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NAME OF AUTHOR: Elaine Greta MacInnis

TITLE OF PROJECT DISSERTATION:

IMPROVING THE QUALITY OF SPIRITUAL CARE
TO END-OF-LIFE IN CANADA: ALLEVIATION OF SUFFERING
Perspectives of the Terminally Ill, Their Families and Professional Caregivers

DEGREE:

DOCTOR OF MINISTRY

YEAR THIS DEGREE IS GRANTED: 2013

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IMPROVING THE QUALITY OF SPIRITUAL CARE TO END-OF-LIFE IN CANADA: ALLEVIATION OF SUFFERING

Perspectives of the Terminally Ill, Their Families and Professional Caregivers

by
Elaine Greta MacInnis

A Project Dissertation submitted to the Faculty of St. Stephen’s College
in partial fulfilment of the requirements for the degree of

DOCTOR OF MINISTRY

Edmonton, Alberta
Convocation: November 4, 2013

DEDICATION

To the memory of my Husband
Alan Douglas Brown, P. Eng.

I have been blessed to have had you in my life.
You supported me in my research and work to discover
ways to alleviate suffering experienced by patients and their families
in the face of impending death.
You truly exemplified in your living and in your dying
3 *"F" Factors*
that gave you *courage and dignity*
to deal with the numerous challenges
associated with the diagnosis of a terminal illness:
Faith – Family – Friends

ABSTRACT

This project/dissertation began with the question: Is it possible to alleviate or diminish a person's pain and suffering in the transitional space from the time of the diagnosis of a life-threatening illness throughout the illness trajectory until death, and his or her family's subsequent period of bereavement? The question evolved from my work as a Hospital Chaplain on the oncology and palliative care units witnessing various ways illness and suffering lead one into the spiritual domain where questions about God and life's meaning or purpose emerge.

The focus of the study took the form of a two-year qualitative research project with staff, patients, family members, and friends who commented on their perceptions and/or experiences within the health care system identified on the *"Continuum of Palliative Care."* [1] The analysis revealed that when serious illness arises in the life of an individual, it is usually accompanied by suffering. Suffering does not affect just the person experiencing illness; illness is a family affair and suffering is pervasively present, yet not always recognized. Spirituality has been found to play a key role in health and illness; however, the spiritual domain is often neglected, overlooked, or forgotten. Health care teams need to be prepared to respond with sensitivity to dying patients and their families; identify spiritual needs /concerns; incorporate compassionate interventions to alleviate or diminish suffering, foster hope and healing to improve the quality of care to end of life, and offer bereavement care after the death.

This research project also developed into personal work. The journey involved coming to an understanding, not only of her husband's terminal diagnosis but her own journey with God and functioning in health care ministry as a Christian exemplifying respect, love, and compassion for patients, their families, and staff of all faith traditions.

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[1] © The Canadian Hospice Palliative Care Association.

ACKNOWLEDGEMENTS

I wish to express my appreciation to the many people whose support and assistance contributed to the completion of my dissertation.

To the patients and their family members who were my teachers on this pathway; who shared their fears, hopes, and dreams with me under the most difficult circumstances of life. The professional colleagues who participated in this study who challenged and encouraged me as they offered insights and the wisdom of their experience. Dr. Brian Berger, the Palliative Care Team York Central Hospital, and Rev. Karen Fox, Coordinator of Spiritual Care were extremely supportive. The importance with which they regarded my work and research was a blessing that encouraged me to keep going when the road got bumpy.

Several other people made important contributions to the successful conclusion of this dissertation. Dr. Leslie Gardner, Dr. Catherine Cornutt, Dr. Kristine Lund, members of my doctoral committee, for the gift of their time and attention in reading the thesis in several drafts. You challenged me to go deeper and to be clearer. The reverence with which they journeyed with me was truly a gift; and Dr. Peter Barnes for his encouragement and willingness to audit my research.

Last but not least, a thank you to the special people in my life; my son John and Cindy MacKay, my daughter Marina and Steve Wilcox, my brother Dr. Edmund MacInnis, twin sister Elizabeth and Hans Jansen who have influenced my life more ways than they know. Without my family’s love and their faith in me this dissertation would not have been a possibility.

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CHAPTER 1

INTRODUCTION TO RESEARCH QUESTIONS

At some time, in some way, we must all face the end of life. And most of us share a
common hope that when death comes to us or to a loved one, it will be peaceful
and free from pain and suffering. We hope to face death surrounded by those we
love, feeling safe, comfortable and cared for. [2]

Reasons for Exploring the Terminally Ill Person's Experience of Suffering

This study originated from my observations of suffering working as an Ordained Baptist Minister and Hospital Chaplain caring for dying patients and their families. When a life-threatening illness and/or a terminal diagnosis occur in the life of an individual or a family member, it is frequently accompanied by suffering. While there have been numerous studies exploring suffering, there have been few in-depth studies exploring the *internal* and *external* experience of suffering from the viewpoint of persons diagnosed with a terminal illness, their families, the impact on one's relationships with self, others, and God in the transitional space from the time of diagnosis throughout the illness trajectory until death.

Although death is an inevitable and natural human experience, it has frequently been shrouded with mystery, anticipated in fear, and envisioned as an experience of immense suffering. Suffering is part of life and the human condition, with suffering experienced personally in a physical, emotional, social, or spiritual way, or experienced as witness to another's suffering.

According to Kahn and Steeves, suffering is a private lived experience unique to each individual. In reality, suffering cannot be assumed to be present or absent in any

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[2] *Living lessons.* (2001). The GlaxoSmith Kline Foundation & the Canadian Hospice Palliative Care Association, 1.

given clinical condition or situation in view of the fact that suffering is dependent on the meaning of the loss or event. The experience of suffering is both intrapersonal and interpersonal since it involves the person's own coping with suffering and the caring of others.[3]

A central component of providing spiritual care in the face of impending death is one's encounter with suffering. Suffering impacts a patient's body, mind, and spirit. The interprofessional health care team meet individuals across the life span and often at the crossroads of suffering and loss. We are in the unique position to help individuals and their significant others who may be in physical, emotional, social, and/or spiritual pain related to impending loss or fear of the unknown. Why is it that suffering and its alleviation, which are a major focus of health care seldom spoken about in health care settings? Reed challenged this silence and failure to acknowledge suffering by health care professionals. "The success of modern science conveys the impression that suffering has been conquered, but sensitive observation in any health-care environment demonstrates that suffering is pervasively present."[4]

Experiences of suffering lead one into the spiritual domain when patients and families attempt to express what they are feeling or experiencing and try to find meaning in their distress and suffering. Patients in this study asked: "Why is this illness occurring at this time in my life?" "Why do some people die before they have a chance to live a full life?" "Will my family remember me?" "Is God punishing me for something I have done?" "What will happen to me when I die?" Suffering does not affect just the person

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[3] Kahn, D. L., & Steeves, R. (1996). An understanding of suffering grounded in clinical practice and research. In B.R. Farrell (Ed.), *Suffering* (pp. 3–32). Sudbury, MA: Jones and Bartlett.

[4] Reed, F. C. (2003). *Suffering and illness: Insights for caregivers.* Philadelphia, PA: F.A. Davis, 4.

experiencing illness; suffering is a family experience linked to and intertwined with the beliefs that one holds about his or her illness. Individual beliefs of patients and family members are involved in both the experience of suffering and in making inferences about suffering.[5] Therefore, it is important to explore cultural, religious, and spiritual beliefs in clinical work with patients facing impending death and their families.

I believe this study gave me an opportunity to learn more about the spiritual experience of terminal illness: the impact a palliative care team's involvement can have on the patient's ability to cope with their diagnosis in the face of impending death, on the patient–family relationship, and the influences of religion and spirituality on the illness experience. Thus, additional questions began to surface. *What* happens in the relationship between members of the health care team and the patient or family that is helpful or unhelpful? More focused on my role as a Hospital Chaplain I asked: *What* spiritual care interventions can be implemented into goals of care that help alleviate or diminish suffering? Are there times when religious or spiritual beliefs can actually interfere with medical care, leading to increased health problems and suffering? *Who* am I in my role as a Hospital Chaplain for the terminally ill person and his or her family in the transition from life to death?

Pondering the origins of my questions brought back memories of my childhood in Nova Scotia where I lived with and experienced the dying of my mother. Since I was involved in the care of my mother, I was intimately connected to her journey in ways that I was not aware of at the time. I recall seeing her furrowed brow and clenched jaw as she silently suffered in pain following radiation treatments. I remember quietly entering her

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[5] Wright, L.M., Watson, W. L., & Bell, J. M. (1996). *Beliefs: The heart of healing in families and illness.* New York, NY: Basic Books.

room just to watch her peacefully sleeping or standing outside the bedroom door listening to her pray for relief from pain and suffering. I tried to imagine what it was like for my mother knowing that she would not live to see her teenage children graduate from high school and university, marry or have children. I wondered how it was possible for her as a registered nurse and educator to maintain a strong faith and eventually come to a place of inner peace and acceptance of death. As a teenager at the age of 13 I had the courage to question God. "Why? "If God loves us, why is she having so much pain and suffering?" My mother who died of cancer at 44 years of age, had a profound impact on my life. The memories of her illness and the journey we shared together as a family leading to her death influenced my calling to ministry and fueled my passion to become an advocate for changes in the transformation of health care and ministry exemplifying competent and compassionate spiritual caregiving "*in action.*"

Spiritual Caregiving: A Calling to Ministry in Health Care

Approximately 26 years ago with the call to ministry, during a period when I was seriously ill and a patient in hospital, I was given an incredibly realistic image in a dream. In the image I was quietly standing at the bedside of a patient who had died; his wife was holding a wooden cross while gently stroking her husband's hand, and the children put their arms on the mother's shoulder. The oldest son, in his early teens, handed me the Holy Bible from his father's night stand and said, "I would like you to read from the chapter in John's Gospel[6] that says I will see my father again and pray for my father and our family." While the interaction between me and the other persons in the image was for the most part nonverbal, it did convey to me the importance of "*a time for listening*" and *"a time for caring"* in our work with patients. The images from my

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[6] John 14: 1- 4. *The holy bible: New international version*. (1996). Grand Rapids, MI: Zondervan.

childhood led me to the *why* questions, and the image in the call communicated *how* to be present with and offer spiritual care under some of life's most difficult circumstances. For years, these images have been deeply rooted in my memory; have impacted my faith and understanding of God who our parents introduced to their children during those early formative years; also the importance and use of sacred rituals and transitional objects in the face of impending death. They have woven my two worlds together: a world that encompasses eternal life with a temporal world here on earth that embraces the vision of a health-care system that supports and nurtures the spirituality of patients and their families while simultaneously helping health care professionals and caregivers to maintain their own spiritual health.

In response to the call to ministry, I left my position as an accountant, making a career change to pursue theological studies, obtaining a Bachelor of Arts in Psychology and Religious Studies from Mt. Saint Vincent University; during this time I obtained my certification in Reality Therapy Choice Theory from the William Glasser Institute in California. I worked part time as a therapist at Stillwater Professional Centre while attending Acadia Divinity College pursuing a Master of Divinity–Master of Divinity Pastoral Counselling Degree, and Diploma in Prison Ministry. During this period I had the privilege of engaging in hundreds of therapeutic conversations about serious illness with individuals and family members. Their conversations repeatedly included memories and descriptions of suffering when hearing their diagnosis for the first time, the meaning they gave to their suffering from spiritual spheres of influence, their beliefs about what caused the illness, fear as they envisioned how they would experience the last days of life before dying, and concerns about how their families would manage emotionally and financially in their absence.

To learn more about ministry in the areas of death and dying and factors that contribute to distress and suffering when diagnosed with a life threatening illness, I pursued Clinical Pastoral Education (CPE) and Pastoral Counseling Education (PCE). The educational units which combined clinical practice were taken at the Nova Scotia Hospital in Dartmouth, the Victoria General Hospital in Halifax, Nova Scotia, and the Royal Alexandra Hospital in Edmonton, Alberta. In the CPE part of the programs I was the chaplain assigned to Intensive Care, Oncology, and Palliative Care units. It was during this time that I began to observe and care for patients whose lives most often ended unexpectedly, frequently with uncontrollable pain and suffering inhibiting their ability to enjoy quality of life. In the PCE part of the programs, Object Relations Theory and D. W. Winnicott's concept of transitional phenomenon became a focus in the therapeutic counseling setting. Even though his interest was clearly in early childhood development, I saw how his theory and the concept of transitional space and transitionality is one that can be applied beyond the context in which Winnicott used it. I could envision ways his theory could be interwoven into an effective approach to gain insight and understanding into the person's transition from life to death; as well, when integrated into professional practice it can provide a compassionate approach in the care of the terminally ill patients as they become aware of their terminal diagnosis and unknown future. My experience with dying persons over the years has led me to believe that the *space* to which Winnicott refers holds the possibility for spiritual nurturing and healing that need to be explored as a phenomenon of ministry in health care.

For the past 14 years, working within the health care system, I have frequently heard patients say: “My faith is the most important influence in my life. It is a source of comfort and support for me, but where do I go for help?” Although caring for the spiritual needs of persons diagnosed with a terminal illness is the role of the minister, this is not an area where clergy respond well. Patients state that their ministers or priests who are aware of their diagnosis of a life-threatening or life-limiting illness failed to identify or respond to their religious and spiritual needs. Unfortunately, I have also witnessed dying patients, who, at their moment of utmost vulnerability, were abandoned and left alone without spiritual support from their faith leaders, faith communities and health care institutions. It distresses me to see the lack of spiritual care or interventions for the dying and their families. I believe every person should be offered spiritual care; we all have the right, not only to have our physical bodies treated with respect as death approaches but, perhaps more importantly, our spirits.

Awareness of Dying: Four Categories Describe the Social Process of Dying

When does the dying process begin? Philosophers and poets say that dying begins at the moment of birth. It is often difficult to discern when serious illness can no longer be managed and the person is facing the end of life. Glasser and Strauss performed thought-provoking ethnographic research in response to the cultural shift in North America from dying at home to dying in the hospital. One of their primary questions was whether patients diagnosed with a terminal illness were experiencing the social process of death in addition to the biological process within the medical context and how this impacted human relationships. The result of their work centers on the term *awareness context.*

Glasser and Strauss[7] identified four categories that describe the *social process* of a patient's awareness of dying: (a) *Closed Awareness:* The patient is unaware of impending death while the staff and/or family engage in tactics to avoid disclosure. This occurs when the patient does not recognize the signs, the physician avoids the subject, the family guards their secret, and the staff keep conversations focused on the superficial level. In many cultures, speaking of death is believed to do more harm than good. (b) *Suspicion Awareness:* The patient suspects his or her prognosis but the family and staff do not speak to the patient about his or her prognosis, they continue to use tactics to avoid the subject of impending death. In this situation feelings are avoided and patients often suffer in silence. (c) *Mutual Pretense:* All parties are aware of the dying but agree to act as if the person is going to live. Neither wants to disturb the other with discomforting news. Tact and silence dominate the environment. Rituals focusing on wellness continue, and conversations focus on safe subjects. If a nurse or family members witness the person crying, they will avoid calling attention to the situation and attempt to change the subject. Many cultures, particularly non-Western cultures, place a high value on avoiding awareness that death is coming closer. (d) *Open Awareness* occurs when staff, family, and the patient acknowledge that the illness is incurable and that death will take place at some point in the near future.

Person Diagnosed with A Terminal Illness: I use this term when referring to an individual who has extensive and/or untreatable disease and who knows that death is relatively imminent as identified in Glasser and Strauss's "awareness of dying" research. They define four different dying trajectories or death expectations: (a) certain death at a

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[7] Glasser, B., & Strauss, A. (1966). *Awareness of dying*. Chicago, IL: Aldine.

known time; (b) certain death at an unknown time; (c) uncertain death but a known time when the question will be resolved; and (d) uncertain death and an unknown time when the question will be resolved.[8]

In this study, trajectories (a) and (b) are applicable and relevant. Trajectory (a), “certain death at a known time,” specifies an approximate or specific time frame in which a person with a terminal diagnosis and their family can begin to prepare for the end of life. In this trajectory, even though the certainty of death is not good news, the person receiving the diagnosis can anticipate his or her death at an estimated known time. There is a rapid progression through this trajectory; the dying process may remain only in the acute phase, for example Stage 4 pancreatic cancer or acute leukemia. Trajectory (b), “certain death at an unknown time,” is for the most part characteristic of chronic fatal illness. In this trajectory, there is certainty of death; however, the living–dying interval may extend over months and even years. The person lives with dying where there is frequently prolonged emotional stress for the dying person and his or her family that result in *internal* and *external* experiences of suffering.

Not often do we have sufficient opportunity to access patients’ words, thoughts, and experiences, questions, and narratives at their weakest and most impaired states that emerge from the experience of living with a serious, life-threatening illness. Nearly 45 five years have passed since Glasser and Strauss performed their research that affirmed the phenomenon of death awareness, the devastating impact of hearing their terminal prognosis, and suffering associated with losses and events that changed the patient’s life suddenly and swiftly. It was a privilege and a sacred trust for me to be present with

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[8] Ibid.

patients and families on their journeys through the illness trajectory and listen to them speak about their experiences in the face of impending death as part of this research in ministry project.

Today, the goals of both hospice care and palliative medicine are clear–to relieve patients' suffering at end of life (hospice) and during the entire course of serious, advanced, or life-threatening illness (palliative medicine)–while also maintaining an acceptable quality of life for such patients. The focus is on the patients' comfort, physical needs, and on their emotional, social, and spiritual needs–a patient-centered approach.[9] Has traditional Western biomedical medicine met the needs of suffering patients who are critically ill or dying? What are the realities facing patients who are dying in Canada today and their families?

The Reality of Dying In Canada During the 21st Century

The National Senate Committee report asserts that every Canadian is entitled to "die in relative comfort, as free as possible from physical, emotional, psychological, and spiritual distress with access to skilled, respectful and compassionate care."[10]

If each of us was given the opportunity to choose our method of death today, we would undoubtedly choose the quick and painless. The reality is quite different. Only 10% of people die suddenly;[11] the rest will require some level of end-of-life medical care. Every year more than 242,000 Canadians die, and 75% of all deaths occur in acute care

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[9] Ragan, S. L., Whittenberg-Lyles, E. M., Goldsmith, J., & Sanchez-Reilly, S. S., (2008). *Communication as comfort: Multiple voices in palliative care.* New York, NY: Routledge, 21.

[10] Carstairs, S. (2000). Quality end-of-life care: The right of every Canadian. Ottawa, Canada: Subcommittee to the Update of Life and Death. The Standing Committee on Social Affairs. *Science and Technology,* 2.

[11] Plonk, W. M., & Arnold, R. M. (2005). *Journal of Palliative Medicine, 8*(5), 1042–1054.

hospitals or long-term care facilities. The leading causes of death are: diseases of the circulatory system (about 35%), neoplasms–tumors or cancers (about 28%), and diseases of the respiratory system (about 10%), which total 73% of all Canadian deaths. Each death in Canada affects the immediate well-being of, on average, five other people.[12]

From mid-2008 to mid-2009, there were 242,863 reported deaths in Canada.[13] The best estimate suggested that somewhere between 16 and 30% of Canadians had some level of access to palliative care, depending on location. A reality check indicates that upward of 70% of Canadians still *do not* have access to even the most minimal form of palliative care to help alleviate emotional, physical, and/or spiritual pain and suffering.[14]

Population growth forecasts envision that the number of deaths occurring annually in Canada will nearly double to almost 480,000 annually by the year 2056. If projections for the rate of deaths per year by 2056 are realized, potentially 2.4 million people will be affected by a death in their family or social circle in any given year.[15] What accounts for this estimated increase? In Canada, demographic trends confirm an increase in the elderly population as the "baby boomers," a term that affectionately identifies this age group, reaches retirement age and the average life expectancy increases due to advances in health care.[16] While Canadians are indeed living longer, many are experiencing poor health as levels of chronic disease are on the rise, accounting for nearly 70% of all deaths

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[12] Canadian Hospice Palliative Care Association. *Hospice palliative care fact sheet.* (2008, October).

[13] Carstairs, S. (2010). *The Senate of Canada Report.* Raising the bar: A roadmap for the future of palliative care in Canada. Statistics Canada Table, Death and Death Rate by Province and Territory.

[14] Canadian Hospice and Palliative Care Association. (2008, October).

[15] Carstairs, S. *The Senate of Canada Report*. (2010a). Data taken from Statistics Canada Table, Projected Births and Deaths According to Three Scenarios (2005–2 056).

[16] Statistics Canada: Population projections for Canada, Provinces and territories, 2000–2056. *Statistics Canada Catalogue, # 91*(520), 124. [http:www.statcan.gc/pub/91-520x/91-520-x20005001-eng.pdf] website.

in Canada today.[17] Consequently, the Canadian Hospice Palliative Care Association states that the demand for palliative care services in hospital and community settings within Canada will progressively increase.[18]

Hospice palliative care, which focuses on the relief of suffering and improving quality of life, could benefit a large majority of those who are suffering and facing impending death and their families. Findings from a recent qualitative research report which analyzed the evolution of hospice palliative care in seven Canadian provinces point to the fact that hospice palliative care continues to remain at the margins of the health care system in Canada today.[19]

As Canadians, we have inherited a death-denying culture of health care delivery which is characterized by being both highly curative and biomedical in nature and, thereby, more interested in healing the biophysical body rather than attending to the psycho-social and spiritual elements of dying.[20] The reality of dying in Canada today presents numerous challenges for patients, families, and health care teams. Unless we attend to pain and suffering as a physical, emotional, social, and spiritual experience, interprofessional health care team approaches and/or interventions may not only fail to relieve suffering but also become a source of suffering.

> The litmus test for assessing the quality of care to end of life we are providing to the terminally ill/dying may well be when suffering results in the loss of a will to live, or a mounting desire to die. Is it possible that the way we care for the terminally ill and/or the dying reflect to some degree the kind of society we

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[17] Canadian Hospice Palliative Care Association. [http://www.chpa.net/about us/history.htm] website.

[18] Canadian Hospice Palliative Care Association. *Fact Sheet.* (2008, April).

[19] Williams, A., Crooks, V., Whitfield, K., Kelley, M., Richards, J. Demingilo, L., & Dykeman, S. (2010). *Tracking the evolution of hospice palliative care in Canada: A comparative case study analysis of seven provinces*. BMC Health Services Research. [http://www.biomedcentral.com/1472-63/10/147].

[20] Armstrong, P., Armstrong, H. (1996*). Wasting away: The undermining of Canadian health care*. Toronto, ON: University Press.

> have created to live in and die in? I believe it does. This challenges us to develop clinical care pathways toward excellence in our care of the dying so patients and their families can realize their full potential to live, even in the face of facing impending death.[21]

Concepts Recommended for Spiritual Caregiving

Henri Nouwen's philosophy of care combined with his vision for compassionate care puts the nature of personal relationships in the very center of human inquiry about the meaning of human existence. Object Relations Theory, because of its strong emphasis on human relationships, combined with Winnicott's hypothesis of transitional space, is a rich mine for understanding spiritual care in a variety of ministry situations.[22] These concepts influenced the foundational questions underlying my research and work in oncology and palliative care.

Transitional Space is the third part of the life of a human being, one that should not be ignored; it is an intermediate area of experiencing where creative impulses of the human spirit continue to emerge spontaneously. Winnicott portrays the transitional space as the realm between one's inner and outer reality.

> The third part of the life of a human being, a part we cannot ignore, it is an intermediate area of experiencing, to which inner reality and external life contributes. An area that exists as a reflective space for the individual engaged in the perpetual human task of keeping inner and outer reality separate yet interrelated.[23]
>
> This intermediate area of experience, constitutes the greater part of experience, and throughout life is retained in the intense experience that belongs to the arts, religion, imagination, and creative scientific work.[24]

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[21] MacInnis, E. (2007). Concepts for compassionate care: Alleviation of suffering –The cornerstone of spiritual care. *Doorway to Room 217*, 3.

[22] Culbertson, P. (2000). *Caring for God's people: Counseling and Christian wholeness*. Minneapolis, MN: Fortress Press, 74.

[23] Winnicott, D.W. (1982). *Playing and reality*. New York, NY: Tavistock, 2.

[24] Ibid., 14.

The transitional space, a potential space for illusory experience, is a remarkable and fascinating kind of place for creative activity of complex classifications we continue to visit long after our childhood days are left behind. Winnicott does not hold that illusions in adult life are to be viewed negatively. Not only does he say that the capacity for illusion is essential in infant development but extends the concept of illusion beyond infancy into the whole of life, stating that it lies at the heart of art and religion.[25] It is in this transitional space that the creative impulses of the human spirit flow spontaneously; this space is often viewed as sacred for the individual in that it is a place where one finds meaning and purpose for one's life. Feminist psychoanalyst, Nancy J. Chodorow,[26] and Feminist theologian, Rita N. Brock,[27] in agreement with Winnicott, claim the transitional space as the basis for *being* as well as life-giving cocreating. The space to which they refer holds unlimited potential for spiritual nurturing and healing as the terminally ill and their families search for meaning amidst life's complexity and desire to experience life to its full potential.

Henri Nouwen's philosophy of care set forth in *Reaching Out: The Three Movements of the Spiritual Life* establishes a *reflective relationship model* for spiritual care with a focus on the "total pain" frequently experienced in the face of impending death.

> Our most important question is not "What to say or do?" but "How to develop enough inner space where the story can be received." Healing is the humble and also very demanding task of creating and offering a friendly empty space where strangers can reflect on their pain and suffering without fear, and find

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[25] Winnicott, D.W. (1975). *Collected papers: Through paediatrics to psychoanalysis.* London, UK: Hogarth.

[26] Chodorow, N. J. (1989). *Feminism and psychoanalytic theory.* London, UK: Yale University Press.

[27] Brock, R. N. (1994). *Journeys by heart: A Christology of erotic power.* New York, NY: Crossroads.

> confidence that makes them look for new ways right in the center of their confusion.[28]

What do health care professionals consider necessary to make the environment for those facing impending death "spiritually healthy?" What would an ideal environment with a compassionate focus on end-of-life care look like? In *Ministry and Spirituality,* Nouwen envisioned a *compassionate model* of spiritual care in action where in the midst of the patients' or their families quest for meaning or healing, they can find signs offering hope, courage, and confidence.

> As healers we have to receive the story of our fellow human beings with a compassionate heart, a heart that does not judge or condemn but recognizes how the stranger's story connects with our own. We have to offer safe boundaries within which the often painful past can be revealed and the search for a new life can start.[29]

Object Relations Theorists developed a systematic understanding of the relationships between individuals and their ability to establish and maintain healthy human relationships as a key factor in developing a healthy cohesive sense of self and others.

Object Relations Theory is built on assumptions: how we assume we are cared for, who we belong to, which others are in relationship to ourselves, and what signals we are safe. The dynamic relationships encompassed in the inner structures of object relations create the foundation for intimate relationships throughout one's life.

> Object Relations are the interactions among one's mental representations of one's self (the object self, self-representation, or self-object), one's mental representation of another person, thing, idea, and so on (the object other, the internal object representation, or illusory other), and the "factual" reality of persons, things, ideas external to oneself (the external object). Object Relations

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[28] Nouwen, H. (1975). *Reaching out: The three movements* of the s*piritual life.* New York, NY: Doubleday.

[29] Nouwen, H. (1969). *Ministry and spirituality*. New York, NY: Continuum International, 32.

> puts the nature of personal relationships in the very center of human inquiry about human existence.[30]

Object relations refer to a psychological process that people use early in life and throughout the life cycle to create internalized images of the self and other people–these patterns and images are known and referred to as "object relations." Horner clarifies the dynamics of object relations; she explains, "What is at first *interpersonal* becomes structured as enduring organizations of the mind – that is, it becomes *intrapsychic* – and then what has become intrapsychic once again becomes expressed in interpersonal situations with others."[31] These object relations are not static images but are complex, significant influences on how we feel about ourselves and connect to other people in relationships; they are templates that both predetermine our responses to others and the way other people respond to us.

An *"object"* is a mental representation of, most commonly, a person, though it may also represent a place, a thing, idea, fantasy, or memory. An object is the product of some sort of relationship created through some event or interaction and is invested with a particular emotional energy such as love, hate, or fear.[32] One of the major functions of an object is to provide the individual with comfort and a sense of security; it does not have to be an object in the physical sense of the word. Horton proposes that in the end it is the emotional significance of the object that counts; he suggests that often music, melodies, jingles, and magical sayings can fulfill transitional functions as well. In fact,

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[30] Culbertson, P. (2000). 74– 75.

[31] Horner, A. (1991). *Psycho-analytic object relations therapy*. Northvale, NJ: Jason Aronson, 7.

[32] Culbertson, P. (2000). 74.

Horton prefers to use the term *"transitional relatedness"* so as to broaden the concept and to place the focus on relationships instead of the object per se.[33]

In the course of a lifetime, the majority of people have relationships with both "good" and "bad" objects. Infants construct their first internalized object representation from aspects of their experiences with primary caregivers. The "good objects" are primary caregivers who are perceived as ones who affirm and love them as well as nurturing their development. By contrast, "bad objects" are primary caregivers who are perceived as unwilling or unable to care for the infant or child.

Transitional Objects: When talking about transitional objects, we are raising attention and awareness to a certain capacity for experience. Early in an infant's life his or her ability to move forward into the world is facilitated by the use of transitional objects. The word transitional is not used as a developmental concept to describe a transition from one stage to the next. Rather, "transitional" is used to describe the way an infant creates a mediating reality between inner and outer realities; from a state of being merged with the mother to a state of being in relation to her as someone who is outside and separate.

The major function of the transitional object is to enable the transference of dependent attachments toward healthy interdependence. Intrinsic to the definition of a transitional object is its use in the process of separation and individuation. The most important dimension of the transitional object is not the object but the nature of the relationship to the transitional object, representing a developmental resting place between hallucinatory omnipotence and the recognition of objective reality.

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[33] Horton, C. (1981). *Solace*. Chicago, IL: University of Chicago Press.

For Winnicott, all experience is both physical and nonphysical, and the transitional object facilitates inner and outer reality to become differentiated. A thing, a person, or an image can function as an object, and it is called a transitional object provided that one's experience of the object is experienced by the person while in his or her transitional space. The transitional object is a synthesis, but one that provides, by virtue of being more than the sum of its parts, a new third alternative; it is never a substitute for something else.

Melanie Klein points out that transitional objects as well as certain object others are constructed by the infant in order to reduce anxiety.[34] While the nature of our transitional objects that comforted us in childhood may change significantly between infancy and adulthood, our need for them and what they provide never seems to disappear.

In fact, the infant or child does not create the transitional object alone; it is a joint creation of both infant and primary parent. The transitional object is something that a child uses as he or she moves from one level of emotional development to another, for example a teddy bear, a soft doll, or a blanket. Since the major function of transitional objects is to provide the individual with comfort and a feeling of security, it does not have to be an object in the sense of the word. Winnicott introduced the terms "transitional objects and "transitional phenomena" in order to illustrate the intermediate area of experience, which he refers to as transitional space.[35]

When does the concept of transitional phenomena begin in the developmental process? The pattern of transitional phenomena appears when the child begins to separate from his

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[34] Juliet, M. (Ed.). (1986). *The selected Melanie Klein.* Berkley, CA: University of California Press.

[35] Transitional object and transitional phenomena. (1953). *International Journal of Psycho-Analysis, (34),* 89–97.

or her mother at around 6 to 12 months of age and continues to be activated during the course of the life cycle. It has been suggested that the emotional feelings of separation can be circumvented by creative playing, with the use of symbols, and with all that ultimately will encompass a cultural life.

> The transitional phenomena that provided the bridge between inner and outer worlds gave continuity to a process where previously, from a psychoanalytical point of view, there seemed to be only mutually exclusive options: either subjectivity or objectivity, either unity with the mother or separateness, either invention or discovery.[36]

Object Relations Theory, which puts the nature of personal relationships at the very center of human inquiry about the meaning of experience, is the most frequent point at which faith, theology, and psychology achieve rapprochement. Used skillfully, this is the proper path to spiritual maturity.[37] How does one define spiritual maturity?

> A person of mature spiritual and psychological life is able to embrace, affirm, and somehow resolve the tensions of life, to integrate them in a more balanced faith orientation and faith existence. Such an individual can look upon religious belief systems and their traditions in increasingly realistic terms which enable the individual to tolerate inherent tensions and ambiguities….At the same time this knowledge through faith is able to acknowledge the existence and validity of other faith traditions adhered to by different persons from many different cultures.[38]

Religion, Religious Experiences and Spirituality

Religion is the public expression of a personal faith as articulated by Strang and Strang. “Religion can be described as a social institution that unites people in a faith in God, a higher power, in common rituals and worshipful acts. A god, divinity, and/or soul

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[36] Phillips, A. (1988). *Winnicott*. London, UK: Fontana, 114.

[37] Culbertson, P. (2000). 99.

[38] St. Clair, M. (1994). *Human relationships and the experience of God: Object relations and religion.* New York, NY: Paulist Press, 47.

is always included in the concept."[39] Each religion involves a distinctive set of beliefs that can be found in all cultures and societies.[40]

Not only is religion vital to the identities of many people, it is often used to cope with troubling life circumstances. What exactly is religious coping? Religious coping is the use of religious beliefs or practices to reduce the emotional stress caused by unwelcome loss or change. Patients and their families "turn over" their concerns to God, trusting to reduce anxiety or increase hope. With respect to religious practices that facilitate coping, patients may pray, read religious or sacred scriptures, attend religious services, or receive the sacraments. Hence, religious beliefs and practices are used to *regulate emotion* during times of illness, change, and circumstances that are out of the patient's personal control.[41]

There is a body of research that clearly demonstrates the health benefits of religious practices, confirming the importance of health professionals incorporating at least a respect for this aspect of the patient's life into their clinical practices.[42] [43] Rather than use the term religion, which is not easy to define, in the next chapter I will refer to *religious experience* in order to keep the focus on the *subjective* experiences that the terminally ill and their families have as the focus of their belief.

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[39] Strang, S. & Strang, P. (2002). Questions posed to hospital chaplains by palliative care patients. *Journal of Palliative Medicine, 5*(6) 858.

[40] Bell, V., & Troxel, D. (2001). Spirituality and the person with dementia: A view from the field. *Alzheimer's Care Quarterly*, *2*(2), 31–45.

[41] Koenig, H .G. (2007). *Spirituality in patient care: Why, how, when, and what?* (2nd Ed.). West Conshohohocken, PA: Templeton Foundation Press, 19–20.

[42] Ellison, C. G., & Levin, S. J. (1998). The religion-health connection: Evidence, theory and future directions. *Health Education and Behavior*, *25*(6), 700–720.

[43] Koenig, H. G., McCullough, M. E., & Larson, D. B. (2001). *Handbook of religion and health*. New York, NY: Oxford University Press.

Religious beliefs may also influence a person’s medical decisions, whether or not to seek health care, and whether to comply with medical treatments. Certain fatalistic beliefs such as “it’s God’s will” or “it’s Allah’s will” or “it’s my karma” can and do influence patients’ actions.[44] A patient in this study with end stage lymphoma captured the definition of fatalism when he affirmed his belief that illness and disease are an inevitable consequence because he broke God’s law; no medical treatment can forestall his death. Identifying religious struggles and fatalistic religious beliefs that affect the seeking or compliance with medical care confirms the importance of obtaining an initial spiritual history and needs assessment that capture religious beliefs at the patient’s point of entry into the health care system.

In the course of the past 14 years, in my experience with terminally ill and dying persons I discovered a gap between what is written regarding ministry to the dying and what in actual fact occurs in spiritual care support for the persons in their transitional space from diagnosis to death. I have observed that this is a space in which ministry seldom enters. For the most part, ministry to the dying remains in the religious system of belief at the neglect of the spiritual realm. In my opinion, it appears that theologians have tried to articulate the spiritual needs of the terminally ill person and his or her family from a distance, from outside the person’s spiritual experience.

Sheldrake states that it would be a mistake to conclude that the contemporary interest in spirituality can be explained entirely in terms of established, traditional forms of religion. As he points out, “It appears that spirituality is one of those subjects whose

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[44] Nelson, K., Geiger, A. M., & Mangione, T. (2002). Effects of health beliefs on delays in care for abnormal cervical cystology in a multiethnic population. *Journal of General Internal Medicine, 17*(9), 709–716.

meaning everyone claims to know until they have to define it."[45] Similar to Sheldrake's observations, I have observed in this study that spirituality is a broader concept than religion and involves a sense of unity with a reality more enduring than the individual self.

Pastoral theologian Robert Wicks made the observation that when people indicate they are interested in "the spiritual way of life" they are de facto, saying: "I deeply value relationships, relationships with themselves, others and God. Spirituality and appreciation of the relationships they have to go hand in hand."[46]

What is spirituality? The concept of spirituality allows one to be conscious of something more than we see or touch–that which has come to be known as the spirit or soul. An overriding dynamic of spirituality is the ability it gives an individual to discern one's sense of "otherness"–that internal image of self that is private.[47] The meaning of the word spirituality is a source of great debate among health care professionals; various definitions have been proposed to capture the essence of spirituality:

> The essence of our humanity related to the existential search for meaning within a particular experience or event.[48] Spirituality is a complex multi-dimensional part of the human experience that includes cognitive, experiential, and behavioral aspects.[49] Spirituality is an inner aspect of personhood that yearns for hope in the midst of despair, for forgiveness in the midst of anger and hurt, and for a sense of connection and love in relationships with others.[50] Spirituality is whatever or whoever gives ultimate meaning and purpose in

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[45] Sheldrake, P. (1992*). Spirituality and history: Questions of interpretation and methods*. New York, NY: Crossroads, 32.

[46] St. Clair, M. (1994). 1.

[47] Hamilton, N. G. (1990). *Self and others: Object relations theory in practice*. Northvale, NJ: Jackson Aronson, 12.

[48] Frankl, V.E. (1985). *Man's search for meaning*. New York, NY: Washington Square Press.

[49] Anandarajah, G., & Height, E. (2001, January). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *The American Family Physician, 63,* 81–89.

[50] Puchalski, C. (2006). *A time for listening and caring: Spirituality and the care of the chronically ill and dying.* New York, NY: Oxford University Press.

> one's life that invites particular ways of being in the world in relation to others, oneself, and the universe.[51]

Ken Pargament defines the word spirituality as a search for the sacred. Pargament is considered one of the leaders in attempting to ground the term spirituality into something more substantial that is, the "sacred" (God, Jesus, Mohammed, the Buddha, Brahman, ultimate truth, or reality).[52] Although not perfect, Koenig affirms that this is a major improvement over definitions commonly used today and at least gives spirituality some kind of distinctiveness, yet is still broad enough to be inclusive of persons who are either affiliated with traditional religion or not.

Persons may not always be aware of the presence spirituality or how closely it is intertwined with hope. However both assume considerable importance when one is given a terminal diagnosis of a life-threatening disease. Is hope possible amidst pain and suffering? Groopman[53] and Christakis[54] believe that the inherent uncertainty of a prognosis is underneath the longing for real hope, because nothing is absolutely determined–there is not only reason to fear but also reason to hope.

Spiritual needs are conceived as the need to find meaning in the midst of illness and suffering; the need to affirm relationships to self, others, God, and nature; the achievement of transcendent values such as creativity, compassion, courage, trust, love, faith, and hope.[55] [56] [57] What is hope? Ersek suggests that hope is a multidimensional

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[51] Wright, L. (2005).

[52] Pragament, K. I. (1999). The psychology of religion and spirituality? Yes and no. *International Journal for the Psychology of Religion, 9,* 3–16.

[53] Groopman, J. (2004). *The anatomy of hope: How people prevail in the face of illness*. New York, NY: Random House.

[54] Christakis, N. A., (2001). *Death foretold: Prophecy and prognosis in medical care*. Chicago, IL: University of Chicago Press.

[55] Emblem, J., & Halstead, L. (1993). Spiritual needs and interventions: Comparing views of patients, nurses, and chaplains. *Clinical Nurse Specialist, 7*(4), 175–182.

[56] Highfield, M., & Carson, C. (1983). Spiritual needs of patients: Are they recognized? *Cancer Nursing, 6* (3), 187–192.

[57] O'Brien, M. E. (1999). *Spirituality in nursing: Standing on holy ground.* Sudberry, MA: Jones & Bartlett.

dynamic life force characterized by a confident, yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant.[58]

There is an emphasis on the identification, or "assessment," of spiritual needs in both the theoretical and research literature. Although an initial spiritual assessment or history can provide baseline information regarding a patient's spirituality, it is important to remember that spiritual needs may change, or new spiritual concerns may arise during the course of the illness experience. It is imperative that an ongoing assessment of patient's needs continue through the illness trajectory.

The Need for Theological Research and Education in Palliative Care

Wright speaks about the significance of family members' spiritual and religious beliefs within the context of illness. "The influence of a family member's spiritual and religious beliefs on their illness experience is one of the most neglected areas in individual and family nursing practice."[59] This "Research in Ministry Project" revealed that routinely the religion section on the patient profile in their charts was left blank; identification of patients' religious and spiritual needs was *not* a part of the initial intake assessment upon admission to hospital or during their period of hospitalization. However, participants in the studies indicated the importance of spirituality and religion at this time in their lives. Similar to Wright's research findings published in 2005, eight

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[58] Ersek, M. (2001). The meaning of hope in the dying. In B. Ferrell and N. Coyle (Eds.). *Textbook of palliative nursing* (pp. 339–351). Oxford, UK: Oxford University Press.

[59] Wright, L. (2005). 130.

years later it appears that spiritual and religious needs continue to be a neglected area in care to end of life within health care.

I have observed in my research of the literature that many who write about religion and spirituality are not trained theologically, so this may account for why many generalizations made in the literature about society's views on death and religion are too simplistic. The lack of understanding and appreciation for the spiritual dimension of terminal illness, death, and dying is also evident in ministry. During my years of ministry I have repeatedly heard patients express their concerns that the church's message lacks nurturing and healing; in addition, they have stated that it fails to speak to their experiences and challenges in the face of impending death.

Care for a person's health goes beyond addressing physical or medical needs. In recent years there has been an increasing awareness of our understanding of health to embrace determinants of health that include biological, social, psychological, spiritual, environmental, and physical factors. The Canadian Council of Health Services Accreditation requirements:

> When developing the service plan, the team considers the client's physical, mental, spiritual, and emotional needs. The team respects the client's cultural and religious beliefs and enables them to carry out their usual cultural and religious practices as appropriate.[60]

Attention to the spiritual needs of patients is a critical dimension of palliative care under the umbrella of health care. Nevertheless, nurses and other members of the interprofessional health care team often struggle with their role in providing spiritual care. Puchalski, speaking at the Harvard Medical School Continuing Education series

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[60] Canadian Council of Health Services Accreditation. (1999). *Achieving improved Measurement (AIM) Program.* Section 13.3 and 14.9. Ottawa: ON.

that I attended, spoke about the moral imperative for the integration of spirituality into health care:

> Our understanding of physical pain is not complete. Likewise our understanding of spiritual and psychological pain accompanied by suffering is even less understood and recognized. How do we learn more, gain new insights and additional understandings so that we can effectively alter the "total pain and suffering" that people often experience as they approach the end of life?[61]

Many health care professionals state they had no formal preparation to become a spiritual caregiver. They believe the essence of their work is love and compassion for others combined with the acknowledgement of a sacred trust to support patients and families in their search for meaning, and often in their search for God, whom they believe has abandoned them in this time of greatest need.[62] The question frequently arises, however–should there be formal preparation for participation is this sacred trust, or should it be left to chance?

The Canadian Association for Spiritual Care (CASC), formerly known as the Canadian Association for Pastoral Practice and Education (CAPPE), strongly recommends a *structured approach* for education of health care professionals who are integrating spirituality and spiritual caregiving into patient care. Their approach is affirmed by leading medical and spiritual care educators, seminaries, and health care institutions in North America.

> An essential aspect of making the health care system a spiritually healthy environment involves preparation of caregivers to understand the importance

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[61] Puchalski, C. (2007). A moral imperative for the integration of spirituality into health care. *Spirituality & healing in medicine: Including the concept of emergence.* Harvard Medical School Department of Continuing Education Series. Boston, MA.

[62] MacInnis, E. (2010). *Improving the quality of care to end-of-life in Canada: Alleviation of Suffering.* Qualitative Research Report, St. Stephen's College, Edmonton, AB.

