure (often over many years) to pain, suffering, grief, and loss yet they demonstrated incredible resiliency despite their frequent exposure to such stressors. Thus, all the
participants understood the importance of attending to their inner being and encouraging spiritual self-care practices in others in order to avoid caregiver burnout and strengthen resiliency. Melissa concurs by stating, "...if I don’t take care of myself I can’t do it for anyone else."

The findings of this study did concur with many of the findings previously identified during my literature review. The nurses interviewed during this research study answered the research question by reflecting on a single caring event in palliative home care that they felt demonstrated spiritual caring in relational practice. Palliative nurses descriptions of spirituality were diverse in nature but generally lined up with one or more aspects of Puchalski's (2009) definition of spirituality. For example, Kay's description of her own inner journey "as a young adult searching my own spirituality has been just those questions... what is the meaning of life, what is the central purpose for my existence and is there a greater power than myself". Astrid emphasized the importance of being "connected" to "the significant and sacred" by saying "it feels like these words... bring you back to the beginning which is “the beginning” … which starts with God, ends with God, the Alpha and Omega… and I think if we really start searching words and searching life and things it just all seems to connect". Lee described spirituality as "food for the soul." The findings also agreed with Boston et al. 2011; Penman et al. 2009; Sinclair et al. 2006b; Sulmasy, 2002) that while spirituality may or may not include religious practices it most certainly involves a journey in life and those relationships and experiences which give life meaning and purpose. The home care nurses in this study did voice that spirituality was a shared experience between the palliative nurse, the individual client, and their family (Sinclair, 2009, 2011; Sinclair et al., 2006a).

Melissa spoke to how difficult it is to tease apart the various strands that distinguish spirituality from culture and religious influences in an individual's being. Similar to the views
expressed by those in other research studies, Astrid and Melissa, expressed a desire to understand how nurses of other faiths or belief systems (i.e. outside of the Judeo-Christian faith) understood the phenomenon of spirituality in palliative home care. For example Astrid wondered if palliative nurses of the Muslim faith have similar perspectives of the phenomenon under study as herself but perhaps just use different language or how agnostics and atheists experience spirituality in coping with, assessing and addressing issues pertaining to death and dying.

Lee expressed the belief that suffering in life is inevitable and that it was an opportunity to become a better person in this life and create positive karma for the next. Astrid revealed a belief that it is not always necessary to “fix” the situation and sometimes we have to allow people to struggle because otherwise we rob them of the opportunity for personal growth and transformation (Nagai-Jacobson & Burkhard, 1989).

Holistic care of individuals with a life-limiting illness and their families was identified as one of the seven subthemes in the literature search and is also identified a prominent finding in this study. Holistic care of those nearing the end of life means supporting them in their treatment decisions (e.g. quality of life versus quantity of life), in settling any unfinished business, and in their journey from the time of diagnosis throughout the grief, loss, and bereavement process (Steinhauser et al., 2000, p. 2476). Many dying people do fear becoming a burden to their loved ones and need help with the practical aspects of end of life planning including determining their goals of care, making a will and a personal directives, ensuring a power of attorney, enduring power of attorney and a living will are in place (Steinhauser et al., 2000, p. 2476). Most of the nurses interviewed for this research study had a strong sense of duty in attending to the spiritual needs of those being cared for at home. Beginning with the initial assessment and throughout the illness experience these nurses intervened by making referrals to resources in the community or
to other members of the multidisciplinary team; through prayer, by engaging in therapeutic conversations; validating thought and feelings; by taking a non-judgemental approach to care; and to reclaim hope (Steinhauser et al., 2000). The participants in this research study demonstrated a commitment to caring for the spiritual needs of those in their charge and stressed the importance of allowing the individual to lead the way (Ronaldson et al., 2012).