> of the spirit, to recognize spiritual issues, and to be able to respond from the heart to these issues….A structured approach assures the "head" knowledge while laying a foundation for the "heart" response that is the essence of spiritual care. It is essential that health care providers believe their role is to provide holistic care that means dealing not only with broken bodies, but broken minds, hearts and souls.[63]

Chaplains, pastoral counselors, spiritual directors, and clergy are all trained in different ways to counsel people on spiritual issues. Health care professionals, such as physicians, nurses, and social workers, have varying amounts of training in spiritual care but generally are not regarded as trained spiritual care providers.[64]

An increasing number of medical and nursing schools are now beginning to recognize the important role spirituality plays in the lives of patients and incorporate spirituality courses in their curricula; many of these courses are electives. This means that the majority of students do not participate in any formal spiritual education process.[65] Zerwekh states that surveys she has conducted with nurses working in health care suggest that most have had little, if any education in spiritual care.[66]

Another factor that needs to be taken into consideration is the large number of health care professionals who not only lack preparation for spiritual caregiving but may have graduated and entered professional practice at a time when even talking about spiritual issues was discouraged by health care educators. Until spirituality and spiritual care is a requirement in the curricula of education for health care providers, it should be included in the initial orientation process for interprofessional teams working in health care

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[63] Benner Carson, V., & Koenig, H. (2004). *Spiritual caregiving: Health care as ministry.* Philadelphia: P.A: Templeton Foundation Press, 70–71.
[64] Puchalski, C. (2006). 230.
[65] Benner Carson, V., & Koenig, H. (2004).
[66] Zerwekh, J. (2006). *Nursing care at the end of life: Palliative care for patients and families.* Philadelphia, PA: F.A, Davis, 214.

facilities to ensure that spiritual needs are addressed as part of holistic care. It is critical for health care professionals to address spiritual issues with their patients, because spiritualty affects the patient's clinical care in a direct manner; spiritual issues can impact clinical care in a variety of ways.[67] Puchalski asserts that spiritual issues are also often underrepresented in the literature, including research based articles related to palliative care.[68]

The National Consensus Project (NCP) Guidelines identify spirituality as an essential dimension of palliative care, however, uniformity of spiritual care practice is lacking across health care settings. The NCP recognizes that the spiritual dimension often receives less emphasis than the biopsychosocial dimensions of care. Barriers to standardized implementation include varying understandings and definitions of spirituality, lack of resources or practical tools, limited education and training is spiritual care.[69]

Because of the overlap between religion and spirituality, the two concepts are often treated as one. With few exceptions, research on spirituality, and even instruments used to measure and access spirituality, have had a Christian focus.[70] There is a need to expand research to focus on the various ways spirituality may be expressed, both within and outside the context of religious and cultural beliefs or for persons adhering to no specific religion.

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[67] SUPPORT Investigators (1995). A controlled trial to improve care for the seriously ill, hospitalized patients: The study to understand prognoses and preferences for outcomes and treatment (SUPPORT). *Journal of the American Medical Association, 274*(20), 1591–1598.

[68] Puchalski, C. M., & Ferrell, B. (2010). *Making health care whole: Integrating spirituality into patient care.* West Conshohocken, PA: Templeton Press, 15.

[69] Ibid., *xxi*.

[70] Zerwekh, J. (2006). 216.

Many former believers in organized religion feel that the church has failed them in their time of greatest need. Maryanne Confoy in *The Contemporary Search for Meaning in Suffering* states the issue is not so much with God, but the ways in which church leaders are preoccupied with issues that do not touch the real life and pressures of their church members, particularly in the face of impending death. People are struggling to make sense in their search for meaning and purpose amidst their routine life situations and the unexpected experience of illness and suffering.

> When doubt is denounced by religious leaders as disloyalty or as a failure in religious orthodoxy, people are led to repress some of their foundational questions and experiences that can lead them to new depths of understanding themselves and the mystery intrinsic to their creedal system."[71]

Palliative care is a multidisciplinary field. The need for interprofessional collaborative research in the area of religion and spirituality is clear. The ability of health care providers to address the spiritual dimensions of life and the commitment to go beyond stereotyped notions of religion is necessary.[72] This will include the enhancement of therapeutic relationships as well as an increase in the effectiveness of psychosocial and medical interventions including complementary therapeutic approaches. Theological research will actively foster collaboration and cooperation between clergy, faith leaders, and health care professionals. Together, we can envision new ways in which spiritual care can be offered to dying persons within our culturally diverse society with its many religious traditions.

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[71] Confoy, M. (2002). The contemporary search for meaning in suffering. In B. Rumbold, (Ed.), *Spirituality and palliative care: Social and pastoral perspectives* (p.27). New York, NY: Oxford University Press.

[72] Dein, S., & Stygall, J. (1977). Does religion help or hinder coping with chronic illness? A critical literature review. *Palliative Medicine, 11,* 295.

> While the mainstream of prior research has been around other types of documents, particularly written documents, qualitative research seeks to transfer the hermeneutical principles from scriptural studies to the understanding and the interpretation of the experiences of the living human document. [73]

I believe that the terminally ill and dying can teach us about the spiritual journey towards death. The terminally ill are our teachers when it comes to death and dying.[74] As a member of an interprofessional health care team, I am aware of ways theological research can and will open the door for conversations about the spiritual dimensions of life and living in the face of impending death. Theological research can help reclaim the sacredness of death. It can help health care professionals, volunteers, and clergy understand the spiritual experience of dying.

> The literature tends to be divided into philosophical discussions of health by theologians or spiritually inclined lay people and a fairly unorganized body of work by empirical researchers, with little integration of the two. There have been attempts by social scientists to integrate religious phenomenon within mainstream theoretical perspectives, but these models have received only limited mainstream application.[75]

While further research needs to be done, religious beliefs and practices may be important resources that persons can draw on to enhance both mental and physical health. A large number of new studies now being undertaken at leading universities are utilizing a variety of research methods, from observational designs to randomized clinical trials, to more rigorously test the associations between religion and health. However, there is significant evidence to date to suggest that religion, health, and medical outcomes are

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[73] VandeCreek, L. (et.al.). (1994). Research in pastoral care and counseling: Quantitative and qualitative approaches. Decatur, GA: *Journal of Pastoral Care, 71*.

[74] Regman, L., & Thiermann, S. (1995). *First person mortal: Personal narratives of illness, dying and grief.* New York, NY: Paragon House.

[75] Dein, S., & Stygall, J. (1977). 291-298.

related, one way or another.[76] If further evidence continues to show these effects are positive, then we will need to actively encourage partnerships and teamwork between health care providers and faith leaders from various religious traditions.

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[76] Koenig, H.G. (2007). 30.

CHAPTER 2

RELATIONSHIPS AND EXPERIENCES IMPACT IMAGES OF GOD

A Sacred Covenant: the Call to Relationship

As a Christian, I have been taught and believe that in the Bible, humankind is revealed as being addressed by God in such a way that the whole of reality comes to us as a Word of God, summoning and inviting us to an equally total response.[77] Human history is encompassed within a divine–human dialogue: God's descent to humanity and humanity's ascent to God; this act of initiative by God and humanity's response are contrasting standpoints to one another. The eternal significance and value of humankind before God constitute a capacity for partnership that makes a covenant possible. From the beginning, creation is grounded in this call to relationship, to grow in the image and likeness of God.

For those who attach their name to Christianity, our various experiences of God are rooted in a God with several distinguishable roles, yet interrelated. Humanity's encounter with the Triune God as Creator, Redeemer, and Sanctifier will be considered as I explore creation and the human responses of faith in Scripture. The emphasis is on God's act of creation and of the human person in God's own image. The Gospel of John highlights the new creation in the Incarnate Word of God and the creative power of love and the manner in which biblical themes can be developed into a model for ministry. This is my belief, and I will discuss how being created in the "image of God" enables one to mirror God in object relations with others; how ministers, faith leaders, and the palliative care team can image God in and through their responses to persons diagnosed

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[77] Smulders, P. (1975). Theology in creation. *Encyclopedia of theology: The concise sacramentum mundi*. K. Rahner (Ed.), (p. 319). New York, NY: Seabury.

with a terminal illness and dying; this is a sacred trust of our call to ministry within health care.

Creation Narratives: The Human Person Created in the Image of God

> In the beginning God created the heavens and the earth. Now the earth was formless and empty, darkness was over the surface of the deep, and the Spirit of God was hovering over the waters.[78]

In an effort to understand who we are, during the course of our lifetime we search for our own true story within a larger, universal story. We turn back the pages of time to the beginning, to the universal story of Creation.

As Christians, when we have knowledge of where we blend into the order of creation, we want to have an understanding of how we were created. The initial starting point for who we are is affirmed in the statement that we are created in the image of God. In Genesis, the Priestly writer comments that the highpoint of creation is attained by the divine announcement: "Let us make man in our image, in our likeness …. So God created humankind in the image of God…God created male and female."[79]

The introduction of Adam and Eve into the Garden of Eden begins a new phase whereby humankind is brought into the presence of God and the rest of creation.[80] The garden is where humankind is to be rooted, a holy place where God dwells.[81] The garden symbolizes divine blessings. It is the fruit of the tree of knowledge of good and evil which brings awareness of its opposites, the specific feature of consciousness.[82] Humankind is forbidden to eat the fruit of "the tree of the knowledge of good and evil."

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[78] Genesis 1: 1-2. *The holy bible. New international version.* (1996). Grand Rapids, MI: Zondervan.

[79] Genesis 1: 26-27.

[80] Eichrodt, W. (1951). *Man in the old testament*. London, UK: SCM, 35.

[81] Isaiah 51: 3; 28: 13; 31; 9.

[82] Kelsey, M. (1978). *Discernment: A study in ecstasy and evil.* New York, NY: Paulist Press, 86–105.

One tree is singled out and humankind is warned of the consequences: “for on the day that you eat from it you will certainly die.”[83] Humanity did not die on that day but became aware of the reality of death. The appearance of shame and fear is the manifestation of the loss of grace, spiritual death.[84]

Prior to feminist studies of patriarchy, sinfulness is associated with blame and guilt, blame has usually been allocated to woman as the originator of sin.[85] [86] Although feminist theologians are not naïve about human suffering, they understand sin as historically and socially produced.[87] If we can comprehend that human relationships are the basic components from which a sense of self is shaped and our intimate relationships are a basic unavoidable determinant of existence, we can understand our brokenness as a consequence of our relational existence. By nature, we are vulnerable and can be easily damaged, and our vulnerability can be a source of the damage that leads us to sin. Sin is an indication of our brokenness, how damaged we are, not of how evil and fundamentally disobedient we are. Recognizing sin as damage increases responsibility and can lead to healing instead of overwhelming us with blame and guilt.

The Genesis account of creation is the background and context in which the *Imago Dei* and God’s covenantal election are first perceived. The concept of the *Imago Dei* established humankind as fundamentally relational and residing within the telos of a unique relationship with God. Even though the concept “image and likeness of God” is found only in the Priestly tradition of the Pentateuch, these passages sum up in one

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[83] Genesis 2:17.

[84] Danielou, J. (1962). *In the beginning: Genesis I-III.* Paris, FR: Seuil, 51–61.

[85] Daly, M. (1973). *Beyond God the father: Toward a philosophy of women’s liberation*. Boston, MA: Beacon Press.

[86] Ruether, R. (1983). *Sexism and God-talk: Toward a feminist theology*. Boston, MA: Beacon Press.

[87] Brock, R. N. (1994). 1–25.

phrase the entire teaching of the Old Testament on the subject of humankind.[88] Toward the end of the Old Testament period, Sirach 17 offers an interpretation of the creation narratives. Indications found in verse 3 show that image is perceived in terms of power. Sirach links the "image of God" to capacity for action; the Book of Wisdom links the "image of God" to action. It is not persons who are capable of observing the law who are the image of God, but persons who in actual fact observe the law. The Book of Wisdom is more straightforward than Genesis in asserting that humanity is "the image of God," rather than "in the image and likeness of God." The sage connects the image of God not to human beings per se (as Genesis) or to a particular religious group (as Sirach), but to a specific quality of existence.[89] The image was understood as predominantly spiritual, residing in the human heart as true righteousness and true devotion. Those who experience and exemplify religious authority are believed to live in an exceptionally close and intimate relationship with God; therefore, they have the spiritual strength to build up humankind by exemplifying God's love in their personal and professional relationships with others–an important characteristic for those offering spiritual care to the terminally ill and their families.

New Creation In Jesus Christ: The Incarnate Word of God

The first words of the Gospel of John echo the first words of Genesis. The similarities between Genesis 1 and the Prologue are seen in the structure of the Prologue.[90] The Gospel begins in eternity; and then creation. In these words the

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[88] von Allmen, J. J. (Ed.). (1958). A *companion to the bible.* New York, NY: Oxford University Press, 249.

[89] Murphy - O'Connor, J. (1977). *Becoming human together.* Willmington, DEL: Michael Glazier, 29.

[90] Brown, R. (1966). *The gospel according to John.* (Vol.1). New York, NY: Doubleday, 4–27.

Prologue stipulates that the “Word became flesh and made his dwelling among us,”[91] this was a new outpouring of the sacred, the beginning of a new age. The Word of God was made visible to humankind in Jesus who becomes the heart of the world. God’s presence comes to us in his incarnate Son so that we can have knowledge of God’s presence from the earth up, that is through the body outward, where our being in the world originates.[92] All creation now becomes centered in Jesus; in him there is a joining of eternity and time, the divine and the human are united in a sacred new covenant.

> It is the “becoming flesh” of the Logos, who is a new and definitive center, that makes the Logos a symbolic reality, and exteriorization of what, until this point, would be an unexteriorized reality. The reality is reached in the symbol of the flesh. [93]

For the writer of John’s Gospel, the shift from heavenly existence to sojourn on earth was of foremost significance.[94] In the Incarnation, the Logos became the Divine Person taking on human nature and completeness.[95] The incarnation acclaims the goodness of humanity, and it encourages us to continue to exemplify that trait on a daily basis. Jesus is a revelation of not only of divine but human greatness also. It was in and through Christ’s example to those in need that our responsibility for a compassionate response to persons who need assistance or help in our present day society was made clear.

The Symbol of God’s Love in the Fourth Gospel

Jesus is presented as “The Word of God,” the exclusive and perfectly acceptable

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[91] John 1:14.

[92] Vogel, A. (1968). *Is the last supper finished? Secular light on a sacred meal*. New York, NY: Sheed, 63.

[93] Cahill, J. (1976). The Johannine Logos as centre. *The Catholic Bible Quarterly, (38*), 66.

[94] Bernard, J.H. (1928). *A critical and exegetical commentary on the gospel according to John.* (Vol.1). New York, NY: Scribners, 19.

[95] John 1:14.

symbol of God's love for humankind, only in the Fourth Gospel.[96] [97] It was John's objective to have the same revelatory function for his readers as the symbolic activity of Jesus had for the first disciples: "Jesus did many other miraculous things in the presence of his disciples, which are not recorded in this book. But these are written that you may believe that Jesus is the Christ, the Son of God."[98]

> The great original symbol of Christian theology, the fulfilment of a superabundant way of the *Imago Dei* in man, is the incarnate Logos, to see him is to see the Father (John 14: 6-10). Hence Christ did not proclaim liberation from symbols but redemption of the symbol.[99]

In the Fourth Gospel both revelatory and mediatory dimensions of the symbol are emphasized in the Johannine Jesus–Jesus is God revealing and God revealed. His words and works reveal the glory of God.[100] The God whom he teaches is the God proclaimed by him and recognized by him. Jesus was chosen by God to reveal who God is and who we are. Jesus is the Way that reveals to humankind life and the way of life.

The New Commandment of Love in Johannine Literature

What is it that inspires persons to exercise their desire to interact in loving ways in our relationships with others? Christians answer, in the words of 1 John 4: 19, that "We love because he first loved us." The commandment to love one another, which is not new in one sense, is new in that it was delivered by Jesus in and for the new age. The

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[96] Schneiders, S. (1977). History and symbolism in the fourth gospel. *L'Evangile de Jean: Sources, Redaction Theologie.* M. de Jonge (Ed.). Gembloux: Duculot, 373.

[97] Leon-Duflour, X. (1981). Toward a symbolic reading of the fourth gospel. *New Testament* Studies, 27, 439–456.

[98] John 20: 30-31.

[99] Splett, J. (1975). Symbol. *Encyclopedia of theology: The concise sacramentum mundi.* K. Rahner (Ed.). (pp. 1656–1657). New York, NY: Seabury.

[100] John 2:11.

writer of 1 John asserts the newness of the commandment is that its truth originates from Christ himself.

The Last Discourses in John's Gospel explicitly present the new commandment as the final challenge of the departing Jesus for his disciples.[101] The foot washing scene is positioned within the context of Jesus's love for his disciples and closes with a discussion on the exemplary character of Jesus's actions. Jesus's example of humility and service must be exemplified by the disciples in their relationships with others. Washing of another person's feet, of which a modern equivalent is difficult to create, is the symbol of the practical ministry which defines the life of the Johannine community during the life of Jesus here on earth.[102] The scene concludes with Jesus' words: "A new commandment I give you: Love one another; as I have loved you, so you must love one another."[103] The new commandment formula infers that the love by which Jesus lays down his life for his friends is proposed as a model for the disciples: love for one another.[104] John presents a model of ministry relevant for spiritual caregiving in today's society. God loved us first, and we see that love reflected in a tangible manner in the faces of human beings around us; therefore, we must respond accordingly in loving ways.

Central to the believer's religious experience is one's relationship to God. The actual beloved and loving God, however, is not seen or touched, but is powerfully present psychologically to the believer. Psychoanalytic Object Relations theory, which is

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[101] John 13: 1-20.

[102] Smith, M. (1981). *Theology and ministry in John: A biblical basis for ministry.* Philadelphia. PA: Westminster, 186–229.

[103] John 13: 34.

[104] John 15: 12-13.

interested in key people in an individual's life, can cast light on a person's relationship with God by considering that special relationship in terms similar to other significant persons in the individual's life.[105] Leroy Howe, an Object Relations theorist maintains that object relations are ultimately the proving ground for our comprehension of God's love:

> Encounters with caring persons, and the relationships with them that transitional objects make possible, themselves are profoundly symbolic. As we have learned, transitional objects help us to sustain a sense of the presence of other caring creatures who with us bear God's image. In this way, they aid us in maintaining relationships. From the perspective of faith, being held and nurtured by someone who loves us as unconditionally as human beings are capable of loving is itself a representation of our most archaic (namely, originating) relationship of all, being held and nurtured by the One who even now is creating us and calling us to fulfill our destiny. This suggests that the one purpose of all our finite relationships is to prepare us for a loving relationship with God. And indeed, for faith, the most important transition in all of life does involve detaching our loyalties and affections from the things of this world, even from those who mediate the love of God to us, in order that we can devote them to their proper "object." [106]

Object Relations Theory Linked to the Christian Faith and Images of God

> The developmental and relational "model" called object relations theory can help us better understand our image of God, religious experience, personal integration, and spiritual maturity…Like most psychoanalytic theories, object relations models point out how past interpersonal relationships shape relationships in the present, including the relationship to the sacred.[107]

Object Relations theory puts forth the idea of a subjective image of God or various representations of God that the individual has developed, similar to other inner images or representations. The consideration of these images provides some understanding of how different people have very different kinds of relationships with God, ranging from

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[105] Rizzuto, A.M. (1979). *The birth of the living God: A psychoanalytic study.* Chicago, IL: University of Chicago Press, 88.

[106] Howe, L. (1995). *The image of God: A theology for pastoral care and counseling.* Nashville, TN: Abingdon, 112.

[107] St. Clair, M. (1994). 2–3.

comforting, loving relationships to no relationship at all. A person might fear God as a harsh distortion of an Old Testament Father God, or feel close to God as a Gentle Shepherd. Psychoanalytic Object Relations theory also helps in a discussion of the uses and changes in the God representation during life, especially at moments of crisis.[108]

An important aspect of the analogies between transitional objects and our ideas or images of God has to do with the *"presence"* that the transitional objects mediate. In the transitional object we experience the presence of God in a "place" that is neither wholly outside nor inside us, neither solely real nor solely fantasized.[109] Herein lies the affective power and significance of symbols, not only for Christians but persons of other faith traditions whose images of the God of their understanding have powerful significance in their lives.

Our ability as human beings to think and cherish symbols begins with transitional objects. Christians discover in transitional phenomena an explanation for the affective power of our distinctive customs. Wearing a cross on a chain around our neck, placing a crucifix on the wall of our home, speaking words of familiar prayers, singing sacred hymns of praise; transitional objects help in mediating the gap between the elusive worlds of inner subjectivity and external reality. We cling to these "treasured possessions" as sources of self-comfort in the face of anxiety or fear that often encompasses impending death and an unknown future. In addition to offering us satisfaction, stability, some sense of control, they offer a direct link between our past as

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[108] St. Clair, M. (1994). 19.
[109] Howe, L. (1995). 112.

we have learned to represent it and to a future that we do not yet know. The things of the playroom are the prototypes of the adult Christian's world of faith. [110]

It is important to take into consideration the concept of good internal objects. It is at this point that approaches to the understanding of God in human experience are now emerging in psychoanalytic thinking. This examination is not about Object Relations Theories in general, but in particular about one's image of God and God's image of humankind from the standpoint of Object Relations Theories. An important aspect between transitional objects and ideas or images of God has to do with two important key concepts: (a) the holding environment and (b) mirroring and cueing.

The Holding Environment

Object relations are created within a specific interpersonal space; Winnicott called this space "the holding environment," that generally resembles what Wilfred Bion called "the container." The purpose of both the holding environment and the container is to facilitate the health and eventual object-integration of an anxious or traumatized object-other. The holding environment does not have to be perfect; it has only to be "good-enough" to facilitate the maturational process of the infant. The conditions of the environment, whether favorable or unfavorable, shape the infant's development and future interpersonal relationships.[111]

A good-enough holding environment is the container for an infant's earliest projective identifications. The infant projects its anxiety, panic, trauma, fear, and alienation, or feelings of being overwhelmed by stimuli too large for it to handle.

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[110] Culbertson, P. (2000). 97.
[111] St. Clair, M. (1994). 75.

Hamilton explains that the good enough parent internalizes the child’s projected feeling, contains it, modulates and alters it, and then gives the transformed affect back to the child in the form of holding behavior or comments acknowledging their feelings. The child can reintroject the transformed affect and thereby alter his or her internal experience. The purpose of the holding environment is to facilitate the formation of self, and one’s identity through developmental experiences that foster a sense of trust, so that the child feels safe to enter into various relationships.[112]

The concept of a holding environment or container is beneficial for people in ministry providing spiritual care to the terminally ill and their families. Spiritual caregivers are called upon to “contain” people cognitively, emotionally, and spiritually (spiritual care and hospital ethics require caregivers not to hold or “contain” patients physically).

Guntrip, who played an important role in making known the ideas of the British School of Object Relations espouses a proreligious position when he says that object relations put the nature of personal relationships in the very centre of human inquiry about the meaning of existence. Given that religion is preeminently an experience of personal relationships, religion extends the “personal” interpretation of experience to embrace our humanity and the universe in one meaningful union. Growth involves personal relationships at every stage. Part of maturity, reaching the full potential of a person in relationship, is to be in relation with a personal God.[113]

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[112] Hamilton, N.G. (1990). *Self and others: Object relations theory in practice.* Northvale, NJ: Jason Aronson, 239.

[113] Guntrip, H. (1969). Religion in relation to personal integration. *British Journal of Medical Psychology, 42*, 325.

Mirroring and Cueing

In the same way good object relations are created within a good container, so too are they created by mirroring and cueing. Donald Winnicott developed the theory of mirroring; his ideas were later echoed by Heinz Kohut as “the mirroring environment.” What the infant sees in the parent’s face, as if in a mirror, is the parent’s image of the infant–how the mother or father sees, feels about, and judges their child; what the parent wishes and hopes for not only in the child, but also for the relationship that is originating between them.[114] These nonverbal behaviors that make up a great part of this relationship are not communications about, nor comments upon, nor interpretations of the relationship; they are considered the relationship. [115]

Winnicott named the state of devotion that characterizes a mother, empowering her to offer herself as an attentive medium for her baby’s growth, as the state of “primary maternal preoccupation” [116] which implies an almost religious sense of the mother’s devotion to her infant. Resembling God’s holding us, the mother provides the holding that is necessary for the self of the infant to emerge and mature.

Mirroring does not go only one way. It is reciprocal and therefore based on cues between both partners in the dyad. The reciprocal nature of interactive mirroring is actually a biblical concept. According to Proverbs 27:19, “Just as the water reflects the face, so one human heart reflects another.” Mirroring and cueing presume a face-to-face relationship. While the significant theological metaphor of “face” is too complicated to

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[114] Howe, L. (1995).

[115] Stern, D. (1995). *The motherhood constellation: A unified view of parent-infant psychotherapy.* New York, NY: Basic.

[116] Winnicott, D. (1982).

explore here, two examples will illuminate the similarity between Winnicott's ideas and the biblical matrix. Exodus 33:11 explains that the intimacy between God and Moses was both unique and magical because God spoke to Moses "face-to-face." The Aaronic Blessing in Numbers 6:25 teach that to wish someone well is to pray that God will mirror them: "May the Lord make his face to shine upon you."

One of the main applications of object relations to religion is the study of the formation of our images of the self and God that take place in the human context, be it of loving and caring parents or harsh and limited parents. By analogy, what we know about relationships between people can supply insight into how we shape our relationships with God and the Sacred. In the interpersonal world of very early human relationships the groundwork is laid for one's relationship with God. The image of God one has is a special kind of object representation.[117] The child's experiences of relationships that generate images of self and others begin with the parents and end with the child's creation of inner representations of the divinity long before the child is exposed to institutional aspects of religion.[118]

Internal Images of God Influenced By Early Childhood Experiences

The "*Idea* of God" and the "*God Representation*"

We cannot understand fully what compels human beings to seek after that which they name "God" until and unless we understand something about our relationship with our teddy bears. [119]

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[117] Rizzuto, A. (1979).
[118] St. Clair, M. (1994).
[119] McDargh, J. (1983). *Psychoanalytic object relations theory and the study of religion.* Lanham, MD: University Press of America.

A child does not intentionally form an image of God out of fantasy, but rather out of concrete experiences of family or questions they ask their parents. By the age of three, we have constructed what Ana-Maria Rizzuto calls "our pet God" based on parental object-others and accumulated messages about God and faith acquired from the cultural environment in which we live. "No child arrives at the house of God without his pet God under his arm." [120]

The earliest true-life religious experiences of childhood, around two or three years of life, are imitative and intertwined with the real mother. The child easily imagines God, and these early images of God have almost exclusively characteristics of the child's own parents, including characteristics of protection and authority. Whatever childhood religious practices the child has, perhaps saying bedtime prayers, seeing parents with bowed heads praying, or going to church, and so on, will be interspersed in the child's imagination with fantasy and fusion. The family is a model for religious experiences, with the sense of authority and protection.[121]

Ambivalence toward parents is reflected in ambivalence toward God. If the mother or father is protective and loving, then there is a building up of images of a loving and kind God. Conversely, as the mother or father punishes the child or is harsh, the child easily attaches images to the parents of fear and avoidance, and likely the child will also attach fearful and awe-inspiring images to the God representation. The basic trust that the child experiences with the mother or father serves as the foundation for a subsequent

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[120] Rizzuto, A. (1982). The father and the child's representation of God: A developmental approach. In *Father and child: Developmental and clinical perspectives.* S. Cath, A. Gurwitt , & J. Ross (Eds.). (p.359). Boston, MA: Little, Brown and Company.

[121] Meissner, W.W. (1984a). *Psychoanalysis and religious experience.* New Haven, CT: Yale University Press.

foundation of a trusting faith in a loving God. Adult ways of experiencing God, both positive and negative, are shaped or colored by these early developmental experiences.[122]

Michael St. Clair makes a distinction between "the idea of God" and "the God representation" that he categorized into three concepts.[123] The *Idea of God* exists at the conscious level of thinking. *The Subject-God*–the God of belief, of rational and intellectual discourse; and the God of theologians and scholars that may not move us emotionally but influences our religious commitment.[124] Theology is that segment of our religious commitment which is influenced by our conscious mind and informed thinking about God that often turns into a topic of conversation. *The God Representation* is made up of images, feelings, and memories from early childhood.[125] *The Object God* is the God of faith, for "faith is a reasoning of the heart by the means of personal images," the God whom we perceive only through the eyes of our significant relationships with internalized object-others throughout our lifetime.[126]

The God Beyond is the One toward whom we move in our spiritual journey through life. While psychological theory cannot prove or disprove God's existence, some Object Relations theorists including John McDargh, Harry Guntrip, and Ana-Maria Rizzuto, are eager to assert the existence of a God who is beyond human capacity, beyond the subject-God and the object-God. *The God-Beyond* is the One who constantly reminds us that, "my thoughts are not your thoughts, nor your ways my ways."[127] The representation of the God Beyond is not available to us until we comprehend the following concept: In our

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[122] St. Clair, M. (1994). 34–37.
[123] Ibid., 23.
[124] Culbertson, P. (2000). 97.
[125] St. Clair, M. (1994). 23.
[126] St. Clair (1994). 29.
[127] Isaiah 55:8.

daily lives the subject-God stands as a corrective to our object-God, thus allowing us to approach God as mature Christians rather than through childish superstition. The subject-God and the object-God are both human creations that can never fully capture the truth of the Source of Our Being. To comprehend the God Beyond, it is essential that we integrate and then transcend the subject-God and the object-God.

Object Relations theorists confirm that despite the claim that the object-God's traits are firmly in place by the end of adolescence, St. Clair, Nelson, and Doehring all agree that we continue to form potent object representations throughout our lives. Though images and representations of God are repeatedly questioned and revised throughout life, it is the object-God that a person is likely to fall back on in times of an emotional crisis or in the face of impending death. One can also resist, reject, or deny any relation to the god image. Even atheists have an image of God in which they do not believe but continue to carry internally and dialogue with.[128]

Terminal Illness: Transformative Life Events Impact Images of God

Transformative life events can change existing images of God, self, and significant others and add new images of God, self, and others.[129] When people are given a terminal diagnosis it draws them to the core questions of life and their existence here on earth. One issue the person facing impending death contemplates is the question of God. The God presented by their official religion may be different from the God of their experienced reality. For the dying person, it is their subjective God that is important, because it is that God who is the specific object of a religious experience.

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[128] Nelson, C. E. (1996). Formation of a God representation. *Religion and Education, 91*(1), 22–39.

[129] Doehring, C. (1995). *Taking care: Monitoring power dynamics and relational boundaries in pastoral care and counseling.* Nashville, TN: Abingdon, 110.

The stories of one's faith tradition told and retold, beliefs embraced, and liturgies honored all convey the reality of God's love. However, only the experience of love already bestowed in one's relationships with others will provide a lasting foundation for one's comprehension of God's love, the credibility of one's belief, and prepare one for a loving relationship with God.

An important aspect of the analogies between transitional objects and God has to do with the presence the transitional objects mediate. In our use of transitional objects, we allow ourselves to feel as if we are in the presence of caring supportive others. The hospital chaplain or minister, as possible transitional objects, helps the dying person maintain the presence of loved ones while simultaneously reflecting the love and presence of God to them.

When a person is faced with the reality of dying in the immediate future, the mourning process begins simultaneously with the wish for immortality.[130] As the death process progresses and regression deepens, a phase often ensues when the dying person attaches either to inner representations of past human relations or to visions of life after death.[131] In the best of possible conditions, when past relationship experiences provided sufficient trust, the dying person can take comfort in transitional objects or an existing loving relationship and pass over into death. In this situation, the dying person withdraws from the world and other persons and transfers the released libidinal interests to this transitional object (the hospital chaplain or his or her religious faith leader), which

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[130] Pollock, G.H. (1975). On mourning, immortality and utopia. *Journal of the American Psychoanalytic Association, 23,* 334–362.

[131] Lowenthal, U. (1981). Dying, regression, and the death instinct. *Psychoanalytic Review, 68,* 63–370.

functions as a bridge to God and existence after death.[132] In an ideal world, the hospital chaplain, as a transitional object, facilitates the transference of healthy attachments and regression as witnessed in separation and withdrawal. The dying person, who is aware of the proximity of death, dies more at peace with images of a loving God. In contrast, when the dying person is isolated or estranged from loved ones, he/she may have images of being abandoned by God, and experiencing the death process may be overwhelming.

In the face of impending death, a primary aim of religion is to provide a meeting ground for God and the person (if this is a need expressed by the patient). In theological reflection, the presence of a compassionate and loving God is perhaps most frequently expressed in the Church's sacraments of the Mass, Eucharist, or Lord's Supper, and the Sacrament of the Sick. God has given us the capacity to reason about things and to keep our experience (to symbolize) by representing (re-presenting) them in various ways. Symbols bring sources of nurturing and courage for facing the unknown. They make present our most important sources of comfort in the use of various transitional objects. These religious symbols affect in expressive forms the meeting of the person and the transcendent God.[133] In the symbol, there is an act of exchange where ascending and descending movements unfold in the time of an action.[134] Rituals allow for transpersonal experiences of being, in which an ordinary state of consciousness is raised above a physical level of the here and now to provide a connection with the transcendence of life

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[132] Hagglund, T.B. (1978). *Dying: A psychoanalytic study with special reference to individual creativity and defensive organization*. New York, NY: International University Press, 19.

[133] Vergote, A. (1964). Religion, belief, and unbelief: A psychological study. *Lumen Viate, 25*, 303–332.

[134] Schneiders, S. (1977). Symbolism and the sacrament principle in the fourth gospel. *L'Evangile de Jean: Sources, Redaction, Theologie.* P.R. Tragan (Ed.). (pp. 221– 236). Rome: Editrice Anselmiana.

to come. Rituals remind the dying person of the sacred, which is sometimes hidden in his or her everyday reality.[135]

A final place in which the transitional experience comes into fulfilment is the religious realm of prayer. While religion may be less of a support for persons closer to death,[136] many consider prayer to be a major vehicle of support.[137] In prayer, the person immerses one's self in the religious experience in a more direct, immediate, and personal way than in any other aspect of religious participation, whether in common, as a liturgical act, or in private, as a more or less intrapsychic function.[138] In prayer, the terminally ill person or his/her family figuratively enters the transitional space where he/she meets the God of his or her understanding.

By looking purposely at transitional objects central to the life of faith of the dying patient, we can discover a dimension to the transitional experience that is often missed by the palliative care interprofessional health care team. The symbols from the life of faith of our patients and their families accomplish the work they are supposed to do because the love they convey originates from God, whom they ultimately represent.[139]

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[135] Roche, J. (1994). Creative ritual in a hospice. *Health Progress,75*, 45–4 8.

[136] Baugher, R., (et al.). (1990). A comparison of terminally ill persons at various time periods to death. *Omega Journal of Death and Dying, 20*, 103–115.

[137] Spilka, B., (et al.). (1981). Spiritual support in life threatening illness. *Journal of Religion and Health, 22*, 98–104.

[138] Meissner, W.W. (1984b). *Religion in psychoanalytic perspectives.* Washington, DC: Georgetown University Press, 182.

[139] Meissner, W.W. (1987*). Life and faith: Psychological perspectives on religious experience.* Washington, DC: Georgetown, University Press, 20–53.

CHAPTER 3

SPIRITUALITY AND SPIRITUAL CARE IN PALLIATIVE CARE

Spirituality in Palliative Care

With the aim of providing a foundation for discussions of spirituality and spiritual care in palliative care, it is imperative that there is a common understanding of the concepts of spirituality. Spirituality is a term that refers to many dimensions of a person's life. Among the myriad of definitions of spirituality the author found common themes to inform our understanding of this concept as related to health care, the first is captured by Dossey:

> A broad concept that encompasses values, meaning, and purpose; one turns inward to the human traits of honesty, love, caring, wisdom, imagination, and compassion; existence of a quality of a higher authority, guiding spirit or transcendence that is mystical; a flowing dynamic balance that allows and creates healing of body-mind-spirit; and may or may not involve organized religion."[140]

Internist Christina Puchalski, whose research and work have been a major influence in the author's work in end-of-life care, asserts that the challenge in defining spirituality is that any definition does not give justice to the full complexity of the human spirit and of the transcendent, however it is understood. Consequently, it becomes difficult to study spirituality and find reductionist methods for integrating spirituality into health care.[141] Puchalski, referring to the consensus conference of clinicians, medical educators, and chaplains held in February 2009, says the interprofessional group of participants

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[140] Dossey, B. M. (1989). The transpersonal self and states of consciousness. In B.M. Dossey, L. Keegan, L. G. Kolkmeier, & C. E. Guzzetta (Eds.). (p.24). *Holistic health promotion: A guide for practice.* Rockville, MD: Aspen.

[141] Puchalski, C. M., & Ferrell, B. (2010). 25.

discussed a definition of spirituality, and through a consensus process arrived at the following definition:

> 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 and others, to nature and to the significant or sacred.[142]

Puchalski suggests that this definition be universally adopted for spiritual care research in palliative care and in general to help standardize the research and literature in the field.

Nurse thanatologist Joy Ufema suggests the interprofessional team use a "cushion of caring" in providing spiritual care for palliative patients and their families.

> By that I mean a relationship of trust and an honest exchange of feelings. It is imperative that you understand each patient's perceptions of his or her situation. That means listening from your heart, your spirit, not your religion; let him/her know that it is okay to practice his/her own comforting spiritual rituals on your unit. When a sick and dying fellow human being honors you by sharing what's deep within his/her marrow, you will know the difference between religion and spirituality.[143]

For patients, their families, and members of the palliative care team, especially those adhering to the Western religious traditions of Judaism, Christianity, and Islam, the concept of spirituality included transcendence and belief in God. This is captured in the voices of those who participated in this research study as expressed clearly by a nurse: "Through my spirituality I can offer and receive love; I can respond to God, our patients and their families, I can appreciate the beauty of God's creation, the changing seasons, and music of the symphony." Not everyone makes the distinction between spirituality and religion. For some people religion and spirituality are so intertwined that they are

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[142] Ibid., 25.

[143] Ufema, J. (1997, March). Insights on death and dying. *Nursing, 66*.

fundamentally one and the same. A social worker stated: “I believe that my Jewish faith tradition is synonymous with my spirituality; when I was diagnosed with breast cancer, I could not image separating the two concepts.” Spirituality may thrive, however, outside the sphere of religion as articulated by a palliative care patient: “I find meaning and purpose in my life by going to Banff National Park, canoeing and climbing to the snow covered peaks of the mountains, breathing in the fresh air and watching the sun rise and set.” Puchalski states that spirituality is not exclusive to religion; it is a much broader concept than religion.[144]

Three characteristics of spirituality put forward by Margaret Burkhardt that became evident throughout this longitudinal study include: *“unfolding mystery,”* related to one’s attempt to understand the meaning and purpose of life in the face of impending death; *“harmonious interconnectedness,”* as demonstrated in an individual’s relationship to other people and/or to God; and *“inner strength,”* which relates to one’s personal spiritual resources and “sense of the sacred.”[145] An oncologist in the study referred to spirituality as: “the cornerstone of holistic palliative care.” He emphatically stated, “It is essential that each member of the palliative care team understand his or her own spirituality, keeping in mind that their personal belief system may often differ significantly from that of their colleagues, patients and their families.” As pointed out by a Muslim faith leader at the health centre referring to harmonious interconnectedness: “Definitions of spirituality represent a variety of worldviews and the opinions of people from divergent cultural walks of life and religious affiliations. It is important that we

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[144] Puchalski, C. (2006).

[145] Burkhardt, M.A. (1989). Spirituality: An analysis of the concept. *Holistic Nursing Practice, 3* (3), 69–77.

exemplify respect in our personal and professional relationships with our brothers and sisters whose faith traditions are different from our personal faith and beliefs."

The Palliative Care Team's Spiritual Posture: Standing on Holy Ground

> God called to Moses from the middle of the burning bush: Moses, Moses! And Moses said, "Here I am." God said, "Do not come any closer, take off your sandals, for the place where you are standing is holy ground." [146]

Possibly no other scriptural theme models my posture for the practice of spiritual care and insights for offering spiritual care in health care than the Old Testament portrayal of Moses and the burning bush. God reminded Moses that, when he stood before his Lord, the ground underneath his feet was holy. As members of the palliative care team, when we stand in the presence of our patients, the ground underneath our feet is holy. It is in our act of service to the terminally ill and their families who are in need, that one encounters the God of their understanding. Just as God was present with Moses so long ago when he stood before the burning bush, God is present in our encounters with patients when we come into the presence of those who place their trust in the interprofessional team that cares for them. Frequently I have made comments similar to those spoken by members of the palliative care team: "I feel that I am standing on sacred holy ground when caring for my patients," or "I have been given a sacred trust as I care for our patients, I am standing on sacred holy ground and sense God's presence."

Sister Mary O Brien, referring to the nurse's spiritual posture, gives insight that can likewise apply to all members of the palliative care team:

> How appropriate, it seems, to envision practicing nurses, who must come together with their patients in caring and compassion, as standing on sacred holy ground. God frequently speaks to us from a "burning bush," in the fearful

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[146] Exodus 3: 4-5.

> whimper of a feverish child, in the anxious questions of a preoperative surgical patient, and in the frail moan of a fragile elder. If we “take off our shoes,” we will be able to realize that the place where we stand is holy ground; we will respond to our patients as we would wish to respond to God in the burning bush.[147]

The Palliative Care Team–Patient Relationship: A Sacred Covenant

I have made a Covenant with my Chosen One.[148]

One of the most important dimensions of the covenantal relationship between the palliative care team and our patients relates to the degree of trust established under the most difficult circumstance of life as they face impending death. The element of trust is exemplified in terms of a covenant relationship. The covenant can be considered “sacred” given the nature of intimacy that takes place in the relationship. Even though it is rarely articulated as such, the concept of covenant sets up expectations for behaviors and attitudes. Examining the term covenant from a spiritual theological perspective validates and supports the concept of the palliative care team’s practice in health care as a sacred covenant.

The word *covenant* is derived from the Hebrew word *berith*, which means a binding agreement or pact.[149] The concept of covenant is one of the Bible’s most pervasive means of describing the relationship between God and the community of faith.[150] There are several examples of covenant in the Scriptures, beginning with God’s covenant with

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[147] O’Brien, M.E. (2003). Prayer in nursing: The spirituality of compassionate caregiving. Mississauga, ON: Jones and Bartlett, 7.

[148] Palm 89: 3.

[149] Senior, D. (1993). Covenant. In M. Downey (Ed.). *The new dictionary of Catholic spirituality* (NDCS). Collegeville, MN: The Liturgical Press.

[150] Ibid.

Abraham in the Old Testament.[151] Found in Old Testament theology, Yahweh's covenant with Israel "established bonds of loyalty and responsibility between God and humanity."[152] The New Testament covenant links Jesus Christ, as the "Son of David" and fulfillment of the Messianic prophecies, as portrayed in the Gospel of Luke: 22:20, "after supper he took the cup saying, 'this cup is the new covenant in my blood, which is poured out for you.'"[153] In New Testament theology, "the life and death of Christ is the perfect covenant between God and man, that is, man's imperfect righteousness becoming perfected through the divine grace of the Incarnation."[154]

Caring for the Sick in Old Testament and New Testament Times

The Hebrew people of Israel acknowledged and responded to the command in their Mosaic Law regarding the provision of care for the sick and frail who were in poor health. There were religious rules with regard to wide-ranging health issues, hygiene, and rules relating to work and rest. "Since these rules were enforced by the group and not left to the will of the individual, they were in effect rules of public health."[155] Robinson asserted that the people of Israel "actually" laid the foundation of public health nursing on enduring principles, [they] naturally regarded visiting the sick, *bikkur holim,* as a religious duty incumbent upon all." [156] The Israelites articulated specific instructions with regard to care of persons with contagious diseases and were well-known for their care of children and those of advanced years. An outstanding religious tradition that the

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[151] Genesis 12: 1-3.

[152] Boadt, L. (1984). *Reading the old testament: An introduction*. New York, NY: Paulist Press, 547.

[153] Nowell, I. (1990). Covenant. In J. Komonchak, M. Collins, & D. Lane (Eds.). (p. 245). *The new dictionary of theology (NDT).* Collegeville, MN: The Liturgical Press. 245.

[154] Livingstone, E.A. (1990). *The concise Oxford dictionary of the Christian church.* New York, NY: Oxford University Press, 133–134.

[155] Sellew, G., & Nuess, C.J. (1946). *A history of nursing.* St. Louis, MO: C.V. Mosby, 34.

[156] Robinson, V. (1946). *White caps: The story of nursing*. Philadelphia, PA: J.B. Lippincott, 4.

Hebrew people espoused relating to their care of the sick encompassed the concepts of "hospitality" and "charity" for another person in need. This resulted in a system of "houses for strangers," supported by each Hebrew citizen tithing a tenth of his or her possessions toward charitable work.[157]

In the early Christian Church, caring for the needs of the sick or injured was given a place of honor and respect; it was linked with one of the primary messages of Jesus: to love one's neighbor, "a new command I give you: love one another…by this all men will know that you are my disciples."[158] In the New Testament there are many illustrations of Christ's healing the sick; His teaching regarding the need to care for our brother's and sister's is reflected specifically in the Parable of the Good Samaritan:

> A man fell victim to robbers as he went down from Jerusalem to Jericho. They stripped and beat him and went off leaving him half dead…[and] a Samaritan traveler who came upon him was moved with compassion at the sight. He went to the victim, poured oil and wine over his wounds, and bandaged them. Then he lifted him up on his own animal, took him to an inn and cared for him.[159]

Thus, Christ in his ministry of healing and teaching prepared the way for his early followers to serve with compassion and sensitivity the needs of the sick. The smallest gesture of human kindness was significant to Jesus, just as a cup of cold water given in his name did not pass unrewarded. "And if anyone gives even a cup of cold water to one of these little ones because he is my disciple, I tell you the truth, he will certainly not lose his reward."[160]

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[157] Pavey, A.E. (1952). *The story and growth of nursing.* Philadelphia, PA: J.B. Lippincott, 29.
[158] John 13: 34-35.
[159] Luke 10:30-36.
[160] Matthew 10:42.

Following the exhortation of Jesus to “give a cup of cold water” in His name, these first disciples responding to the instructions of Jesus opened their homes, as well as their hearts, to those in need of physical and emotional support or care. This could be considered as the forerunner to the modern day hospice movement. These examples of care, when incorporated into the philosophy of hospice palliative care can offer hope and healing to the dying.

In a commentary on the parable of the Good Samaritan, Kodell noted that Jesus’s story was intended to challenge a prevailing but discriminating attitude prevalent in the society of the time–the fact that a Samaritan, a member of an ethnic group despised by some could behave so lovingly to someone shunned by many. In his reply to the scholar of the law who was trying to justify himself, the scholar added in verse 29: “And who is my neighbor?” Jesus related the parable of the Good Samaritan in reply. As Kodell pointed out, this parable exemplifies the love commandment: “while the lawyer suggests that not all persons are his neighbors, Jesus’ reply indicates that one must consider everyone a neighbor regardless of nationality or religious heritage and affiliation.”[161] Thus, Christ in his ministry of healing and teaching prepared the way for his early followers to serve with love, compassion, and sensitivity to the needs of the sick from all walks of life. This Gospel narrative provides the palliative care team with a model of unquestionable concern and non-discrimination for offering care to the dying and their families in need; it provides a conceptual framework to support a theology of caring in end-of-life care. Prior to discussing the author’s personal theology of caring in a later

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[161] Kodell, J. (1989). *The gospel according to Luke.* Collegeville, MN: The Liturgical Press, 62.

chapter, on which my practice of ministry in health care is based, key concepts of theology and caring in palliative care will be explored briefly.

Theology: Faith Seeking Understanding

The term *theology* is derived from the Greek words *theos* meaning "God," and *logos* or "science." The present-day meaning of theology is "an intellectual discipline, i.e., an ordered body of knowledge about God."[162] The study of theology is often portrayed according to Anselm of Canterbury's perception of faithfulness as "faith seeking understanding." In this context faith is viewed as "a stance of the whole person towards God, characterized by radical trust, hope, love and commitment."[163] The author found patients, family members, and the palliative care team's personal understanding of theology was informed by numerous factors: religious and denominational heritage, formal and informal religious education, religious and spiritual experiences, current faith practices, and cultural heritage.

Caring: Remembering Our Vocational Call To Care

As members of the palliative care team, it is important to remember our vocational call to care. James Nelson, in his study *Rediscovering the Person in Medical Care,* defined caring as "an active attitude which genuinely conveys to the other person that he or she does really matter …. It is grounded in the sense of uniqueness and worth which, by the grace of God, the other has."[164]

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[162] Hill, W.J. (1990). Theology. In J.A. Komonchak, M. Collins, & D.A. Lane (Eds.). (p. 1011). *The new dictionary of theology.* Collegeville, MN: The Liturgical Press.

[163] Fehr, W.L. (1990). The history of theology. In J.A. Komonchak, M. Collins, & D.A. Lane (Eds.), (p. 1027). *The new dictionary of theology.* Collegeville, MN: The Liturgical Press.

[164] Nelson, J. (1976). *Rediscovering the person in medical care.* Minneapolis, MN: Augsburg, 63.

An ethic of caring that focuses on relationships and responsibility is one aspect of the broader field of feminine ethics. In an ethic of care, the decision maker focuses on identifying actions that promote and maintain relationships and views the patient as a unique individual within a network of relationships.[165] In caring for the vulnerable, sick, and dying, Fry, Killen, and Robinson maintain that the actions and judgements made using care-based reasoning must be measured against what it means to be "caring" within the context of the responsibilities the decision maker has to others; care-based reasoning does not involve the application of abstract ethical principles to the situation or impartiality on the part of the decision maker.[166]

The most fundamental ethical principle within the practice of palliative care is the principle of respect for persons. The idea of an ethic of caring is particularly appealing to health care professionals providing spiritual care to the terminally ill and their families in their practice and is linked to the concept of covenant. Henri Nouwen envisioned the concept of covenant that underlies the spiritual care relationship: "In the covenant there is no condition put on faithfulness. It is the unconditional commitment to be of service."[167]

Shea attempts to provide a working knowledge of the spiritual, especially as it relates to health care, by identifying three component parts–personal beliefs, stories and practices that shape and direct the lives of individuals as they both seek and offer health

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[165] Davis, A.J., Aroskar, M.A., Liaschenko, J., & Drought, T.S. (1997). *Ethical dilemmas & nursing practice* (4th Ed.). Stanford, CT: Appleton & Lange.

[166] Fry, S.T., Killen, A.R., & Robinson, E.M. (1996). Care based reasoning, caring and the ethic of care: A need for clarity. *Journal of Clinical Ethics, 7,* 41–47.

[167] Nouwen, H. (1986). 93.

and healing.[168] This researcher agrees with Puchalski that it is within Shea's masterful presentation that we can identify and clarify the moral warrants, that is, the scope and grounds of the ethical obligation to address spirituality in the health care setting with specific reference to end-of-life care and alleviation of suffering.[169]

In recognition of the palliative care team and their practice of spiritual caring, the author observed "compassionate care in action" throughout this longitudinal study. The team exemplified in words and acts of kindness the three key activities of caring identified by O'Brien[170] in their mandate to serve the sick: "*being*" present with patients in their experiences of pain, suffering, or other concerns; "*listening*" to patients as they express in words anxieties or emotions, such as loneliness, depression, fear, anger, which may impede the attainment of spiritual well-being; and "*touching*" patients either physically, emotionally, or spiritually to validate their connectedness with others and God. These three activities, being, listening, and touching, grounded in one's philosophy of life such as that articulated in the parable of the Good Samaritan, demonstrate elements of ministry in health care; they also constitute a theology of caring.

Holistic Spiritual Care: The Body, Mind, and Spirit Connection

When our society advanced scientifically as a result of medical research and technology during the past half century, it became increasingly more difficult for many working in health care to give credibility to the importance of the spiritual nature of the

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[168] Shea, J. (2000). *Spirituality and health care: Reaching toward a holistic future*. Chicago, IL: The Park Ridge Centre.

[169] Puchalski, C. (2007). A moral imperative for the integration of spirituality into health care. *Spirituality & healing in medicine: Including the concept of emergence.* Harvard Medical School Department of Continuing Education Series, Boston: MA.

[170] O'Brien, M.E. (1999). 14.

human person, especially in issues related to health/illness and the accompanying concerns of patients and their families. More recently, the author discovered in her research study that caregivers are recognizing that sensitivity to the patient's spiritual needs is critical if they are to provide authentic "holistic" health care.

In particular, the philosophy of palliative care supports the intimate connection of body, mind, and spirit. The author observed the palliative care team's attention to the whole person, which one member of the team stated as: "a prerequisite in our offering compassionate care to the patient as a person and the uniqueness of each dimension, as well, the interrelatedness of the three." In *The Wholeness Handbook*, Emeth and Greenhut describe elements of the body, mind, and spirit: the "*body*" is the physical substance of a person that can be perceived in empirical reality; the "*mind*" is the dimension of an individual that conceptualizes; and the "*spirit*" is the life principle that is shared with all humanity and with God. Their hypothesis states: "It is the dimension of personhood that drives us to create, love, question, contemplate and transcend."[171]

Authors Dossey and Keegan defined the concept of holism, which undergirds holistic health and holistic nursing care in end-of-life care, including the body, mind, and spirit connection as "the view that an integrated whole has a reality independent of and greater than the sum of its parts."[172] They describe holism as comprising a philosophy of positive, interactionally based attitudes and behaviors that can exist not only in one who is well but also in one who is seriously or terminally ill.[173] Patients and families in the study suggested that members of the palliative care team, to be supportive of a holistic

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[171] Emeth, E.V., & Greenhut, J.H. (1991). *The wholeness handbook: Care of body, mind & spirit for optimal health.* New York, NY: Continuum, 27–28.
[172] Dossey, B.M., & Keegan, L. (1989). 4.
[173] Ibid., 5.

approach in their care, need to envision the spiritual needs of their patients as deserving of attention equal to that provided in response to physical and psychological concerns.

Spirituality and Spiritual Well-Being

Spirituality is often the lens through which people interpret their world and their reality as they search to understand themselves, their needs, and their relationship to self, others, nature, and God. The word spirituality derives from the Latin word *spiritus*, which refers to breath, air, and wind. The word spirit connotes "whatever is at the center of all aspects of one's life or that which gives life to the person."[174]

Moberg conceptualized spiritual well-being as encompassing both vertical and horizontal dimensions that involves transcendence. The vertical dimension refers to our sense of well-being in relation to God, while the horizontal dimension refers to a sense of purpose in life and life satisfaction.[175]

The term spiritual well-being is designated historically as having emerged following the White House Conference on Aging held in 1971. It was David Moberg, a Sociologist of Religion, who categorized spiritual well-being as relating to the "wellness or health of the totality of inner resources of people, the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning giving center of human life which influences all individual and social behavior." [176]

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[174] Dombeck, M.B. (1995). Dream telling: A means of spiritual awareness. *Holistic Nursing Practice*, *9*(2), 37– 47.

[175] Moberg, D.O. (1997). Subjective measures of spiritual well-being. *Review of Religious Research*, *25*(4), 351–364.

[176] Moberg, D.O. (1979). The development of social indicators of spiritual well-being and quality of life. In D.O. Moberg (Ed.). (pp. 1–13). *Spiritual well-being: Sociological perspectives.* Washington, DC: University of America Press.

The concept of hope has been identified as central in several definitions of spiritual well-being. Spiritual well-being is described as "an integrating aspect of human wholeness, characterized by meaning and hope;" [177] as well, "the need to feel hopeful about one's destiny."[178] Droege, in discussions of the "faith factor" in healing proposed that when an individual does not experience spiritual well-being, serious spiritual maladies may occur such as depression, loneliness, existential anxiety, and meaninglessness."[179] This concept was clearly evident in the author's research with numerous terminally ill patients in the study.

Several viewpoints of spiritual well-being also contain some reference to philosophy of life and transcendence. Blaikie and Kelson refer to spiritual well-being as "that type of existential wellbeing which incorporates some reference to the supernatural, the sacred or the transcendental."[180] Barker witnessed in observations with individuals that spiritual well-being is "to be in communication with that which goes beyond oneself in order to be whole in oneself."[181]

The perception of faithfulness was identified in this study as a factor connected to spiritual well-being. Religiousness or "religiosity," as it is sometimes identified in the sociological literature, refers to religious affiliation and/or practice. Kaufman described

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[177] Clark, C.C., Cross, J.R., Deane, D.M., & Lowry, L.W. (1991). Spirituality: Integral to quality care. *Holistic Nursing Process, 3*(1), 67–76.

[178] Lindberg, J.B., Hunter, M.L., & Kruszewski, A.Z. (1994). *Introduction to nursing: Concepts, issues, & opportunities*. Philadelphia, PA: J.B. Lippincott, 110.

[179] Droege, T. (1991). *The faith factor in healing.* Philadelphia, PA: Trinity Press, 13.

[180] Blaikie, N.W., & Kelson, G.P. (1979).Locating self and giving meaning to existence. In D.O. Moberg (Ed.). (p. 137). *Spiritual well-being: Sociological perspectives.* Washington: DC: University of America Press.

[181] Barker, E. (1979). Whose service is perfect freedom? In D.O. Moberg (Ed.). (p.154). *Spiritual well-being: Sociological perspectives.* Washington: DC: University of America Press.

religiousness as “the degree to which religious beliefs, attitudes and behaviors permeate the life of an individual.”[182] For patients of the Jewish and Christian faith traditions, they captured Christy and Lyon’s definition of spiritual well-being: “a right relationship of the person to God, and following that, a right relationship to neighbor and self.”[183] This perception is associated with one of the primary messages concerning relationships found in Scripture: “Love the Lord your God with all your heart and with all your soul, and with all your strength and with all your mind; and love your neighbor as yourself.”[184] The principle of the love commandment was referred to by a female patient of the Jewish faith tradition in the following case study. It exemplifies how Merriam was able to share her deepest concerns and emotions with the hospital Rabbi, her need for reconciliation and inner peace in the face of impending death:

> Merriam spoke about a time when she was deeply hurt by words and actions of a colleague, a clinical nurse specialist. With the reality that she was nearing death, she made a decision to contact the person who hurt her; together they were able to find forgiveness for each other. She quoted a passage from the Old Testament that guided her decision: “Do not seek revenge or bear a grudge against one of your people, but love your neighbor as yourself.” [185] She died a week later with her family and the colleague whom she had forgiven next to her bedside. Shortly before she lost consciousness, she quietly spoke these words to her Rabbi: “I am at peace with my life and now trust my future to God.”

Spirituality: Spiritual Distress and Suffering at End of Life

Milton Hay views spirituality as four interrelated dimensions that can be used as the basis for assessing and alleviating spiritual distress and suffering. The four dimensions

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[182] Kaufman, J.H. (1979). Social correlates of spiritual maturity among North American Mennonites. In D.O. Moberg (Ed.), *Spiritual well-being: Sociological perspectives* (pp. 237–254). Washington, DC: University of America Press.

[183] Christy, R.D., & Lyon, D. (1979). Sociological perspectives on personhood. In D.O. Moberg (Ed.), *Spiritual well-being: Sociological perspectives* (p. 98). Washington: DC: University of America Press.

[184] Luke: 10:27.

[185] Leviticus 19:18.

are community, meaning, religious needs, and inner resources.[186] Thus, spiritual distress at end of life is an impaired ability to experience meaning, hope, connectedness, and transcendence. It commonly involves an intensification of alienation and disconnection, while dying forces a progressive series of separations and detachments from life itself.[187]

Three significant insights for the author regarding suffering and spiritual distress were observed in my clinical research with patients and families throughout this study. (a) A discourse on suffering invariably initiates a discourse on spirituality if patients, families, and the palliative care team are open to it. (b) Spiritual distress may be experienced by the terminally ill person or family member who is questioning the reason for his or her suffering. (c) If the palliative care team are to be helpful in caring for their patients, they must acknowledge that suffering and often the senselessness of it are ultimately spiritual issues. A common theme observed in the study is articulated by Wright who states, "Suffering invites and leads us into the spiritual domain. A shift to and emphasis on spirituality are frequently the most profound responses to suffering from illness."[188]

Manifestations of spiritual distress include anger, guilt, blame, hatred, expressed absence of meaning, expressions of alienation and turning away from friends and family, inability to enjoy, and one's inability to participate in religious activities that have previously provided comfort. [189] The four dimensions of spirituality identified by Milton Hay and manifestations of spiritual distress/ suffering were revealed in patient interviews

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[186] Hay, M. (1989, September/October). Principles in building spiritual assessment tools. *American Journal of Hospice Care,* 25–31.

[187] Zerwekh, J. (2006).

[188] Wright, L. (2005). 131.

[189] Doenges, M., Moorehouse, M., & Gissler-Murr, A. (2004). *Nurse's pocket guide: Diagnosis, interventions and rationales*. Philadelphia, PA: F.A. Davis.

and observations during visits with patients on the palliative care unit throughout the study. The following excerpts from a patient's interview capture the concept of spiritual distress and suffering:

> *Ricardo*: The loneliness, oh the loneliness, my boys don't come to visit, I feel so alone and lonely; it's the breakdown in my relationship with my wife [pause] I need to be honest and say ex-wife and boys. I need to restore my relationship with them [long pause as he wipes away tears from his eyes] she found another Italian so I guess that will never happen. I feel so guilty about the affair I had a few years ago with the woman next door. I felt a need to be honest with my wife so I told her what happened, she immediately filed for divorce. I have this overwhelming sense of guilt about the affair and feel angry with my ex-wife because she could not find forgiveness for me in her heart.
>
> The nuclear family is like a wolf pact they stay together – the sense of alienation I feel is the worst thing that has ever happened to me. Their abandoning me is like a reflection in the mirror because family reflects the value of who I am as a person. My life has no meaning and purpose; because they don't come to visit it causes me to feel depressed and lonely – my life has lost meaning and purpose. Loneliness is the worst enemy and it is a source of my suffering…oh yes, my suffering is worse than the disease, it causes me pain and gets deep into my mind and heart. I cannot help think if my wife and children who cannot forgive me for what I have done wrong. Will God be able to forgive me? My faith and involvement in church activities gave me comfort in times of crisis; I have turned away from my faith community because my ex-wife continues worship there. Is God punishing me and allowing me to suffer because of what I did in the past?

Culturally Competent Spiritual Care to End of Life

There is increasing cultural diversity within our Canadian society today that challenges the palliative care team to look through different lenses in providing holistic care. Culture is defined as a way of life. While culture is often identified with ethnicity, it is a far broader concept which encompasses spirituality and class.[190]

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[190] Doka, K., & Davidson, J. (1998). *Living with grief.* Philadelphia, PA: Hospice Foundation of America, 4.

Every culture has a worldview or construct of reality that defines the individual within the reality of facing impending death. A patient's cultural background is therefore a factor which is central in defining and creating their reality and determining their purpose in life. Even though there may be numerous cultural similarities and universal aspects to life, family, hope, love, funeral customs, grieving, and caring, it is important to recognize that cultural diversity exists. Diversity refers to differences between people based on beliefs, shared teachings, norms, customs, language, and meaning that influences the individual, and family's response to illness, treatment, death, and bereavement.[191]

The key to accommodating cultural diversity is to understand one's personal values, beliefs, and customs related to the celebration of life, coping with illness, and death. Members of the palliative care team bring their own cultural perspectives and life experiences into the caregiving setting. It is essential that all members of the team be sensitive and responsive to those entrusted to their care in the face of impending death in a culturally appropriate manner. Death is acknowledged as a common experience; however, the author observed that often there was a failure of several health care members to recognize that loss, grief, death, and bereavement occur within a cultural context. Across cultures people differ in their beliefs and attitudes about life, illness, and death; in what they feel; what evokes emotions; the implications of those feelings; and ways of expressing and dealing with emotions. [192]

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[191] Showalter, S. (1998). Looking through different eyes: Beyond cultural diversity. In K. Doka & Smith, R. (Eds.). (pp. 71–82). Living *with grief.* Philadelphia, PA: Hospice Foundation of America.

[192] Rosenblatt, P. (1993). Cross cultural variation in the experience, expression, and understanding of grief. In D. Irish, K. Lundquist, & V. Nelson (Eds.). *Ethnic variations in dying, death, and grief* (pp. 13–19). Philadelphia, PA: Taylor & Francis.

With recognition and acknowledgement that cultural diversity exists, and their need to learn more about the norms and practices of patients' cultural backgrounds, a newfound educational opportunity became available for the interprofessional team during the research project to gain knowledge about various cultures during the final eight months of the study. A Multifaith Information Series on "Care to End of Life" was presented by faith leaders from various communities The author observed and noted that in their developing cultural competencies, team members began to listen carefully as they gathered cultural information and explored spiritual beliefs and values about suffering, dying, and death rituals. Understanding these things may help health care providers and families work together to create the most positive and personal atmosphere possible. This became apparent as I listened to a conversation the palliative care nurse *Patricia* had with *Lateffa*, a Muslim patient's wife:

> Is there anything that we should know about you or your family's culture or religious tradition? How do you make sense of illness and dying right now? What gives you comfort? Are there any rituals or practices that are important within your faith tradition as the moment of death approaches?

Lateffa was able to tell the nurse that her husband, Yusef, is a devout Muslim. Two days ago my husband asked me to read one of his favorite poems, "The Compass," written by Salimah Riber-Dewji, saying the words give him comfort as he faces the unknown. [Lateffa took a book from her husband's night table and read the following poem]:

> Allah, my compass give me direction, the location of my soul that I may find my way home… I've walked the streets of sadness with tears filling the gutters… I've flown over the miles of loneliness and landed on fields of pain … I've swam across rivers of darkness and been washed ashore islands of

> fear… O Allah my compass give me direction for the location of my soul that I may find my way home… [193]
>
> Then Lateffa paused and handed me type written notes on a piece of paper she took from her purse saying: “My friend is a hospital chaplain and she gave me this overview to give to Yusef’s care team; we want to ensure that our religious and cultural traditions are followed. In the past when my mother died no one called us; we were not there to say prayers and worst of all a male nurse washed her body. Please follow the following rites and rituals of our Muslim faith tradition when my husband dies.”
>
> As the moment of death approaches, Yusef (if he can) should recite with the help from others the Islamic Creed (Shahadah)… A Muslim who is near my husband should recite some chapters from the Quran, particularly (Surah Ya-seen), Chapter 36, and ask God for Mercy and Forgiveness for my dying husband. It is important that after death his eyes are gently shut, his hands and mouth closed with a bandage running under his chin and tied over his head, and his arms and legs are straightened. It is okay for our family to shed tears and grieve, but we are not allowed to wail, tear our garments like some of my friends from other faith traditions… [Long Pause…with tears rolling down Lateffa’s face she continues] His body should be washed, by a close Muslim relative or friend who is a man; however, as his wife it is permissible for me to wash my husband’s body. After washing his body is shrouded with white sheets. Then he is taken to the mosque where the Imam will offer funeral prayers. As soon as prayers are over, then he is taken to the graveyard for burial. Yusef’s body should be positioned so that when turned on his right side, faces Mecca. [194]
>
> Yusef died two days following the above conversations. The palliative care team followed Lateffa’s wishes; an Imam was called to the patient’s bedside where rituals and practices of his Muslim faith were conducted as requested which reflected respect for the diversity and religious customs of our patient population.

A hospital chaplain *Joan* captured the essence of the palliative care team’s need to develop cultural competencies in a taped interview, making the following remarks:

> Knowledge about the patient’s culture should serve only as starting point in assessing individual beliefs and activities. In providing culturally sensitive care we can attend to the cultural needs of our patients by gathering information about their distinctive rituals, practices, and beliefs; above all, it is essential to discover what is meaningful for the patient. This is accomplished through

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[193] Sayed, A.R.M. (2002). *Islamic perspectives on prayers & coping with sickness*. Mississauga, ON: Islamic Society of North America, 150.

[194] Ontario Multifaith Council on Spiritual & Religious Care. (2006). *Multifaith information manual* (4th. ed.). Toronto, ON: Webcom Limited Printers, 177.

> listening, observing, and asking about unknown practices and rituals of patients and families that are significant and meaningful. Furthermore, it is important to determine what strengths the person draws on when confronting death, dying, or bereavement, such as internal resources provided by one's belief system or past experiences, and external resources such as family, friends and cultural customs and practices.

Spirituality and culture are considered to be among the most significant factors that structure human experience, values, behaviors, and illness patterns. With the diagnosis of a life-threatening illness, a crisis occurs on many levels–physical, psychological, familial, social, and spiritual. [195] A recurring theme that emerged across the diverse cultural backgrounds of the research participants who revealed a transformation of identity began when they received the diagnosis of a terminal illness. In view of the uniqueness and individuality of each person in the study, even people of the same religion or culture, many had different upbringings, experiences, needs, concerns, and interpretations of their illness. The author's study clearly highlighted this reality; the nature of the life-threatening illness may be different and the person may be at different points along the illness trajectory on the continuum of palliative care in adapting to the reality of his or her disease; everyone experienced a transformation of identity.

The author also observed that spiritual and cultural concerns often filter through the illness experience or may surface at any point across the illness/dying trajectory. For patients and families experiencing life-threatening illness, their concerns also encompassed suffering which included challenges relative to the body, mind, and spirit connection.

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[195] Doka, K., & Morgan, J. (1993). *Death and spirituality*. Amityville, NY: Baywood.

Ethnic and cultural differences were identified as influential in approaches of coping with a life-threatening illness, the perception of pain, the support of the dying, the behavioral manifestations of grief, mourning styles, and funeral customs. Therefore, assessment of the patients' and their families' spiritual needs is an essential component of palliative care. A nurse educator with end-stage renal failure who asked if she could participate in the author's research offered insightful advice in a taped interview:

> For the palliative care team striving to provide holistic health care, the spiritual dimension and needs of the patient and their family must be carefully assessed and considered in all therapeutic planning and implemented into goals of care. Spiritual care cannot be separated from physical, social, and psychological care; it must also be culturally sensitive. Frequently in my role as a nurse, before I had both legs amputated, standing at the bedside of patients, I had opportunities to interact with them, listen to their stories, and pray with them. It is on the spiritual level, being present with them as they question the meaning and purpose of their life, when they ask me to pray for them, and often when they would spontaneously pray for me, I realized that I was truly standing on holy ground.

Experiences of illness and dying are very personal experiences that take individuals to the very core of their humanity and occur within the context of one's spiritual and cultural traditions. Through sensitive and competent spiritual care, we can safeguard patients and families from the ultimate misfortune of depersonalization that unfortunately often takes place within the health care system. The palliative care team must endeavor to care for patients in a personalized environment that offers "a spirit of hospitality and compassion for the stranger" who comes into our care under difficult and challenging circumstance in his or her life. Sulmasy believes that when a patient's spirituality collapses in the face of illness, a clinician with the right perspective will understand much more acutely how desperate their plight really is and will treat the wounds of such patients with even more liberal applications of the wine of fervent zeal and the oil of compassion.[196]

Taking a Spiritual History and Assessment of Spiritual Needs

Spiritual and cultural competencies are central tenets of palliative care. Through the lenses of a philosophy of care, palliative care combines active and compassionate therapies to support and comfort individuals and families who are living with life-threatening illness. Palliative care strives to meet the physical, psychological, social, and spiritual needs, while remaining sensitive to personal, cultural, and religious beliefs and practices.[197]

The majority of patients welcome a discussion of spiritual matters and want the palliative care team to consider their spiritual needs.[198] [199] Many researchers have identified the need for sensitive consideration of spiritual concerns of dying patients.[200] [201] A survey conducted by the George H. Gallup International Institute in a national research study showed that people overwhelmingly want their spiritual needs addressed as they approach impending death.[202] Even nonreligious patients– 45%– thought that

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[196] Sulmasy, D. (1977). *The healer's calling: A spirituality for physicians and other health care professionals.* New York, NY: Paulist Press, 52.

[197] Ferris, F., & Cummings, I. (Eds.). (2005). *Towards a consensus in standardized principles of practice.* Ottawa, ON: Canadian Palliative Care Association, 5.

[198] O'Brien, M.E. (1999). Sacred covenants: Exploring spirituality in nursing. *AWHONN Lifelines,* 3(2), 69–72.

[199] Post, S., Puchalski, C., & Larson, D. (2000). Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Annals of Internal Medicine*, *132* (7), 578–583.

[200] Conrad, N.L. (1985). Spiritual support for the dying. *Nursing Clinics of North America, 20,* 415–426.

[201] Moberg, D.O. (1982). Spiritual well-being of the dying. In G. Lesnoff-Caravaglia (Ed.), *Aging in the Human Condition* (pp. 135 –1 55). New York, NY: Human Sciences Press.

[202] George H. Gallup International Institute. (1997). Spiritual beliefs and the dying process. *Report on a National Survey, 2,* 31–43. Conducted for the Nathan Cummings Foundation & Fetzer Institute.

physicians should inquire politely about their spiritual needs,[203] particularly at the end of life.[204]

Researchers exploring spiritual needs at various points along the illness continuum have discovered that spirituality is highly valued during the diagnostic and treatment phases of the disease.[205] The importance of spirituality and having one's spiritual needs recognized and fulfilled is well supported for individuals receiving treatment for recurrent cancer,[206] patients receiving chemotherapy,[207] and those who have been diagnosed as terminally ill.[208] [209]

A spiritual history opens the door to a conversation about the role of spirituality and religion in a person's life. People often need permission to talk about these issues. With certain signals from a member of the interprofessional team, patients may feel that such topics are not welcome or appropriate. The role of the professional caregiver is to listen and encourage people as they search for answers.[210]

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[203] Moadel, A., Morgan, C.K., A., Fatone, A. (et al.). (1999). Seeking meaning and hope: Self-reported spiritual and existential needs among the ethnically-diverse cancer patient population. *Psycho-Oncology, 8,* 378–385.

[204] Ehman, J.W., Ott, B.B., Short, T.H. (et al.). (1999). Do patients want physicians to inquire about their spiritual and religious beliefs if they become gravely ill? *Archives of Internal Medicine, 159,* 1803–1806.

[205] Ferrell, B., Dow, K., Leigh, S., Ly, J., & Gulasekaram, P. (1995). Quality of life in long-term cancer survivors. *Oncology Nursing Forum, 22,* 915–922.

[206] Taylor, E.J. (1993). Factors associated with meaning in life among people with recurrent cancer. *Oncology Nursing Forum, 22,* 1399–1405.

[207] Messias, D., Yeager, K., Dibble, S., & Dodd, E. (1997). Patient's perceptions of fatigue while undergoing chemotherapy. *Oncology Nursing Forum, 20,* 915–922.

[208] Reed, P. (1991). Spirituality & well-being in terminally ill hospitalized adults. *Research in Nursing and Health, 10,* 335–344.

[209] Sodestrom, K., & Martinson, I. (1987). Patient's spiritual coping strategies: A study of nurse and patient perspectives. *Oncology Nursing Forum, 14* (2), 41–46.

[210] Zerwekh, J. (2006). 231.

Indeed, the most valuable information the author obtained with regard to taking a spiritual history and assessment of spiritual needs was in 2007 while attending the Harvard Medical School Department of Continuing Education Series. The following information was transcribed from my handwritten notes of a presentation given by Dr. Christina Puchalski:

> Obtaining a spiritual history involves simply listening to patients as they express their fears, hope, and beliefs. A spiritual assessment is intended to elicit information about their core spiritual needs and how the nurse and other members of the health care team can respond to them. Just as a medical history is completed using a systematic review of physiological systems, hospice and palliative care programs incorporate spiritual assessment instruments into their medical records; these are used to guide conversations about spirituality. They are not intended to be used as checklists or routine paper work, but rather as examples of how to initiate a spiritual history and to focus listening as patients talk about their beliefs and what gives their life meaning. Listening and responding to spiritual needs are best conducted within the context of a relationship.[211]

"I HOPE FOR" End-of-Life Spiritual History and Needs Assessment Guide ©

Adapted from the HOPE Spiritual Assessment Tool; Permission granted by Dr. Gowri Ananadrajah.

Hope is *a powerful life force,* which helps one seek and find new possibilities based on an attitude of trust. It is directed toward the future attainment of a desire, which to the patient is realistically possible and personally significant.[212]

Dr. Gowri Anandarajah and Dr. Ellen Height began the process of including spirituality as an aspect of patient care in their *HOPE Questions for a Formal Spiritual Assessment in a Medical Interview.*[213] This was the springboard that led the author into qualitative research with regard to exploring patient and family end-of-life needs and

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[211] Puchalski, C. (2007).

[212] Ersek, M. (2001). 339–351.

[213] Anandarajah, G. & Height, E. (2001). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *American Family Physician, 63,* 81–89.

[213] Hay, M. (1989). 25–31.

developing the *“I HOPE FOR”* End-of-Life Spiritual History and Needs Assessment Guide [Appendix C] incorporated into this study. During a conversation, a patient diagnosed with a terminal illness where his needs were being assessed said, “Elaine, if you really want to know what my needs are, ask me what I hope for.” Consequently, the questionnaire to explore what patient’s hopes are in the face of impending death was named. Dr. Anandarajah was contacted and gave her permission to adapt the *HOPE* Questionnaire to include an assessment of end-of-life spiritual needs.

This tool using a narrative approach personalizes the process by applying the mnemonic: ***“I HOPE FOR”*** as a way to remember the eight components to cover during a spiritual assessment, they are: (a) **I**ndividual Cultural Practices with Respect to Medical Care may have implications for specific treatment plans or options; (b) **H**ope, Meaning, and Purpose; (c) **O**verview–Emotional and Social History ; (d) **P**hysical and Medical History; (e) **E**thical Decisions–End-of-Life Care; (f) **F**aith and Beliefs History, (g) **O**rganized Religion and Religious Practices; (h) **R**ituals and Personal Spirituality Practices specific to the patient’s ethnic and cultural beliefs. This spiritual history and needs assessment guide can assist the clinician who is conducting the assessment to have meaningful discussions with patients.

The spiritual history is a necessary part of the overall patient history in order to give the patient an opportunity to discuss spirituality, if this is important to the patient. A spiritual history is that part of the patient encounter where the person can tell his or her story and share beliefs and values. It is a part of the overall assessment that is less technical. Many patients state that it is in this type of encounter that compassionate care can be a sensed and experienced. The spiritual history can also be done with family members as a way to find out what resources of spiritual strength the family members have, as well as to learn more about the family's values. It also helps to connect with the family.[214]

A spiritual assessment is a process by which the clinician and/or other members of the palliative care team can identify a patient's needs and develop plans to provide quality care to end of life. The assessments should be ongoing to measure spiritual well-being, or its opposite, spiritual distress, from the time of diagnosis of a life-threatening illness until death.

There are many ways to ask questions. It is important that one take into consideration the ethnic and cultural background of the patient and family members; many families consist of blended cultures and faith traditions. Patients are more likely to disclose their religious beliefs, needs, and concerns to professionals who demonstrate they are prepared to listen, are nonjudgmental, and open to discussion.

Remen[215] affirms that most people use symbolic or metaphorical language and images in their attempt to express spiritual thoughts. Clinicians and researchers will need to listen carefully to the stories patients and families tell and how they respond to questions in order to interpret deep, underlying meanings that encompass impending death. It is within their stories that suffering can be identified and the potential for healing looms.

Wright identified *narrative* as an effective way to engage individuals and families in conversations about suffering and spirituality that have the potential to invite healing.

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[214] Puchalski, C. (2006). 237.

[215] Remen, R.N. (1996). *Kitchen table wisdom: Stories that heal.* New York, NY: Riverhead.

The *medical* narratives are a way to discuss the disease, tests, medications, and their impact on the terminally ill. The *illness* narratives are a way for the terminally ill/dying and his/her family to tell their story of suffering and its effects on their relationships personally and professionally from their worldview. The *faith/belief* narratives focus on the beliefs that patients, families, and health care professionals have about the illness.[216] Similar to Wright's hypothesis, throughout this study, the author observed that it is within these stories that suffering emerges. By taking the time to listen and ask questions, one can determine the impact of suffering and develop a spiritual care plan with the patient. For each person the spiritual care plan will be different, depending on the issues that arise from the time of diagnosis and throughout the illness trajectory. So far, I have discussed the theoretical concepts for quality end-of-life care. How can one put these concepts into practice? Perhaps an actual case study using the *I HOPE FOR Spiritual History and Needs Assessment Guide* will exemplify the effectiveness of providing end-of-life palliative care throughout the illness trajectory, dying, death, and bereavement.

Palliative Care is planned and delivered through the collaborative efforts of an interprofessional team including the individual, family, caregivers, and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.[217]

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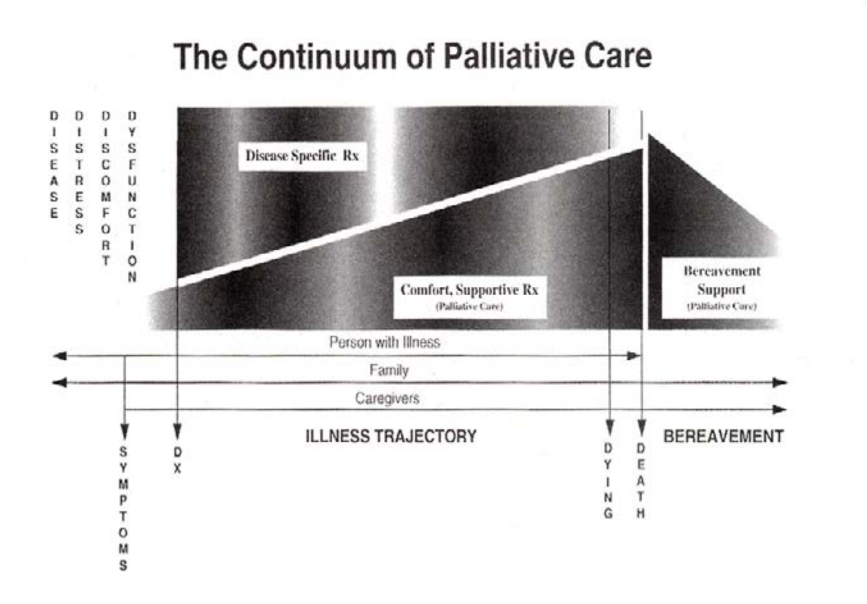
[216] Wright, L. (2005). 37.
[217] Ferris, D., & Cummings, I. (2005). 5.

Diagram 1 – The Continuum of Palliative Care [218]



A Family's Experience Through the Continuum of Palliative Care

Case Study

Mr. James Smith is an 86-year-old veteran of the Royal Air Force who served in England during World War II. He married his wife Mary in London, and moved to Canada shortly after the war ended. Subsequently, they settled in Toronto and had two children, Mike, and Joseph. Living in a quiet neighborhood, Mike described his father as a "very frugal man who took pride in 'providing well' for his wife and family." As "head of the family," an ethnic and cultural tradition passed down through the generations, James pledged that this tradition would continue for succeeding generations through his children and grandchildren.

For the past five years, James has been the sole caregiver for his 83-year-old wife, diagnosed with Alzheimer's disease. Mary has not recognized James during the past four years. When the children called home and asked to speak to their father, Mary would tell them, "your dad is not here but the other guy with the glasses is here."

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[218] Ibid.

James was referred to the oncology clinic on March 26, 2010. Accompanied by his son, Mike, they met with an oncologist who gave them the “bad news” that Mr. Smith had leukemia and his condition was critical; in addition a large malignant mass was discovered on his right lung. James was admitted directly to the oncology unit. On his first evening in hospital, he fell out of bed; his injuries were extensive.

I met James the next day. I observed that he had required numerous stitches and the bruising to his face was obvious, with egg like pouches under his eyes. James was quick to point that he is not like many people who wonder why God has allowed this to happen. He told me that he was an Anglican who had not attended church in several years because he had to stay at home to take care of his wife. “I am very spiritual, I read my Bible every day and pray in the morning and before I go to bed at night.” With a twinkle in his eyes, James told me Mary was Jehovah’s Witness: “She tried to convert the children and me – but finally gave up when she realized how important my faith tradition is – I’m a Brit. you know – I have to stay faithful to England’s official religion!”

James was anxious to talk about his faith and spirituality. I was able to follow the patient’s lead in light of the fact that he initiated a conversation about the importance of his Anglican religion: “It gives me hope as I contemplate about life and life after death.” I was able to take into consideration and focus on the patient and his family’s spiritual needs using the *I HOPE FOR End-of-Life Spiritual History and Needs Assessment.* The interprofessional team began to implement into James’s goals of care Cicely Saunders’s philosophy of holistic care. This called for consideration not only of the physical and psychological needs but also of the spiritual and social needs of the patient and his family.

The oncologist, nurses, and the pharmacist [who monitored his medications] managed James’ pain and symptoms. The social worker became aware of the caregiver burden/stress and burnout of the family as a result of caring for their mother, an Alzheimer’s patient who recently was diagnosed with cancer. The ethicist assisted James and his family in their decisions around end of life ethical decisions not to put James on life support and his decision for DNR orders. In addition, the social worker and hospital chaplain provided emotional support as Mike “now the head of the family” [once his father became ill] made the decision to place their mother in a nursing home when a bed became available.

As his chaplain, I explored what type of music James liked. He was provided with a CD player, music and hymns from his faith tradition and era. For example, he was quick to point out: “My favorite hymn is *Guide Me Oh Thou*

Great Jehovah, the newer versions use the word *Redeemer* – I really don't like that word – do you have the *Jehovah* version?" I observed tears in his eyes as he listened to John McDermott sing his favorite hymn and a medley of war songs. At his request, during regular visits, I read to him from Scripture, listened to him tell me stories about Mary seen in the picture sitting on his table. James told me it was taken of her during World War II and she was wearing the *Royal Air Force* uniform.

Late one evening I visited James who was sitting by his bed looking out the window; the moon was brightly shining on the flower gardens and the water in the pond below. James pointed toward lights that could be seen on the horizon several miles away. "Mary's over there, she is going into a nursing home next week in St. Catherine's. I want to see her but she would be terribly upset if she saw my face with all these bruises" [I suspected he knew that his condition was deteriorating rapidly]. The cleaning lady, who was nearby heard his comments and suggested he put concealer and liquid make up on to cover up his injuries, to our surprise he agreed.

The following day Mike and his wife brought Mary to the hospital for a visit. When she entered his room, I believe we saw "a miracle" unfold before our eyes – it was the first time in four years she recognized her husband. For almost thirty minutes, she recalled when they met in London, got married in St. Paul's Cathedral; together they shared many happy times in their life story. Their life reviews validated the significance of the relationship they shared together over the years.

The Palliative Care Team standing in the background outside the room watched the unfolding of a life review that will stay in our memories for a lifetime. After the first half hour before Mary slipped back into a loss of memory, the hospital photographer took pictures of the entire Smith family together for the last time. Before they left the hospital that day, she returned with framed photographs of James and Mary holding their wedding photo taken at the end of World War II.

On Easter Sunday, I celebrated *Holy Communion* with James, his sons Mike and Joe – the Lord's Supper – the bread and the wine – symbols of God's love and the promise of eternal life for those who believe. I sensed James knew this was the beginning of his journey into the mystery of a new life. This was the last time I saw James, I left for vacation the following morning. James died on May 26th two months following his admission to the hospital.

The following week Mike came into my office. When I asked him the question, “What was helpful for you and your family during your father’s illness and admission to hospital?” He replied, “The medical care, emotional support, and spiritual care that was provided for my father and our family by the interprofessional team on a daily basis – this was such an important aspect of his care. Although there was no cure for the disease that took my father’s life, I believe my dad died a peaceful death.”

Later in our conversation I asked Mike: “Were there things that you considered not so helpful or we could have done differently in your father’s care?” Mike took time and paused before speaking. “I received a phone call from a physician that I had never met telling me that our father’s care was being transferred to a palliative care doctor immediately. He said that Mr. Smith would be moved straightaway to the geriatric unit in the hospital until a bed became available on the palliative care unit; this could take approximately two to three months. The doctor’s ‘death sentence verdict’ came on the same day we placed mother in a nursing home in St. Catherine’s.

Later during the day of the phone call, the palliative care doctor and I met with Mike who had a request that his dad be allowed to stay in the same room on the oncology unit until a bed became available on the palliative care unit. Mike said this was important so his father could look out the window toward St. Catherine’s where his mother would be in a nursing home that overlooked Lake Ontario. Mike continued, “He agreed. The doctor was so caring and compassionate. Dad died four days following my conversation with the palliative care physician. [Sobbing, and holding his head in front of his face] “We were not prepared for the emotional turmoil that occurred. I felt overwhelmed by the communication process, our father’s death, and mother being placed in a nursing home – all on the same day.”

A week later, upon returning to work, Mike’s director gave him notice of termination of his job as manager of a large store. On July 30th Mike’s brother Joe died suddenly of a massive heart attack; his mother Mary died September 15th at the nursing home in St. Catherine’s. Feeling totally devastated, Mike remembered seeing bereavement follow up as part of our Palliative and Supportive Care Services. When he called the palliative care unit they referred Mike to the *Journey Through Grief Toward Healing and Hope Bereavement Program* that was part of this research project. Recently, Mike told me it was through the bereavement support group he experienced hope and healing and is now able to move forward into the future. Words written by the Parish Nurse (in chapter 7) who facilitates this group with me capture the significance of bereavement care and attending support groups following the death of a loved one.

From this case study, one can recognize the numerous issues, questions, and challenges that confront the interprofessional team on a daily basis. We continually seek answers to questions such as: “How can we meet patient needs in a more compassionate way?” “What must we do to bridge the gap between health care and spirituality in order to facilitate spiritual care for patients and their families?”