Spiritual assessment tools was identified in my literature review however was barely touched upon in my interviews with palliative home care nurses. Spiritual needs assessment in palliative home care does use an identifiable assessment tool but it is the nurse's ability to engage in therapeutic conversations, her courage and skill in dealing with complex end-of-life issues, and her ability to be creative in accessing spiritual care resources that often make the difference in whether the person receives the support they need to die at peace. Often the advanced nature of the individual's illness might preclude the client having the energy to engage in a therapeutic conversation with the nurse. Participants in this research study as well as findings in relevant research literature reviewed did express the importance of exploring what is meaningful to the client in terms of religious rituals, hopes, fears, care decisions, and the meaning of spirituality (Borneman et al., 2010; Gowri & Hight, 2001; Puchalski & Romer, 2000).

Challenges to Nursing Care of the Spiritual Needs of the Dying was identified in my initial literature review but was only briefly touched upon during my interviews with the palliative home care nurses. The challenges identified by the nurses in my research study included time constraints (Ronaldson et al., 2012), difficulty accessing spiritual care resources in the community, and nurses' understanding of their role in relation to caring for the spiritual needs of those in their care (Rose & Glass, 2009; Sulmasy, 2002). The nurses' interviewed for this study
did identify a need to normalize spiritual care in nursing practice through self-reflection and openly dialoguing about spirituality (Hayden, 2011).

**Holistic Care of Individuals Living with a Life-Limiting Diagnosis**

Holistic care of the dying involves a philosophical shift away from cure toward maintaining the integrity of the individual and creating space for healing interactions to occur. This study confirms this assertion as many of the nurses interviewed believed that healing and wholeness are still possible at the end of life or they would not engage in therapeutic conversations with clients and loved ones about their spiritual concerns. The nurses in this study reflected an approach to care that is both holistic and ethical (Sommerville, 2006) and respectful of the individual's humanity (Hayden, 2011; Ronaldson et al., 2012; Tiffen & Bentley, 2009; Sinclair et al., 2006b; Sulmasy, 2002). Some of the nurses in this research study expressed that they struggle with teasing apart the differences between culture, religion, and spirituality however research has shown that these boundaries are artificial and that in reality all the strands are woven together in a "living nexus" (Bush & Bruni, 2008, p. 539).

**Existential/Spiritual Pain and Suffering**

Research studies have either linked (Boston et al., 2011; McGrath, 2003) or tried to differentiate (Bolmsjo, 2001) between spiritual and existential pain/suffering/distress. I would propose that the individual's experience of living with a life-limiting illness is whatever they say it is. While nurses may interpret that the individual at the end of life is suffering or being in pain, the individual themselves may not understand their experience in that way. The individual may feel suffering is too strong a word for their experience but frame their spiritual concerns using words such as "challenges" or "pain." Framing the conversation using language that is meaningful to the individual is part of the art and skill of relational nursing practice. The
participants in this study demonstrated their understanding of the experience of spirituality in relation to pain/suffering as they reflected upon their experiences in caring for individuals with a life limiting illness and their families. Research literature has identified that the individual's experience of suffering is connected to their feelings of loss (past, present and future) and fear of dying (Arman & Rehnsfelt, 2003; Berlinger, 2007; Bolmsjo, 2001; Boston et al., 2011; Bruce & Boston, 2008; Mako et al., 2006; Sinclair, 2009, 2011). However, acceptance of "what is" may help the individual to lay the foundation to transcend their experience (Nagai-Jacobson & Burkhardt, 1989).

**Spiritual Care Health Needs at the End of Life**

The stories participants shared during their interviews did reflect an understanding shared by 70% of the respondents in a cross-sectional survey conducted by Steinhauser et al. (2000). The issues that is most important to individuals approaching the end of life include: pain & symptom management, preparation for death, achieving a sense of life completion, decisions about treatment preferences and holistic care. Being mentally aware, having funeral arrangements planned, not being a burden to their families, and finding peace with God were also important concerns identified in Steinhauser et al.'s (2000) study and expressed in the stories participants shared during this study. The participants of this study did use a variety of nursing interventions to help individuals and families meet their spiritual needs (i.e. referral to a Social Worker or Chaplain, prayer, active listening, validation of thoughts and feelings, unconditional support, and instilling hope (Steinhauser et al., 2000). The participants of my study, like the hospice nurses in Ronaldson et al. (2012) study were committed to client-centered care in meeting spiritual care needs.
Challenges to Nursing Care of the Spiritual Health of the Dying