I believe this case clearly exemplifies the need for training [of some professionals] in how to communicate “bad news” and the need for continuing education concerning what encompasses quality end-of-life care. In addition, amidst cutback to health care, it starkly reveals the need for additional beds on the palliative care unit in order to provide continuity of care for patients with caregivers the patient and family have previously met in the oncology clinic within the health care setting. Finally, the need for emotional and anticipatory grief support throughout the illness trajectory and bereavement follow-up, as put forth in the continuum of palliative care model, is essential.

CHAPTER 4

THE RESEARCH EXPERIENCE

Entry Into the Hospital Environment

> Somehow we have lost the human and passionate element of research. Becoming immersed in a study requires passion: passion for people, passion for communication and passion for understanding people. This is the contribution of qualitative research, and it can only enhance educational and human services practice. For too long we have allowed psychometrics to rule our research and thus to decontextualize individuals. In depersonalizing the most personal of social events, education, we have lost our way. Now it is time to return to a discourse on the personal, what it means to be alive.[219]

In order to gain access to the group to be studied I first had to obtain access to the official organization. Since I had been employed within health care for 10 years in the Toronto area, gaining entry into the hospital was uncomplicated Two years previous to conducting this research study, I had obtained approval from York Central Hospital and their Research Ethics Board to conduct phase one of this longitudinal research project. Phase one sensitized me to the patients' experience of terminal illness and to the environment in which this research was conducted. The staff at that time saw my work experience in professional chaplaincy as a stepping stone to the present study. This is an environment where I have become well known to staff through their interest in the topic of study. I have over a period of time earned the trust of hospital staff working in oncology, palliative care, dialysis, intensive care, cardiology, complex continuing care, and various acute medical care units.

I began by making personal contact and explaining the study to key people in the

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[219] Janesick, V. (1994). The dance of qualitative research design: Metaphor, methodology, and meaning. In Danzin, N. & Lincoln, Y. (Eds.). *Handbook of qualitative research* (pp. 209–219). Thousand Oaks, CA: Sage.

organization: administrative staff, nursing managers, the coordinator of spiritual care, nursing staff, and multidisciplinary team members. Face-to-face contact with staff, including physicians, oncologists, and palliative care doctors, was extremely helpful in explaining the purpose and procedures of the study, in establishing rapport and developing trust. Through this communication process, the staff identified potential participants. Having the trust of staff and their awareness of my role as a researcher and skills as an investigator made approaching patients and other participants in the study easier.

As soon as the formal entry into the organization was completed, I spoke to patients about the study. The patients were informed of the purpose and method (how data would be collected) of the study. I also discussed the sort of information that would be used in the final document and how I planned to use the research findings. I then approached the patients' and their families about the study. Rapport and relationships of trust with many patients and their families existed before the second phase of this study, and this was a factor that made it relatively easy to begin the research process. However, sustaining rapport with participants required particular diligence and sensitivity on my part. While it was important to be recognized, accepted, and retain close rapport with participants, it was important to maintain a professional relationship with them. Friendly rapport with informants opens doors to more informed research; however, it can also create problems, as the investigator may become a spokesperson for the group studied, losing his or her distance and objectivity, may "go native" a term used by Gold,[220] when they become a member of the group and relinquish the academic role.[221] I consciously tried to safeguard against this happening.

Choice of a Qualitative Research Approach

Qualitative research methods are recommended when the question pertains to seeking an understanding or describing a particular phenomenon or event of which little is known, or when a sensitive topic is to be studied (i.e., the experience of suffering from the perspective of the terminally ill and their families). Accordingly, some researchers consider qualitative research to be one of the best methods of research for researching many aspects of terminal illness and palliative care.[222] Qualitative methods are suited to research questions dealing with subjective experience and perceptions with situational meaning, also when describing a phenomena or problem from the perspective of the individual being studied.[223] Denzin and Lincoln state:

> Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subjective matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials, hoping always to get a better fix on the subject matter at hand. To this end, then, qualitative researchers may deploy any of a wide range of interconnected methods – case study, personal experience, introspective life story, interview, or observational, historical, and visual texts – to capture

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[220] Gold, R. (1969). Roles in sociological field observations. In G. McCall & J.L. Simmons (Eds.), *Issues in participant observations: A text and Reader* (pp. 30–39). Menlo Park, CA: Addison-Wesley.

[221] Fontana, A., Frey, J. H. (1994). Interviewing: The art and science. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 361-367). London, UK: Sage.

[222] Wilkie, P. (1997). Ethical issues in qualitative research in palliative care. *Palliative Medicine, 11,* 321–324.

[223] Field, P. A., & Morse, J. M. (1985). *Nursing research: The application of qualitative approaches.* Rockville, MD: Aspen, 11.

> moments and meanings, both problematic and routine, in the observed individuals' lives.[224]

Understanding comes contextually and as a whole rather than by isolating each element and analyzing it in isolation. Using this approach, the underlying assumptions and attitudes are examined within the context in which they occur. VandeCreek states that the qualitative process is circular rather than linear.

> Its purpose is to discover the meaning of human experience and to communicate this understanding to others. It does this through narrative rather than through numbers, with the understanding that its narrative words evoke the human experience attached to them. The narrative description, as all human communication can only approximate the human experience. Qualitative research can never offer facts or the reality, but only a relatively faithful analogy of what the human experience means to the participants in the study.[225]

To accomplish this undertaking, qualitative inquiry engages the researcher in the experience rather than remaining outside and separate from the phenomena being studied, as would be the case if the research were quantitative. In this method, rapport and trust, not control and manipulation, are essential. The quality of this methodology is measured in terms of depth of involvement with participants rather than in terms of numbers (i.e., how many).

The difference between qualitative research and quantitative research is found in the essence of relationship which Martin Buber speaks of as an *I–Thou* engagement, in which both people meet and experience one another in the context of their personhood.[226] VandeCreek speaks of the dialogue that takes place on two levels: externally and internally between the researcher and participants.

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[224] Denzin, N. K, & Lincoln, Y. S. (1994). Entering the field of qualitative research. *Handbook of qualitative research.* London, UK: Sage, 2.

[225] VandeCreek, L. (et al.). (1994, October). Research in pastoral care and counseling: Quantitative and qualitative research. *Journal of Pastoral Care,* 77.

[226] Buber, M. (1958). *I and thou.* New York, NY: Scribners.

> In qualitative research, the researcher is inside the research activity, personally engaging, while the object of the research activity is also a human personality, free intelligent, and also personally engaging. The two work together in the discovery process on a level of mutual dependence and trust.[227]

Although there may be similarities in the various interpretative methods, the frameworks underlying the methods are different. Each approach is based on a philosophical orientation that influences how one interprets the data.

Hermeneutic Phenomenology: A Heideggerian Interpretative Approach

Phenomenology as a research method is the human scientific study of phenomena, and explores the structures of consciousness in human experiences.[228] Phenomenology serves as the rationale behind efforts to understand individuals by entering into their field of perception in order to see life as these individuals see it.[229] A phenomenological interpretative approach was chosen because of this researcher's interest in examining the *internal* and *external* experiences of suffering among the terminally ill and their families and to discover interventions to alleviate or diminish suffering throughout the illness trajectory until death.

> Understanding the 'lived experiences' marks phenomenology as philosophy, as much as it is a method of research…the procedure involves studying a small number of subjects through extensive and prolonged engagements to develop patterns and relationships of meaning.[230]

According to Leonard, appreciating the implications for research of a phenomenological view of the person involves the researcher going beyond the

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[227] VandeCreek, L. (et al.). (1994, October). Research in pastoral care and counseling: Quantitative and qualitative research. Decatur, GA: *Journal of Pastoral Care, 71*(84).

[228] Polkinghorne, D.E. (1989). Phenomenological research methods. In R.S. Valle & S. Halling (Eds.). *Existential-phenomenological perspectives in psychology.* New York, NY: Plenum.

[229] Bruyn, S.R. (1966). *The human perspective in sociology.* Englewood Cliffs, NJ: Prentice Hall.

[230] Creswell, J. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications, 12.

qualitative–quantitative, objective–relativism debate. She believes it will involve a fundamental shift in orientation away from traditional notions of objectivity as unitizing and generalizing, with the goal of prediction and control.

> Heideggerian phenomenologists propose there is no privileged position for "objective" knowing and that all knowledge emanates from persons who are already in the world, seeking to understand persons who are already in the world. One is always in the hermeneutical circle of interpretation. Researchers and research participants are viewed as sharing common practices, skills, interpretations, and every day practical understanding by virtue of their common culture and language….Further, because persons are fundamentally self interpreting beings for whom things have significance, understanding human action always involves an interpretation, by the researcher, of the interpretation being made by those persons being studied. This interpretative approach is called *hermeneutics*.[231]

Phenomenology attempts to explicate the meaning of the experience as we live in our everyday existence, our life world.[232] Phenomenology explores the inseparable connection a person has to the world; a person's being in the world; van Manen states:

> In doing research we question the world's very secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and in us. Then research is a caring act: we want to know that which is most essential to being. To care is to serve and share our being with the one we love… If our love is strong enough, we will not only learn about life, we will also come face to face with its mystery.[233]

Phenomenological research endeavors to discover the deeper meaning of lived experience, its essence. It attempts to describe and interpret these meanings with a degree of depth and richness. In searching for what it means to be human, the researcher asks: "What is this particular experience like for you?"

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[231] Leonard, V. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.). (p. 55). *Interpretative phenomenology.* Thousand Oaks: Sage.

[232] van Manen, M. (1994). *Researching lived experience: Human science for an action sensitive pedagogy*. Edmonton, University of Alberta: Althouse, 9.

[233] Ibid.

We can only understand something or someone for whom we care. It is this aspect of our humanness that includes one's quality of inwardness, of spiritual awareness and spiritual refinement that the researcher brings to phenomenological inquiry. The word that characterizes phenomenological research is "thoughtfulness," which in the works of Heidegger is portrayed as caring attunement, a heedful, mindful wondering about the design of life and what it means to be a person.[234]

The Heideggerian Phenomenological View of Personhood: Its Significance in End-of-Life Research

Heideggerian Phenomenology is a method of studying patients and families that flows out of asking what it means to be a person; and by exploring their life world we come to understand the impact of being diagnosed with a life-threatening illness. Leonard states, "there is no question that traditional science has accomplished astonishing results in the past two centuries, particularly with regard to disease."[235] But as Baron points out, "these accomplishments are not great in and of themselves; they derive their significance from what they mean for human beings and what effect they have on suffering and individual capability."[236]

Leonard states, "Persons in the phenomenological view have not only a world in which things have significance and value but quantitatively different concerns based on their culture, language, and individual situations."[237] From the Heideggerian concept of

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[234] Heidegger, M. (1962). *Being and time.* (Trans. J. MacQuarrie & E. Robinson). New York, NY: Harper and Row, 335–58.

[235] Leonard, V. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), *Interpretative phenomenology.* Thousand Oaks, CA: Sage Publications, 45.

[236] Baron, R. (1985). An introduction to medical phenomenology: I can't hear you while I'm listening. *Annals of Internal Medicine, 163*, 606– 611.

[237] Leonard, V. (1994). 50.

person, she identifies five essential facets of a person; these aspects of personhood became apparent in this study and significant for working with persons diagnosed with a life threatening illness:

1. *The Person as Having a World:* The first essential facet of a person centers on the relationship of the person to the world. World in the phenomenological sense is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture. Language in particular sets up a world; language creates the possibility for particular ways of feeling and of relating that make sense within a culture. Human existence is involved in the working out of possibilities that exist, or do not exist for us by virtue of our being "thrown" into a particular cultural, historical, and familial world. [238]
2. *The Person as a Being for Whom Things Have Significance and Value*: "In everyday terms we understand ourselves and our existence by way of activities we pursue and the things we take care of."[239] Thus, "to understand a person's behavior or expressions one has to study the person in context; it is only in context that what a person values and finds significant shows up."[240] Understanding the relational context allows for more appropriate interpretation of what significance things have for a person. A person's world provides the only access to what is possible or impossible.[241] This point has important significance

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[238] Leonard, V. (1994). 46-49.

[239] Heidegger, M. (1975). *The basic problems of phenomenology.* (Trans. A. Hofstudter). New York, NY: Harper & Row, 157.

[240] Leonard, V. (1994). 51.

[241] Ibid., 49-51.

for interprofessional health care teams working in clinical settings with patients and their families facing impending death.

3. *The Person as Self-Interpreting:* The Heideggerian phenomenological view of person claims that one's self-interpretations are not generated in individual consciousness as subjects related to objects but rather are given in our linguistic and cultural traditions and make sense only against a background of significance. Every encounter is an interpretation based on one's background.[242]
4. *The Person as Embodied:* In the phenomenological view, the notion of person includes a view of the body that is fundamentally different from the Cartesian notion of the body as an object of possession; rather than having a body, we are embodied. It is assumed that our common practices are based on shared embodied perceptual capacities.[243] Our bodies provide the possibility for the concrete action of self in the world. It is the body that first grasps the world and moves with intention in the world; Merleau-Ponty calls this bodily intelligence.[244] "Viewed as intentional, bodily functioning can express affective, cognitional influences in a way perhaps inexplicable within the Cartesian model."[245] Baron states, "Health is the state of unselfconscious being that illness shatters."[246] Our daily life and experiences in which the embodied self is taken for granted breaks down in illness; our self-understanding of self as embodied is crushed. It is in this state of "breakdown" that patients and their families develop insight into their taken-for-

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[242] Heidegger, M. (1975).

[243] Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science, 8*(1), 1–4.

[244] Merleau-Ponty, M. (1962). *Phenomenology of perception.* (Trans. C. Smith). London, UK: Routledge, Kegan Paul.

[245] Leder, D. (1984). Medicine and paradigms of embodiment. *Journal of Medicine and Philosophy,9,* 29–83.

[246] Baron, R. (1985). 609.

granted self-understanding of health: the unity of self and body. “That the body is not a mere extrinsic machine but our living center from which radiates all existential possibilities is brought home with a vengeance in illness, suffering, and disability.”[247] This insight gives the interprofessional team a new point a reference from which to comprehend the patient’s understanding of illness and ways to provide “total care” that encompass the physical, psychological, social, and spiritual aspects of personhood.

5. *The Person in Time:* The Heideggerian phenomenological notion of person includes a view of person or being-in-time that differs fundamentally from more traditional Western notions of time. Our traditional view of linear time is often an endless succession of nows: “the common conception thinks of the now as free-floating, relationless, intrinsically patched on to one another and intrinsically successive.”[248] This analysis of time presents us with the problem of conceiving continuity or transition. Heidegger describes the past as having-been-ness. “In every sense and in every case everything we have been is an essential determination of our existence…I am my own having-been-ness.”[249] People who are being-in-time cannot be studied except within the context of one’s having-been-ness and being expectant; it’s past and future by which it is comprised. Temporality is the term Heidegger uses to describe time that makes more sense than our concept of linear time that creates the problem of relating the past and the future to the now. “The not-yet and no-longer are not patched onto the now as

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[247] Leder, D. (1984). 34.

[248] Heidegger, M. (1975). *The Basic Problems of Phenomenology* (A. Hofstudter, Trans.) New York, NY: Harper & Row, 249.

[249] Ibid., 275.

> foreign but belong to its very content; because of this dimensional content, the now has within itself the character of transition."[250]

For this researcher, the Heideggerian approach of understanding the person as "being in time" captures the voices of the terminally ill and their families who participated in this study, and what Object Relations Theory refers to as their "transitional space" from the time of diagnosis to death and the "transitional objects" they use to cope with their experiences of suffering. Related to Heidegger's concept of temporality is his view of the essential structure of one's humanity that he describes as care.

> Care is having our being *be* an issue for us. We exist existentially in terms of what we care about and for the sake-of-which. Temporality, the not-yet belongs to the now because we exist in terms of what matters to us.[251]

These aspects of the Heideggerian phenomenological view of a person have implications for research as we seek to understand patients and families through their lenses of experience in the face of impending death; this approach will enable interprofessional teams to develop clinical care pathways to enhance the quality of care throughout the illness trajectory to the end of life.

Psychological Theories Used to Identify Research Participant's Experiences

From the days of the earliest church, those who have trained others for ministry have looked to psychology for clues for how to understand people. Today, there appears to be an openness of the church to influences from outside its own language and traditions that clearly legitimates the adaptation within hospital ministry of secular theories and scientific modes of thought that have emerged from the human sciences of psychology,

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[250] Ibid., 275.
[251] Leonard, V. (1994). 54.

sociology, anthropology, and psychotherapy.[252] The primary theoretical influences in relation to my research with the terminally ill, their families, and caregivers include: (a) Object Relations Theory; (b) Family Systems Theory; and (c) Narrative Counseling Theory.

Family Systems Theory

Family systems theory springs from cybernetics, the science of understanding how responsive living beings are to the context within which they live. Family systems theory generally looks at the intergenerational heritage of one's family of origin–our parents, grandparents, and can also include our great-grandparents–and how each person continues to carry the effects of everything that has happened to them and how they coped with life. The manner in which the system operates is determined by a set of unspoken rules and roles that specify how individual parts of the system contribute to the functioning of the whole. The rules and roles are designed to keep the system in a state of balance or, or as it is called in family systems theory, "homeostasis." Friedman defines homeostasis as "the tendency of any set of relationships to strive perpetually, in self-corrective ways, to preserve the organizing principles of its existence"[253] What distinguishes systems thinking from the view of families taken in individual psychology is the emphasis on the interactive dynamics among the people in the family system.

Narrative Counseling Theory

Narrative counseling theory analyzes the way we construct and use our stories

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[252] Gerkin, C. (1997). *An introduction to pastoral care.* Nashville, TN: Abingdon.

[253] Friedman, E. (1985). *Generation to generation: Family process in church and synagogue*. New York, NY: Guildford, 24.

about both self and others in order to form and maintain a sense of identity. In general, that multiple and even conflicting meanings drawn from a single story is known as "reader" or "listener" response theory. According to Culbertson, one of the most basic theories of narrative psychology is that the meaning of any statement is what the person has heard–or in the response that the statement generates–and not within the intentions of the person or storyteller from whom the utterance originates. No matter how clear or well intentioned, the storyteller has no control over what is heard, and what is heard is the bottom line, the truest meaning.[254]

"We must then approach stories we hear in counseling not by asking 'What does this story mean?' but 'What does this story do'?"[255] Through shared meanings, stories define family boundaries; it is clear who belongs to "us" and to whom we belong. These family stories create a sense of homeostasis or stability for they articulate our family's values and beliefs and our sense of connection with our familial and cultural past history.

Object Relations Theory

Object relations theory is built on assumptions: how we assume we are cared for, who we belong to, who others are in relationship to ourselves, and what signals we are safe. Object relations theory is considered by many to be particularly suited to communal cultures, as well as to Western cultures, because of its strong emphasis on human relationships. Object relations do not focus on isolated individuals but what happens when people come in contact with other people. In other words, object relations put the

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[254] Culbertson, P. (2000).
[255] Ibid., 49.

nature of personal relationships in the very center of human inquiry about the meaning of existence.

According to Culbertson, an "object" is a mental representation of, most commonly, a person, though it may also represent a place, a thing, idea, fantasy, or memory. An object is the product of some sort of relationship created through some event or interaction, and is invested with a particular emotional energy such as love, hate, or fear.[256]

Object relations theory supports a discussion of how the use and changes in God representations will evolve during the course of a lifetime, especially in moments of crisis or in the face of impending death. This theory can help us better understand our images of God, our religious experience, our personal integration, and our spiritual maturity. The theme articulated is that an individual's early human relationships shape the individual's image of God and that the relationship with God needs to be seen in the context of a person's human development and current situation.

Phenomenological Inquiry: A Heuristic Research Method

Narrative as a method was identified by Wright as an effective way to engage individuals and families in conversations about suffering and spirituality and has the potential to invite healing. Wright states:

> Too often patients and family members are encouraged to tell only their medical story or narrative. The medical narrative relates the disease or condition, complete with medication, dosages, and tests, whereas the illness

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[256] Ibid.

> narrative details the story of suffering, together with the effects of suffering on the individual, his or her relationships, and his or her world. [257]

Accordingly, I used a narrative approach to invite and listen to stories told by patients and families as they focused on the central underlying meaning of their lived experiences that emphasizes the intentionality of consciousness; their experiences contained both the outward appearance and inward consciousness based on memory and meaning for the person. A narrative approach was also applied in the focused group discussions with staff. [258]

Heuristics is a form of phenomenological inquiry that brings to the forefront the personal experiences and insights of the researcher who is the primary instrument of qualitative inquiry. Moustakas's significant contributions to research in psychology are through his portrayal of the heuristic research method, which is autobiographic in nature.

> Heuristic inquiry is a process that begins with a question the researcher seeks to illuminate. The question is one that has been a personal challenge and puzzlement in the search to understand one's self and the world in which one lives. The heuristic process is autobiographic, yet with virtually every question that matters personally there is also a social and or perhaps universal significance.[259]

Heuristics is an approach to self-inquiry and dialogue aimed at finding the underlying meanings of important human experiences; it asks: "What is *my* experience of this phenomenon and the experience of others who also experience this phenomenon intensely?"

> The researcher comes to understand the essence of the phenomenon through shared reflection and inquiry with coresearchers as they also intensively experience and reflect on the phenomenon in question. A sense of

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[257] Wright, L. (2005). 37.

[258] Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

[259] Moustakas, C. (1990). *Heuristic research: Design, methodology, and applications*. Newbury Park, CA: Sage, 15.

> connectedness develops between the researcher and participant in their mutual effort to elucidate the nature, meaning, and essence of a significant human experience.[260]

There are two focusing or narrowing elements of heuristic inquiry within the larger framework of phenomenology. First, the researcher must have intense interest and personal experience with the phenomenon to be studied. Second, research participants who are part of the study must also share an intensity of experience with the phenomenon. Heuristics is not inquiry into casual experiences but focuses on intense human experiences from the view of both the investigator and study participants. It is the combination of personal experience and its intensity that yields understanding of the fundamental essence of the phenomenon.[261]

The Researcher's Assumptions and Biases

Qualitative research is interpretative research; the researcher as the primary data collection instrument is required to identify his/her experiences in the field of study, personal values, assumptions, and biases at the onset of the study. The investigator's contribution to the research setting can be useful and positive rather than detrimental.[262] My own perceptions of suffering have been shaped by personal/professional experiences and observations; I have served as a professional counselor, educator, ordained minister, and hospital chaplain providing spiritual care to the terminally ill and their families in times of illness or facing end-of-life issues, decision-making, loss, grief, and

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[260] Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd. Ed.). Newbury Park, CA: Sage, 2.

[261] Moustakas, C. (1994).

[262] Lock, L.F., Spirduso, W.W., & Silverman, S.J. (1987). *Proposals that work: A guide planning dissertations and great proposals* (2nd. Ed.). Newbury Park, CA: Sage.

bereavement. In light of previous experience working closely with the terminally ill, I bring certain assumptions and biases to this study:

1. As well as being a physical and social event, death is also a spiritual and existential event.
2. Spirituality is an innate universal dimension of all persons. Patients and their families frequently use spiritual coping strategies to manage their illness experience.
3. Individuals have a transitional space and use transitional objects throughout their lifetime; thus, transitional phenomena play an important role in the journey of the terminally ill toward impending death.
4. Compassionate communication combined with a warm and caring environment enhances an individual's sense of spiritual well-being and often helps to alleviate or diminish suffering.
5. In general, terminally ill patients or their families often cannot express their experiences of living with a threatening illness. Language is often found to be deficient as they attempt to speak about their feelings and suffering in the face of impending death, or one's experience of God (as understood by the person). Individuals often communicate with the use of metaphors, symbols, images, rituals, prayer, and religious interpretations.
6. The transitional journey does not have to be long or complete to be meaningful. There are moments in time along the way that can be life giving and may encompass deeply spiritual experiences that often result in healing.

7. The terminally ill and their families as well as members of the interprofessional team can encounter the sacred in the shared transitional space known as terminal illness.

Focus of Issues Investigated in the Study

Working on oncology and palliative care units over the years and accompanying observations of suffering resulted in my desire to examine this phenomenon. Issues examined in this study included: (a) *internal* and *external* experiences of suffering from the time of the diagnosis of a life-threatening illness throughout the illness trajectory until death, and the ensuing period of bereavement as identified on *The Continuum of Palliative Care*,[263] (b) factors that contribute to the experience of suffering,(c) indicators of suffering, (d) the level and depth of suffering (physical, emotional, social and spiritual) in the face of impending death, (e) differentiate dimensions of loss, grief, and bereavement that encompass the diagnosis of a life-threatening illness and death, (f) identifying categories of needs and specific need requirements of patients diagnosed with a terminal illness and their families, and (g) identifying concepts for a compassionate model of spiritual care with interventions that can be implemented into clinical care pathways to reduce or diminish suffering, improve the quality of care, and facilitate hope and healing when cure is no longer a reality.

Research Questions

The **primary research questions** that directed this research study from the perspective of a person diagnosed with a terminal illness and their family:

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[263] Canadian Hospice Palliative Care Association. (2005). *The continuum of palliative care.* (Appendix B).

1. What issues or concerns contribute to the experience of suffering?
2. What helps alleviate or diminish the experience of suffering?
3. From the perspectives of the interprofessional team:
4. What interventions help to alleviate or diminish suffering experienced by the person diagnosed with a terminal illness and his or her family?

The **subsidiary questions** embedded in this research study:

From the perspective of a person diagnosed with a terminal illness and his or her family:

1. In what ways do medical narratives or illness narratives identify suffering or contribute to the diminishing or alleviation of suffering?
2. What influence or connection do beliefs about illness have in the experiences of suffering?
3. How is God (as defined by that person) or the Sacred experienced in the transitional space known as terminal illness?
4. What spiritual practices or rituals contribute to spiritual wellbeing?
5. What physical/medical needs, emotional/psychological needs, social/relationship needs, spiritual/religious needs or desires need to be fulfilled to diminish or alleviate their suffering?
6. What particular qualities or characteristics of the interprofessional team support the terminally ill person and their family to foster hope and dignity at end of life and help diminish or alleviate spiritual suffering?

Sample of Participant Interview Questions: Appendix D

Research Participants Consent Forms: Appendix E

Rationale for Selection of Research Participants

It is essential that qualitative researchers select participants (informants) for their study purposefully. Patton states that the logic and power of purposeful sampling lie in selecting information-rich cases from which one can learn a great deal about the issues of central importance to the purpose of the research.[264] The persons diagnosed with a terminal illness and their families are a rich resource and our teachers when it comes to death and dying. Their lived experiences are untapped resources of knowledge and experience. As a researcher, I believe that giving them a voice and honoring their stories will help others better understand their spiritual journey, their experiences of illness and suffering as they anticipate impending death.

Selection of Primary and Secondary Research Participants

Creswell recommends "criterion sampling," which is the purposeful selection of participants and represents a key decision point in a qualitative study.[265] Participants were carefully selected using Patton's *maximum variation sampling*[266] to include voices from a variety of religious and cultural backgrounds as well as to illustrate various classifications of life-limiting terminal diagnosis: (a) Cancer ($n = 16$); (2) Parkinson's disease (end stage $n = 2$); (3) renal failure (end stage $n = 2$); (4) heart failure (end stage $n = 3$); (5) multiple sclerosis (end stage $n = 2$).

Drawing on the criterion of *homogeneous sampling,* participants were chosen for phase two of the research study (a continuation of phase one major applied research project) where similar cases were selected in order to describe this subgroup in depth.[267] Research participants in this study included: patients ($n = 25$) and family members ($n = 15$); the interprofessional palliative care team and spiritual care volunteers ($n = 13$).

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[264] Patton, M.Q. (1990). 71-72.
[265] Creswell, J. (1998).
[266] Patton, M.Q. (1990). 182-183.
[267] Glesne, C. (1999). *Becoming qualitative researchers* (2nd Ed.). New York, NY: Longman.

Participants were referred to the study by staff members at York Central Hospital (YCH) working on the palliative care unit or the oncology clinic; Universal Care–a private health care service located within the hospital setting at YCH; professional colleagues involved in end-of-life care in the community; family members who heard about the research study and contacted the researcher requesting to take part in the study; or direct contact with patients who are known by the researcher and were asked to participate in the study. I used a process called “*purposeful sampling*” as I looked for strategic informants, persons who were immersed in the experience of having received the diagnosis of a terminal illness, capable of reflecting on and articulating their spiritual experiences. Patton provides guidelines for sampling and suggests that the logic and power behind purposeful selection of informants is that the sample should be information rich.[268]

Selection of *primary participants*:

1. The diagnosis of terminal illness and an awareness of their diagnosis;
2. Cognitively competent and able to give consent to participate;
3. Ability to understand and speak English;
4. Eighteen years of age or older; and
5. No personal ties with investigator.

Selection of *secondary participants*:

1. Partner, parent, sibling, or children 18 years of age or older;
2. Ability to understand and speak English;

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[268] Patton, M.Q. (1990).

3. Mature, reflective individuals;
4. A relationship with the person who received a terminal diagnosis and a witness of their experiences in the transitional space from the time of diagnosis;
5. A member of the interprofessional palliative care team directly involved in the patient’s care;
6. No personal ties with the investigator.

Whenever a patient or a family member involved in this study approached the investigator for counseling during the research process, he/she was referred to his or her family doctor. The rationale for referring participants was to ensure that my role as investigator would not become blurred with my role as a chaplain researcher in this study.

Scope and Limitations of the Research Study

The scope of this study was confined to: (a) spending time with primary and secondary participants, listening to their medical and illness narratives; (b) interviewing and observing primary participants, patients who were told by their doctor that they had an incurable illness or a life-threatening illness; and (c) secondary participants–family members (as defined by the patient) of a person who has been diagnosed with a terminal illness; and (d) staff members who observed and/or provided care for the patient and family members. Participants were selected by the researcher who were patients admitted to York Central Hospital (YCH) in Richmond Hill, Ontario and surrounding area, and/or under the care of palliative care physicians in their home within the *communities* YCH serves, their families and staff.

Limitations of this qualitative research project: (a) The study was limited to patients diagnosed with a life-threatening illness; therefore the findings are not generalizable to all areas of nursing and health care; (b) participant selection was limited to persons over 18 years of age and family who had a relationship with the person diagnosed with a terminal illness, spoke English, thus reflecting ethnicity, therefore, not all family members met the criteria for participation in the study.

Ethical Considerations Related to the Research Study

This population of research participants is particularly vulnerable due to their experience of suffering, losses, and dying. As a researcher I had to take into consideration the harm that could be done to the participants before conducting the study. Not all risks could be identified from the onset due to the evolving nature of the research design. The interview process or sharing one's medical or illness narratives could stir up powerful emotional responses within the participant, and the process could become a burden for a patient who is already fatigued or uncomfortable due to pain or symptoms of his or her illness or treatments. It was incumbent upon me as a researcher to be sensitive to the patient's energy levels and emotional status at all times. Participants were informed at the onset of the study that, should their sharing of information become too painful for them, the interview would be stopped and support would be made available to them.

Even though most social science research does not place patients in situations which directly or overtly jeopardize their health and well-being, most psychological research does involve some risks. The ethics of this study required that the risk–benefit equation be considered: the risks of the patient's involvement in the research against the possible benefits of the project (both to the subject and to society). As the principal researcher, I faithfully adhered to the Tri-Council's Guiding Ethical Principles for Research Involving Humans. The rationale for studying this vulnerable population was the furthering of knowledge in order to improve the quality of end-of-life care with the hope that information gleaned will benefit other patients and families in similar situations.

The investigator took steps to minimize risks to patients; only patients whose clinical status was stable and who were capable of participating were chosen. In addition, I was reassured by reports of the interprofessional team and by the patients themselves that the primary reason for their interest in the research was the hope that their insights and comments would lead to improvements in end-of-life care for patients facing impending death and their families.

Confidentiality: Participant observations, interviews, and case studies invade the life of the informant, and sensitive information is frequently revealed.[269] The interviews were conducted and audiotaped by me to ensure participant confidentiality; the audiotapes were labeled with a number, and the transcriptions were labeled with pseudonyms. No other identifying information was attached to the audiotapes and transcripts. The audiotapes, case studies, the printed transcripts, field notes, and identification data of the participants were kept in a folder in a locked, secure place within my office at home; I personally transcribed the audiotapes and other pertinent information related to case

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[269] Spradley, J.P. (1980). *Participant observation.* New York, NY: Holt, Rinehart & Winston.

studies to ensure confidentiality. Access to these data as well as corresponding computer files was permitted to no one except me; my personal computer is password protected.

Informed Consent: I approached each prospective participant and verbally informed him/her of the following: purpose of the study, benefits envisioned from it, tasks to be performed when participating, right to withdraw at any time without penalty, right to have personal information held confidential, and any potential psychological risks and how they would be managed by the investigator. Participants were assured that data and materials collected as part of the study would be kept in a safe storage area; they were also informed that information would be shared with members of the investigator's doctoral committee; they would not be identified by name in any of these discussions. In addition, information from this study would be used to develop educational seminars and programs for health care professionals. Initially, consent was obtained verbally from the participants, followed by the formal written consent that followed reading and signing the consent form before the interview began. The consent form became part of the working file. Three different consent forms were devised: Patient Consent Form, Interprofessional Team Member Consent Form, and Family Member Consent Form. (Appendix E)

Ethical Approval: Informed contacts with members of York Central Hospital were helpful in providing valuable information on how to access the institution and steps required for ethical clearance for the study. The York Central Hospital Research Ethics Board granted ethical approval for phase one, a 12 month research study, and extended their approval into phase two on a year-by-year basis so the research could continue longitudinally.

Data Collection in a Hermeneutic Inquiry

In hermeneutics the primary source of knowledge is everyday practical activity. Heideggerian phenomenologists suggest that there is no privileged position for "objective" knowing and that all knowledge is derived from persons who are already in the world, seeking to understand persons who are also already in the world. Further, because persons are fundamentally self-interpreting beings for whom things have significance, understanding human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied. This interpretative approach is called *hermeneutics*.[270]

> Human behavior becomes a text analogue that is studied and interpreted in order to discover the hidden or obscured meaning. This meaning is hidden because it is so pervasive and taken for granted that it goes unnoticed….The data for the text analogues can come from interviews, participant observation, diaries, and samples of human behavior….Because our everyday lived experience is so taken for granted as to go unnoticed, it is often through breakdown that the researcher achieves flashes of insight into the lived world, although it is important to note that the taken-for-granted, everyday lived world can never be made explicit.[271]

Although approaches to data collection continually expand in the qualitative investigations,[272] procedures for data collection in this research study involved seven basic types: (a) observations of research participants who were patients diagnosed with a life-limiting illness, their families, and the interprofessional teams who care for them in the hospital and community, (b) informal conversations, (c) taped semi structured interviews that used narrative story-telling to collect data, (d) focused group discussions

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[270] Leonard, V. (1994). 58–59.
[271] Ibid., 55.
[272] Creswell, J. (1994).

with staff using a narrative approach, (e) case studies, (f) field notes and numerous documents (ranging from private to public), and (g) audio-visual materials (including materials such as photographs, compact discs, and videotapes). Thus, as the principal investigator, I analyzed the multiple kinds of data sources and multiple theoretical perspectives.

To assist in the data collection phase I kept a field log and a detailed account of how I spent my time both on site and in the transcription and analysis phase. I recorded details related to my field observations in a field notebook, and kept a field diary to record my own thinking, feelings, experiences, and perceptions throughout the research process. (When the research study is completed in 2013, field notes containing patient identification and information from patient records will be destroyed.)

Data analysis was ongoing throughout the study, which encompassed the methodology of "thematic analysis" of specific statements, searching for all possible meanings. Emerging from the Duquesne Studies in Phenomenology, the central tenets of this thinking are:

> To determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions, general and universal meanings are derived, in other words, the essence or structures of the experience.[273]

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[273] Moustakas, C. (1994). 14.

Treatment of the Data: Interpretive Analysis

Merriam[274] and Marshall and Rossman[275] assert that data collection and data analysis must be a simultaneous process in qualitative research. Creswell claims that qualitative data analysis primarily entails classifying things, persons, events, and the properties which characterize them.[276] Transcribed interviews, observational notes, diaries, and samples of human behavior were treated as text analogues for interpretative analysis. Data analysis in this hermeneutic study was carried out in three interrelated processes identified by Leonard.

The raw data were collected from narratives or story-telling in individual interviews and structured focused group discussions; it was recorded and transcribed verbatim for each participant. These transcriptions along with case studies and field notes were subjected to phenomenological thematic analysis.[277]

> In the thematic analysis, each case (all interviews, field notes, etc.) is read several times in order to arrive at a global analysis. When several cases have been read in this way, lines of inquiry are then identified from the theoretical background that grounds the study and from themes consistently emerging in the data. From this, an interpretive plan emerges. Each interview is then read from the perspective of the interpretive plan. As this microanalysis is carried out, additional lines of inquiry may emerge from the data and are added to the interpretive plan. All whole cases are then subjected to the additional interpretive analysis. The interpretative effort culminates in the identification of general categories that form the basis of the study's findings.
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> The second aspect of the interpretive process involves the analysis of specific episodes or incidents: all aspects of a particular situation and the participant's responses to it are analyzed together. The analyzed event encompasses the individual's situation – her concerns, actions, and practices – and not her

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[274] Merriam, S. (1988). *Case study research in education: A qualitative approach*. San Francisco, CA: Jossey-Bass.

[275] Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2nd. Ed.). Thousand Oaks, CA: Sage.

[276] Creswell, J. (1994).

[277] Leonard, V. (1994). 59.

> opinions, analyses, or ideology. From this analysis come “exemplars”: stories or vignettes that capture the meaning in a situation in such a way that the meaning can then be recognized in another situation that might have very different objective circumstances. An exemplar is “a strong instance of a particularly meaningful transaction, intention, of capacity.”[278]
>
> The last aspect of the interpretative analysis involves the identification of paradigm cases: strong instances of particular patterns of meaning. Paradigm cases embody the rich descriptive information necessary for understanding how an individual’s actions and understandings emerge from his or her situational context: their concerns, practices and background meanings. They are not reducible to formal theory – to abstract variables used to predict and control Rather, what are recognized are “family resemblances” between a paradigm case and a particular clinical situation that one is trying to understand and explain.[279]

Verification and Trustworthiness of Research Findings

To ensure credibility for this research study, several verification steps identified by qualitative researchers Merriam,[280] and Miles and Huberman[281] were employed: (a) triangulation of data–data were collected through multiple sources to include interviews, observations, focused group discussions, case studies, and document analysis; (b) member checking–the participant (informant) served as a check throughout the analysis process. Ongoing dialogue regarding my interpretations of the informant’s experiences ensured the truth (accuracy) and value of the data; (c) long-term and repeated daily observations at the research site of similar phenomena, as well as observations in the homes of patients in the community over the course of the research study; (d)

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[278] Benner, P. (1985). 1– 14.

[279] Chesla, C. (1988). *Parents caring practices and coping with schizophrenic offspring: An interpretative study.* Unpublished Doctoral Dissertation. University of California, San Francisco, 3.

[280] Merriam, S. (1988). *Case Study Research in Education: A Qualitative Appr*oach. San Francisco: Jossey-Bass.

[281] Miles, M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis: A Source Book of New Methods* (2nd Ed.). Thousand Oaks: Sage.

participatory modes of research that involved staff, patients (if health condition permitted), and families were included in most phases of the study checking interpretations and conclusions; (e) clarification of researcher bias–at the onset of this study I identified researcher bias in my proposal to the Research Ethics Board at York Central Hospital, and St. Stephen's College, which is articulated under the heading *The Researcher's Assumptions and Biases;* and (f) examination by my appointed research supervisor–St. Stephen's College, University of Albert requires a supervisor to examine and monitor the research process.

An Interpretative Account: Evaluation of Report Findings

To present this research study's findings involved distilling the data down to their most essential terms while at the same time providing the reader with enough evidence for the reader to participate in the validation of findings.[282]

Data collection strategies and analysis are similar across qualitative methods. Lofland and Lofland suggest the way findings are reported is diverse. [283] Miles and Huberman speak to the importance of creating a data display and suggest that narrative text has been the most recurring form of display for qualitative data.[284] This is a naturalistic research study; therefore, the results are presented in descriptive, narrative form rather than as a scientific report.

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[282] Benner, P. (1985).

[283] Lofland, J., & Lofland, L.H. (1995). *Analyzing social settings: A guide to qualitative observations and analysis* (3rd. Ed.). Belmont, CA: Wadsworth.

[284] Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis: A source book of new methods* (2nd Ed.). Thousand Oaks, CA: Sage.

I have used "thick description," a term coined by Geertz as a description that goes beyond the mere reporting of an act (thin description). Thick description is a means of depicting and probing the intentions, motives, meanings, contexts, situation, and circumstances of an action.[285] The objective of using this type of reporting was to provide a lens through which the readers can gain insight and understanding into the lived experiences of the terminally ill and their families instead of making abstract generalizations about the challenges they encounter.

> It is a tenet of this kind of research that there can always be another, deeper and perhaps more persuasive, interpretation of a phenomenon. The forestructure of the study may be quite different from one study to the next and will therefore produce quite different accounts of the same phenomenon. Competing accounts do not negate each other. Rather, they set up conversation. The decreased emphasis on one true account of a phenomenon has a further effect beyond the scope of an individual research project: it encourages the creative exchange of perspectives and ideas in human science research.[286]

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[285] Denzin, N. (1988). *The Research Act* (Rev. Ed.). New York, NY: McGraw-Hill, 39.
[286] Leonard, V. (1994). 61.

CHAPTER 5

RESEARCH FINDINGS: THE PALLIATIVE CARE TEAM

> Death is not the ultimate tragedy of life. The ultimate tragedy is depersonalization, dying in an alien and sterile environment, separated from the spiritual nourishment that comes from being able to reach out to a loving hand, separated from a desire to experience the things that made life worth living, separated from hope.[287]

This chapter will present insights from my literature search–a part of this research study, research findings gleaned from four focused discussions groups with the palliative care team, as well as selected taped interviews with individual doctors, nursing staff, patients, and their families. In addition, I will be discussing two important points for developing a compassionate approach to patient care: mirroring of the concept "you matter" and strategies to guard against the reality of social death and depersonalization. The chapter will conclude with the palliative care team's conceptual framework for a compassionate model of care to end of life.

Palliative Care Continues to Face Resistance in Efforts to Alleviate Suffering

Throughout this study, listening to the voices of research participants, conclusions similar to those of Joyce Zerwekh during her 26 years of hospice nursing practice reveals the palliative care movement continues to face resistance in their efforts to address suffering and dying from the main stream health care community.[288] Four primary barriers were identified. (a) Preoccupation with aggressive lifesaving interventions. (b) Fear of many physicians or associated medical staff to acknowledge suffering and use

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[287] Cousins, N. (1979). *Anatomy of an illness*. New York, NY: Norton, 23.
[288] Zerwekh, J. (2006).

drugs to palliate as a means to relieve suffering. The use of opioids and sedatives provoked fears such as suppressing respiration, reducing consciousness, causing addiction, and being misled by patients who were suspected of exaggerating their pain. A number of physicians mentioned their fear of being investigated for overprescribing opioids. (c) Suffering that results from health care professionals hiding behind their own fear of death; they postpone communicating with patients the reality of their diagnosis and prognosis. Consequently, palliative care was frequently offered too late in a patient's disease trajectory for them to benefit from medical interventions for pain and symptom management, emotional and spiritual care, or anticipatory loss and grief and bereavement support. This concept is evident in words spoken by Mary (following section) describing her family's experience and husband's death on an acute care unit. (4) Physicians and nurses often fear their own vulnerability if they acknowledge and take time to respond to the suffering of patients in the face of impending death. This was evident in comments made by several nurses nearing retirement during a research focused discussion as part of this study: *Resistance to Addressing Suffering and Dying in Community Based Hospitals.* One nurse stood and requested to read the following quote from an article in the *Journal of Hospice Palliative Care Nursing*; she stated that it captured many of their spoken or silent fears and vulnerabilities:

> Many of us spent our entire nursing career learning how not to react to suffering: a neutral face, a steady hand, no eye contact. We regard patient's complaints with suspicion. We admire those who silently endure; they allow us to avoid confronting their suffering.[289]

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[289] Zerwekh, J. (2002). Fearing to comfort: A grounded theory of constraints to opioid use in hospice care. *Journal of Hospice and Palliative Nursing, 4* (2), 83–90.

The Need to Develop a Compassionate Approach in End-of-Life Care

> Why are you afraid? I am the one who is dying! But please believe me, if you care for me with a compassionate heart, you can't go wrong. If you respect me as a person, then you can't go wrong. Death may get to be routine for you, but facing my impending death is a new experience for me. (Palliative Care Patient)

Dr. Harvey Chochinov developed the concept of "dignity therapy" as an approach for working with the dying. He speaks of the importance of care tenor, the tone of care the interprofessional team offers patients or the tone patients perceive. Care tenor represents everything we convey to patients beyond mere words. He says care tenor should signify "*You matter.*" He proposes caregivers should think of themselves as being akin to a mirror. "With every clinical contact, patients gaze our way, looking for an affirming reflection in which they can recognize themselves. If all they see is their illness, they may feel the essence of who they are has vanished."[290] While members of the health care team might think of themselves as always giving the message *"You matter,"* their distancing from patients and focusing on tasks may inadvertently give patients the perception they do not matter. [291]

The author observed there was a need to provide education and training for staff in the philosophy of palliative care. In addition, their need to develop an attitude of compassion combined with compassionate communication skills in interactions with patients and families. This was most evident among nurses on acute care units. Similarly, this was observed on the palliative care unit when nurses and agency staff, who had no

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[290] Chochinov, H.M. (2012). *Dignity therapy: Final words for final days.* New York, NY: Oxford University Press, 30.

[291] Georges, J. J., Grypodonck, M. E., & De Casterle, B. D. (2002). Being a palliative care nurse in an academic hospital: A qualitative study about nurse's perception of palliative care. *Journal of Palliative Care Nursing, 11,* 785–793.

prior education, training, or experience in the area of palliative care, were called to the hospital to cover shifts.

Even in hospitals with well- developed palliative care programs, referrals to the palliative care team were applicable to only a small percentage of deaths. In many circumstances, it is simply not reasonable to relinquish all efforts at lifesaving and to certify that the patients are within six months of death.[292] Mary's voice in a taped interview four months following her husband's death echoes heartbreaking suffering similar to the experiences of several patients and families in this study; their need for open honest communication and early referral to palliative care was not acknowledged.

> My husband was admitted to hospital on Friday when he came in for his second chemotherapy treatment. I was told by the oncologist on Monday evening that he is "very sick," he died at four o'clock Tuesday morning. [Sobbing and tears rolling down her face she pauses to gain composure]. We were not offered palliative care even when I requested it, nor any emotional or spiritual care support. The nurses did not ask if we wanted a hospital chaplain to spend time with us prior to David's death; we never had prayers or the chance to say our good-byes. There were so many things we could have done; so many things were left incomplete. I feel so guilty that I told our children they could go home that Monday evening; they also feel an overwhelming sense of guilt that they were not with their father at the time of his death and are upset that he was not offered the Sacraments of the Sick.

Patients and families say they want information to be shared within a realistic and appropriate time frame in a compassionate way directly from their physician; however, cultural sensitivity needs to be taken into consideration in light of the ethnic diversity of our Canadian society.

Ficchione believes that the crisis of physical illness leads to adaptive tasks and the testing of coping skills that will determine the outcome of a crisis. As a physician, he has

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[292] Santa-Emma, P., Roach, R., Gill, M. S., Spayde, P., & Taylor, R. (2002). Developing and implementation of an inpatient acute palliative care service. *Journal of Palliative Medicine, 5*(1), 93–100.

learned from his patients that the worst part of illness is often fear of social isolation that encompasses separation and/or loss of dignity linked to professional depersonalization, a place where spirituality in health care and medicine is not examined or nurtured.[293]

Today, the majority of deaths occur in institutional settings with professional caregivers. The concept of social death involves no longer being acknowledged or seen by other persons. Social death occurs as the terminally ill are progressively isolated from the living. These individuals experience little eye contact, with minimal communication, and minimal caring. They may be discussed as if they are not there by physicians and/or nurses standing near the patient's bed.[294] Such discussions are an unfortunate practice that often takes place during medical rounds when several staff members are working together at the bedside of the patient. This was observed mainly on acute care medical units where the spiritual and emotional realms are commonly ignored by caregivers whose focus is on solving the puzzles of disease and battling against death. Social isolation and professional depersonalization are not limited to acute care units in the hospital.

A palliative care education day was organized with the objective to raise awareness of the concept of compassionate caregiving. A segment of the program focused on the impact of staff interactions with patients and families to capture the concept of depersonalization, social isolation, and iatrogenic suffering. Discussions centered on the question, "What can we learn from this case study to improve the quality of care to end of life?" Participants were encouraged to resist the dehumanizing tendencies introduced in

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[293] Ficchione, G.L. (1999). *Spirituality and healing at the bedside*. Paper presented at Harvard University Spirituality and Healing Conference, Denver, Colorado.

[294] Kastenbaum, R. J. (1995). *Death, society, and human experience.* Boston, MA: Allyn & Bacon.

the case study as they care for their patients diagnosed with a terminal illness. Together, staff was able to identify goals *to personalize care* offered to dying patients and families in an effort *to counter depersonalization*:

1. Create an atmosphere for comforting; a “person centered” environment with an emphasis on providing an approach to patient care that exemplifies compassionate care.
2. Discover who the dying patient is as a person; listen to his or her story that frequently will include *medical narratives* and *illness narratives.*
3. Refuse to participate in the conspiracy of silence that often occurs with families around decisions to convey the diagnosis of a terminal illness.
4. Inquire about the patient’s preoccupation with complicated medical interventions that ignore the reality that death is approaching.
5. Inquire about the patient and/or his or her family’s requirements–physical, emotional, social, and spiritual needs, rituals or practices, and incorporate into their goals of care.
6. Discourage social isolation and abandonment of the dying by encouraging professional caregivers and loved ones to provide a caring presence in hospital surroundings.
7. Respect the dying patients’ wishes.

Mrs. P’s case study further on in this chapter will illustrate lessons learned; ways the interprofessional team can work together and share information to provide a personalized approach to counter depersonalization and social isolation.

A Conceptual Model of Care to End-of-Life

One of the fundamental principles of palliative care is that the patient and family together are the unit of care. To alleviate or diminish suffering experienced by patients diagnosed with a terminal illness, a conceptual framework for end-of-life care and practice was identified. An effective model for the delivery of palliative care observed in this study was adapted from Dame Cicely Saunders's conceptual theory of *"whole person suffering."* Saunders put forward the hypothesis that suffering has four interrelated dimensions: physical, psychological, spiritual, and social; she says suffering deeply influences each domain of the bio–psychosocial–spiritual aspects of care.[295] Saunders's conceptual model formed the basis for compassionate care to end-of-life that the author witnessed throughout this research study *once* patients came under the umbrella of palliative care. Mary in the above case study requested palliative care for her husband; unfortunately, the request was not honored.

Palliative Care: An Interprofessional Team Model

Palliative care's reliance upon the interprofessional team model as a key factor for successful outcomes requires an understanding of the distinction between interprofessional and multiprofessional practice. As the primary researcher, I observed on acute care medical units a traditional multiprofessional team model*;* the physician primarily directs care of the patient, and family needs may or may not be considered in care plans. Multiple disciplines on the health care team may be involved in the patient's assessment and in the delivery of patient care; it appears their work is often

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[295] Saunders, C.M. (1976). The challenges of terminal cancer. *Scientific foundations of oncology*. Simmington, T., Carter, R. L. (Eds.). London, UK: Heinemann.

uncoordinated and independent. The primary method of communication between disciplines is found in their notes on the patient's medical chart. I detected that quite often inadequate communication occurs between members of the professional health care team; there is a tendency for each discipline to establish its own goals of care for the patient.

In contrast, within the interprofessional palliative care team model, observations reveal communication and decision making between team members is a shared, collaborative leadership style; it is based upon needs and goals identified by the patient and his or her family. An important theme the researcher observed on the palliative care unit during the course of this study–the identity of the interprofessional team supersedes personal identities and agendas; a concept identified by Cummings: "the sum of the whole is greater than its parts and is valued and respected"[296] was evident on a daily basis and during weekly palliative care rounds where team members shared information.

A certified palliative care nurse *Monique,* captured the essence of interprofessional team work during an initial taped interview early in the research study when she stated:

> Teams are an integral component of end-of-life care; they are the glue that holds together the hospice approach to patient care within the hospital environment. The purpose of the team is to build a caring community, with patients and their family at the center. Care providers, including physicians, nurses, nursing assistants, pharmacists, physical or occupational therapists, social workers, chaplains, complementary therapists, and volunteers come together as an integrated whole to respond to each patient's needs, 24 hours a day, 7 days a week. The team is responsible for addressing the diverse needs of the patient and family.

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[296] Cummings, I. (1998). The interdisciplinary team. In D. Doyle, G. Hanks, & N. MacDonald (Eds.). (pp. 20–30). *Oxford textbook of palliative medicine* (2nd. Ed.). Oxford, UK: Oxford University Press.

The *Interprofessional Team Model* approach for providing end of life palliative care was identified as the preferred model by participants in this research study. As the primary researcher, observations of the success of this “*Compassionate Model of Care*” required a high level of commitment from members of the team that encompassed development of trust, openness to frequent communication, and problem solving.

The palliative care team’s roles and responsibilities were part of a focused discussion group, *Roles & Responsibilities of the Palliative Care Team.* A detailed account of roles discussed mirror my literature search as part of the research process carried out by the author can be found in Appendix F.

The Process of Shared Leadership

Leadership is task dependent, and tasks are defined by the patient’s changing situation. An important and interesting approach observed on the palliative care unit during research observations was that patient and family care management is a *process,* not an event. The Clinical Care Leader, *Marina,* in the focused discussion group, made the following comments in her description of various ways the palliative care team is involved in the process:

> To be effective, the team must have an ongoing, collaborative practice that incorporates shared goals, care planning, role blending, and shared leadership. Frequent dialogue between different team members with differing areas of expertise and perspectives fosters continuing development and evaluation of the interprofessional palliative care team’s therapeutic approaches. For example, the nurse shares her concern about the patient’s uncontrolled pain and vomiting; the chaplain shares her concern about the patient’s suicidal ideations and her worries about divine judgment; the social worker notes unhealthy family dynamics between the patient and her daughter’s husband who appears extremely uncomfortable with having his mother-in-law return to their home. The plan of care evolves as they interact with each other. As a chaplain

researcher on the unit, you presented Mrs. P's case at Grand Rounds as an example of the effectiveness of our shared leadership model.[297]

The case study that the Clinical Care Leader made reference to (below) exemplifies the importance of shared leadership as the palliative care team work together to improve the quality of care to end of life.

A Case Study Reveals the Need for Shared Leadership

Mrs. P is a 64-year old university professor; her early childhood teachings about religion and beliefs for living were influenced by a very conservative Anglican background. Her husband died in September 1999 of lung cancer. Six months later she was diagnosed with ovarian cancer. Undergoing surgery plus several courses of chemotherapy and radiation, the treatment appeared to be successful. In May 2009 she was diagnosed with a tumor on her right breast: immediately she underwent chemotherapy and radiation. Following these treatments, the oncologist reported that her cancer was not spreading and that the size of the tumor was actually diminishing. However, she did not believe him, holding the firm belief that the tumor had metastasized. Another blow followed; in April 2010, her mother, with whom she has had a conflicted relationship since childhood, died suddenly. Her mother constantly reminded Mrs. P that she never wanted her and had attempted to have an abortion.

Following her mother's funeral service, she arrived at the emergency department with severe physical pain and an apparent panic attack; a series of negative tests resulted in Mrs. P being sent home. Subsequently, two days later, following suicidal thoughts and an unsuccessful attempt to take her life, Mrs. P was admitted to the Crisis Unit for 48 hours of observation. Her eldest daughter convinced her to go to the home of her youngest daughter and son-in-law, where she had resided for the past year (six months previously she sold her home). Thereafter, she had been hospitalized a further four times in six weeks.

During her most recent hospital stay, Mrs. P was diagnosed with advanced breast cancer and her prognosis is poor. She exhibited anger and impatience with both her doctors and family members. It was clear she had irritated her family and driven away most of her friends. Her physician made a referral to the interprofessional palliative care team to intervene with the intent to discern the sources of Mrs. P's suffering. As chaplain, I was asked to meet with Mrs. P based on her physician's preliminary observations and conclusions that her

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[297] MacInnis, E. (2011, November). *Improving the quality of spiritual care to end of life.* Presentation at Grand Rounds, York Central Hospital Richmond Hill, Ontario.

religious beliefs and coping strategies had negative connotations and she displayed indicators of distress and suffering.

On previous admissions, I had visited Mrs. P on a regular basis; we had developed a positive rapport. Hence, a trusting environment had already been established for implementing the narrative inquiry approach *(medical, illness, and faith belief narratives)* as part of her needs assessment. Using the mnemonic: *"I HOPE FOR"* as a way to remember the eight areas to cover when conducting a spiritual needs assessment, profound suffering was disclosed as the story of her life unfolded.

Sitting at her bedside, leaning toward her, exhibiting empathy, verbally and nonverbally acknowledging her painful and difficult situation, I listened as she described the major events that were causing her pain and suffering. At first, Mrs. P cried, but then began to speak about the isolation she had experienced since her husband's death. She admitted that she had stopped socializing with her friends shortly after her husband died because she was angry with them for not being supportive enough during her time of grief. She also talked about her children. They had been angry at her following her admission to the crisis unit, especially her son-in-law. They feared that she would again attempt to take her life, although Mrs. P denied this would happen again; she repeatedly expressed her wish to die to the chaplain. I immediately requested involvement of the social worker, complementary therapist, and psychiatrist to support the interprofessional team in their care for Mrs. P. In the following weeks her needs were assessed on an ongoing basis while she was in hospital.

The social worker and I (the chaplain) explored her social situation, were able to recognize the *fight or flight response* activated by the unhealthy dynamics within her living arrangements. Her son-in-law made insulting remarks, and preceding each emergency visit threatened that if she attempted suicide one more time, she would never again see her grandson. The negative impact on her health and sense of well-being was evident in her body language as well. The complementary therapist provided therapeutic touch and aroma therapy on a regular basis. After acknowledging the pain these events have caused her, we asked Mrs. P about any physical pain she was experiencing. She indicated there was "still a bit of pain, it is somewhat better than it has been." At this point in time, we (the social worker and chaplain) decided to explore some goals that Mrs. P. would like to accomplish in the next few days or weeks, what were some of the things she was hoping for? As a team, we were able to facilitate many *Hope Fostering Strategies* into her care plans.

A family conference was scheduled with the physician, social worker, and chaplain to meet with Mrs. P's family; her daughters were in attendance (the son-in-law refused to attend). Mrs. P was able to express what she has shared with the social worker and chaplain in the meeting. Her daughters validated their mother's feelings and acknowledged the dysfunctional relationship that exists with her son-in-law; he also has refused to permit Mrs. P's friends to visit in their home. Together, they decided the time had come for their mother to find an apartment where she would have space to entertain friends and renew friendships. The social worker was instrumental in helping Mrs. P obtain financial assistance and accommodations within her income range. Using cognitive behavioral therapy approaches such as cognitive restructuring, combined with mindfulness training techniques, Mrs. P was able to manage her stress more effectively. As she continued to receive counseling, Mrs. P became aware of her options and the need to make choices among them. Mrs. P began to break the negative stress cycle that had been an accepted part of her life.

As her chaplain, I drew upon concepts of theological reflection put forth by Killen and deBeer[298] as a means of exploring her experiences in conversations with the wisdom of her religious heritage. These conversations were a genuine dialogue seeking to hear about her beliefs, actions, and perspectives, as well as those from her Anglican faith tradition. Our conversations respected the integrity of both. Using the discipline of theological reflection, I was able to confirm, challenge, clarify, and expand how she understood her own experiences in light of the doctrines of the Anglican religious tradition. Mrs. P revealed that she was having episodes of shame and guilt about something that happened when she was 18 years of age. She felt that God was punishing her for what she had done. She wanted to know if she told me the truth, would I judge her as unworthy and refuse to visit her? Abandonment was identified as a major issue in her life. I reassured Mrs. P that I would not judge her and regardless of what she told me, I would continue to offer her unconditional *agape* love.

Through tears of relief, she revealed she had had an abortion, “I killed my twin babies; it was unacceptable for a single woman to become pregnant outside of marriage in the early ’60’s.” As we talked about forgiveness and God’s grace, I observed the emergence of an inner peace never before present with Mrs. P. As the hospital chaplain, I felt that I was standing on sacred holy ground listening to her as she prayed asking God for forgiveness of her sins. Mrs. P requested the Sacrament of Holy Communion, which I offered her along with prayers and blessings. The outcomes of our theological reflections were new truths and meaning for Mrs. P including living without guilt, feeling loved by God, and her family. These were new realities in Mrs. P’s life.

Consequently, surprising transformations began to occur. Mrs. P’s pain and symptoms became easier to manage. When the physician, social worker, and chaplain visited, she described the transition from the hospital to her new apartment as “life giving.” Mrs. P and her son-in-law have been able to forgive many of their past hurts, and her friends are now beginning to visit on a regular basis. Even her grandson visits twice a week. Mrs. P is increasingly perceived by her family as kind, good humored, pleasant to visit, and appears to be appreciative of the interprofessional team’s efforts to support her in the

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[298] Killen, P., & deBeer, J. (1999). *The Art of theological reflection.* New York, NY: Crossroads, 51.

> community through palliative care home visits. Mrs. P has discovered a renewed sense of hope, purpose, value, self-worth, and meaning–a clear example of spiritual healing. Mrs. P was readmitted to hospital five months after moving into her apartment and died within three days. Surrounded by her family, her daughters described their mother's death as "a peaceful journey into eternal life, a place where there will be no more pain and suffering."

This case study demonstrates that many factors contribute to pain and suffering. When patients feel that someone who cares listens to them, they no longer feel the need to seek out attention by negative behaviors or place excessive demands on those closest to them, including the interprofessional team. Ultimately, caring for the spiritual needs of patients can be seen and measured in the reduction of hospital visits as the decrease in the level of *total pain and suffering;* in addition, patient and family satisfaction reports reveal that compassionate care to end of life offered by an interprofessional palliative care team is an important aspect of care.

Occupational Stress Affects the Quality of End-of-Life Patient Care

For the past 15years, as a Chaplain working in health care, I have been interested in the subject of occupational stress in oncology and palliative care. How do professionals cope on a day-to-day basis with dying and death? What stressors impede the health care team's ability to provide compassionate care to end of life and alleviate or diminish the patient's and/or their family's distress and suffering? What strategies can management implement to prevent burnout? Professionals who work with patients facing impending death show comparatively high levels of stress and burnout. But, paradoxically, the emotional stress of working in oncology and palliative care is seldom acknowledged by the professionals themselves or by the institutions in which they work.

Many participants in this study described caring for patients at the end of their lives as a privilege. But at the same time, the interprofessional team disclosed that caregiving can be emotionally draining and takes a toll on individual team members' sense of well-being. During the course of the research, observations and conversations with staff reveal they encounter two kinds of stress working with the terminally ill and dying that often come into play at the same time: (a) stress arising directly from their work with patients and families and (b) stress arising from within the work environment.

One of the research focused group discussion's focus was *Exploring Sources of Stress Experienced by the Palliative Care Team.* I asked participants this question: "What is stress?" It became apparent that most people have an experiential understanding of the term "stress" but when asked to define it; many found it hard to verbalize. The lack of an adequate common definition is a fundamental problem when one is researching stress. What is stressful for one person on the team may not be stressful to another, and what is stressful for a person one day may not seem so stressful the next day. A working definition of stress that participants in the focused discussion group agreed on states, "stress occurs when there is an excess of demands over the individual's resources to meet them." Both the demands and the sources can be *internal* (from within the individual) or *external* to them (other people, staff not coming to work for a scheduled shift, tension that arises from lack of education and training for staff in the philosophy of palliative care, and lack of equipment are but a few examples). Participants in the focus group stated that before our discussions began, it was important for them to hear me say that their experience of stress is not a sign of "weakness," just as managing to cope with a high level of stress is not a measure of one's personal strength.

Nurses, physicians, and other team members identified factors that contribute to their experience of stress working with dying patients and families: (a) experiencing the patient's decline and death, especially with patients with whom there has been a history of long-standing relationships; (b) witnessing suffering of patients and families, feeling helpless and overwhelmed by their sorrow; (c) being present when family conflict erupts when some family members want nurses to give morphine to relieve pain and suffering, while at the same time, one or more family members state they fear the patient will become addicted and fight to have the pain medication withheld; (d) patients and families seeking aggressive therapies that are not appropriate or they are demanding their loved one remain on life support when there is no hope for a return to some measure of quality of life the patient previously had.

> *Jennifer:* Daily, nurses witness patients and families make troubling or distressing choices near the end of life; caring for the dying requires that we acknowledge our lack of control, that means letting go of one's agenda that is in the best interest of the patient, I find this extremely stressful.
>
> *Mary:* [With agitation and stress in her voice] In spite of the difficulties we repeatedly experience with patients and families, organizational stress within our work environment actually causes more stress than witnessing suffering. There are days when I return home after work I am just too exhausted to enjoy the company of my children and husband.
>
> *Jane:* [Palliative Care Nurse Specialist] Patients and families often have high expectations that we can relieve suffering; they have no idea that without the power and resources to meet their expectations, the result is emotional burdens that have a negative impact on our sense of well-being. I wonder if administration realize how often we are stretched to our limits with increasing workloads that result from cutbacks in registered nursing staff on the units?

During the second research focused discussion group exploring *Stress and Burnout in the Field of Oncology and Palliative Care*, staff members working on the palliative care unit and oncology clinic stated:

> *Sharon:* I have specific personal and professional beliefs, values, and practices that have been deeply integrated into my approaches to nursing care, when they are challenged by colleagues I frequently experience considerable stress. A few years ago in another hospital, I actually crashed as a result of burnout.

> *Peter:* Yesterday, a nurse spoke of a recent study at Princess Margaret Hospital (PMH), a world renowned cancer hospital where stress levels of staff in oncology and palliative care were compared; the study found 63 percent reported experiencing ‘a great deal’ of stress at work, there was no difference in the distress reported by oncology and palliative care staff. [299]
>
> *Jonathan:* As an oncology physician, I would like to speak about my observations working in the oncology clinic and on the palliative care unit. What I observe here in this hospital and listening to conversations among staff, it appears that stress levels are similar in each department. Administration need to put in place programs for staff to address their concerns that I witness that frequently result in stress, burnout and compassion fatigue.

Compassion Fatigue: A Key Factor in Caregiver Burden

The concept of *compassion fatigue* was developed by Joinson[300] in 1992 and promoted by Figley’s theory that compassion fatigue captures the essence of caregiver burden as it presents in both psychological intensity and the exhaustion felt by those committed to caring for the dying.[301] In the focus discussion group mentioned above, members of the palliative care team spoke about their experience of compassion fatigue:

> I have no energy for this type of work anymore…. At the end of the day I feel totally drained and empty, I have nothing left to contribute to the care of my patients and their families…I feel exhausted physically, emotionally and spiritually… At the end of the week I ask myself, why am I doing this? I have so many questions and so few answers.

Compassion fatigue is described as being almost identical to post-traumatic stress disorder, except that it applies to those emotionally affected by the trauma of another,

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[299] Dougherty, E., Pierce, B., Ma, C., Panzarella, T., Rodin, G., & Zimmerman, C. (2009). Factors associated with work stress and professional satisfaction in oncology staff. *American Journal of Hospice and Palliative Medicine, 26*, 105–111.

[300] Joinson, C. (1992). Coping with compassion fatigue. *Nursing*, *22*(4), 116–122.

[301] Figley, C.R. (Ed.). (2002a) *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*. New York, NY: Brunner/Mazel.

usually a patient or family member.[302] With tears in her eyes, *Christina*, a palliative care nurse, described an experience on the unit the previous day:

> I could not believe we had four patients die on the palliative care unit yesterday during our shift; I was constantly going from one room to another trying to comfort grieving families. Shortly after the patients expired, we were told to go in and discreetly check if the family was ready to leave because there were patients in the emergency department waiting for the beds. It seems that the patient navigation team is not willing to let the family or staff members have the necessary time they need to grieve for the patient who just died. Perhaps they need sensitivity training, they have no idea how the death of our patients impact staff.

Burnout: Key Contributing Factors Impact Patient Care

Currently within the field of health care the most common outcome measures of occupational stress are distress, compassion fatigue, and burnout. What is burnout? *Burnout* is a form of mental distress manifested in "normal" people who have not suffered prior psychopathology, who experience decreased work performance resulting from negative attitudes and behaviors.[303] Burnout is a psychological syndrome in response to chronic interpersonal stressors on the job.[304]

Three *key dimensions of burnout* identified by Maslach, Schaufeli, and Leiter were observed during this study among nursing staff and physicians working with terminally ill and dying patients:

1. Overwhelming *emotional exhaustion*–the basic *individual stress dimension* of burnout. Individuals refer to feelings of being over extended and drained of

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[302] Figley, C.R. (Ed.). (2002b). *Treating compassion fatigue*. New York, NY: Brunner Routledge.

[303] Maslach, C., & Leiter, M. (1997). *The truth about burnout: How organizations cause personal stress and what to do about it.* San Francisco, CA: Jossey-Boss.

[304] Maslach, C., Schaufeli, W.B., & Leiter, M. (2001). Job burnout. *Annual Review of Psychology, 52*, 422.

emotional and physical resources.[305] Participants in the discussion group mentioned actions such as distancing oneself emotionally and cognitively from work as a tactic to cope with work overload.

2. Feelings of *cynicism* and *detachment* from the job are conveyed as *depersonalization*–the *interpersonal context dimension* of burnout which denotes a negative, callous, or excessively detached response to various aspects of one's job responsibilities. It is an attempt to put distance between oneself and various aspects of the job.[306] Reflecting on remarks made by staff, there appears to be a clear relationship between exhaustion and cynicism related to work overload and social conflict.
3. A sense of *ineffectiveness* combined with a *lack of personal and/or professional accomplishment*–the *self-evaluation dimension* of burnout refers to feelings of incompetence, and a lack of achievement and productivity in the workplace.[307]

Observations and conversations with nurses, physicians, and other members of the palliative care team indicate that the above aspects of burnout clearly result from a lack of resources to get work done combined with administration's lack of positive affirmation for staff when they go above and beyond the job description requirements. Participants in the focus group identified contributing factors to their experiences of stress that lead to burnout: (a) reductions in the ratio of qualified registered nurses to deliver quality medical care and education for patients and families; (b) insufficient time to provide spiritual care for patients; several nurses stated, "this is part of our calling, but

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[305] Maslach, C., & Leiter, M. (2008). Early predictors of job burnout and engagement. *Journal of Applied Psychology, 93,* 498– 512.

[306] Ibid.

[307] Maslach, C. (2003). Job burnout: New directions in research and intervention. *Current Directions in Psychological Science, 12,* 189–192.

we barely have time to complete our nursing tasks"; (c) lack of critical information; and (d) lack of appreciation and positive feedback from those in management positions. A senior physician stated, "Several contributing causes of stress among the medical team are not merely structural but embedded in the history and culture of medicine. Like patient-centered care, creating a 'person-centered work environment' is a significant unmet goal of modern medicine, but tackling the effects of stress may also require challenging something of the historical culture of medicine."

Staff Recommendations: Strategies to Reduce Stress and Burnout

> A work environment that does not acknowledge the implicit stress of end of life care or cancer care is more likely to promote a culture of emotional detachment, distance, and lack of support between staff. If emotional distress is not expressed it is likely to go underground. By contrast a workplace culture that encourages staff to talk through difficult clinical experiences and mutually support one another is one which enables professionals to remain emotionally involved in their work, while continuing with other fulfilling areas of their lives.[308]

During a third research focused discussion, Strategies *to Reduce Stress and Prevent Burnout*, participants acknowledged that their being compassionate and caring ultimately comes at a price. Too often the price is overtaxed health care staff that often become emotionally drained and fearful of their own health. Face-to-face contact with distressed patients is an inevitable source of emotional stress for the interprofessional team working in end-of-life care with patients and families; nevertheless its stressful effects should at least be minimized and addressed by management. *Edmund*, an ethicist in the group, said:

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[308] Figley, C.R. (1998). Burnout as a systemic traumatic stress: A model for helping traumatized family members. In C.R. Figley (Ed.). *Burnout in families: The systemic cost of caring*. Boca Raton, FL: CRC Press.

> Health care managers need to encourage their staff to develop ways of sustaining their ability to care, rather than becoming emotionally detached and distant as a way of coping. They should also ensure that their team has sufficient opportunities to discuss stress in the workplace rather than allow it to accumulate or be taken home.

Darcy, a social worker, took the ethicist's idea even further stating:

> If our team wants to improve the quality of care we provide to the dying and their families, we must diligently work to support each other and remain healthy physically, emotionally, and spiritually; only then can we provide a compassionate model for spiritual care in action.

Together, members of the palliative care team identified recommendations and strategies that administration should take into consideration and support unit managers in order to promote a healthy work environment, reduce staff stress and prevent burnout. Following are their suggestions:

1. Provide new staff working in end-of-life care with orientation training that emphasizes self-care and the responsibility of individual staff members to express concerns about their own levels of stress.
2. Clarify the parameters of what is expected in each person's professional role so as to reduce ambiguity within their positions (where does the job end?) and identify professional roles and responsibilities.
3. Provide training for staff in the psychosocial aspects of end-of-life care. By developing proficiency in communication skills, professionals will increase their confidence in handling difficult situations and reduce the possibility of contributing to iatrogenic suffering experienced by patients–a result of insensitive communication by the professional team.

4. Advise staff to balance the demands of their professional work and personal life with the objective to reduce feelings of guilt as they experience heavy workload demands.
5. Authorize the palliative care team to exercise independence and responsibility within their area of expertise with the aim of promoting creativity, innovation, and personal development of new approaches to improve end-of-life care.
6. Work toward creating a mutually supportive work environment where staff are encouraged and given the opportunity to regularly take time to talk about and reflect on their work.
7. Permit concerns to be expressed and worked through to a healthy resolution rather than suppressed. This can take place in a number of venues: informal contacts, team meetings, clinical supervision, and discussions such as the focused group discussion, *Strategies to Reduce Stress and Prevent Burnout.*

The Palliative Care Team: Providing Quality Care to End of Life Interventions Must not Exclude the Concept of Hope

> Because we have declared limits on treatment or cure does not mean that we have pronounced the limits of human potential. Patients are invited to open themselves to new targets of hope, to draw on strengths not yet experienced.[309]

Ersek defined hope as a dynamic life force characterized by a confident, yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant.[310] When people first receive a life-threatening diagnosis, they focus on hope for a cure. At the end of life, hope is not just

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[309] Jevne, R. (1993). Enhancing hope in the chronically ill. *Humane Medicine, 9*(2), 121–130.

[310] Ersek, M. (2001). The meaning of hope in the dying. In B. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 339–351). Oxford, UK: Oxford University Press.

associated with cure but extends beyond a physical nature to that of a social, psychological, and spiritual nature.

An underlying philosophy of care endorsed by the palliative care team in this study stipulates that palliative interventions should be offered in the context of hope rather than a response to a hopeless situation. When medical interventions for a cure fail, patients often look to other team members for help and support. Central to the instillation of hope is a caring relationship between members of the palliative care team, patients, and their families. Unless the palliative care team understands the nature of hope and the various ways it can be expressed, our care can impede rather than promote hope and healing.

The fourth research focused discussion group investigated the theme *Supporting Patients and Families at End of Life: Implementing Interventions to Foster Hope and Healing.* Participants were asked to review professional literature in preparation for this discussion group on the topic of hope to share with colleagues. The focus of the discussion was to identify definitions of hope and approaches that can be used to enable patients to discover hope as a way to promote healing and wholeness. The most all-embracing explanation of hope presented was from the work of Jevne and Nekoliachuk. Several staff members captured aspects of their hypothesis.

> Hope is a complex process that occurs in the context of time….Hope is not always logical or tangible; it is about creating the possibility of something better in the future….Hope is experienced in the context of people's past lives….Hope is influenced by patient's roles, culture, relationships, and expectations….Hope occurs in the present as people grapple with the uncertainties of life before them….Hope considers a range of possible outcomes that are desirable…. Hope is about possibility – not probability…

> Hope uses the strengths and wisdom of the past to build a bridge to the future.[311]

When people receive a life-threatening diagnosis, they first focus on hope for a cure. A palliative care nurse specialist in the group introduced the Victoria Hospice Society's concept of *The Hierarchy of Hope:*

> Each level of *the Hierarchy of Hope* is filled with many specific hopes and/or 'hopelets' that will be particular to each person. Patients are sustained by their ability to collect these small, tangible 'hopelets' and string them together in a way that gives them increased hope and strength.[312]

Participants who work as part of interprofessional teams in the hospital and community identified two types of hope they observe among patients at the end of life: (a) Hope to live more fully and deeply in the time remaining and (b) Hope for life beyond death.[313] A Hospital Chaplain *Karen* spoke about her observations of patients' experiences of hope:

> Hope is what maintains a person's spirit and enables them to go on; as the patient is dying *what* they hope for may change, but it does not go away. I have been a hospital chaplain for almost twenty years, I can confirm that a patient's hope for a cure may change to hope for freedom from pain; their day to day experiences focus on enjoying precious moments of life; having time to achieve important goals before their life is over; sharing friendship with families and people who have given their life meaning and purpose; relief from suffering, dying with dignity and entering into eternal life.

A palliative care nurse specialist, *Sharon*, in the focus group identified essential characteristics needed to provide compassionate "patient centered" care to end of life:

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[311] Jevne, R., & Nekoliachuk, C. (1999). *A hope research manual: Points of departure, rays of hope.* Presentation at Approaching the 21st Century Conference I attended, Edmonton, Alberta.

[312] Cairns, M., Thompson, M., Wainwright, W., & Victoria Hospice Society (Eds.). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Baltimore, MD: Health Professionals Press, (p. 114).

[313] Kempt, C. (2001). Spiritual care interventions. In B. Ferrell, & N. Coyle (Eds.), *Textbook of palliative nursing.* Oxford, UK: Oxford University Press.

> The professional palliative care team who provide compassionate care in their relationships with patients and families must exemplify unconditional positive regard, encouragement, combined with an understanding and ability to help families focus on goal directed interventions that emphasize what the patient still wants and hopes to achieve in his or her lifetime.

Palliative Care Team's Interventions That Foster Hope and Promote Healing

Hope is an important component of the emotional stages associated with the journey of facing impending death. Throughout this study I have observed that hope is a factor that supports patients and families to meet the challenges associated with the diagnosis of a life-threatening illness. The following hope fostering interventions were recommended by the palliative care team in focused discussion groups and individual interviews: (a) Provide effective relief of pain and other distressing symptoms. (b) Encourage the patient to maintain meaningful relationships with others, including family, friends. (c) Urge patients to keep in touch with work colleagues in order to feel a sense of "being a part of something." (d) Focus efforts on specific short-term goals attainable in the next few days or weeks. (e) Promote spiritual practices that provide a sense of meaning that transcends suffering. (f) Help patients and families understand that hopes can change with time and circumstances. (g) Assist patients in redirecting their hope to things that are within reach. (h) Acknowledge the patient's positive personal attributes such as determination, courage, and serenity. (i) Assume an attitude of light-heartedness; you may be the only one the patient can laugh with.

The palliative care team recommendations were implemented into clinical care pathways as part of the goals of care, with positive outcomes. We now turn to the next chapter where the voices of patients and their families reveal their concerns as they journey through *the Continuum of Palliative Care.*

CHAPTER 6

RESEARCH FINDINGS: PAIN and SUFFERING

A SHARED JOURNEY THROUGH THE CONTINUUM OF PALLIATIVE CARE

Personal Narratives – A Source of Knowledge About Illness and Suffering

As part of the literature search for this research study, an important insight I gleaned from the work of Japp et al. is that personal narratives are at the core of public knowledge; they also serve as building blocks for knowledge about illness and suffering.[314] Mishler stated narrative accounts reveal both the voice of medicine and the voice of the life world of patients.[315] In this study I have had the privilege of listening to the stories of patients and families, their discussion of the disease complete with a description of medications and tests (medical narratives), and the story of their suffering as they expressed the effects of a terminal diagnosis on their relationships and their life world (illness narratives). In addition, I also observed the ability of the interprofessional team to witness, remain present, and genuinely listen to the stories of patients' and their families' suffering. Patients identified this as compassionate care and, similar to Wright's research, it was frequently identified as the starting point in the patients' emotional and spiritual healing.

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[314] Japp, P. M., Harter, L. M., and Beck, C. S. (2005). Overview of narrative and health communication theorizing. In L. M. Harter, P. M. Japp, & C.S. Beck (Eds.), *Narratives, health, and healing: Communication theory, research, and practice.* Mahwah, N.J: Lawrence Erlbaum.

[315] Mishler, E.G. (1984). *The discourse of medicine: Dialectics of medical interviews.* Norwood, NJ: Ablex Publishing.

Research Participants Describe Their Experiences of Suffering

From their point of view, suffering affects not only the person experiencing the illness, but also his/her family members–suffering is a family affair. Formulated meanings that frame participants' descriptions of their experiences of suffering:

> To experience an unanticipated life threatening illness that alters or threatens one's life and relationships; acute or chronic pain; fear and uncertainty about one's future; severe distress that includes enduring anguish, loss, and grief, loneliness, conflict; breakdown in communication; fractured relationships; longing for significant relationships; isolation and exclusion from normal life activities; a loss of hope or hopelessness; unwanted or undesirable change that affects the body, mind, and spirit in a negative way.

The Three "S" Phases of Suffering

In the course of this research study, three *"S"* phases of suffering were identified: (a) the *silent* phase, during which patients and their families were unable express their suffering; their voice is silent; (b) the *searching* phase, during which the sufferer is searching for words to express the suffering he or she is experiencing; and (c) the *speaking* phase, during which the person who is experiencing suffering recovers his or her voice and is able to express in words, metaphors, analogies or through stories the depth of their suffering.

Reflecting on conversations with patients and families facing impending death, it appears that the dying process is a particularly confusing and uncertain time in the lives of many people. Participants in this study validated Mooney's research: "it is a time when they are most defenseless, dealing with circumstances that they have no control over, they are frightened and confused."[316] *Michael* eloquently validates this concept that

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[316] Mooney, K. (2003). Understanding our place: The importance of professional boundaries. *Hospice and Palliative Care Insights, 3*(2), 18.

mirrors the voices of participants in this study as reflected in a taped interview that exemplifies the three "S" phases of suffering:

> At times my suffering is unbearable because I feel so alone and lonely, there is no one in my family that I can talk to about what is happening. For a long time I could not find words to express my feelings. I have shed most of my tears in private. I cry alone because no one would understand my horrendous losses and shattered dreams for the future [long pause while he wipes away tears, goes over to the window and touches the leaves of several house plants he brought from home]. At times I am so frightened and confused when my pain escalated to the point I am crying and pleading for more morphine to help control it. I am uncertain what the future holds; there are a few nurses who come in and sit with me and when I tell them what is happening, they console and comfort me. For the most part, I suffer in silence trying to put on a brave front when others are around.

Pain and Suffering Described by a Research Participant

Kerri, a 55 year-old nurse practitioner and educator whose career was cut short by end stage renal failure and complications that led to a below-the-knee amputation, knows all too well the reality of pain, experiencing post amputation pain and the problems of managing phantom pain and residual limb (stump) pain. When asked how she would describe pain and suffering she clearly articulated her experience that is reflective of the voices of numerous participants in this study:

> I will try to describe pain from my nursing background and put it in terms that non-medical people can understand. Pain is a physiological occurrence that results from the stimulation of certain types of nerve cells with an intense feeling of discomfort, which usually indicates tissues have been damaged. Pain signals can be classified into three basic types–neuropathic, somatic, and visceral. Neuropathic pain is complex chronic pain that is the result of damage to the peripheral and or central nervous systems. Somatic pain is generally described as musculoskeletal and the nerves that detect somatic pain are located in the skin and deep tissues of the body. Visceral pain comes from inside the body, it is the pain we feel when our "soft" organs and body tissues are damaged or injured. Pain signals undergo an extremely complex internal processing, so patients categorize their experiences of pain in different and interesting ways, such as tingling, sharp, dull, burning, aching, cramping, pressure, never ending–never going away, or any other imaginable sensation. Pain can also be classified into acute and chronic depending on the duration of the pain. Acute pain such as immediate post-op pain is over quickly and is dealt with narcotics and nonnarcotic analgesics (pain medicines); whereas

> chronic pain that is often of lower intensity and never goes away needs to be dealt with quite differently.
>
> Suffering, on the other hand is dissimilar from the pain that results from stimulation of nerve cells; suffering has to do with the experience of a person and the meaning they attach to it in relation to their situation in life.
>
> Suffering, O God, it can also be so long…so long with no end in sight. Suffering feels like an assault on your total body when one experiences a life threatening illness that alters your relationships that you hold near and dear to your heart. Suffering is a very heavy feeling that puts you down in the dumps where you feel like “why worry anymore–nothing is going to change for the better.” Emotional and physical suffering go hand in hand; if your body is physically in pain, you will also be in pain emotionally and that is what I call suffering. It feels like you are down in a pit and you are trying to climb out of the pit. Some people have no trouble climbing out of the pit, while other people have to do it an inch at a time until they attain the goals they hope for–and sometimes they can still be suffering. My experience with end stage renal failure is like being on a roller coaster and there is a lot of emotional and spiritual suffering. I sometimes wonder if there is a God, and if so, where are you God?

Spiritual Pain and Suffering

What is spiritual pain and suffering? Listening to patients’ and families’ “illness narratives,” a term coined by Wright,[317] participants in this study expressed their definition of spiritual pain and suffering as: “a fracture or shattering in a person’s belief and value system that had in the past provided strength, hope, and meaning in their life.”

Patients frequently described the moment they heard their diagnosis of a terminal illness as the beginning of immeasurable suffering and the beginning of an inward existential or spiritual searching for answers. They began to reevaluate their lives and ask questions about what is ultimate and true on a recurring basis in an attempt to connect with the central essence of their lives. Questions patients in this study frequently asked:

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[317] Wright, L. (2005).

> Does my life have meaning and purpose? Why do I exist? What caused my illness? Why am I suffering? Will I experience unbearable pain and suffering at the end? What will happen to me when I die? Is there life beyond death? Does God really exist? Will God forgive me? Can the person(s) I hurt forgive me? Can I forgive those who have hurt me? Will my family, friends and professional colleagues remember me?

As a hospital chaplain and researcher working with patients nearing the end of lives and their families, I listened to their voices that revealed contributing factors to their experiences suffering:

> *Marlisa*: I felt so frightened and alone when I had a seizure at home. I was lying on the kitchen floor in sheer terror for 12 hours thinking that I was going to die alone. My mind kept going back into the past to Auschwitz and lying on the camp floor thinking that I am going to die and asking where is God now? Am I going to die alone before anyone finds me? Have I done something that God is punishing me for? I began to feel hopeless because I could not move or get up to phone for help. Why am I laying here suffering for so long? Where are my friends when I need them? Will my friends and family remember me after I die?
>
> *Elizabeth*: I thought I had experiences suffering living with MS and could put into words my thoughts and feelings about suffering, that was until the day I was told the heartbreaking news about my brother Harold's unexpected death. At first I was unable to find words to express what I was feeling emotionally in the depths of my soul. I searched for ways to communicate to others what I was feeling inside. In time I was able to begin to express in words and metaphors the depth of my heart pain and suffering. My heart was shattered into pieces when I realized my faith that had always given me strength and courage failed to give me comfort when I needed it the most. The brother I love was suddenly taken away. Although he was in a wheelchair from childhood, he came to visit me each week in the hospital. His visits gave me something to look forward to; now that is gone my faith is fading. At times my anguish and suffering are unbearable as I yearn for him to come through the door with his boyish smile. Why did God let this happen? Is there life beyond death? I pray there is so I can see Harold again.
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> *Peter*: Perhaps the most vivid image of suffering I have experienced, and it is impossible to find words to adequately describe the evening when the doorbell rang and my mother answered it. There were two police officers standing there; they asked my mother to call me into the living room. When we were seated, one of the officers told me that my wife Jane who has been diagnosed with stage four pancreatic cancer was shot in a robbery and taken to hospital. I will never forget my mother's screams and her saying how could God let this

> happen to my daughter? How could God let this happen to my daughter? To see her anguish and grief was heartbreaking. [Jane was a patient under the care of the palliative care team in the community; she died a week later in the intensive care unit. The following conversation took place a week after Jane's funeral.]
>
> My suffering at times is so intense that I am losing my desire to live and want to die. Everything that provided strength and meaning in my life has been shattered; I question my faith and belief in God that in the past has carried me through some pretty tough situations. I have this overpowering sense of loss and grief, at times everything seems so hopeless.
>
> *Frank:* I felt so helpless sitting by Helen's bedside and watching her struggle to breathe. I know that she suffered in silence and didn't express her fears and agony in words, but I could see it in her eyes. I think it was her way of trying to protect me, or at least this is what I was observing. It was so painful and my heart was breaking as I watched her physical abilities deteriorate and her distress and agitation increase.
>
> I knew in my heart that she was not going to get better, so for me it was distressing to sit there day by day. Suffering is obviously a horrible experience and you don't realize the anguish that one experiences until you are actually in the situation and feeling so helpless. Suffering is a very private experience and unique to each person; it was very difficult for both of us because we could see that the other person was suffering as well.