Research literature identifies several barriers that Australian nurses experienced in addressing the spiritual care needs of the dying which included: "...opposing social forces, an inner dialectic tension between nurses' expectations of their professional practice and what is valued in their practice setting" (Rose & Glass, 2009, p. 185). Nurses' perceptions of their role contribute to the ambiguity nurses experience in relation to spiritual care of the dying. For example, nurses may perceive the focus of their care should be on managing physical symptoms more so than the spiritual needs of the individual. Nurses struggle ethically with knowing the right thing to say or do in addressing spiritual care needs of the palliative population (Sulmasy, 2002). Time constraints was another barrier to addressing spiritual needs of the dying (Bolmsjo, 2001; Puchalski, 2007; Ronaldson et al., 2012; Sinclair et al., 2006b). The participants of this study did tend to emphasize broader spiritual issues such as helping others find peace, comfort, and meaning in the final phase of life (Kruse et al., 2007). Some of the participants did stress the importance of self-reflection and openly dialoguing with other team members about spirituality in caring for those at the end of life in order to "normalize" spiritual care in nursing practice. In addition to ongoing education in spiritual care of the dying participants in this study identified therapeutic communication skills, self-confidence and having role models to emulate as being important in helping to normalize spiritual care at the end of life (Tiffen & Bentley, 2009). The participants of this study also identified a need for clear nursing practice guidelines and policies, continuing education and better education and documentation tools to support them in their practice (Hegarty et al., 2005).

The findings indicated that palliative nurses in home care may find communication to be a challenge with dying individuals due to limited energy of the individual and individuals may be
reluctant to share their spiritual concerns if they sense the nurse is not comfortable therapeutic conversations. Multiple voices within the family unit in combination with any number of meanings individuals will ascribe to their experience of living with dying can make engaging in healing conversations even more complex (Wright, Brajtman & Bitzas, 2009).

**Implications for Practice**

The findings of this study contribute to the relatively small amount of research data pertaining to the essence of spirituality in palliative home care from the nurses' perspective thereby contributing to the limited pool of knowledge health professionals have about this phenomenon. In giving voice to this population of health care providers future studies can be designed that may contribute to improved quality of life, comfort, and peaceful death for home care clients identified as "palliative" and their family caregivers.

The findings of this descriptive phenomenological study may help to improve Advanced Practice Nurses (APNs’), Primary Nurses’, and nurse researchers' understanding of the meaning of the phenomenon of spirituality in palliative home care. Husserl (1964) believed that we can improve our understanding of a phenomenon by returning to the its' source. Application of our understandings that arise from findings in phenomenological research are as important as findings that arise from quantitative studies in that they possess the potential to improve client care outcomes (Colaizzi, 1978). Taking this new understanding to a higher level in nursing education, research, and practice may prove beneficial in the design of future nursing interventions that are both respectful and responsive to the expressed spiritual care need(s) of terminally ill individuals and family caregivers.

The findings in this study also highlight the need for educational programs that help nurses' achieve confidence in their therapeutic use of self. Registered Nurses' awareness of the potential
benefits of attending to the spiritual needs of those at the end of life may help to alter the individual's and/or family caregiver's fears, anxieties, pain and may improve health care outcomes by supporting the whole person and not just focusing on symptom management.

Facilitate Peer Support

The finding in this study indicates that experienced palliative care nurses who engage in spiritual self-care recognized the importance of supporting the spiritual self-caring practices of individuals with a life-limiting diagnosis and their family caregivers. The findings of this study indicate the importance of facilitating opportunities for reflective practice in nursing as well as the importance of engaging in self-reflection on those experiences which inform our own spirituality. Providing opportunities for nurses to share their expert knowledge with their peers may prove to be very beneficial both personally and professionally and improve nurses' resiliency in addressing complex care needs in the home.