Insight Into Intense Spiritual Pain and Suffering

Like Hauser and Kramer,[318] I observed that as a patient's physical pain increases, suffering and existential distress intensify; likewise, so does his or her family's as they compensate to meet the demanding needs of loved ones. Participants confirmed Hearth's (1993) study that found caregivers maintained a stark recollection of the fear and loss of hope that accompany the inability to relieve a loved one's pain and provide comfort within an appropriate time frame.[319] These haunting memories are often the

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[318] Hauser, J., & Kramer, B. (2004). Family caregivers in palliative care. *Clinics in Geriatric Medicine, 20* (4), 671–688.

[319] Hearth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing, 18* (4), 538–548.

cause of intense suffering, as articulated by *Lillian* reflecting on her husband *Peter's* death:

> My fear and suffering along with our children resulted from agency nurses' failure to give medication for agitation and restlessness on time and giving incorrect medication in the wrong saline locks on Peter's arms. In the middle of the night I awoke to the alarm bell ringing and saw Peter struggling because he managed to take off his Bi-Pap mask. I went to the nurse's station and had to pound on the window to wake his nurse who was sleeping at the desk. Following shift change, Peter's nurse observed cuts on his face that resulted from pulling off his mask and my distressed emotions; the nurse suggested that you [researcher] spend time with us as a family. Both incidents were reported; however, there was no follow-up by management with our family; as a consequence it has left a bitter memory in our minds and hearts; it has been three months since his death. [Long pause as Lillian wipes away the tears from her eyes] No family should have to live in fear for their loved one's safety as they approach death, especially on a palliative care unit. Nevertheless, we are satisfied with Peter's care provided by the palliative care doctor who recognized our need for time to adjust to Peter's impending death. When he was admitted to the palliative care unit from ICU, this gave us time as a family to complete unfinished business and do some of the things we needed to do and say our good-byes. Reflecting on Peter's 65th birthday party we had in his room, I observed the warmth of hospitality extended to us by so many of the nurses and other staff on the palliative care unit and this continued until the day he died.

Suffering In the *Present,* Remembering the *Past,* Envisioning the *Future*

The capacity of health care professionals to witness patients' stories of suffering is central to providing care and is frequently the genesis of healing.[320] [321] [322] Throughout this study, using the Heideggerian phenomenological concept of what it means to be a person, the author explored the experience of suffering with participants using a narrative approach. Remembering past experiences often stimulated fear, physical symptoms, and anguish or suffering in their present situation when terminally ill patients envision what will happen in the future.

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[320] Frank, A.W. (1994). Interrupted stories, interrupted lives. *Second Opinion*, *20* (1), 11–18.

[321] Kleinman, D. (1988). *The illness narrative.* New York, NY: Basic Books.

[322] Wright, L. (2005).

It follows that suffering experienced by patients and families in this study had a temporal component. In order for a situation to be a source of suffering, it must affect the person's perception of the future. Suffering occurred when one's perception of the future included fear of impending death, often perceived as the total destruction of personhood. It became clear that experiences during one's lifetime have the potential to affect the patient's sense of well-being; suffering in this context needs to be explored, conveyed, and talked about. Participants in this study were encouraged to tell not only their medical narrative, but also their illness narratives. Similar to Tapp, I observed that conditions emerged for healing to occur (a) when spaces were created for therapeutic conversations that moved beyond social conversations, and (b) when these conversations were purposeful, deliberately exploring family support, uncertainty, and death.[323] When life reviews were implemented within therapeutic conversations, many participants confirmed that talking about their experiences and the effect of their illness on the family unit became the context in which they began to gain insights into their experiences of suffering; with professional counseling support several reported a decrease in both emotional and spiritual suffering, which often led to a sense of inner peace. The following case study illustrates this concept and how a life review uncovered two tragic experiences in *Franconia's* past that contributed to her suffering as she envisioned her future in the face of impending death:

> Franconia is an 82-year-old lady diagnosed with metastatic colon cancer. On February 11th she fell and fractured her right femur. She told me that the doctor said it could be fixed with a plate, cables, and screws, so she had surgery. Dr. B. indicated to the palliative care team that he is trying to keep this lady as comfortable as possible. On March 12th during my [researcher] visit with

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[323] Tapp, D.M. (2001) Conserving the vitality of suffering: Addressing family constraints to illness conversations. *Nursing Inquiry, 8* (4), 254–263.

> Franconia she appeared to be in distress indicating she was having severe abdominal pain; I spoke to the nurse who gave the patient medication. Franconia, tightly holding my hand requested that I not leave so I quietly sat by her bedside; as the pain medication began to reduce her suffering she began to tell me about coming to Canada as a war bride and becoming the mother of four children. The television was on in the background; suddenly we could hear the sound of gunshots. Franconia bolted upright in bed with a look of sheer terror in her eyes and appeared to be in a state of shock. Gently holding her hand I asked if she could help me understand what had just happened. Through tears she recounted how the Nazis had stormed her street, when she heard gunshots she peeked through the curtains of an upstairs bedroom window and saw her parents and four of her teenage friends shot and struggling as they died. Hiding under a bed she trembled as the Nazi soldiers went through their house and then left; she has lived with this haunting memory all her life. Franconia then recalled the time police came to her door with the heartbreaking news that a drunk driver had tragically killed her 19-year-old daughter. She said, "I am so angry with God and could never forgive the man who killed my daughter." Franconia says she lies in her hospital bed thinking about what has taken place in her life–"a life of tragedy." As Franconia faces her impending death she is living in terror of what will happen to her when she dies. "Is there a God, and if there is will he be able to forgive the anger I voiced against him? Can I find it in my heart to forgive the man who took away the life of a young girl who hadn't even started to live?" Clearly forgiveness was a major concern for Franconia and elements of her suffering encompass the past, the present, and the future. With the nurses' compassionate comforting care interventions and the hospital chaplain implementing several spiritual care interventions, Franconia claimed her suffering began to decrease saying, "I have this calming sense of inner peace."

Unnecessary and Preventable Suffering

As a hospital chaplain and researcher working with patients nearing the end of life and their families, I witnessed suffering every day. Of course, a great deal of the suffering related to disease progression was unavoidable, and there were many losses associated with their suffering. However, I also witnessed suffering that is unnecessary and preventable, such as iatrogenic suffering resulting from activities or interactions of the interprofessional team with patients and families. In a taped interview, John and his daughter Alana capture the concepts of iatrogenic suffering and depersonalization and the impact it had on the family's experiences and offer insights that can counteract iatrogenic suffering in the following case study:

> *John:* Several of the nurses on the acute care unit didn't pay attention to what I was trying to say….they would not listen to me when I asked questions about my medications ….they ignored me and didn't answer my questions … and in an authoritative voice said, "just take your pills John."….They always appear to be in a hurry and too busy to explain to me what medications they are giving me. I like to know what pills I am taking. I want to have control over what is happening in my life. The fact that I no longer know what is happening – and no one will tell me is frustrating, and definitely causes distress and suffering.
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> *Alana (patient's daughter)*: There are a few nurses with an attitude that implies "we deliver our medication on the hospital's timetable" and they don't want to take time to listen gives us the message, "here, take your pills, I have to go." And there are others that insist Dad take his pills and hover over him as if he were a child until he takes them, saying "we are not allowed to leave the room until you take your pills." I sit here and feel that Dad is being rushed; and even though he has trouble breathing, he will try to take the pills, while at the same time saying "I have to breathe, I can't do this, I have to breathe." You know, the nurses look at you with this annoyed expression that gives the message "come on, come on, I have to get going." We are feeling under pressure for Dad to quickly take the medications–it is so distressing to watch Dad struggle as he tries to breathe and take pills at the same time.
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> *John*: It causes me stress, a lot of stress, and I feel that the nurse didn't really care about me as a patient; she was avoiding eye contact with me and offered no explanations when I asked her to tell me what the pills were. I felt frustrated and upset. I would like to tell the nurses to respect us even though we have "the death sentence" we are still living people until we die. It helps when they take the time to sit and talk with me as a person, not just another dying patient. Having someone with a kind, soft, gentle tone of voice that can speak English and be truly present and available is important. [Pause] I will get a bit philosophical here, in the words of Existentialist Gabriel Marcel who once said, "True presence is something that reveals itself immediately and unmistakably in a look, a smile, an intonation, or the touch of a handshake." I can promptly discern the nurses that care about me as a person; they are aware that I also want to be treated with respect and dignity.
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> *Researcher*: At the close of this interview I observed a twinkle in John's eyes as he took a piece of paper from his night table, and in a British brogue read the following quote: *"Life is pleasant. Death is peaceful. It's the transition that's troublesome"* written by Isaac Asimov, as a way of summarizing his experiences of living with a life-threatening illness and his hope for the future to experience a peaceful death.

I have from time to time observed suffering resulting from health care professionals hiding behind their own fear of death and as a result postpone communicating with patients the reality of their diagnosis and prognosis. As a consequence, I have seen palliative care frequently offered too late in a patient's disease trajectory for them to benefit from either its medical interventions for pain and symptom management, or from emotional, social, spiritual, loss, grief, and bereavement support. Following are excerpts from a taped interview with *Mary* four months following her husband's death, illustrating this concept and the suffering their family is experiencing:

> My husband was admitted to hospital on Friday when he came in for his second chemotherapy treatment. I was told by the oncologist on Monday evening that he is "very sick," he died at four o'clock Tuesday morning [sobbing and tears rolling down her face she pauses to gain composure] we were not offered palliative care even when I requested it, nor any emotional or spiritual support. The nurses did not ask if we wanted a chaplain to spend time with us prior to David's death, we never had prayers or the chance to say our good-byes; there were so many things we could have done, so many things were left incomplete. I feel so guilty that I told our children they could go home that Monday evening; they also feel a devastating sense of guilt that they were not with their father at the time of his death.

Mary's voice echoes the heartbreaking suffering similar to the experiences of several families in this study, their need for open, honest communication and early referral to palliative care. Participants stated they want information to be shared in a compassionate way directly from their physician, thus confirming that the majority of terminally ill patients in Western culture do want to know their condition and their life expectancy;[324] however, cultural considerations need to be taken into consideration in light of the diversity of our Canadian society.

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[324] Hagerty, R., Butow, P., Ellis, P., Lobb, E., Pendelbury, S., Leigh, N., McLeod, C., & Tattersall, M. (2005). Communicating with realism and hope: Incurable cancer patients' views on the disclosure of prognosis. *Journal of Clinical Oncology, 23*(6), 1278–1288.

Intuitive Suffering: Observing Frequent Deaths on the Palliative Care Unit

There is an average of 25 deaths per month or 300 deaths per year on the Palliative Care Unit (15 beds) at York Central Hospital (one month 44 deaths occurred on the unit). Patients and families said they experience heightened suffering when they observe a roommate die or see the bodies of other patients taken to the morgue. In Judaism, the Jewish funeral home comes directly to the deceased patient’s room, and family members accompany the body to the funeral home. The majority of patients said when they observe so many deaths they perceive this as a “living reminder” of the unavoidable reality of their own death. *Rachel*, with tears streaming down her face and sobbing powerfully, expresses the impact witnessing frequent deaths on the palliative care unit:

> It’s like I am holding up the mirror and imagining I’ll be the next one laying on the gurney with the Star of David covering me from the stares of others as they take me down the hall to the funeral home. Last week it broke my heart to watch Merriam’s daughters and their father who was so distraught and weeping as they walked beside the gurney toward the elevator. My heart is breaking knowing that I too will die shortly and take a similar route with Sharon and my grandsons walking beside me.

Suffering When Patients Feel Abandoned by Health Care

Patients diagnosed with a terminal illness in this study said they needed medical care that goes beyond daily bathing and “diaper changing.” Numerous patients stated they could benefit from “quality end-of- life care” and supportive services that included physiotherapy, professional emotional and spiritual support, music therapy and recreational therapy.

What is quality end-of-life care? Quality end of life care refers to a coherent conceptual framework that clinicians use in their approach to care of patients at end of life. Providing quality of care for patients at end of life is just as important as at other times, although historically this has not been mirrored in the care patients receive.[325] What does quality end-of-life care entail? The Institute of Medicine–National Academy of Sciences–has proposed the following six categories encompass quality end-of-life care: (a) overall quality of life; (b) physical well-being and functioning; (c) psychosocial well-being and functioning; (d) spiritual well-being; (e) patient perception of care; and (f) family well-being and perceptions of care.[326] These six categories are inherent in the philosophy and principles of the Canadian Hospice Palliative Care Association.

Terminally ill patients in this study for various reasons were not provided physiotherapy as part of their goals of care; when they observed other patients receiving physiotherapy, this raised ethical questions for them as well as their families. Their perceptions of not receiving physiotherapy or other supportive services when requested resulted in their feeling abandoned by the health care system and was identified as a major contributing factor to their experiences of suffering. *Douglas*, reflecting on his experience, echoes the voices of numerous terminally ill patients in this research study:

> I am a devoted Anglican and a life deacon in the church; I grieve over my inability to take part in religious and spiritual group activities. Every Tuesday morning I hear music coming from down the hallway; it is a group I can't attend because my legs don't work anymore. When I asked for physiotherapy I was told it would not be offered to me because there was no money in the budget to provide it. I also need to talk to a chaplain or someone with whom I can share the sacred music I love and discuss my faith and beliefs. There are pastoral visitors who drop by for social visits but they do not have the professional training to help me deal with my deep thoughts and fears about dying; the spiritual support I requested was not offered to my daughter Tracey or myself. I have some deep-rooted religious concerns, which I cannot discuss with the young female priest at our church, especially in light of the fact I am a life deacon. I feel abandoned by the health care system I trusted would be there

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[325] Martin, K., Gibson, J., & Singer, P. (2008). Priority setting. In P. A. Singer & A.M. Viens (Eds.). (pp. 53–56). *The Cambridge textbook of bioethics*. New York, NY: Cambridge University Press.

[326] Field M.J., Cassell C.K. (1997). Approaching death: Improving care at the end of life. *Institute of Medicine Report.* Washington, DC: National Academy Press.

> for me when I needed help. The emotional and spiritual suffering is beyond anything I could have imagined. Dear God, is there anyone here at the hospital who can help me sort through my faith issues so I can die in peace?

Like Douglas, *Mar Lisa* repeatedly asked for physiotherapy to be scheduled on a daily basis and was denied access to this type of services; emotional pain and suffering can be heard in her voice as she echoes dissatisfaction and disillusionment with the health care system:

> I have repeatedly asked for physiotherapy to be scheduled daily. I feel like I am being "written off" the health care ledger because I am dying; I have already been "wiped off" the slate in the hospital's palliative care account. I was told that if I want physiotherapy I should sell my condo and use the money to pay for it myself….The bottom line, it is all about expenses and the cut backs to our health care system. I say this because I am an accountant and I will not live to vote in the next election. Do government officials who make the decisions regarding health care funding really care whether or not I get physiotherapy or ever walk again? I don't think so. I feel so abandoned and alone.

Similar to Douglas and Mar Lisa, Dr. R. (as he insisted staff call him–saying his name was too difficult for most English speaking people to pronounce) has worked for many years as a Clinical Bioethicist. It has been over two years since he received a diagnosis of cancer which has recently metastasized to his bones and spine, resulting in his inability to walk safely on his own. Late one afternoon during a visit with Dr. R. he was complaining about the state of health care and how essential services like physiotherapy are being cut, saying, as researchers, we need to raise awareness of how these cuts impact patients' sense of well-being. *Dr. R.* picked up a book[327] from his night table, opened it, and after turning several pages made the following comments:

> As a result of observations and conversations I have had with clinicians, managers, and administration over the past 15 month period, it appears that "priority setting" involves deciding which resources to allocate to competing

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[327] Martin, K., Gibson, J., & Singer, P. (2008).

> needs. Health system sustainability here in Ontario is related to the effectiveness of the priority setting decision-making within the hospital setting. The demand and cost of health care, related services are constantly increasing; therefore, setting priorities regarding what will or will not be provided is vital to the sustainability of all health care systems. However, I believe those who are working in finance and administration need to consider the impact of their decisions of not offering essential services to patients who are dying. I haven't been sent to the Palliative Care yet, but looking in the mirror, I see the writing on the wall. If I am not offered physiotherapy to help strengthen my legs then my situation is hopeless, I might as well give up–just the thought of it causes me immense suffering.

This research study did not focus on ethical decision making related to terminally ill patients; however, it appears that decisions made related to allocation of resources for services did impact several patients' perceptions of services they believed would be available for them. However, I have observed that when the services mentioned above were not being offered, patients' experiences of suffering frequently increased.

Patients' Changing Focus of Hope Can Alleviate Their Suffering

Patients in this study confirmed Groopman's theory that there is still hope when physical improvement is not a possibility.[328] In spite of their knowledge that physical recovery or cure was no longer possible, a repositioning of hope in the final phase of life for many patients helped to alleviate or diminish suffering when they were able to accomplish desired short term goals. A shifting of the patients' focus from their body to their spirit (soul) achieved similar results. When death was estimated to occur within two weeks, the patients' relationship with the interprofessional team and God (the God of their understanding) was perceived as an important source of support, offering hope and healing.

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[328] Groopman, J. (2005). A strategy for hope: A commentary on necessary collusion. *Journal of Clinical Oncology*, *23*(6), 1278–1288.

This researcher observed that, in a number of cases where patients condition progressively deteriorated and the interprofessional team acknowledged their spiritual needs, made referrals to the hospital chaplain or community faith leaders who assisted them to continue their spiritual and religious rituals or practices, their center of hope began to change and moved toward the spiritual; patients frequently used the words "inner peace" to describe their feelings at this point in their life journey. Words spoken by Cousins in videotape eloquently illustrate the concept of spiritual healing I observed taking place with a number of patients throughout this study: "learning to live without fear, to be at peace with life, and ultimately death."[329]

Family Caregivers' Changing Focus of Hope Can Alleviate Their Suffering

Family caregivers' attitudes and focus of hope throughout the illness trajectory changed as the patient's condition deteriorated; three phases were identified: (a) an initial desire for a cure and complete recovery to (b) high-quality of care to end of life for their loved one, to (c) having the patient's pain and symptoms effectually managed so their loved one can die in comfort. Families frequently stated this change in perception helped to alleviate their suffering. These findings correspond to a study by Clayton et al.[330] who drew similar conclusions. The following case study reveals Stanley's awareness of his wife Elizabeth's ability to maintain hope, which enabled him to remain present with her in the role of caregiver throughout the illness trajectory; his focus of hope eventually changed from hope for a cure to hope for a peaceful death. This concept is revealed in *Stanle*y's words.

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[329] Cousins, N. (1989). *Beliefs become biology*. Victoria, BC: University of Victoria.

[330] Clayton, M., Butow, P., Arlond, R., & Tattersall, M. (2005). Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer, 103* (9), 1965–1975.

> My wife died in September, she continued to have chemotherapy until August. Elizabeth was diagnosed with MS 30 years ago and uterine cancer in 2005. How can one have quality of life as they experience the side effects of aggressive types of treatment? Elizabeth never regretted the treatments during her 10 months at York Central Hospital, she never complained. Looking back, I believe we were able to make almost every day a good day because she never lost hope, although I must admit that our hope changed over time; she continued to maintain a positive attitude and a gracious personality. You [researcher] joined us on several occasions when her Thursday afternoon girl friends of over 30 years visited Elizabeth every week and we had coffee time and reminisced of times past in the atrium. I remember you [researcher] asking, "Elizabeth, what helps you cope and maintain such a positive attitude?" I will never forget her smile as she held my hand, looked into my eyes and said, "The love and support of my family, friends and my faith." Elizabeth's faith was strengthened and renewed when she attended the two nights of the Jewish Passover Seder Meal provided by the Spiritual Care Department at York Central Hospital. The Jewish holidays were always a special time in our home as she recounted the stories of our faith tradition to our children and grandchildren. Rabbi Berman [chaplain] at her funeral captured the depth of her courage when he said, "in her weakness she resonated the strength of her faith and courage," as well, her love for family and their support were also a source of strength when her hope changed from cure to hope for spiritual healing; this helped to alleviate Elizabeth's 30 years of personal struggle and suffering. It was her courage that enabled me to sit by her bedside month after month; our focus was on making each day count and she was able to enjoy life almost to the end. I finally realized that my hope had gradually changed to hope that Elizabeth would experience a peaceful death surrounded by her family and friends; this became our reality, you [researcher] were there with us when she passed away peacefully.

A Daughter's Reflection: Our Mother's Care to End-of-Life

The following letter was written by the daughter of an elderly patient describing her care and sent to the CEO of the hospital approximately three months prior to her mother's death. *Ruth* describes the essence of spiritual care provided for patients on the palliative care unit.

> My mother, Mary is currently in Palliative Care. As a family we are quite pleased with the caring and supportive atmosphere in which she is spending her final days. We have found on the whole, the staff to be excellent and attentive.

> In particular, Elaine’s visits have become a highlight of Mom’s life. She comes regularly to just sit and chat with Mom as part of her daily check – she doesn’t change diapers or dispense medications, she just listens. Elaine addresses Mom’s need to still be seen as a person – not just a progressive disease. Elaine sees the integrity, beauty and dignity that we see in Mom, and she helps her make meaning of her life. Whether it is in exploring end-of-life issues or concerns, helping her with grief and loss, praying or just sitting and holding her hand on rough days, Elaine has been there for Mom. While we visit regularly, Elaine helps Mom deal with thoughts and feelings that we could never broach with her.
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> We were also particularly impressed that during our recent meeting with Mom’s Palliative Care Team, Elaine was included. My partner is a professional minister who has been involved in research on spiritual care in health systems and she thinks that your hospital is on the right path with their use of professional spiritual care providers. It truly re-enforces the belief that healing must incorporate the physical, mental, and spiritual self. While Mom isn’t going to get better physically – she will die in the next couple of months – Elaine has helped her heal her heart and mind at the end of a life full of challenges.

(Permission given by the patient’s family’s to use this letter in my research project)

A Shared Journey: Facing Death

What must it be like to wake up every day knowing that the disease within you will likely cause your death? The time of dying is a frightening time when pain and suffering are often the reality as the patient and his or her family’s experience encompasses numerous losses. By confiding in me and sharing their stories, some experienced a sense of healing; others realized the extent of their illness that resulted in suffering and despair.

Listening to the voices of patients, I realized a story is not just a story. In its most innate and proper sense, it is someone’s life. The people who participated in this study did so with the hope and expectation that the information they offered could serve as a key to unlock the knowledge, compassion, and commitment needed to develop a comprehensive model of “compassionate spiritual care in action” for people nearing the end life. Their truth must be spoken–you do not have to be alone in your experience of loss, suffering, dying, grief, and bereavement. For in our aloneness we are broken, and in our standing with others we cannot be broken, as is described in this story by Clarissa Pinkola Estes:

One Stick, Two Sticks: The Way of the Old African Kings[331]

> An old man is dying. He calls his people to his side. He gives a short, sturdy stick to each of his many offspring, wives and relatives. “Break the stick,” he instructs them. With some effort, they all snap their sticks in half.
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> “This is how it is when a soul is alone and without anyone. They can be easily broken.”
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> The old man next gives each of his kin another stick, and says, “This is how I would like you to live after I pass. Tie your sticks together in bundles of twos and threes.” He waits quietly as his family ties the sticks together. There are many bundles, some of two sticks, some of three sticks. “Now break the bundles in half.”
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> No one can break the sticks when there are two or more in a bundle. The old man smiles saying, “We are strong when we stand with another soul. When we are with others we cannot be broken.”

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[331] Kuhl, D. (2002). Quote by Clarissa Pinkola Estes (p. *xxvii*). In *What dying people want: Proclaiming wisdom for the end of life.* Toronto, ON: Doubleday Canada.

CHAPTER 7

RESEARCH FINDINGS:
DIMENSIONS OF LOSS, GRIEF AND BEREAVEMENT

Introduction: A Shared Journey on the Way to Healing and Hope

This section will present my research findings from an extensive literature search and research in the area of loss, grief, and bereavement. The themes presented relate directly to my observations and conversations as a hospital chaplain/researcher in the company of patients diagnosed with a terminal illness, their families at York Central Hospital, and in the community of Richmond Hill, Ontario. Additional information was gleaned from participants in the *Journey Through Grief Toward Healing and Hope Bereavement Support Groups* at Yorkminster Park Baptist Church, Toronto, Ontario.

There is a deep link between my personal experience of loss, grief, and bereavement and those who grieve the death of a loved one. As I listen to the pain of other people I also have to be able to acknowledge and listen to my own pain. Personal pain associated with the death of my husband, Al Brown, on October 24th, 2010; and to all that was broken hearted within my own being. Therefore, I needed to step back from the research project for a period of time to heal my inner spirit; this time frame covered approximately one year. The wounded image can only be restored and healed as we journey together with others. The world is not divided into those who grieve and those who care for them. We are all wounded, and we contain within our hearts that love which, when extended, is for the healing of those we meet as we journey on the pathway of life. What we cannot do alone, perhaps we can do together. God invites us to be cocreators with God and with each other as instruments of healing and hope.

While we do not yet have, and I'm certain that we never will totally possess, all the knowledge there is to know about loss, death, grief, and bereavement, I trust this research study will be an agent for change in how we care for the dying and their families. Our own personal and professional perspectives on dying, death and grief will probably change as we grow with each new loss we encounter. Loss, transition, and grief change us and create new opportunities to learn about life and living as well as dying and death. Perhaps through deepening of our human capacity to respond to each other in times of grief, we can continue to enrich each moment of our living.

This study did not include an in-depth discussion on of the general topics of death and religion. The focus of the content in this chapter is primarily on the psychological and social aspects of loss, grief, and bereavement. This is not meant to imply that the religious background of a person is not an important determinant in the experience of one's loss and grief. If, as professionals, we fail to acknowledge the influence of religious beliefs related to the expression and experience of grief, there is a chance of totally misunderstanding the persons who are entrusted to our care.

Without a doubt, a number of reasons exist why people often turn to faith leaders or clergy to help them with their impending loss and grief; it is my personal belief that patients and families want the interprofessional team who care for them to consider this special dimension of their personhood. Perhaps we need to remind ourselves that the capacity to provide care for those who are grieving with compassion is at the heart of caring for families in the face impending death and bereavement care following the death of a loved one.

The theoretical approach in my work with patients in the face of impending death and bereavement support for their families is gleaned from the professional wisdom of three renowned professionals in the field, Dr. Christina Puchalski, Dr. Alan Wolfelt, and Dr. Therese Rando. The insights gained while attending their in-depth training sessions has been incorporated into my private counseling and bereavement support groups that I offer in the community. One important lesson I have learned is that healing is heart-based, not head-based. As an ordained minister, hospital chaplain, and grief counselor, I have observed that healing is facilitated by three factors: (a) support offered by a knowledgeable caring and compassionate interprofessional palliative care team; (b) being open to the support of others, and (c) a variety of hospice palliative care services available within the hospital environment and in the community where the patient lives.

Introductory Definitions: Loss, Grief, Bereavement, and Mourning

Loss: Loss is defined as “the condition of being deprived of someone or something that one had.”[332] Losses can be actual, potential, physical, or symbolic. Losses associated with death and dying include loss of health and accompanying normal physiological functions, roles and relationships, and life itself, a dominant theme of patients in the study.

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[332] *The American Heritage Dictionary*. (1992). Englewood, CO: Houghton Miffin Company, 1063.

Thirty years ago Mitchell and Anderson[333] described six types of losses associated with loss, bereavement, and grief that were observed and identified as significant for participants in this study: (a) *Materialistic Loss*–material loss involves separation from a physical object or surroundings. (b) *Relational Loss* – in relationship loss, an individual no longer has the ability to relate to another individual. (c) *Intra-Psychic Loss* –impacts an individual's self-image through loss of what might have been, changed perceptions, lost emotions (i.e., faith, hope, or courage) or emotions that result when a major task has been completed successfully. (d) *Functional Loss* – occurs through bodily decline that is a result of deterioration from illness or aging. (e) *Role Loss*–results when an individual changes or loses (e.g., healthy person to terminally ill person) an established role or acquires a new role (e.g., patient). (f) *Systemic Loss*–involves the loss of contact with customary behaviors or functions within a system, such as absence from one's normal work or home environment.

Loss can be primary or secondary. *Primary loss* refers to the initial loss (whether of health for the patient or possibly loss of the patient through death for their significant others). *Secondary loss* results from the initial loss and is psychosocial in nature. For example, the patient as a result of his or her diagnosis of a terminal illness may also experience secondary losses of roles, job, income, and so on. Significant others may experience secondary losses of roles, income, and their own health and so forth. Primary and secondary losses were identified as a major source of suffering that encompassed the diagnosis of terminal illness.

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[333] Mitchell, K. R., & Anderson, H. (1983). *All our losses, all our griefs*. Philadelphia, PA: Westminster Press.

Participants in the study identified two general categories of loss: *physical loss* and *psychological loss*. An elderly gentleman on the palliative care unit gave an example of physical loss as he spoke about a tornado that swept through the town of Woodbridge destroying his home and car the day he was going home on a day pass: “I was devastated, this was just as painful as the doctor telling me I had cancer and I only had a short time to live.” A 55-year-old patient with end-stage renal failure described the devastating impact of having both legs amputated as a result of her deteriorating condition: “I wake up in the middle of the night and can feel pain in my lower legs and feet; I reach down and touch my knees, then suddenly realize there is nothing below my knees.” A young mother spoke about her diagnosis of cancer and the need to have her breasts surgically removed: “You can’t imagine the heart pain I feel when my husband turns his head away when he comes into the bedroom while I am getting dressed. I feel like a mutilated woman.” Often friends and family may recognize physical losses; however, they frequently fail to recognize the deep psychological pain and suffering underlying such losses.

Grief: Grief is defined as “deep mental anguish, such as that arising from bereavement.”[334] Rando describes grief as a normal reaction to the perception of loss. Grief is generally a transitory acute state in response to a loss, with the probability that the individual’s ability to function may be disrupted temporarily. In addition, the person may be disorientated, distracted, and/or distressed.[335] Working with patients in this study, I found that in order to help patients and families cope with their grief, it

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[334] *The American Heritage Dictionary*. (1992). 96.

[335] Mallinson, R. K. (1999). Grief work of HIV positive persons and survivors. *Nursing Clinics of North America, 34*(1), 163–177.

was important for them to gain insights into their grief experience and how it affects each person differently. In this way, they were able to understand their sometimes frightening and confusing experiences and identified what Rando classified as five important inferences of grief.[336]

1. Grief refers to a process and is experienced in each of three major ways: psychologically through a person's feelings, thoughts, and attitudes; socially through a person's behavior with others; and physically through bodily symptoms.
2. Grief is a continuing development, involving many changes over time. It will come and go and appear at different times.
3. Grief is a natural, expectable reaction. In fact, the absence of it is abnormal in most cases.
4. Grief is a reaction to all kinds of losses, not just death.
5. Grief is based upon one's unique, individualistic perception of loss. It is not necessary for one to have the loss recognized or validated by others for one to experience grief.

Anticipatory Grief: Anticipatory grief follows the awareness of impending loss. It is a mourning of something yet to come. As with normal grief, in anticipatory grief we become aware of promises to oneself or another that may never be kept, intentions that have no future, and anger at how someone has lived or not lived. Our dreams seem to crumble slowly into ashes, and we are powerless to stop them. Anticipatory grief is just as real as any other grief, and there is a need for spiritual care support. [337]

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[336] Rando, T.R. (1988). *How to go on living when someone you love dies*. Lexington, MA: Lexington Books, 11–12.

[337] Culbertson, P. (2000). 142.

Normal Grief: Grief is normal when individuals are able to acknowledge their loss and feel emotionally connected to and trusting of others.[338] It is normal if they feel that life holds meaning and are not consumed by anger; if they continue to have a sense of themselves and their own ability to function at work and home. For individuals grieving normally, sadness diminishes over time and they are capable of adjusting to new circumstances and gradually reinvest in life.[339]

Complicated Grief: Grief is considered complicated when individuals isolate themselves from others, have lost a sense of meaning, are consumed by anger, fail to invest in life and adjust to new circumstances. Complicated grief can also be called traumatic, dysfunctional, pathological, abnormal, or unresolved. Grief is considered complicated when the person is so disturbed that function is impaired at home or work or in other social roles. In general, when is complicated grief recognized? Complicated grief is diagnosed when symptoms have lasted for two or more months. Prigerson and Jacobs have described the symptoms of complicated grief that fall into two categories: (a) preoccupation with the deceased that impairs function; and (b) marked and persistent symptoms, including feelings of futility or loss of meaning, absence of emotional response, feeling dazed, difficulty acknowledging the death, self-destructive behaviors, and excessive bitterness or anger.[340]

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[338] Prigerson, H. G., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria and preliminary empirical test. In M. Strobe, R. Hannson, W. Strobe & H. Schut (Eds.). *Handbook of bereavement research: Consequences of coping and care.* Washington, DC: The American Psychological Association.

[339] Culbertson, P. (2000). 142.

[340] Prigerson, H.G., & Jacobs, S.C. (2001).

Disenfranchised Grief: Many deaths and other losses cannot be acknowledged or mourned openly, which creates serious difficulties for survivors.[341] To be enfranchised is to have rights and privileges. Disenfranchised grief occurs when people die and we cannot publicly declare our attachments; we have no public right to grieve. The relationship might have been an extramarital one, for example. Similarly, when nurses, physicians, and other members of the palliative care team lose patients, there is no place for us to mourn. Our grief is also disenfranchised. Other losses that often cannot be fully recognized are gay or lesbian relationships; families are often stigmatized by the relationship, and the surviving partners are not acknowledged or permitted to share in rituals of mourning or funeral services. Words spoken by John emphasize this reality: “I was told by Peter’s mother I was not allowed to attend visitation at the funeral home or the funeral mass. My heart is broken, we were so in love with each other; doesn’t anybody care about how I feel?”

In disenfranchised grief, an individual is likely to suppress his or her feelings rather than acknowledge them. When grief and mourning are denied, physical and emotional symptoms can persist and turn into complicated grief. Grief as the underlying cause of symptoms, however, is often not acknowledged by the bereaved or recognized by health care providers. When John came to the bereavement support group and shared his story, members of the group acknowledged his loss; together we planned a “lighting of candles” tribute of remembrance for Peter the following week.

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[341] Parkes, C.M. (1999). *Bereavement: Studies of grief in adult life*. Madison, WI: International Universities Press.

Members of the bereavement support group read selected Scripture passages, John gave a brief eulogy, and prayer was offered.

Bereavement: Bereavement is defined as “the condition of being left desolate or alone, especially by death.”[342] Rando describes bereavement as the state of having suffered a loss. McCall describes bereavement as the overall reaction to the loss of a close relationship and sees it as a description of various patterns, phrases, and/or states that an individual goes through when grieving.”[343] Mallinson depicts bereavement as the long-term process of the survivor’s accommodating his or her life without the loved one.[344]

The Three Phases of Grief and Mourning

“Grief is a circular staircase.” [345]

There have been numerous descriptions offered regarding the grief process. These I have observed throughout this study that describe experiences of dying patients diagnosed with terminal cancer, Parkinson’s disease, end-stage heart disease, or renal failure and frequently coping with amputations. Theories and descriptions have different names or focus on different topics; they all involve loss; they all cover the same basic feelings. Rando put forth the hypothesis that all of the responses fall into three broad categories, which essentially encompass three major phases of response: *avoidance, confrontation,* and *accommodation.* [346]

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[342] *The American Heritage Dictionary.* (1992). 175.

[343] McCall, J. B. (1999). *Grief education for caregivers of the elderly.* New York, NY: The Haworth Pastoral Press.

[344] Mallinson, R.K. (1999). 163–177.

[345] Pastan, L. (1978). *The five stages of grief.* New York, NY: W.W. Norton., 62.

[346] Rando, T. (1993). *Treatment of complicated mourning.* Champaign, IL: Research Press, 40–43.

Note that I am using the word *phase* and not the word *stage*. Previous work in the field has been misinterpreted implying that grief was an orderly, unchanging process, which gave the impression that all people grieved in the same way, progressing in only one direction. Throughout this study, observations confirm that many people share many aspects of grief; their responses are very personal and unique. Effective interdisciplinary spiritual care must take into account the specifics of the mourner's unique relationship with the deceased, the mourner's unique personality, and the unique expectations of the mourner's own culture related to death and dying. Participants in this study experienced three phases of grief.

The Avoidance Phase

In the avoidance phase, that period of time in which the news of the death is initially received, the person often wants to avoid the terrible acknowledgement that the person they loved is no longer living. Their world is shaken; the mourner often feels a sense of being overwhelmed. Similar to physical shock the human body experiences with trauma, the human psyche goes into shock when confronted with the death of a significant person in one's life. As recognition of what has happened starts to seep in and shock starts slowly wearing off, denial immediately surfaces in statements expressed by families such as:

> *Angela:* I can't believe it! Jacob was diagnosed with cancer less than a month ago. I can't believe it! I can't believe it! Jacob cannot be dead, he is only 44 years old and we are expecting our first child in two months; nurse you must be mistaken! Jacob, wake up!
>
> *Christopher:* Karen, open your eyes and talk to me! Oh, God, help me. I will not survive without her. Tomorrow will be our 40th wedding anniversary. [Reaching into his briefcase and taking out two plane tickets] We were to leave next week for our dream vacation in Hawaii. This must be a nightmare, our life together was so happy and we were both looking forward to spending many

> more years travelling. How I dread making the phone call to our children in England. They wanted to come to see their mother last week, I told them she was fine and we would go to England when we returned from Hawaii.
>
> *Colin:* Doctor, I trusted you to care for my wife, why did you let this happen to her? I told Mary to stop smoking or she would get lung cancer, she would not listen to me. I asked you to talk to her and tell her the risks and dangers of smoking; couldn't you have done something to make her give up such a filthy habit? How am I going to live my life without her?
>
> *Helen:* My daughter is only 16 years old, she had so many chemotherapy treatments and only least week you gave us the impression that she would be able to come home. I feel numb and wonder if there wasn't something more that could have been done? I will need to find courage and strength to tell her brothers that April is not coming home. I guess I better put on a strong front and call the funeral home to make arrangements for her service.

At this time, the person may feel disbelief and need to know why the death occurred. He or she may experience an outburst of emotion; on the other hand, he or she may quietly withdraw, act mechanically without feeling, and continue to feel confused and disorganized. Sometimes surviving family members initially appear to accept the death and then start to act responsibly, for example, comforting others and making necessary decisions. In most cases like this, the loss is recognized but the emotions of grief are consciously put aside as the grievers try to be strong for themselves and others.

The Confrontation Phase

This is a time when the person confronts the reality of his or her loss and gradually absorbs what it means. Each pang of grief, each stab of pain the mourner feels, whenever their desire or need to be with that person is unfulfilled; it brings home the reality that they are alone, their loved one is no longer with them. Frequently family members make comments, for example:

> *Heinz:* I told the bereavement support group, when I reach out in the middle of the night to touch Sherri, my hand touches only the sheets on the bed we shared for 30 years, I have this overwhelming sense of grief and being alone. I find myself weeping in the middle of the night. It has been over nine months since Sherri died, I at times think I'm a wimp because I don't like being alone.
>
> *Iris:* At times I feel so confused and frightened when I realize Bob is no longer alive and I will never see him again. Last month I went up to the Arctic as a member of a geological exploration team to study climate control. Late one night, standing on the deck of the boat looking at the moon and stars, I asked God, "Where is Bob? I need to know he is safe so I can begin to put my life back together. God, why are you so silent? This is all so confusing at times, I want to believe in you God–can't you give me some sign or message?
>
> *Liz:* Finally Gerald's pain and suffering is over. I couldn't have taken much more of helplessly watching him in pain, his suffering was unbearable for several months at home, and finally he agreed to go to emergency one evening. He was admitted to an acute care unit until there was a bed available in palliative care. He is now safe in God's keeping where there will be no more pain and suffering. My mother would be pleased to hear me say that since I doubted if there really was a God–she told me I should be a good Catholic girl and remember what I was taught in Sunday school. A friend of mine told me I should see a psychologist to deal with some of my thoughts and feelings, at times I feel so angry that Gerald died before he really had time to live.

Frequently there are times when people who are grieving find that their emotions and needs are in conflict with one another; likewise, their thoughts of how they should handle all the financial details that encompass the death of a loved one. It can be a very overwhelming, confusing, and frightening time in their lives. Their responses stem from having a loved one permanently taken away and from attempting to readjust to a new world without the presence of that significant person.

The Accommodation Phase

In the accommodation phase there is a gradual diminishing in the symptoms of acute grief. Slowly the bereaved are beginning emotional and social reentry into the everyday world. Their loss is not forgotten. Accommodation means that the mourner can integrate the past with the present and accept the new person that is emerging since the death of his or her loved one. He or she will never forget, but will not always be acutely bereaved. The loss is put in a special place that, while allowing it to be remembered, will also free the person to move forward to new attachments without being tied unhealthily to old ones. Members who attended the bereavement support groups in this research study exemplify this concept:

> *Wendell:* I surprised myself when I heard myself laughing. It has been such a long time since Marilyn told me she loved my corny jokes and the sound of my laughter when I was on stage and played the part of comedian and classical guitarist. I remember her attending my concerts and rolling her eyes at some of my jokes, and then we would laugh together. I will always remember the times we spent together, but it time for me to focus on my musical career–I am starting to find meaning in the things I do each day.
>
> *Sophie:* How can I be grieving one day and happy and laughing with the girls the next day? They say I should consider dating again. I must admit that I do enjoy talking to Dennis on the phone. Last week he suggested that we go out for dinner and see a movie so I accepted his invitation. At first I felt so guilty when I came home, then I remembered Peter telling me he wanted me to enjoy life and hoped that when I met someone and started dating that I would always remember him.

The Purpose of Grief and Mourning

Mourning, grief, and bereavement often are used interchangeably. Traditionally, mourning encompasses a sociocultural dimension and involves customs and rituals that are influenced by sociocultural and religious beliefs. The ultimate goal of grief and mourning is to take the person beyond the intense pain associated with the loss of a loved one. It requires working actively on adapting to loss. The therapeutic purpose of grief and mourning is to get the person to the point where he or she can live with the loss in a healthy manner, after having made the necessary changes to do so.

Dr. Christina Puchalski states that we grief affects the way we live our lives following the death of a loved one. We grieve not only for the person who has died but, to a large extent; we grieve for ourselves after the loss of someone we love. She states:

> We grieve for ourselves as people who have been left behind and who must now pick up the pieces of our lives, face the pain and loss, and rebuild our future. Grief is hard work. Sometimes it may feel as though the person who has died is the lucky one: They are now free from pain, but ours has just begun.
>
> We are each of us, companions on the journey through life. We can provide a safe place for others to mourn, help them explore their feelings, and simply be there. Our mere and magical presence is perhaps one of the most valuable gifts that we have to offer one another…. My guess is that you have come to work in end-of-life care issues because you have suffered the loss of someone significant and have survived and opened another door.[347]

The Purpose of Bereavement Support Groups

The purpose of the *Journey Through Grief Toward Healing and Hope Bereavement Support Groups* (part of this study) is to help participants recognize their loved one will never physically come back into their lives again; and support them to make the necessary internal (psychological) and external (social) changes to accommodate to this reality and begin to reinvest in life once more. *Journey Through Grief* is organized around the “six needs of mourning” (see chapter 8) that all mourners must yield to–and indeed embrace–if they are to go on to find continued meaning in life and living. I have followed Dr. Alan Wolfelt’s bereavement support group model. Participants are reminded that it is not only the physical and emotional but also the spiritual that needs to be explored in our

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[347] Puchalski, C. (2006). 334-335.

journeys through grief. The following reflections capture the essence or spirit of this group.

Reflection: The Significance of Church Based Bereavement Support Groups[348]

By Parish Nurse Heather Hetherington

In the spring of 2005, I found myself in the position of Parish Nurse serving in a multi-staffed, centrally located Toronto Baptist Church whose congregation numbered seven hundred members and five hundred adherents. Although a large percentage of congregants were aged sixty or older, a growing number of young professionals with children were actively involved, and the Church was becoming more ethnically diverse. I soon discovered that there seemed to be "pain in every pew" and one major area of concern was the physical, emotional and spiritual effect of loss and grief, experienced by many members at any one time.

The Health and Wellness Committee was blessed to have a Certified Grief Counselor as a member, in the person of the Rev. Elaine MacInnis, and they were thankful that she was willing to develop, initiate and lead a six week Bereavement Support Group *Journey Through Grief Toward Healing and Hope.* Reverend Elaine invited me to join her in co-facilitating this group. Although I felt somewhat hesitant and "untrained" for the task, I look back with gratitude, for little did I know how that initial group, and subsequent groups, would impact my own personal life; increase my knowledge of interventions that I could use to support others in their grief process; and also provide an opportunity for the Church to extend help to others in the broader community.

The format for all our Bereavement Support Groups was the same. The group met for two hours once a week for six weeks. Our venue was a warm and comfortable lounge in the Church and refreshments were provided at a "break time." Each group was small, ranging from eight to ten persons, although for one group, fourteen people were initially registered (registration was limited to ten people). Each participant received a binder for handouts that were given out weekly and each weekly meeting began with a meditation for working through grief[349] and the evening ended with a prayer.

As folks gathered on the first evening, they were usually very quiet and one could sense their stress, grief, and concerns in the atmosphere of the room. One of the most important goals of the leaders was to create a warm caring environment and a "safe place" where everyone would feel free to express their painful emotions of grief. A second goal was to foster trust amongst those

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[348] Hetherington, H. (2012). Parish Nurse, Yorkminster Park Baptist Church, Toronto, Ontario.

[349] Whitmore Hickman, M. (2002). *Healing after loss: Daily meditations for working through grief.* New York, NY: Harper.

present. To aid in achieving these goals, each person signed a covenant pledging confidentiality, respect for the beliefs and values of others, participation in discussion (although not beyond a personal level of comfort) and regular attendance.

Since I served as Parish Nurse and often knew information or had been involved in providing care to a family who were now grieving the loss of a loved one, I always asked permission of the group to be present, and was always accepted.

During the first two sessions, each participant was encouraged to share as much as they wished with the group, regarding their recent bereavement. Tears flowed freely and feelings were not "handled" but felt.

For me personally, I shared with the group the loss of our infant grand-daughter, who had died three months earlier, after only two and a half hours of life. Victoria Grace was a beautiful full-term baby, a second child for our eldest son and his wife, and to witness their incredible pain and grief, had engulfed our family. Perhaps it was only in this setting that I began to understand the principle, set forth by James Miller, that "only by giving your loss expression will you begin to heal." Focusing on my work had previously been my only way of dealing with my feelings of loss.

It appeared that around the third week of meeting, all members were comfortable with one another and began to say they were looking forward to the next week's meeting. Connections of understanding were beginning to form, as members felt more inclined to converse with each other and some reported making phone calls to each other during the week, or going for lunch after Church on Sunday. Loneliness and social isolation were gently being increasingly eased.

Over the years that the Bereavement Support Group has been offered, it has become obvious that this ministry has also reached out to many who have had no connection with the Church. On one occasion a woman who had just been walking by the Church, decided to come in and sit quietly in the Sanctuary. On her way out she noticed a pamphlet, publicizing the next Bereavement Support Group, she called me and asked if she could come or was it "just for Church members?" She was welcomed and shared that she had lost her only child, a daughter, in a car accident. She was overwhelmed by grief and help was also provided through counseling by Rev. Elaine on a one to one basis in addition to meeting in the group.

Coming to the bereavement support group following the death her dearest friend and roommate, was a result of Miss J's encounters with Rev. Elaine in the hospital setting. Miss J's friend had been a patient on the palliative care unit where Rev. Elaine served as chaplain. The hospital offered no ongoing bereavement support for families following the death of a loved one. Miss J, a well-educated woman with no family of her own and no link to any faith tradition, desperately sought spiritual help and comfort from the only person she felt she could talk to, Rev. Elaine. When she first joined the group she was the only "outsider" as she put it, but soon she felt she was among friends. Experiencing a fall, Miss J fractured her ankle and soon found that other members in the group were concerned for her.

Handouts of the sessions she had missed, homemade soup, offers of transportation to appointments and plenty of phone calls, just to keep in touch, were offered and accepted. Later in the year, when my own Mother died, Miss J came, walking with difficulty to the Funeral home to offer her support to me. Another lesson in dealing with loss was learned. As James Miller writes, "in allowing other to help you, you help everyone: them and you."

However a "once a year" Bereavement Support Group left a gap for support when perhaps it was most needed – the Christmas season. It was suggested that a Service of Comfort and Hope be held the third Saturday of December, at 11:30 a.m. followed by a lunch provided by the members of the Health and Wellness Committee. The Service, held in the Chapel of the Church, uses prayer, Scripture and includes a short homily, offered by the Minister of Pastoral Care or Rev. Elaine MacInnis. During the time we gather for lunch, Rev. Elaine offers strategies to those present to help them cope during the Christmas season, a time that is especially tender and difficult. This Service has become a meaningful part of the Advent season to many outside our faith community who have joined with us after seeing our printed information on the web or noticed an announcement on our digital signage outside the Church. As numbers at the Service of Comfort and Hope increase yearly, the need to provide spiritual care to those suffering loss and grief underscores the continuing need and opportunity for ministry to reach beyond the walls of our church.

Co-facilitating the Bereavement Support Groups has been an ongoing sacred privilege but it assumed a special poignancy for me when Rev. Elaine MacInnis suffered the loss of her husband, Al. She had offered wisdom and compassionate care to the grieving in our congregation; it was now our turn to come alongside her. Faith, family and friends are the underpinnings that provide support as one begins the journey through grief; this we were taught by Rev. Elaine, a ministry that reaches out in the name of "The Lord Yahweh who wipes away the tears from every cheek" *(Is. 25-1).* With the support of one's own family (for some that may only be the "Church" family) and the strengthening support that stems from friendship, the *Journey Through Grief Bereavement Support Group* leads to *healing* and *hope*.

Case Study: A Family's Experience of Facing Death and Finding Hope

So far I have discussed the theoretical underpinnings and planning required providing quality end-of-life spiritual care and bereavement support for families following the deaths of loved ones. How can one put these concepts into practice? Perhaps an actual case study will exemplify the effectiveness of narrative, myth, and rituals and their importance in family relationships. The following case study is a segment of my spiritual care for *Lois*, a retired sergeant in the Canadian Armed Forces.

> When I asked Lois what she considered a significant moment in her life, she smiled, pointing to a photograph of herself in uniform saying: "Ah, the day I joined the Air Force." Over the course of her time in hospital we shared many stories of her life in the military. Here is an account of her final days.
>
> On Maundy Thursday, just before Easter I asked Lois if she would like to receive Holy Communion. She indicated that she would like to wait until her sister Joyce and Bruce arrived home from Florida with their children to be with her and share communion with them at her bedside.
>
> On Good Friday, when I visited Lois, a gentleman had brought flowers wrapped in florist paper. Being of a curious nature, I asked if she would like me to remove the paper. Inside was a beautiful Easter lily–the symbol of new life and hope beyond this life here on earth.
>
> On Holy Saturday, I celebrated with Lois and her family the Lord's Supper with the symbolic bread and wine–a representation of God's love and the promise of eternal life for those who believe. I sensed Lois knew this was the beginning of her journey into the mystery of her new life to come.
>
> Later in the day, Lois told me she would die on Easter Sunday evening–she felt the timing would symbolize for the family her faith and belief in life after death. The hospital called me at 6:30 p.m. with the message that Lois had died peacefully in her sleep. I could not help thinking that perhaps Lois had willed herself to die on one of the most sacred of days in the Christian faith tradition.
>
> Lois loved her family, especially her nieces and nephew. She had taken time to teach each child about butterflies. Lois had requested that I read the following story at her funeral service.

The Greek word for *soul* is *psyche*, and is often symbolized as a butterfly. In her book *Hope for the Flowers*, Trina Paulus tells the story of how two caterpillars named Stripe and Yellow were transformed into butterflies. Yellow had seen another caterpillar spinning a cocoon and asked, "If I decide to become a butterfly what do I need to do?" "Watch me, came the reply, I am making a cocoon. It may look like I am hiding, I know, but a cocoon is no escape. It is an in-between house where change will take place …. During the change, it will seem that nothing is happening but the butterfly is already in the process of becoming. It just takes time." Yellow had been afraid when Stripe left her to climb to the tree branches and began to spin the chrysalis to become a butterfly, but she took the risk and spun her own cocoon, later to emerge and unfold her wings as a beautiful butterfly.

At that time in Lois's service I told those attending of the time I came upon a poster hanging in an art shop. On it was a golden butterfly, its wings spread against a blaze of blue sky. "Your soul is your greatest work of art," the caption read. As I looked more closely, however, I noticed in the bottom left hand corner of the poster the husk of an empty cocoon, a reminder that the brightly colored wings and works of art don't just happen. They require the courage to let go and spin the chrysalis.

In a conversation with Lois, when talking about butterflies, she made this comment: "We are born to live for a certain period of time, then at the end of our days here on earth, we will be born into a new life." Somewhere in our musings, Lois made a comment about the symbol of her life as living in a cocoon where she is incubating and is gradually being transformed until she emerges into her new life at the time of her death. During this time together, Lois requested that following her funeral service and dinner reception when we went to the cemetery I was to give the following message to her nieces and nephews:

"I (Aunt Lois) planned that each person who goes to Park Lawn Cemetery be given a Monarch butterfly–the symbol for soul–I want you to release it into the air to symbolize my faith and belief that my soul has returned to God, our Creator and Redeemer."

At the cemetery, as part of the committal service, each person was handed a tiny white box with a picture of a butterfly on the top, inside, a Monarch butterfly. I was given a signal, and we released the butterflies just as the *"Snow Birds"* flew past the gravesite. As one nephew said, pointing to the vapor trail coming from the planes, "Aunt Lois's soul is soaring toward God, just like the vapor trail coming from the planes she flew in the military."

I have chosen Lois's case study because it clearly demonstrates the importance of quality care to end of life that supports a "peaceful death." When cure was no longer anticipated, healing and hope became viable alternatives. Lois died peacefully with a sense of hope, surrounded by a loving family who were sad, but comforted by her inner peace linked to her Christian faith.

A Chaplain's Personal Reflections:
A Journey Into the Valley of the Shadow of Death Leading to Hope and Healing

When I began this research project, I never considered many of the experiences research participants shared with me would become a personal reality three years following my marriage to Al on a beautiful summer day in Nova Scotia.

Accompanying my husband on a business trip to Victoria, British Columbia late in July 2010, I took along some journal articles to read while Al was working during the day. Sitting on the deck of our suite at Laurel Point Inn overlooking the harbor, watching sea planes landing on the water and taking off, I had time to stop and reflect on my personal and professional life. While reading an article, *Heuristic Research: A Review and Critique of Moustakas's Method* [350] by Sandy Sela-Smith, I gained new insight and understanding into how the death of several significant family members impacted my life and worldview that influenced my calling to Ministry in Health Care as well as my passion for providing spiritual care for families experiencing loss, grief, and bereavement.

Sela-Smith critiqued Moustakas's heuristic process, linking it to what Polanyi referred to as tacit knowledge, which is deeply imbedded knowledge not normally available to conscious awareness. She proposes that the interiority of our experience, where feelings, which may previously not have been noticed as significant, are not just the core component of the terrain but the dominant one despite the profound efforts of the intellect to alter this reality. Sela-Smith refers to the interiority of self-reference in all

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[350] Sela-Smith, S. (2002). Heuristic research: A review and critique of Moustakas's method. *Journal of Humanistic Psychology*, *42*, 53, 82–111.

understanding that is expressed within the unseen connective tissue that flows in and between people that is frequently discovered in *dream work*. She refers to this interior experience as *"the final frontier"* that may create images of climbing to the heights of rugged mountain peaks that requires setting aside the skills of controlled, objective observation, surrendering to embrace subjective experience, and leaping into the unknown. My experience of the last frontier and leap into the unknown can be best explained by relating it to a personal experience that occurred less than two weeks after reading Sela-Smith's article.

When I began this research project, little did I realize that research participants diagnosed with a life-limiting or terminal diagnosis and facing impending death as well as families who shared their experiences and feelings from the depths of their hearts would become a personal reality in our life less than three years following my marriage to Al on a beautiful summer day in Nova Scotia. Briefly I will attempt to describe the two weeks prior to receiving devastating news that changed our lives.

On Friday evening at the end of Al's two-week business trip to Victoria, British Columbia, we travelled to Vancouver for the weekend, staying at Inn on the Quay overlooking the Fraser River. On Saturday we were invited to Al's son Ian and his wife Becky's home for a salmon BBQ with the Brown extended family connections. Shortly following our arrival at their home around two o'clock, Al disclosed he was not feeling well and went back to Inn for a rest and would return around six o'clock. During conversations around the dinner table I noticed Al was particularly quiet and ate only a small portion of his meal; this was unusual since he always complimented Ian on his expertise of preparing and cooking Pacific salmon (one of Al's favorite meals). However, I did observe the pride of a grandfather for his twin grandsons, Nick and Jeremy and granddaughter Kasanna as they told him about their school activities, adventures with friends, how much they enjoyed coming to Nova Scotia to Grandpa Al and Elaine's wedding, and recounted their explorations while vacationing on the east coast.

The next day, as we were about to leave for the airport, my husband indicated he was feeling ill and experiencing abdominal pain; when we arrived at the airport in Toronto, I suggested we go to the hospital emergency clinic immediately. Al declined my suggestion, stating that once he was home in his own bed that would make a difference in the way he felt. In less than an hour Al asked me to take him to the hospital; after initial assessments Al was given morphine for his increasing level of pain; he was admitted as an in-patient and would spend the night in emergency until a bed became available the next day. The doctor suggested I go home and come back around noon. I reluctantly left the emergency department around two o'clock in the morning. I was exhausted emotionally and physically when I finally went to bed. I had a dream that embodied what Sela-Smith refers to as *"the final frontier."* Taking into account profound insights discovered in dream work set forth in Sandy Sela-Smith's article, it took over two years for me to find the courage to speak and write about a dream that was a forerunner to our journey into the valley where together we experienced heartbreaking loss, grief, and bereavement.

I had *a dream*; in the dream Al and I had travelled once again to the Grand Canyon. As we stood overlooking breathtaking scenery, dark clouds began to cover the beauty of the terrain below; suddenly the tour guide asked us to return to the bus that would take us to the airport for our flight back to Las Vegas. On the trip back we experienced a great deal of turbulence linked to an unexpected thunderstorm. We returned to our hotel, had an exquisite dinner, and then went to bed. During the night I turned on the light and saw Al with his hands folded on his chest; he was not breathing; I touched his hands and they were cold, suddenly I realized Al had died in his sleep. I felt a deep, stabbing pain in my heart and tears tumbled down my cheeks; my heart was breaking. The thought of Al dying was overwhelming; I woke in a panic, too frightened to cry, and felt totally alone. Less than six hours after what I describe as a nightmare experience, the dream became the forerunner to reality where our world as husband and wife changed dramatically as we were about to leap into the unknown–a journey in the valley of the shadow of death. I was so disturbed by the dream and felt I could not share my thoughts and feelings, holding them deep within my heart.

When I returned to the hospital around noon, Al was not in his room. I looked at a piece of paper on the night table and stared in shock and disbelief when I saw a sketched drawing of a pancreas with the doctor's notes stating his diagnosis and possible treatment plan. I discovered that Al was diagnosed with stage four pancreatic cancer less than 24 hours following his admission to hospital on August 2, 2010. He was given the "bad news" *alone* in his hospital room, then immediately taken to the operating room for a medical procedure. Immediately I went to the nursing station; there was no one who would answer my questions at that time. The nurses told me I would have to wait and speak to the doctor; I felt so isolated and alone. If only there had been someone present with us who could answer our questions when Al returned to his room. We held each other, unable to find words to express our feelings; we were in a state of shock and disbelief at the events that were suddenly unfolding in our life. During the succeeding 12 weeks we were *never offered* emotional or spiritual care support within the health care system.

Our life together as a family had taken a surprising, difficult turn; my external observable world that I shared with my soul mate and best friend changed dramatically as we embarked on a shared journey living in the valley of the shadow of death and the unknown. I entered unfamiliar terrain where I had to set aside my skills of controlled, objective observation linked to my role of ordained minister working in health care as a professional hospital chaplain/researcher and surrender my professional responsibility to embrace the subjective experience as a wife living in the face of her husband's impending death. Immediately I felt the need to put on a brave façade in order to support my husband. However, the influence of Sela-Smith's *heuristic self-search inquiry* brought to light the need to transform my early childhood conditioning around repressing tears and feelings that surrounded the untimely deaths of my mother Lillian at age 44 following a four-month battle with cancer; my cousin Dana MacInnis who was killed in an automobile accident at 16 years of age a few weeks after earning his driver's license; and my father Edmund's death in his early 60s. The time had come for me to hold up the mirror and acknowledge my resistance in reconnecting to the I-*who-feels.* Finally, I reached a point of acceptance and surrendered to my feelings that led to an inner transformation enabling me to enter into open, honest communication with my husband that was part of our relationship from the time we first met. Together, we were able to safely acknowledge our feelings of deep pain and heartbreak as we began the journey into uncharted territory.

Undoubtedly one of the most difficult moments surrounding Al’s illness came when he personally conveyed his diagnosis/prognosis to his sons in person. When Al returned home from the hospital, he booked a flight for Ian to come to Toronto, then called Jay and Will to come to our home to reveal news that would be devastating for them to hear. Al asked me to be in the living room with him, indicating that my presence would give him strength to break the “bad news.” To this day, I vividly remember the overwhelming pain I felt and witnessed among a loving father with his sons when Al told them the cancer had metastasized and his prognosis was less than three months to live; I felt my heart was breaking as I tried to hold back tears. The reality of what was happening so quickly was frightening; our observable world was changing rapidly and dramatically with the realization that the cancer had spread to vital organs; the fact that there was no cure was overwhelming; the goals of care changed from treatment options to comfort measures only to help alleviate pain and suffering. Once the boys were told the reality of his illness, Al spoke to his brothers and sisters to update them on the events that had unfolded.

When I asked Al what gave him the courage to meet the challenges of each new day, he immediately replied, “Three ‘*F’ factors–Family, Friends, and Faith*.” These three dimensions of relationship brought meaning into our days of journeying to the “final farewell.” It was the quality of our family’s and friends’ touch, their gaze, and their presence that communicated to us the heart of God: “I am with you.” Their care and compassion enabled us to create times where we could truly live in the face of impending death.

The *“Family Factor”* was exceptional–remarkable! Al’s sisters were a comforting presence over the 12 weeks both at home and in the hospital. Mary Ellen traveled from Owen Sound; she immediately moved in and took care of our household needs, preparing meals, taking us to medical appointments, and made sure I kept our monthly financial commitments up to date (in spite of my protests I did not want to learn how to use on-line banking–today I am thankful for her persistence!). Eleanor (Ellie), who lives in Whitby, would go to the hospital in the evening after visiting hours ended and stay with Al late into the evening. At his funeral service, prior to reading Scripture, she told us, “I would read to Al selected passages from The Holy Bible, the stack of magazines so neatly stacked by the window, Trains Magazine, The Economist, Scientific American, Time Magazine, and my new “fav” (favorite) Elevator World.” (Sounds of laughter could be heard in the church from the large number of people representing the elevator industry in Canada and the United States who had come to know Al over his 46 years as an Electrical Engineer). Elaine, a registered nurse who lives in Orangeville and works at Headwaters Hospital, was able to get compassionate care leave and kept watch during the overnight shifts in order to ensure her brother received quality nursing care. Ken, Al’s brother, who is the present owner of the Brown family pharmacy in Walkerton, brought cases of nutritional supplement drinks, medical appliances for safety in the shower, and other related health care needs to our home. Gord, the professional chef in the family, who lives in Hanover, prepared meals and drove to Toronto on several occasions to fill up our freezer.

On Thanksgiving Sunday, I asked Al if there was anything on his “wish list” that he would like to have fulfilled in the next few weeks. His answer was twofold: to see Mary

Ellen and Bill's new home on Georgian Bay and return one more time to the Brown family cottage, now transformed into Gord and Laura's home on Lake Rosalind in Bruce County near the town of Walkerton, where the Brown family lived during the summer months. Al's wish became a reality when behind-the- scene-plans were put into action; his cousin Bill and his wife Kim arrived at Tamarack Circle with their motor home, and we travelled up to Georgian Bay amidst the beauty of God's creation and the fall foliage of vibrant colors. It was a trip down memory lane; on Sunday we went to "the cottage," where Gord prepared an exquisite family dinner. Before dinner Al was able to walk down to the dock and get into Gord's boat for a trip around the lake; the stories of adventures of the young Brown boys at the family cottage brought laughter and tears. The significance of "life reviews" affirmed the value of family and family support that enhanced our life in the face of impending death. Al was admitted to hospital two days following our family weekend and never returned home.

The *"Friends Factor"* was a significant component in our relationship during the 10 years I had known Al, particularly during the last three months of his life and the 2 ½ years since his death. Al's friends from Waterloo Engineering days, colleagues at KONE and various elevator companies in Canada and the United States travelled to Toronto to spend time with Al in the hospital and at home. Their many expressions of love and support validated the depth of friendship they shared over the years. As I mentioned earlier, we were *never offered* emotional or spiritual care support during Al's hospital admissions. However, three friends and colleagues who are ordained ministers and professional chaplains exemplified in their continual presence the importance of Christian love and support that has continued to this day. As I write this reflection on the journey through the valley of the shadow toward the light of healing and hope, there is a convincing awareness that families need others on the pathway of life in times like this as we move into the future without the physical presence of our loved ones.

The *"Faith Factor"* was a central component in our life together as husband and wife that gave us hope in the face of impending death. Following our wedding, Al made the decision to become a member of Yorkminster Park Baptist Church. He became actively involved in a project that had been on hold for a few years; Dave King needed someone with an electrical engineering background to work with him to get the webcasting of worship services up and operational. Together they worked on the project, which was ready to launch shortly before Al's death; they did test runs so Al could watch the Sunday morning services at home or in the hospital–this became a sacred hour as we were able to worship from a distance with the congregation. The ministry team came to our home and the hospital weekly for prayers and spiritual care support; we were truly blessed to be part of such a caring and compassionate church family. Paradoxically, Al's funeral service was the first live webcast from Yorkminster Park watched by professional colleagues, family, and friends in various countries around the world. Al's faith was reflected in the choice of Scripture readings, hymns, and in the sermon where Rev. Dr. Peter Holmes described him as a "man of great faith" who exemplified his love for God daily in both his personal and professional life. Referring to the Gospel of John, chapter 14 and Psalm 23 he said: "Al knew he was dying and he believed, he believed that the Good Shepherd would come and take him to his heavenly home where there would be no more pain and suffering."

Faith–Family–Friends and "The Final Farewell." Al died surrounded by his family and our mutual friends, Scott Graney and Liz Siydock (a Social Worker and Child Life Specialist I worked with at St. Joseph's Health Centre). In her eulogy *Liz* described our final farewell*:*

> Scott called me at home to say Al didn't have much time left. When I arrived at the hospital Elaine asked the family if we could have some time alone. Elaine told Al, "Lizzy's here, you know, Lizzy with the crazy colored hair." Al was in and out of consciousness as we shared stories, we laughed and cried together. I want to share with you the most beautiful expression of love I have ever witnessed. Elaine stood up, took Al's hand and kissed him on the forehead; she then began to pray speaking of the many rooms in God's house and how one is prepared for us. Elaine then paused and shared these words with Al: "I said to the man who stood at the gate of the year, 'Give me a light that I may tread safely into the unknown.' And he replied, 'Go into the darkness and put your hand into the hand of God. That shall be to you better than light and safer than the known way!' " Elaine kissed Al again saying: "Al, my love, when you are ready, put your hand into God's hand, I am ready to let you go now into God's safekeeping." Al quietly took his last breath–his death was the most peaceful death I have ever had the privilege to witness in all my years working in health care.

Today, before I wrote this reflection I watched the video of Al's memorial service and precious memories of the many ways our family, friends, and family of faith at Yorkminster Park Baptist Church supported the Brown–MacInnis family. My children John and Marina, and twin sister Elizabeth and husband Hans who live in Nova Scotia, my brother Ed, living in Ottawa, were a comforting presence in the week prior to Al's death and during visitations at the funeral home, church service, and reception. As well, my nephew Marc Purcell and his partner Ann Barker were once again by my side two weeks later for Al's graveside service in Orangeville.

In order for healing to take place we need to have companions on the journey to walk with us along the road toward healing. On my journey through grief, embracing

Wolfelt's *Needs of Mourning* [351] I see where I have been and where I am today. I am now beginning to live again not forgetting the treasured past we shared together.

"To live…to love…to learn…to leave a legacy…" This mission statement written by Stephen Covey could easily have been written by my husband Al Brown–this was his philosophy for a life well lived. In May of 2011, KONE moved to a new location in Mississauga and honored Al's life and work as an Electrical Engineer with the company he loved and served with great passion for 46 years. They designed *The Al Brown Training Centre* and offer the *Annual Al Brown Award for Technical Excellence* to an outstanding employee in Al's memory. This was communicated to Al in September while in hospital. In my thank you to KONE at their opening ceremonies, I shared these words:

> Little did I know when I met Al in 2000 that he would leave such a legacy for those left behind following his death. Reflecting on all the e-mails, phone calls, and visitors he received from the time of his diagnosis with cancer last August until his death on October 24th 2010, speak to the tremendous influence he had on so many people.
>
> Less tangible is the legacy of the lives Al touched or empowered. He helped so many people to conquer our fears, believe in ourselves, and to accomplish things in our lives we never thought possible.
>
> A note I recently received from a professional engineer and colleague compared his friend Al to a pebble skipping across the water on a lake–the ripples and waves keep on spreading outward.
>
> Al taught us all *"To live…to love…to learn…to leave a legacy…"* in both our personal and professional lives. His memory and the values he exemplified will live on in the lives of those who knew him and help KONE to become a leading force in the industry.

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[351] Wolfelt, A. (1997). *The journey through grief: Reflections on healing.* Fort Collins, CO: Companion Press.

CHAPTER 8

OVERVIEW: RESEARCH IN MINISTRY PROJECT DISSERTATION

> Who is there in all the world who listens to us? Here I am, this is me in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can't express, my terror, my abandonment. Oh, listen to me for a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. Oh God, is there no one to listen? [352]

Introduction

I believe that at the very heart or essence of one's professional practice in health care as members of the palliative care team is their encounter with suffering. The interprofessional team will need to be prepared to respond with spiritual sensitivity to patients and their families living each day in the face of impending death. This chapter connects suffering and spirituality, identifies sources of suffering, and acknowledges specific interventions patients, their families, and professional caregivers say can be implemented into their goals of care to alleviate or diminish suffering.

It is in ordinary, everyday life that our encounters with suffering and spirituality often become extraordinary experiences. So, what constitutes and characterizes suffering? What are the underlying causes of suffering? Is it possible to alleviate or diminish suffering? To understand the complexities and the many possible and varied answers to these questions, I have included in the following sections a summary of themes from interviews with patients diagnosed with a terminal illness facing impending death, their families, and professional caregivers. As well, I include my observations of their various experiences in both the hospital setting and the community where they live that have provided insights into their experiences of pain and suffering.

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[352] Saunders, C.M. (1988). 29–32.

Unavoidable Suffering: Losses Related to Disease Progression

Terminal patients require a compassionate caring presence, particularly in light of the losses they continually encounter in the dying process. Dying patients say they often experience dying gradually through a series of losses, and they feel each loss acutely. Therefore, it is important for the interprofessional team to be sensitive to the unique experience of each individual and his or her family. The following themes emerged as a summary of the “small deaths” patients in this study identified:

- Loss of health
- Loss of career or vocation
- Loss of identity roles
- Loss of financial security
- Loss of personal self-care abilities
- Loss of intimacy
- Loss of independence
- Loss of dignity and self-worth
- Loss of significant relationships
- Loss of a future
- Loss of cognitive competencies

Unnecessary and Preventable Suffering: When Family Conflict Issues Erupt

The effects of family conflict in the context of impending death can be immensely challenging and potentially devastating, particularly when patients become too sick to communicate their wishes in the decision-making process related to their care. Family responses and the potential for family conflict to erupt were observed when one or more of the following five issues emerged:

- Perceptions that some family members are not contributing to caregiving efforts.
- Aspects of patient care for pain and symptom management are not communicated, understood, or been approved by either the patient or his/her family members.
- Conflicting patient and family religious views (i.e., rituals or sacrament of the sick).
- Patient or family disagreements or denial about the magnitude of the diagnosis.
- Historical (past) patient and family conflicts that are long-standing and magnified by the present situation.

Throughout this study, as a researcher I observed that the interprofessional team became increasingly distressed when they witnessed conflict among family members and patients that resulted in suffering. Several nurses stated, “It is the patient who pays the greatest price for family conflict at the end of life.”

Unnecessary and Preventable Suffering: Iatrogenic Suffering

Iatrogenic suffering refers to the unintended pain, suffering, or adverse conditions that result from an activity or interaction of the physician or other members of the health care team. Some interactions of the interprofessional team identified by patients or family members as a source of their suffering are:

- Continuing aggressive treatments beyond the point where there is hope for a cure.
- Avoiding eye contact; seeing only parts of the patient, not the whole person.

- Would not come into the room, stood by the door, told me the “bad news” of my diagnosis, then quickly left without giving me the opportunity to voice my concerns or ask questions.
- Doubting the reality of the patient’s pain and failure to provide medication for effective pain and symptom management.
- Was not interested in me as a person, treated me like I was just another dying patient.
- Short or superficial contact; abrupt verbal statements indicating that the health care professional is “too busy to talk or listen.”
- Speaking in a tone of voice or manner that belittles, degrades, demeans, humiliates, or shames the patient or family members.
- Touching patients in ways the or she perceive as “cold” or “rough”; “doing things” without prior explanations regarding regular nursing tasks or medications prescribed.

Unanticipated Suffering: Caregiver Burden and Anxiety

Family caregivers were often unprepared for the time when a family member entered the end stage of living that required acute levels of care. The large number of stressors that surfaced became all-consuming for the caregivers and frequently resulted in:

- A weakening of significant personal relationships due to lack of time to nurture the relationship in ways that give meaning and purpose to one’s life.
- Restrictions of involvement in healthy activities that were in the past personally rewarding and significant.
- Loss of professional identity, or career limitations that resulted in a lack of promotions as a result of family obligations or restrictions.

- Financial obligations and added responsibility of maintaining a home without dual incomes and someone to help share the workload.
- Juggling or shifting roles within the home to maintain daily routines or responsibilities.
- Caring for a loved one in hospital while observing other family members continuing their regular routines.

This increased pressure combined with observing a loved one's suffering often produced feelings of helplessness, frustration, confusion, anger and soaring anxiety as a result of caregiver burden.

Patient Barriers to Accepting Pain Relief: The Result: Silently Enduring Suffering

Few things are of more concern to patients at end of life and to their families than their desire that pain and symptoms will be well managed. This study identified barriers patients themselves constructed as justifications for not accepting pain relief that resulted in their silently enduring suffering:

- Perceptions that reporting pain could be considered whining or complaining, resulting in their decision to be a "good patient" and not report the full extent of their pain.
- A reluctance to report pain out of their fear that pain is a sign the disease is worsening.
- A belief that pain is an inevitable part of a terminal diagnosis and must be tolerated.
- A concern about treatment side effects, resulting in their reluctance to follow treatments as recommended by their physician.
- A fear of addiction, or worry about opioids side effects, resulting in their hesitation

to take medication.

- A perceived expectation that the patient must be stoic and accept one's suffering.

Physician Barriers to Offering Pain Relief: The Result: Patient's Suffer

Under treatment of pain at the end of life is a thought-provoking health care problem, caused in part by its subjectivity and in part by medical professionals' unstated beliefs or concerns. Despite a solid body of evidence regarding the possibilities of effective pain relief, there has been little improvement over the past 30 years to alleviate pain associated with terminal illness.[353] This study identified physician and/or clinician barriers to offering effectual pain relief that include:

- An assumption that terminal pain is inevitable.
- A failure of clinicians to evaluate or appreciate the severity of a patient's pain and symptoms or associated problems.
- A lack of knowledge about the philosophy and principles of palliative care and misconceptions about palliation as an opportunity for reducing pain at end of life.
- A fear by many physicians and nurses that they will cause of addictions or suppress respiration.
- A tendency to doubt of the reality of the patients' claim they are in pain and suffering.

Spiritual Issues and Concerns That Result in Suffering

As the person diagnosed with a terminal illness faces impending death, numerous themes related to spiritual issues and concerns surfaced once a relationship of trust was

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[353] Pasero, C., & McCaffery, M. (2004). Comfort-function goals. *American Journal of Nursing*, *104* (9), 77–8l.

established with me as a researcher. In the process of taking a spiritual history and an assessment of spiritual needs, the dying patients, as well as their families described their experiences: what they have been experiencing emotionally, socially, or spiritually (illness narratives). Spiritual issues and concerns identified by participants in this study:

- Abandonment by God and/or significant others
- Abandonment by the health care system
- Anger at God or others
- Despair
- Fear of not being remembered
- Feeling frustrated and/or out of control
- Need to forgive, and to receive forgiveness from God and others
- Guilt and shame
- Hopelessness
- Loneliness
- Loss of meaning and purpose
- Need for reconciliation
- Spiritual pain and suffering
- Uncertainty about the future

What Patients' Say They Want Health Care Professionals to Know

Typical of my interaction as a researcher with patients and families in this study was the final interview question. Participants were invited to share what they believe health care professionals need to know in order to improve the quality of care to the end of life. *Michael's* response in a taped interview echoes the voices of participants in this study:

> Well, this is not the end yet; there are still some things I can recommend that will help to alleviate patients' suffering. I want to emphasize the importance of being able to participate in activities. I'm one of the lucky ones, most of the patients here on the palliative care unit are too sick to go over to the activity room, they tell me they feel forgotten, abandoned, and alone with nothing to do but stare at the ceiling or watch television. Douglas [patient sharing his room] said he would like someone with professional training to talk with him about religion, you know–those faith things that are causing him to become so emotional and tie into his fear of dying. I am referring to the spiritual stuff you hear people talking about on this unit. [Pause]
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> What we need is staff to have more education and training about how to care for patients who are palliative [pause] such as ways to communicate honestly with us, how to take time to really listen to patients who are in pain instead of quickly giving medications that may relieve their physical pain but not the "real problem" such as underlying emotional, social, and spiritual pain and suffering. I think if you have just three words to get your message across, tell them that *respect, empathy, and compassion are essential in care of the dying.*
>
> Tell them to take time to sit down and listen, find out who I really am as a person and not just someone with the diagnosis of a terminal illness; find out what is really important to me, what my needs are, what my hopes and fears are [pause as he puts his head into his hands and wipes tears from his eyes]. Help me work through my fears. I want to know what to expect as the end comes near, right? I want to know that the palliative care team will be there with me and not abandon me like my son. I want to hear that my life is important and that I will be remembered. I keep repeating to myself the words above the entrance to the Palliative Care Unit:
>
> *"Listen to me…Care for me…Comfort me…Remember me.."*

A significant ongoing message from patients and families throughout this study was brought forward by Geist-Martin et al.[354] They identified the need for education of physicians, staff, and administration regarding the philosophy of palliative care, with a major emphasis on spiritual care and its implementation into daily clinical practice in the care of patients diagnosed with a life-threatening illness and their families.

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[354] Geist-Martin, P., Ray, E.B., & Scarf, B.F. (2003). *Communicating health: Personal, cultural, and political complexities.* Belmont, CA: Thompson-Wadsworth.

Nurses' Caring Interactions That Help Alleviate or Diminish Suffering

Patients in this study spoke about the caring interactions of the nurses. In their stories, they were describing what Martin Buber refers to as *I-Thou* relationships that involve a real encounter with genuine presence and availability.[355] The following formulated meanings of statements by patients in this study reflect themes of caring interactions patients identified that helped to alleviate or diminish suffering:

- Their ability to help a patient feel valued as a person worthy of respect.
- Their ability to truly listen to patients' issues/concerns and respond with genuine empathy and /or compassion.
- Their soft gentle voice explaining in a compassionate and comforting tone what they are about to do to make the patient feel more comfortable (i.e. daily nursing tasks or unanticipated care requirements).
- Their insights and skill for recognizing and responding to patient and/or family needs.
- Their dedication and caring attitude, combined with spontaneous checking in with patients on a regular basis.
- Their physical presence and taking time to sit with patients, to hold their hand, and to speak words of comfort and hope as they offer emotional support.

Clinical and Spiritual Care Interventions Can Alleviate or Diminish Suffering

When the interprofessional team took into consideration the "total" needs of the patient and what was happening in their life worlds, numerous patients and/or families indicated that the following interventions helped to alleviate or diminish suffering:

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[355] Buber, M. (1958). *I and thou.* New York, NY: Scribers.

- Provide effective relief of physical pain/symptoms, permitting a refocusing on the spiritual.
- Provide professional individual counseling to deal with emotional or spiritual issues.
- Provide meaning-centered group psychotherapy for terminally ill patients and families.

  Offer complementary services–music therapy, recreational therapy, therapeutic touch, and so on.
- Implement meaningful hope-fostering strategies, that focus on attainable short-term goals that focus on transitional experiences and transitional objects significant to the patient.
- Encourage maintaining meaningful relationships with others, including family and friends.
- Provide recognition and affirmation of the patient’s significant relationships.
- Help the patients recall, through “life reviews,” the meaningful events in their lives.
- Facilitate the offering and receiving of forgiveness and reconciliation.
- Encourage the continuation of the patient’s spiritual or religious practices such as meditation, prayer, attending worship services (sacraments and communion if requested), observing faith tradition holidays; and assist their participating in cultural celebrations.
- Lend a voice in the reading of sacred texts and/or spiritual writings.
- Offer the patient or family spiritual or religious assistance as death approaches (if this is considered an important aspect of their life).
- Offer information on where to obtain grief or bereavement support in the community.

Discussion of Research Findings

The focus of this phenomenological research was to gain insight and understanding into the experience of suffering, loss, grief, and bereavement from the perspectives of patients diagnosed with a terminal illness, their families, and professional caregivers. The goal was to discover and find ways to implement interventions into care plans to improve the quality of care to end of life in Canada. Analysis resulted in: (a) a description of the essential structure of pain and suffering; (b) factors that contribute to experiences of pain and suffering; (c) interventions that alleviate or diminish distress or suffering, thus assisting patients to maintain a sense of dignity throughout the illness trajectory until death; (d) identification of dimensions of loss, grief, and bereavement; and (e) discovery the importance of bereavement support groups for family and friends following the death of a of loved one.

As a researcher, I agree with Dr. Harvey Chochinov's hypothesis that, as the field of palliative care develops, it is becoming clear that adequate palliation must comprise more than good pain and symptom management; it must also include attention to the emotional/psychological, social, existential, and spiritual domains of distress.[356] These basic tenets of palliative care are well established and have confirmed their goal of helping patients die with dignity, free from pain and suffering.

Research Participants Express Their Hope: Improving End-of-Life Care

It was the hope of participants in this study that sharing their experiences will become a catalyst for improving the quality of care to end of life and a source of

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[356] Chochinov, H. et al. (2004). Dignity and psychotherapeutic Considerations in End-of-Life Care. *Journal of Palliative Care*, *20*(3), 134–142.

knowledge in the development of educational programs for future generations of health care providers. Patients and their families can teach the interprofessional team spiritual lessons, if not medical ones. The author believes it is important for health care teams to understand and appreciate this, but such a stance requires utmost humility and a profound respect for our patients and their families. As William Osler once wrote, "it is a safe rule to have no teaching without having a patient for a text … the best teaching is that taught by the patient."[357] In this research project, I can confirm that patients and families were my best teachers. I gained insight into their experiences from the time of a diagnosis of a terminal illness; their experiences throughout the illness trajectory until death; and their families' experiences of loss, grief, and bereavement.

Participants want it made known that pain needs to be distinguished from suffering, that not all physical pain includes suffering, and not all suffering includes physical pain.[358] These findings appear to correlate well with other clinical researchers, who have found in their experiences with patients that spiritual suffering underlies a considerable amount of the pain patients and families experience.[359]

Barriers That Interfere With Pain Relief Often Result in Suffering

Previous research findings of Coyle and Layman-Goldstein[360] and Zerwekh[361] identified barriers that interfere with pain management that often result in patients'

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[357] Osler, W. (1903). Our need for a radical reform in our methods of teaching medical students. *Medical News, 82*, 49– 53.

[358] Puchalski, C. (2006).

[359] Sulmasy, D.P. (2002). A bio-psychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist, 43*. Special Issue 3, 22–24.

[360] Coyle, N. & Layman-Goldstein. (2001). Pain assessment and management in palliative care. In M.L. Matzo & D.W. Sherman (Eds.). *Palliative care nursing: Quality care to end of life*. New York NY: Springer.

[361] Zerwekh, J. (2006).

suffering. This study identified similar barriers to pain relief that I characterized as patient-related barriers to accepting pain relief and physician/clinician, related barriers to offering pain relief.

Zerwekh's findings identified cost as a barrier that restricted patients' receiving effective analgesics; also when pain relief involves painful injections, some patients will decide to endure pain rather than have an injection with a needle. The fact that her study was in the United States and this study was predominately within a Canadian hospital setting in the affluent community of Richmond Hill is a possible explanation why cost of medications was not identified as a barrier in this study. However, patients' fears associated with needle injections to dispense medication were a contributing factor to their suffering in silence that crossed both borders.

Caregiver Burden: Families Are Not Prepared for the Challenges of Caregiving

Family caregivers in this study were often unprepared for the time when their loved ones entered the end stage of living and required near acute levels of care. They said that observing a loved one's suffering, such as nausea, pain, confusion, distress, anxiety, incontinence, wound management, insomnia, and daily hygiene, became all-consuming for them as caregivers, resulting in caregiver burden. Their experiences confirm previous research that has shown a decline in caregiver psychological well-being, an increase in caregiver burden, anxiety and caregiver suffering, especially when the patient is agitated or experiencing pain and distressing symptoms.[362] Paradoxically, in spite of caregiver burden and suffering, several partners expressed their caregiving as "a labour of love."

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[362] Markowitz, J., Gutterman, E., (et.al.). (2003). Health related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease and Associated Disorders, 17(*4) 209–214.

Alleviation of Suffering: The Focus of Palliative Care

Formulated meanings of significant statements of both male and female patients and family members were integrated into a description of compassionate caring interactions displayed by nurses that eased their distress or suffering. In my analysis of the research findings, it is noted that both sexes mentioned that the unsolicited and spontaneous caring behaviors of nurses, their taking time to sit and listen to patients, and responding to patients' concerns with empathy and compassion were of major importance. Patients reported feeling valued as a person rather than "just another dying patient" on the palliative care unit or in the oncology clinic receiving treatment.

However, I found a difference between men and women in their perceptions of caring interactions. Men mentioned nurses' physical actions of comfort and reassurance, while women noted emotional support at a more intimate and deeper level than men. From rereading the original transcripts, case studies, and field notes, I concluded that the women in this study expected a deeper level of emotional support and felt more comfortable to verbally request it. The men either did not admit the need for this level of emotional support or they did not feel free to request it.

The Importance of Dignity and Respect

The impact and effect of compassionate caring interactions combined with clinical interventions including spiritual care, when requested, on the palliative care unit were also observed in the oncology clinic. Patients in this study, for the most part, felt that their expressed needs were being heard and responded to with respect. They said their dignity and sense of self-worth were being maintained to the extent possible under their present circumstances. Conversely, on numerous occasions I observed "iatrogenic suffering." This is the unintended pain and suffering inflicted by physicians, nurses, or clinicians that result from activities or failure to respond in a caring way. This was identified as a significant source of patients' suffering, damaging their sense of dignity and self-worth

Martin Buber[363] raised awareness of the *I and Thou* relationship as one in which persons regard each other with dignity, respect, and integrity. An *I–Thou* relationship appeared to be highly valued in this study by patients and their families. When health care professionals interacted with them in this caring manner, *I–Thou* interactions were identified as a source of comfort that helped to alleviate distress and suffering. However, when the relationship becomes an *I–It* relationship, the health care professionals' body of knowledge speaks only to the disease. Research participants said whenever an *I–It* style of relationship occurred; it conveyed to them a lack of empathy, and respect and a total disregard for them as persons. This type of interaction was identified as a contributing factor to their suffering.

One surprising result arising from observations and patient interviews was the concept of depersonalization. Depersonalization frequently results in suffering caused by clinicians speaking to the disease, "ovarian cancer in room 328," or ignoring and dismissing the patient as a person. Delivering "bad news" while standing in the doorway of the patient's room, or failing to take time to stay with the patient to answer any questions or concerns he or she may have related to their illness was identified as a source of considerable suffering.

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[363] Buber, M. (1958).

Spirituality and Spiritual Care in Health Care: Are We Missing the Mark?