Strengths and Limitations

The strength of this study is the value it places on the lived experience of spirituality in caring for persons nearing the end of life and their family caregivers. "Experience is considered as one's perception of one's presence in the world at the moment when things, truths, or values are constituted" (Morse & Field, 1996, p. 125). The findings of this study also have the potential to improve patient care outcomes and nurses' job satisfaction.

The Registered Nurse's viewpoint is significant in relation to spiritual caring practices of dying individuals being cared for in the home and their family caregivers. The nurses' in this study valued the opportunity to be heard and recognized as possessing valuable knowledge about themselves and their world. Their knowledge has the potential to improve not only their own health care practices but the health care of their colleagues and those they care for. The new
understandings that emerge from this study may help to improve client care outcomes by promoting the most humanistic standard of care possible as well as impact nursing policies in the practice setting (Morse & Field, 1996, p. 158). Another strength of this study is that it has captured an embodied perspective of spirituality that has high clinical relevance as opposed to a more theoretical approach.

The limitations of this study arise from its' subjective nature. Outcomes may be affected by the individual participant's ability to recall events, their emotions, the choice of interview setting, and how busy they are. The nurse researcher's skill in interviewing and her perception of what is being communicated may also be influenced by similar factors. Nurse researchers in phenomenological research attempts to approach the phenomenon under study without preconceived notions about what will be found in the investigation. Data from self-reflection is used by researchers "to help them become aware of, and bracket out, the presuppositions and assumptions they bring to the investigation" (Polkinghorne, 1989, p. 47). However, human beings are fallible so it is likely impossible to ferret out all of the researcher's underlying biases, assumptions and presuppositions. The drawback in this is that the researcher may attempt to direct the study as opposed to letting the data speak for itself. Journaling throughout this research process helped me to identify the biases, assumptions, and presuppositions that occurred as did consulting with my Thesis Advisor and advisory committee.

The small group of participants in this phenomenological study may limit its transferability as the variability with eight participants is likely to be limited. It was not possible for all variables within the palliative population to be included in the small number of subjects in this phenomenological study. The findings of this study are transferable in the sense that it provides "insights into others' experiences while enriching our own" (Morse & Field, 1996, p. 158).
Recommendations for Further Research

Research into what factors may influence, promote, and deter spiritual caring practices among Registered Nurses in palliative home care as well as the health care system’s capacity to provide resources to support nurses in their caring practices may result in improved client care outcomes and caregiver satisfaction with the health care system. Building opportunities for reflective practice regarding spirituality and the kinds of spiritual concerns palliative nurses' encounter may not only provide opportunities for the development of personal knowledge but improve nurses' use of therapeutic self in the engagement of relational practices with clients and family caregivers. It also has tremendous potential to improve client care outcomes, reduce health care costs associated with the management of pain and suffering, and increase nursing job satisfaction. Henoch, Danielson, Strang, Browall and Melin-Johansson's (2013) randomized, controlled study concluded that management can improve client care outcomes and nursing staff’s confidence in managing spiritual care needs by providing short-term educational opportunities inclusive of reflective practice. International research of palliative care researchers and clinicians indicates there is a "need to strengthen the evidence-base of spiritual care at the end of life by evaluating models of practice and staff training and developing accessible and viable interventions" (Selman et al., 2014, p. 2). Research also indicates there is a need to improve empirical evidence to inform clinical practice and policy guidance" (Selman et al., 2014, p. 2). The reality is that with limited health care dollars the palliative home care program is unlikely to hire a chaplain for the home care program as helpful as this might be. However the role of CNS's can be expanded to address some of the issues and gaps to address the spiritual needs of the palliative population being cared for at home. There is also a need to identify and address systemic barriers to spiritual care as unsupported spiritual care needs as recent research
out of the U.S. suggests these unmet needs will result in higher costs associated with end-of-life care "particularly among ethnic minority groups and patients with high levels of religious coping" (Selman et al., 2014, p. 2). The understanding of the phenomenon under study would benefit from methodological diversity and rigor (Selman et al., 2014); interdisciplinary, culturally sensitive studies and a more diverse population such as rural and generalist home care nurses or by including other disciplines that provide client care in the home. Perhaps either a phenomenological study with a more diverse sample or an ethnographic study that looks at the culture of the palliative care team in urban and rural settings would provide a more accurate picture of "the collective soul" (Sinclair et al, 2006a) of the palliative team.

**Conclusion**

Key findings in this study demonstrate the importance of providing opportunities for reflective practice in regard to spirituality and health as well as the importance of attending to one's own spiritual health through personal reflection. Toward this aim I did achieve my intended aims. Future studies would benefit from methodological diversity and rigor; interdisciplinary, culturally sensitive studies with a more diverse population such as rural and generalist home care nurses. As a result of my role as a co-investigator in this research study my understanding of spirituality in caring for individuals approaching the end-of-life and family caregivers has been has been enriched. First of all I have developed an overwhelming conviction that the focus of spiritual care should be on promoting health and quality-of-life as well as helping individuals to negotiate a peaceful and dignified death. While it is important to address issues pertaining to death and dying the focus of nursing care should be in identifying and building on the strengths of individuals and families. Helping individuals with a life-limiting illness and family caregivers explore their thoughts and feelings around death and dying while
providing them with information and situational support will help them prepare for this final stage of life. While nurses often find creative ways to address spiritual needs when we create opportunities for reflective practice everyone is the richer for it because we learn from each other. Descriptive phenomenological research, like people, is never really complete (Colaizzi, 1978). Research can be terminated when the researcher is satisfied and data saturation has been achieved. However, as this research study comes to a conclusion another door of understanding is waiting to be opened as we evolve in our personal knowledge of the lived experience of spirituality in the context of palliative care in the home (Merleau-Ponty, 2002).
Figure 1: Three Main Themes Emerging From the Research Study The Essence of Spirituality in Palliative Home Care: the Nurses' Perspective.
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Appendix A: Recruitment Letter

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TITLE:

*The Essence of Spirituality in Palliative Home Care: The Nurses’ Perspective*

SPONSOR:

* N/A

INVESTIGATORS:

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**Tf:** (403) 220-6258

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.
BACKGROUND

Understanding lived experience of spirituality in palliative home care is an emerging phenomenon in nursing research. Although the majority of research literature on the topic of spirituality in health care has been written by nurses in the last 25 years very little has focused on the experience of Registered Nurses working in a palliative home care setting. During a recent clinical practicum in partial fulfillment for my degree in Master of Nursing I noted that the nurses I spoke with held various points of view as to whether or not spiritual care was even a part of nursing work. Their viewpoints were informed by different world views, beliefs, values and experiences. This made me curious as to how palliative home care nurses understand spirituality in their area of practice. Were nurses engaging in spiritual care but not really recognizing it as such? Do palliative home care nurses feel supported in caring for the spiritual needs of their clients? Did my informal survey indicate a need for increased education and spiritual care resources in the workplace such as well-defined practice guidelines and spiritual assessment tools to guide nurses in their caring practices? I believe the essence of spirituality will emerge as these amazing nurses share their perspectives. It will be an opportunity for nurses to share their successes and provide an opportunity to build toward greater capacity for caring for the spiritual needs of dying individuals and their families in the home care.

WHAT IS THE PURPOSE OF THE STUDY?

To gain an understanding of the essence of spirituality in palliative home care from the perspective of nurses.

WHAT WILL I BE ASKED TO DO?

Registered Nurses will be invited to share their experiences of spirituality in caring for dying adults with advanced illness and their families in the community. Nurses will be interviewed individually. Conversations will take place in a quiet, private environment that is mutually agreed on. The interviews will be conducted at the nurse’s convenience. Each interview will take about one hour. During the interview the researcher will take the occasional note with permission. Depending on the nurse’s preference there may be more than one interview.
Are There Risks or Benefits If I Participate?

In this type of research there is always a degree of risk. There is no way to know what is going to come up in conversation, especially when the purpose of the interview is to hear the unique experiences of palliative home care nurses. Sharing these experiences may bring forth painful memories or highlight fears for the future. Each participant, as an employee of Alberta Health Services, has access to support from the Employee Family Assistance Program (EFAP) via self-referral. The telephone number for EFAP is 1-877-273-3134. Psychosocial support as a result of participating in a research interview is also available through the South Calgary Health Clinic, Walk-in Therapy Clinic (ph. # 403-943-9374), which requires no appointment or referral to access psychosocial counseling. If participants in this study find the interview process too emotionally painful a moment will be offered to compose themselves and if that is not adequate the interview may be stopped and rescheduled.

WILL I BENEFIT IF I TAKE PART?

Speaking about one’s experience can help the individual make sense of their own journey with caring for adults with a life-limiting illness as well as bring awareness of what other members of the health care team may be experiencing.

The information we get from this study may help us to provide better support in the future for individuals and their families living with terminal illness.

DO I HAVE TO PARTICIPATE?

Study participation is voluntary. There will be no negative implications or consequences to you if you do not choose to participate. Consent will be ongoing, allowing the participant to withdraw at any time from the study. It must be noted though that due to the nature of phenomenological research, once the analysis phase is initiated the ability of the researcher to totally remove your interview data or the resulting different understanding that the researcher has gained will be impossible.
WHAT ELSE DOES MY PARTICIPATION INVOLVE?
Your participation does not involve any other commitments.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?
Participants will not be paid for participating. If the interview location selected necessitates paying for parking, the researcher will cover this expense.

WHAT HAPPENS TO THE INFORMATION I PROVIDE?
Participants are assured that all information will be kept confidential. All information will be kept on a password protected computer, and after the research is completed all files will be transferred to an external memory device that will be stored in a locked cabinet for five years with all paper documents related to this research study. Only members of the research committee and the University of Calgary Conjoint Health Ethics Research Board will be able to see the data. As per Alberta privacy rules, after 5 years all data will be destroyed.

WILL MY RECORDS BE KEPT PRIVATE?
Anonymity is of particular difficulty in this research proposal as the sample size is small, and the use of multiple direct quotes in the final research report may identify the nurse through their experience, even if their names are withheld. Therefore a promise of strict anonymity cannot be guaranteed. Due to the highly personal nature of the data and the central focus of this research being articulated of the individual nurse’s experience, attempts to remove any possibility of recognizing an experience or event from the reported data would compromise the results of this research. Further, there is the potential for parts of this research to be published. Names will be altered where necessary to protect as much as possible the identity of all participants. The use of personal demographics will be limited in the final report and all subsequent publication.
APPENDIX B: Consent Form

SIGNATURES (WRITTEN CONSENT)

Your signature on this form indicates that you understand to your satisfaction the information provided to you about your participation in this research project and agree to participate as a research subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Dr. Shelley Raffin Bouchal at (403) 220-6258

If you have any questions concerning your rights as a possible participant in this research, or research in general, please contact the Chair of the Conjoint Health Research Ethics Board, University of Calgary at (403) 220-7990.
The University of Calgary Conjoint Health Research Ethics Board has approved this research study.
A signed copy of this consent form has been given to you to keep for your records and reference.
Attention all Community Care Coordinators – Registered Nurses working in Palliative Care you are invited to participate in a qualitative research study exploring your perspectives of spirituality in palliative home care. This study is in partial fulfillment of the requirements for a Master of Nursing Degree through the Faculty of Nursing offered by the University of Calgary.

Ethics I.D. Approval #

If you have any questions about the study or are interested in the study please contact Ruth Herbert at email address: herbertr@ucalgary.ca or call 403-256-9096

Ethics I.D.#: REB13-0007
APPENDIX D: Interview Guide

Guided Questions

What is your lived experience of spirituality?

As a palliative home care nurse how does your understanding of spirituality impact the care that you provide?

Tell me about a time when you had a spiritual experience in caring for a dying individual and/or their family?

How does your spirituality connect you with your individuals and families in your care?

How has your experience with individuals living with a life-limiting illness and their families impacted your own spiritual life?

In what way is the work you do purposeful and meaningful to you?

If there is one thing you could tell me about your experience of spirituality that hasn’t already been said what would that one thing be?

* Questions may be modified slightly during interviews.