In this study, spiritual issues and concerns were identified as contributing factors to both the patients' and their families' experiences of pain and suffering. These findings are similar to previous research results of Hay,[364] MacInnis,[365] and Puchalski.[366] They validate a theory put forth by Reed that spirituality is an ever-present, sometimes dominant part of the human experience and integral to health.[367] Health in this case is defined not necessarily in terms of cure of physical illness but in terms of a sense of well-being that encompasses the physical, emotional, social, and spiritual aspects of personhood.

Shea[368] attempts to provide a working knowledge of the spiritual, especially as it relates to health care, by identifying three component parts–personal beliefs, stories, and practices that shape and direct the lives of individuals as they both seek and offer health and healing. As a researcher, I agree with Puchalski that it is within Shea's masterful presentation that we can identify and clarify moral warrants.[369] Moral warrants are the scope and grounds for the ethical obligation to address spirituality in the health care setting with specific reference to end-of-life care and alleviation of suffering.

Participants in this study stated they believe it is essential for health care teams who work with the dying to be sensitive to their spiritual pain and suffering. The rationale for their view is based on the fact that their belief and value system that previously provided

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[364] Hay, M. (1989). 25–31.

[365] MacInnis, E. (2010). *Improving the quality of spiritual care to end of life in Canada: Alleviation of suffering*. Qualitative Research Report. St. Stephen's College, University of Alberta.

[366] Puchalski, C. (2006).

[367] Reed, P.G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research In Nursing and Health, 15,*

[368] Shea, J. (2000).

[369] Puchalski, C. (2006).

strength, hope, and meaning to their lives has been fractured or shattered. They believe attention to dying patients and their families' spirituality and spiritual needs should be an essential component of end-of-life care. So far, from their experiences, participants in this study felt there was unsatisfactory and insufficient spiritual care support provided within the hospital environment.

Confirming the above perception that there is insufficient and unsatisfactory spiritual care support in health care, nurses and other health care professionals participating in this study reported struggling with the expectation they provide spiritual care to dying patients. This is similar to findings of Wright[370] and Zerwekh[371] who identified the importance of spirituality and spiritual care as an essential dimension of holistic nursing in end-of- life care; they also confirmed that spiritual care remains inadequate.

Searle[372] suggests that despite the technological and scientific emphasis on care, nurses have a unique and intimate relationship with patients which should enable them to address spiritual issues, conflict, or pain. MacLeod's hermeneutic inquiry undertaken to explore the meaning of spirituality and spiritual care practices in family systems nursing, also the first of its kind, suggests that the suffering observed within the health care environment requires nurses to respond to the spiritual.[373] Wright emphasizes that nurses

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[370] Wright, L. (2005).

[371] Zerwekh, J. (2006).

[372] Searle, C. (2001). Spirituality. In S. Kinghorn & R, Gamlin (Eds.), *Palliative nursing* (85–98). London, UK: Bailliere Tindall.

[373] MacLeod, D.L. (2003). *Opening spaces for the spiritual: Therapeutic conversations with families living with serious illness*. Unpublished Doctoral Thesis. University of Calgary, Calgary, Alberta.

must have as their primary goal the creation of an environment for alleviating and/or healing emotional, physical, and spiritual suffering.[374]

Throughout this research study, dying patients' emotional and spiritual needs emerged that required sensitive responses by the interprofessional team. However, unlike physical pain, which can be addressed with medications, there is no template to deal with spiritual pain or suffering. Thus, findings from this study reveal a failure of interprofessional teams to take an initial spiritual history and needs assessment; identify and deal with spiritual issues and concerns at end of life; this aspect of patient care remains inadequate. Indeed, we are missing the mark when it comes to taking into consideration a patient's spirituality and incorporating spiritual care into clinical care interventions for the dying within the health care environment.

Religious Beliefs and Spirituality: Is This A Neglected Area in Health Care?

In the opening chapter of this dissertation, I presented a definition of religion that captured the essence and importance of religion articulated by participants of various religious traditions who took part in this study: "Religion can be described as a social institution that unites people in a faith in God, a higher power, and in common rituals and worshipful acts. A god, divinity, and/or soul are always included in the concept."[375] There is a body of research that clearly demonstrates the health benefits of religious practices, confirming the importance of health professionals incorporating at least a respect for this aspect of the patient's life into their clinical practices. [376]

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[374] Wright, L. (2005).

[375] Strang, S. & Strang, P. (2002).

[376] Koenig, H.G., McCullough, M.E., & Larson, D.B. (2001). *Handbook of religion and health.* New York, NY: Oxford University Press.

Similar to my previous research (phase one of this longitudinal research study), I observed positive outcomes related to religious rituals and practices with patients in the last months and weeks of life that helped to alleviate or diminish suffering. Patients faithful to their religious tradition stated that religious practices such as prayer, meditation, and attending worship services helped them develop a sense of meaning and purpose in life; nurtured their spiritual needs; and offered them hope in the face of impending death. I also observed the negative impact of religious rituals and practices when imposed on patients without their permission, resulting in injury to their human spirit and increased suffering.

Zerwekh's research identified that distinguishing between religion and spirituality was a concern for many health care professionals.[377] Despite the origins of nursing having a strong religious base, several nurses in this present study viewed spirituality and spiritual care in religious terms, feeling it to be the responsibility of chaplains or other religious/faith leaders in the community. They expressed concern about the ethics of health care professionals entering into discussions that may be interpreted as religious in nature, and about the implied risk of imposing their own beliefs on patients.

Finally, Wright speaks about the significance of family members' spirituality and religious beliefs on their illness experience saying this is one of the most neglected areas in health care.[378] This research confirms Wright's findings that patient's spirituality and religious beliefs were frequently not considered as part of the initial intake assessment. In this study, repeatedly the religion section on the patient's chart was left blank. What

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[377] Zerwekh, J. (2006).
[378] Wright, L. (2005).

message does this bring to light? It appears that spirituality and religious needs of patients were not considered or acknowledged as an important aspect of patient care within the health care system and rarely incorporated into goals of care for patients. In addition, this study validated that one's images of God often change, are questioned, or viewed negatively as a result of the diagnosis of a life-threatening illness.

In spite of the fact that participants in this study indicated the importance of spirituality and religion at this time of their lives, it still appears to be a neglected area in end-of-life care. Is it possible that budget cuts to health care are having a negative impact observed in the lack of professional chaplains as well as spiritual and religious care services within health care?

Conclusions and Implications

When the interprofessional palliative care team saw and responded to the patient as a person rather than a disease, this improved the quality of the patient's care to end of life; provided a nurturing environment where the patient was not just "another dying patient" but a person worthy of respect and the best possible care the interprofessional team could offer. Fostering an environment where one is existentially present or available, showing genuine interest in the patients by truly listening and responding to their needs or concerns as they tell their stories was considered by both patients and families to be one of the most important aspects of patient care. This approach encouraged healing and frequently alleviated emotional, physical, and/or spiritual suffering. These findings have implications in the areas of education, research, and professional practice to improve the quality of end-of-life care.

Education

The findings of this study have implications for the inclusion and integration of existential philosophical thought into undergraduate education for medical and nursing students as well for other related health care professionals. With some understanding of existential philosophical concepts, students can begin to build their professional practice related to end-of-life palliative care on a meaningful philosophical base.

If compassionate communication and caring are valued as a base for professional practice within the health care system, then educators have the responsibility to provide access to courses that exemplify techniques and skills in this area. If compassionate communication and care are valued attributes for professional health care teams, then demonstration of this attribute must be evident for students to see in educators. It is critical that effective educators exemplify presence, authentic listening skills, and respect for the uniqueness of each individual. Thus, students will know what will be required of them when responding to patients and families facing impending death in our religious and culturally diverse society.

Research

The findings of this study show that data can be gathered directly from individuals, analyzed, and the findings communicated so that the meanings for the person as they live in their life world are not distorted, reduced, or fragmented. Rather, the meanings are viewed holistically as part of the individual’s total experience. Qualitative data can provide information, but cannot provide what it feels like to experience pain and/or suffering.

One consideration is that phenomenological research can never exhaust the investigated phenomenon. The results of phenomenological research are “the essence of certainty to be established with reservations.”[379]

Phenomenology tells what humankind is all about outside the boundaries of traditional science.[380] Palliative care will enhance its research possibilities if it can learn to treat the qualitative data as such rather than seeking its transformation into quantifiable measurements.

Implications for Future Education and Research

Three areas for future education and research are: (a) determine ways to identify and categorize specific needs of patients diagnosed with a terminal illness and their families needs in rural and metropolitan settings; (b) examine the phenomenon of suffering associated with ethical decision making in our ethnic and culturally diverse Canadian society when cure is no longer a reality; and (c) provide educational programs for interprofessional health care teams with regard to understanding family systems theory and cultural diversity of families that often result in conflict surrounding end-of- life treatment and decision making.

Professional Practice

Taking into consideration the total needs of the patient and what is happening in his/her life world is of utmost importance and central to providing quality end-of-life care. Issues or concerns, therefore, should be defined from the patient’s or family’s point

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[379] Merleau-Ponty, M. (1962).

[380] Rieman, D.J. (1998). The essential structure of caring interaction: Doing phenomenology. In *Qualitative inquiry and research design: Choosing among five traditions* (p. 290).Thousand Oaks, CA: Sage.

of view. It is logical to assume that the best source of information about the patient and family is from their own unique point of view. This will entail the interprofessional team being existentially present. Existential presence in a caring interaction does not have to entail long periods of time. However, it does imply that the team member will be truly present to the patient or family member in thought, words, and actions that convey gentleness, empathy, compassion, and respect–personalized compassionate care.

Implications for Professional Practice

This research study identified five areas of need, if implemented into goals of care which would improve professional practice, enhance the quality of care provided to end of life, and sponsor bereavement support for families following the death of a loved one:

1. The need for truthful information regarding the patient's diagnosis and prognosis early in the disease trajectory (consideration of the patient's culture is important); information about treatment options and predictable side effects; explanations from nurses and/or doctors regarding management of pain and symptoms causing distress and suffering; information regarding the last few weeks and days of life, and how to recognize the signs of imminent death. Participants said it is critical that health care providers continually engage in anticipatory guidance by monitoring the patient's decline, interpreting and conveying information to the patient's family so they can feel secure and supported.
2. The need for sensitive spiritual assessments and professional interventions regarding spiritual distress and suffering. Spiritual suffering/distress or religious struggles should be treated with the same priority and urgency as pain and symptom management; just as pain is screened routinely, so should spiritual suffering, and become a part of

routine patient care. The most common issues and concerns raised were the lack of emotional and spiritual support for patients and families throughout the illness trajectory. Research participants suggested that health care services should incorporate professional chaplains/counselors, spiritual care services, alternative therapeutic approaches, and grief counseling as part of their support within the hospital environment; these services should be available outside of normal working hours.

3. The need for physicians and clinicians to develop compassionate communications skills; and in their conversations with patients and families balance honesty with empathy and hope. Patient and family suggestions include continuing education for health care professionals so they can learn how to communicate with seriously ill and dying patients; learn how to listen when patients evaluate the severity of their pain; and not doubt the reality of the patient's pain and suffering.
4. The need to raise awareness with regard to the process of loss, grief, and bereavement. Participants in this research study confirmed there is a need for bereavement support following the death of a loved one; this type of support was not offered within the health care system; information regarding bereavement support groups was not made available following the death of a loved one.
5. The need to raise awareness with regard to the lack of resources that hinder the provision of quality end-of-life care. Participants felt that pressure should be brought to bear on politicians and policy makers to expand resources to provide additional nursing staff, chaplains, recreation and occupational therapists, music therapists, and complementary therapies within the health care environment and home-based

palliative care programs that adequately and humanely support patients, and their families' caregiving efforts.

Implications for Ministry in Health Care:

Ministry With Those Who Mourn: Bereavement Support Groups

Being present with others who have lost a loved one and are going through a similar experience can be extremely comforting. The *Journey Through Grief Toward Healing and Hope Bereavement Support Group* [381] provides a safe place for participants to share their own unique journey in a nonthreatening atmosphere. This group enables people to develop coping skills and understand the complex feelings and emotions known as grief.

The six-week *Journey Through Grief Bereavement Support Group* is based on the "companioning philosophy" put forward by Dr. Alan Wolfelt. *Companioning* is the art of bringing comfort to another by becoming familiar with his or her story. To companion the grieving person is to break bread literally or figuratively as well as to listen to the story of the other. It is sharing in a deep and profound way. Therefore, companioning the bereaved is not about assessing, analyzing, fixing, or resolving another's grief. Instead, it is about being totally present to the mourner, even being the temporary guardian of his or her soul.[382]

The death of someone loved changes our lives forever. The moment from "before" to "after" is almost always a long, painful journey. The bereavement support group offers a combination of education and interaction which creates an atmosphere in which grief is

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[381] MacInnis, E. (2010). *Journey through grief toward healing and hope bereavement support group* was designed as part of my research for the Doctor of Ministry Degree . It was offered through the health and wellness committee at Yorkminster Park Baptist Church, Toronto, Ontario.

[382] Wolfelt, A. (1997). *The journey through grief: reflections on healing.* Fort Collins, CO: Companion Press.

validated; where people can normalize their reactions and learn about the six needs that all mourners must yield to–indeed embrace– if they are to go on and find continued meaning in life and living: (a) Acknowledging the reality of the death; (b) Embracing the pain of loss; (c) Remembering the person who has died; (d) Developing a new self-identity; (e) Searching for meaning; (f) Receiving ongoing support from others.[383]

In the supportive environment of this group, people feel understood. Their grief is given legitimacy. They learn that grief is a natural human reaction to loss. Thus, free to explore their grief, the participants can work through the many emotions and tasks or needs that lead to reconciliation and begin to move forward; remembering the past makes hoping for the future possible.

Summary

The gold standard for end-of-life care is to have interprofessional teams share patient information with members of the team and work interdependently to provide quality of care for patients who are facing impending death. Once a patient is accepted into palliative care services, the team provides expert medical and nursing care, pain management, emotional, and spiritual care support expressly tailored to the patient's and family's needs and wishes.

Careful observations in this study reveal this is not necessarily the standard of practice for patients diagnosed with a terminal illness, particularly those admitted to acute care units in the hospital setting. Another shocking finding revealed that a spiritual history and needs assessment was not part of the patient's assessment for end-of-life care

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[383] Wolfelt, A. (1988). *Death and grief: A guide for clergy.* Muncie, IN: Accelerated Development.

within the hospital setting; no standard spiritual assessment tool could be found in the patient's medical chart.

In conclusion, reliably excellent and respectful care at the end of life is attainable, but realizing it will require numerous changes within the delivery of health care in Canada. I close with a vision put forth in the Institute of Medicine Report that captures the voices of the participants in this study and their vision for improving the quality of care to terminally ill patients and their families:

> Any *humane system of care* is one that people can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices. A humane system honors and protects those who are dying; conveys by word and action that dignity resides in people, not physical attributes; and helps people to preserve their integrity while coping with unavoidable physical insults and losses. Reliably excellent and respectful care at the end of life is attainable, but realizing it will require many changes in attitudes, policies, and actions. System changes – not just changes in individuals' beliefs and actions are necessary.[384]

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[384] Field, M. J., & Cassell, C. K. (1997). *Approaching Death: Improving care at the end of life. Institute of Medicine Report.* Washington, DC: National Academy Press.

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Appendix A

DEFINITION OF KEY TERMS

For the purpose of this study, the following terms are defined, however, because of the inductive, evolving methodological design in qualitative studies; other terms may be defined as they emerge from the data collection.

1. *Anticipatory grief:* The concept of anticipatory grief refer to grief experiences that take place prior to but in connection with a significant loss that is expected to take place but has not yet occurred–for example, grief that occurs in advance of, but still somehow still in relation to impending death. A forewarning of impending death is a necessary condition for anticipatory grief, but the heart of the matter is the grief reaction to the anticipated but not yet actually realized, loss.[385]

2. *Bereavement:* Is defined as the experience of loss of a person to whom one has a significant attachment. The condition of being left "desolate or alone, especially by death."[386] The state of having suffered a loss.[387] The "overall reaction to the loss of a close relationship" and descriptive of various "patterns, phases, and/or stages that an individual goes through when grieving."[388] Bereavement is depicted as a long term process of the survivor's accommodating his or her life without his or her loved one.[389]

3. *Caring:* Caring is defined as "an attitude which genuinely conveys to the other person that he or she does really matter. It is grounded in the sense of uniqueness and worth which, by the grace of God, the other person has.[390]

4. *Distress symptoms:* Distress symptoms observed in end-of-life palliative patients include but are not limited to pain, anorexia, fatigue, weakness, nausea, vomiting, dyspnea, constipation, anxiety, and delirium.[391]

5. *Family member:* A person or persons who have an enduring emotional attachment to the person diagnosed with a life threatening terminal disease, and

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[385] Corr, C. A., Nabe, C. M., Corr, D. M., (Eds). 2011. 269.
[386] *The American Heritage Dictionary.* 1992. 175.
[387] Rando, T. 1988.
[388] McCall, J. B. (1999). 42.
[389] Mallinson, R.K. (1999).
[390] Nelson, J. (1999). 13.
[391] Coyle, N., Alderhart, J., Foley, K.M., & Portenoy, R.K. (1990). 83–93.

who share his/her experience throughout the illness trajectory. This definition will apply whether relationship links exist or not.[392]

6. *Grief:* Is defined as "deep mental anguish, as that arising from bereavement.[393] Grief is a normal reaction to loss that affects emotions, thinking, behavior, and the physical body. Grief reactions are automatic, like a reflex, and are expressed according to cultural expectations.[394]

7. *Healing:* Healing is a restoration of one's life balance with or without a cure; healing is a repairing of our bond with self, with the deepest levels of who we are as a person. "Healing takes into account the wholeness of the person, recognizes the interrelationship of body, mind and spirit, and acknowledges the role spirituality and/or religious belief can play in the healing process."[395]

8. *Hope.* A multidimensional, dynamic life force characterized by a confident, yet uncertain expectation of achieving a future good, which, to the hoping person is realistically possible and personally significant.[396] Hope is the elevating feeling we experience when we see in the mind's eye a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along the path. True hope has no room for delusion.[397]

9. *Interprofessional team:* A small number of people with complementary skills who function according to their specialization and are interdependent. In the context of this palliative care research project, the team included physicians, nurses, social workers, physiotherapists, dieticians, chaplains, and other health care workers. They worked together for a common purpose or a result (outcome) on a short-term or permanent basis.[398]

10. *Loss:* Is defined as "the condition of being deprived of someone or something that one had."[399] Losses in this research study were identified as actual, potential, physical, or symbolic. *Primary loss* refers to the initial loss (whether of health for the patient or loss of the patient through death for significant others). *Secondary losses* stem from the initial loss such as the death of a loved one.[400]

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[392] MacInnis, E. (2010a). Research participants formulated meaning.
[393] *The American Heritage Dictionary.* 1992. 796.
[394] MacInnis, E. (2010a).
[395] *Health Ethics Guide.* (2000). 20.
[396] Ersek, M.(2001).
[397] Groopman, J. (2004).
[398] MacInnis, E. (2010a).
[399] *The American Heritage Dictionary.* 1992. 1063.
[400] MacInnis, E. (2010a). Research participants formulated meaning.

11. *Medical and illness narratives:* The *medical narrative* (story) means to discuss the disease or condition complete with medication, dosages, and tests, whereas the *illness narrative* is the story of suffering and the effects of this suffering on the individual, his or her relationships, and his or her world.[401]

12. *Object relations:* Refers to a psychological process that all people use early in life and throughout it to create internalized images of the self and other people. The patterns and images are known as "object relations."[402]

13. *Object relations theory: An* "object" is a mental representation of, most commonly, a person, though it may also represent a place, a thing, idea, fantasy, or memory. An object is the product of some sort of relationship, thus being created through some event or interaction, and is invested with a particular emotional energy such as love, hate, or fear.[403]

14. *Pain:* Pain is subjective, which means it cannot be measured objectively. It is an intense feeling of discomfort, which usually indicates tissues have been damaged. It includes psychological and behavioral responses. Pain is known to observers only through patient reporting.[404]

15. *Palliative care*: As a philosophy of care, palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and their families who are living with life-threatening illness. Palliative care strives to meet physical, psychological, social, and spiritual needs while remaining sensitive to personal, cultural, and religious values, beliefs, and practices. Palliative care may be combined with other therapies aimed at reducing or curing the illness or it may be the total focus of care.[405]

16. *Person with a terminal Illness:* An individual who has extensive and/or untreatable disease and who knows that death is relatively imminent as identified on the *"Awareness of Dying"* trajectories or death expectations; two of the four apply to this study: (a) certain death at a known time; and (b) certain death at an unknown time.[406]

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[401] Wright. L. (2005). 37.
[402] Culbertson, P. (2000).
[403] Ibid.
[404] St. Marie, B. (2002).
[405] Canadian Hospice Palliative Care Association. (2005).
[406] Glasser, B., & Strauss, A. (1966).

17. *Qualitative research*: This is an inquiry process of understanding based on a distinct methodological tradition of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. The natural setting in this research study was the hospital environment and in the community.[407]

18. *Religion:* Religion can be described as a social institution that unites people in a faith in God, a higher power, in common rituals and worshipful acts.[408]

19. *Spirit:* Spirit is widely understood to be the aspect of our reality that is independent of matter, unconfined by the constrictions of time or space. The concept of *Spirit* is elusive, subjective, and hard to grasp; there are a number of definitions: (a) the image of God within every person, making one a thinking, feeling, moral, creative being able to relate meaningfully to God (as defined by that person), self, and others. (b) A human drive to bond with the transcendent. (c) An animating, life-giving dimension that transcends all other dimensions of the person. (d) The literal breath of life … The real person, the part of us that nobody can see, the part that does not die … the inside you … Provides people the capacity to become conscious of God.[409]

20. *Spiritual care* includes: pastoral visiting, spiritual direction, individual and group prayer, and opportunities for celebrating the sacraments and other religious rites. Spiritual care is important in all situations of illness and loss; it is essential in the context of end-of-life care.[410]

21. *Spiritual/religious care:* Is characterized by a sensitivity and respect for the varying spiritual and religious needs of persons from diverse faith traditions that are experiencing spiritual suffering that often accompanies serious illness. It also provides opportunities for patients and families to participate in the life of a religious community as they receive compassionate care from faith leaders.[411]
22. *Spirituality* is the essence of our humanity related to the existential search for meaning within a particular life experience or event.[412] It is a complex and multi-dimensional part of human experience which includes cognitive, experiential,

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[407] Creswell, J. (1998).
[408] Strang, S., & Strang, P. (2002).
[409] Stoll, R. J. (1989).
[410] *Health Ethics Guide*, (2000). 29–30.
[411] MacInnis, E. (2010a).
[412] Frankl, V.E. (1985).

and behavioral aspects. Spirituality can be expressed in philosophical, religious, spiritual, or personal beliefs, values, or rituals.[413]

23. *Spiritual suffering*: A person's perception of a fracture or shattering in one's belief and value system that had in the past provided strength, hope, and meaning in his or her life.[414]

24. *Spiritual well-being.* A state of mind in which one feels his or her life is affirmed in a relationship with God (as defined by that person), self, community and in an environment that nurtures and celebrates wholeness.[415]

25. *Suffering:* Is defined as "the condition of tolerating or enduring evil, injury, pain, or death or the source of pain or distress." [416] Suffering affects the body, mind, and spirit, the state of severe distress associated with events that threaten the intactness of a person.[417]

26. *Transitional object:* The transitional object is something that a child uses for comfort and security as he or she moves from one level of emotional development to another; a teddy bear for example. While the nature of our transitional objects may change greatly between infancy and adulthood, our need for them never disappears. The human ability to think and cherish symbols began with transitional objects and we hang on to those "treasured possessions" as sources of self-comfort such as the Star of David (Jewish faith) or a cross worn around the neck (Christian faith), or a crucifix on the wall.[418]

27. *Transitional space:* The transitional space is a realm between inner and outer reality. The third part of the life of a human being, a part we cannot ignore; it is an intermediate *area of experiencing*, to which both inner reality and external life contribute. It exists as a reflective space for the individual engaged in the perpetual human task of keeping inner and outer reality separate, yet interrelated.[419]

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[413] Anandarajah, G., & Height, E. (2001).
[414] MacInnis, E. (2010a). Research participants formulated meaning.
[415] Moberg, D. (1997).
[416] *The American Heritage Dictionary.* 1992. 1063.
[417] Cassell, E. (2004).
[418] Culbertson, P. (2000).
[419] Winnicott, D. W. (1992).

Appendix B

THE CONTINUUM OF PALLIATIVE CARE

Palliative Care is planned and delivered through the collaborative efforts of an interprofessional team including the individual family, caregivers, and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.[420]

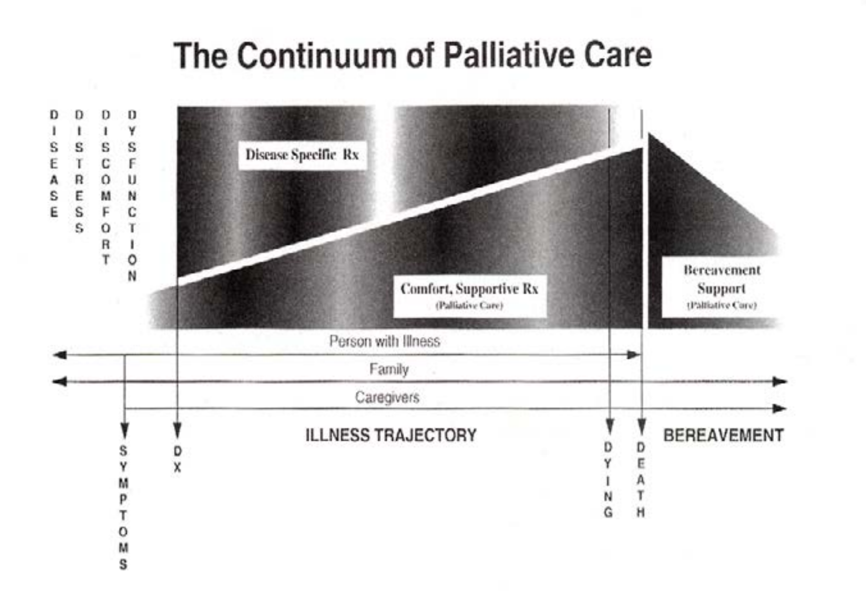

Diagram 1 – The Continuum of Palliative Care

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[420] Ferris, D., & Cummings, I. (Eds.) (2005). *Towards a consensus in standardized principles of practice* (p.5). Ottawa, ON: The Canadian Palliative Care Association.

Appendix C

"I HOPE FOR" SPIRITUAL HISTORY & NEEDS ASSESSMENT GUIDE ©

Adapted from the HOPE Spiritual Assessment Tool, permission granted by Dr. Gowri Anandarajah.

Rev. Elaine MacInnis

Suggested Questions: A Narrative Inquiry Approach

"I HOPE FOR" Spiritual History and Needs Assessment Guide is not to be used as a checklist but rather as a guide for knowing how to initiate a spiritual history and ways to begin conversations about spiritual issues, topics of meaning and value, what to listen for as the patient talks about his or her fears, dreams, hopes and beliefs in the face of impending death.

I Individual Cultural Practices with Respect to Medical Care

- In your culture are there norms or practices that affect decisions regarding medical treatment? Who is responsible for making those decisions?
- What is your preference about receiving medical information with regard to your illness? Are members of your family in agreement with your preferences?
- Are there cultural norms about who should or should not be involved in your medical care? (i.e., male or female interprofessional team members)
- Are there cultural traditions or practices you want incorporated into your care plans?
- Are there dietary restrictions or requirements that we should be aware of?

H Hope, Meaning, and Purpose

- What is there in your life that gives you *internal hope and* support as you meet the challenges of this illness?
- In the past, what did you hold onto during difficult times?
- What are your *external* sources of hope, strength, and comfort today?
- What nourishes your spirit and sustains you since you received your diagnosis?
- What gives your life meaning and purpose?

O Overview: Emotional and Social History

- How has this illness changed your life? What has been the reaction of members of your family to your diagnosis?
- Are you experiencing changes in your mood or behavior as a result of your illness?
- What are your greatest fears concerning yourself and your loved ones?
- Do you have anyone in your life to be with you and support you at this time? In what ways can they help?

- Are there issues or needs relating to family, friends, or care of pets that we should be aware of?
- What are some of the things that have been significant or are important in your life? (e.g., jobs, careers, pets, historical items, etc.)
- Are there family values or stories you would like to share with those you love?

P Physical and Medical History

- What is your understanding of what is happening to you because of your illness?
- Do you have any fears or concerns about your diagnosis or the plans for your care?
- Are you experiencing pain or symptoms that may be causing you distress or suffering?
- Has your illness (or current situation) affected your ability to take care of yourself?
- Do you have any trouble getting around your home, getting to the telephone or the bathroom, or going to your medical appointments?
- Are there any aspects of your personal care that you need assistance with?
- Do you have any concerns with your current or future living arrangements?

E Ethical Decisions: End-of-Life Care

- In the event that you are unable to speak for yourself, who would represent your beliefs and values about health care?
- Have you been able to discuss your wishes and decisions concerning your care with anyone? If so, can you tell me who that person is?
- Do you have a will? Have you chosen a power of attorney?
- Are there any steps that you may need assistance with to ensure your wishes are carried out?
- Is there any part of your medical care that you wish to forgo or have withdrawn?
- Before withdrawing treatment, is there anything about your care that you feel is incomplete or would like to have incorporated into your care plans?
- Are you comfortable with decisions made with respect to: CPR, the use of intravenous fluids, and feeding tubes?

F Faith and Beliefs History

- Do you consider yourself to be a spiritual or religious person?
- For many people, their faith and beliefs are a source of comfort and strength in dealing with serious illness; do you have spiritual beliefs that help you cope with stress? (If the patient responds “no,” you might ask, “What gives your life meaning?”)
- Has your faith been a source of comfort to you at this time?

- Do you have beliefs that help you cope with the challenges associated with your illness? If the patient responds “no,” you might want to ask, “What gives your life meaning?”
- Have your beliefs influenced how you take care of yourself since your diagnosis?
- Do you have any concerns or doubts between your beliefs and your medical situation or decisions that may be causing you fear, distress, or suffering?
- In what ways do faith and/or beliefs influence how you view care at the end of life? (resuscitation, feeding tubes, ventilators, etc.).
- Are there aspects of your faith and/or beliefs that you would like us to keep in mind as we plan together for your care?

O Organized Religion and Religious Practices

- Do you believe in God? What is your relationship with God?
- Do you consider yourself part of an organized religion?
- Which aspects of your religion or religious beliefs do you find most helpful in your current situation? (e.g., prayer, reading scripture, attending religious services). Which aspects are not so helpful at this time?
- Has your illness or current situation affected your ability to do things that nurture the religious aspect of your life?
- Are you actively involved in a religious community? Is this of support to you? How?
- Do you have any needs related to your religious tradition that should be incorporated into your care plans?

R Rituals and Personal Spirituality Practices

- Do you have personal spiritual beliefs and practices that are independent of organized religion? What are they?
- When given the diagnosis of a life-threatening illness, this often raises questions about one’s spiritual dimension of life; what effect has your illness had on your spirituality?
- Are there aspects of your spiritual practices that you find helpful? How do they help? (e.g., listening to music, meditation, relaxation, etc.).
- Are there any rituals or practices that are part of your daily routine that you may wish to have continued as part of your goals of care?
- Would it be helpful for you to speak to a professional chaplain or faith leader in your community?

Note: The “*I HOPE FOR*” Spiritual History & Needs Assessment Guide © was developed as an assessment tool for the author’s Qualitative Research Study “Improving the Quality of End of Life in Canada: Alleviation of Suffering – Perspectives of the Terminally Ill, Their Family & Professional Caregivers” at York Central Hospital, Richmond Hill, Ontario in partial fulfillment of the requirements for the Degree of Doctor of Ministry, St. Stephen’s College, University of Alberta, Edmonton, Alberta.

Appendix D

SAMPLE INTERVIEW QUESTIONS

Patient Interview

Question 1: When did you first learn about your diagnosis, and who told you?

Question 2: Can you talk about your thoughts and feelings when you heard about your diagnosis?

Question 3: Can you talk about who was there to support you in the first few weeks and months since you were told about your illness; what helped you get through those days?

Question 4: What has been the effect of this illness on you and your family?

Question 5: What changes have there been in your life since you were diagnosed with an illness that may possibly be considered life threatening?

Question 6: From your experience, how would you describe pain and suffering?

Question 7: What helps alleviate or lessen your experience of pain or suffering?

Question 8: Can you talk about any illness-related experiences either at home or in the community that caused you or your family distress or suffering?

Question 9: What helps alleviate or lessen your experience of suffering?

Question 10: When one experiences the crisis of a serious illness and is hospitalized, patients have said that emotional and spiritual support care are important; can you comment about your experience of receiving emotional and spiritual support during your hospitalization?

Question 11: What are some of the things that help you cope with the challenges associated with your illness?

Question 12: Communication is an important aspect of palliative care; can you comment on your observations and/or experiences with regard to the interprofessional team's communication with you or your family?

Question 13: In your experience with the interprofessional team, can you identify interactions or activities that may have caused you suffering?

Question 14: In your experience with the interprofessional team, can you identify interactions or activities that help to alleviate or diminish suffering?

Question 15: For many people their religious and spiritual beliefs are important in dealing with serious illness; can you share with me if religious faith and/or beliefs are important to you at this time?

Question 16: Are there any aspects of your faith or beliefs about illness that may be causing you distress or suffering?

Question 17: Can you identify what services are needed in order to enhance the quality of life and care for patients at this time? How are they being incorporated into goals of care?

Question 18: I invite you to share any suggestion that you believe health care professionals need to know so they can improve the quality of care for patients to the end of life.

Closing Comments:

Thank you for willingness to participate in this study. I will type up the interview and give you a copy so you can make any corrections or clarifications before I include your information in my research project.

Appendix D

SAMPLE INTERVIEW QUESTIONS

Family Member Interview

Question 1: When did you first learn about _____ (family member's) diagnosis; and who told you?

Question 2: Can you talk about your thoughts and feelings when you heard about _____ (family member's) diagnosis?

Question 3: Can you tell me who was there to support you in the first few weeks and months since you were told about _____ (family member's) illness; what helped you get through those days?

Question 4: What has been the effect of _____ (family member's) illness on you and your family?

Question 5: What changes have there been in your life since ______ (family member) was diagnosed with an illness that may possibly be considered life threatening?

Question 6: From your experience, how would you describe pain and suffering?

Question 7: What helps alleviate or lessen your experience of pain or suffering?

Question 8: Can you talk about any illness-related experiences either at home or in the community that caused you or your family distress or suffering?

Question 9: What helps alleviate or lessen your experience of suffering?

Question 10: When a family member experiences the crisis of a serious illness and is hospitalized, it has been said that emotional and spiritual care support are important. Can you comment about _____ (family member's) or your personal experience of receiving emotional and spiritual support during _____ (family member's) hospitalization?

Question 11: What are some of the things that help you cope with the challenges associated with _____ (family member's) illness?

Question 12: Communication is an important aspect of palliative care; can you comment on your observations and/or experiences with regard to the interprofessional team's communication with you or your family?

Question 13: In your experience with the interprofessional team, can you identify interactions or activities that may have caused _____ (family member) or you suffering?

Question 14: In your experience with the interprofessional team, can you identify interactions or interventions that help to alleviate or diminish suffering?

Question 15: For many people religious and spiritual beliefs are important in dealing with serious illness; can you share with me if religious faith and/or beliefs are important to you at this time?

Question 16: Are there any aspects of your faith or beliefs about illness that may be causing you distress or suffering?

Question 17: Can you identify what services are needed in order to enhance the quality of life and care for patients at this time? How are they being incorporated into goals of care?

Question 18: I invite you to share any suggestion that you believe health care professionals need to know so they can improve the quality of care for patients to the end of life.

Closing Comments:

Thank you for willingness to participate in this study. I will type up the interview and give you a copy so you can make any corrections or clarifications before I include your information in my research project.

Appendix D

SAMPLE INTERVIEW QUESTIONS

Palliative Care Team Interview

Question 1: I have observed that some families do not want their loved one to know the extent of their illness; it is the paradox of truth telling. Can you comment on what you have observed with patient families around the paradox of truth telling?

Question 2: Patients and families have told me they experience fear that result in distress and suffering because they do not know what is going to happen in the last hours of their life; what have been your observations?

Question 3: What factors contribute to the patient's or families' experience of suffering

Question 4: **C**an you identify clinical interventions that help to alleviate or diminish patients and their families' experience of suffering?

Question 5: **C**an you identify hope- fostering strategies and/or interventions that will help to foster hope and healing when cure is no longer a reality?

Question 6: Communication is an important aspect of palliative care; can you comment on your observations and/or experiences with regard to the interprofessional team's communication with patients and families?

Question 7: Spiritual care has been identified as an important aspect of palliative care; can you comment on your observations of the delivery of spiritual care for patients and their families?

Question 8: There was a music therapist on the palliative care unit; can you comment on the effect of music therapy in the life world of the patients?

Question 9: Can you speak about the ratio of nurses to patients on the palliative care unit and any issues or concerns you may have?

Question 10: Have the cut-backs to health care had an impact on services provided by palliative care?

Question 11: Can you identify what services are needed in order to enhance the quality of life and care for patients at this time? How are they being incorporated into goals of care?

Question 12: There is an average of 28 to 30 deaths each month on our 15-bed palliative care unit. I have observed that patients and their family on the unit become friends with other families very rapidly; what is the impact of witnessing so many deaths on the unit in is such a short period of time for patients and their family?

Question 13: Can you comment on your observations with regard to religion, faith, beliefs, and rituals in end-of-life care?

Question 14: There is a memorial service for patients who have died at York Central Hospital every four months; can you comment on whether this type of service is significant or not for families of patients who have died and for staff?

Question 15: I invite you to share any suggestions that you believe health care professionals need to know so they can improve the quality of care for patients to the end of life.

Question 16: Patients and families have said they hope information from this research study will be used to educate staff and in the development of an educational series for training health care professionals. What things would you like to see included in future training for staff?

Closing Comments:

Thank you for willingness to participate in this study. I will type up the interview and give you a copy so you can make any corrections or clarifications before I include your information in my research project.

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APPENDIX – E

RESEARCH STUDY: PARTICIPANT CONSENT FORMS

Improving the Quality of Care to End-of-Life in Canada

A study to identify underlying issues or factors that contribute to the *internal* and *external* experiences of suffering when diagnosed with a life limiting terminal illness. From the perspectives of the patient, their family members, and professional caregivers what clinical interventions alleviate or diminish suffering (physical, emotional, spiritual or social/relationship) when implemented into patient care plans?

PATIENT CONSENT FORM

This consent form is part of the process of informed consent. It is designed to give you an idea of what this research study is about and what will happen to you if you choose to be in this study.

If you would like to know more about something mentioned in this form, or have any questions regarding this research study, please be sure to ask the researcher whose name and telephone number is on the last page of this form. Read the consent form carefully to make sure you understand all of the information it provides. You will be given a copy of the form to keep.

Your participation in this study is entirely voluntary. You do not have to take part in the study and your care does not depend on whether you take part or not.

This study may not help you directly, but it is our hope that it will teach health care professionals important information about end-of-life care that will help others in the future.

BACKGROUND INFORMATION

Health care professionals in clinical rounds regularly discuss pain and symptom management, a major focus of health care. However, conversations about suffering are

not routinely brought forward in their encounters with patients or their families once curative treatment has stopped. Individuals diagnosed with a terminal illness who are facing impending death often seek help from members of the interdisciplinary team.

Spiritual concerns have been found to be almost universal among hospitalized patients. *Ninety-four percent* of people admitted to the hospital agree that spiritual health is as important as physical health. Individuals with a life threatening illness often seek support from chaplains and community faith leaders. Recent research in spiritual matters suggests that those who avail themselves to services that take into consideration the patient's spirituality and spiritual needs experience comfort and peace during this difficult time.

STUDY PURPOSE

Previous research conducted by the investigator confirmed the fact that a compassionate interdisciplinary team approach enhances the quality of care to end-of-life when spiritual needs are identified and attained. The purpose of this study is to gain insights and understanding into issues that contribute to *internal* and *external* experiences of suffering. In particular, the investigator is interested in learning more about what clinical interventions can help diminish or alleviate suffering or hinder this process.

STUDY DESIGN

You are being approached for possible participation in this study because your doctor and/or members of the interdisciplinary team at York Central Hospital believe you could help us gain valuable insights into your experience of being diagnosed with a life threatening illness and issues of concerns that may have caused distress and suffering.

If you choose to take part in this study, you will be asked to meet with the investigator at a mutually agreeable place, on 1 or 2 occasions to discuss your experiences and give your views and observations. The discussion could take approximately 1 hour or less and will be tape-recorded. The recording will be transcribed to facilitate analysis. There may be less formal observations or interviews within the hospital setting or in the family home. You will be involved in dialogue regarding my interpretation of your experiences to ensure accurate descriptions and conclusions.

POTENTIAL BENEFITS

Participation in this study may be of no personal benefit to you. However, based on the results of this study, it is hoped that through education and training of health care professionals, the quality of patient care will be improved so patients and families can experience a *Compassionate Model of Care.*

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SIDE EFFECTS

There are no known side effects to participate in studies of this nature, but the discussions that will take place may trigger unexpected emotional distress. If you wish to obtain assistance in this regard, the Spiritual Care Department at York Central (905) 883-1212 ext. 7562 will provide this support. The investigator will help you obtain an appointment to see them if you wish or assist you in finding help with a counselor in the community.

WITHDRAWAL FROM THE STUDY

You may withdraw from the study at any time if you wish, no questions will be asked.

COSTS

You may be coming to York Central Hospital more often than if you were not part of the study, if you choose to meet with the investigator at York Central. If this is the case, there may be some extra costs, such as parking, which will be your responsibility.

CONFIDENTIALITY

The information that is collected as part of this study will be shared with the investigator's doctoral committee, health care providers who work in Oncology and/or Palliative Care at York Central Hospital, and hospital Chaplains. The hospital Chaplains will be asked to sign an Oath of Confidentiality. The doctoral committee and health care providers are already bound by existing confidentiality agreements. You will not be identified by name in any of these discussions.

I shall ensure that confidential information is not inappropriately accessed, used, or released directly by me, or by the virtue of my signature or security access to premises or systems.

At all times I shall respect the privacy of patients, their family, and others in this study.

Data and information collected, as part of this study will be kept in a safe storage area.

UNDERSTANDING OF PARTICIPANTS

I am signing this form to show that I have read the consent form, and that I agree to take part in the study as a participant. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in this study, I am to be kept as informed as my initial consent.

I am free to ask for further explanations about this study. I understand that Elaine MacInnis, the investigator will answer my questions. I can contact her by phone calling York Central Hospital (905) 883-1212 ext. 7561 or her private counseling office at (416) 243-2302 and she will answer any questions I have about this study.

If I feel at any time that I have not been informed to my satisfaction about the risks, benefits, or alternatives of this study, or that I have been encouraged to continue in this study after I wanted to withdraw, I can call the Patient Relations Advocate Brenda Tan at phone number (905) 883-1212 ext. 7495.

I will get to keep a copy of this consent form for information and for future reference.

(PRINT NAMES CLEARLY)

Name of Patient	Signature
Name of Witness	Signature
Name of Investigator	Signature

Date

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APPENDIX – E

RESEARCH STUDY: PARTICIPANT CONSENT FORMS

Improving the Quality of Care to End-of-Life in Canada

A study to identify underlying issues or factors that contribute to the *internal* and *external* experiences of suffering when diagnosed with a life limiting terminal illness. From the perspectives of the patient, their family members, and professional caregivers what clinical interventions alleviate or diminish suffering (physical, emotional, spiritual or social/relationship) when implemented into patient care plans?

FAMILY MEMBER CONSENT FORM

This consent form is part of the process of informed consent. It is designed to give you an idea of what this research study is about and what will happen to you if you choose to be in this study.

If you would like to know more about something mentioned in this form, or have any questions regarding this research study, please be sure to ask the researcher whose name and telephone number is on the last page of this form. Read the consent form carefully to make sure you understand all of the information it provides. You will be given a copy of the form to keep.

Your participation in this study is entirely voluntary. You do not have to take part in the study and your care does not depend on whether you take part or not.

This study may not help you directly, but it is our hope that it will teach health care professionals important information about end-of-life care that will help others in the future.

BACKGROUND INFORMATION

Health care professionals in clinical rounds regularly discuss pain and symptom management, a major focus of health care. However, conversations about suffering are

not routinely brought forward in their encounters with patients or their families once curative treatment has stopped. Individuals diagnosed with a terminal illness who are facing impending death often seek help from members of the interdisciplinary team.

Spiritual concerns have been found to be almost universal among hospitalized patients. *Ninety-four percent* of people admitted to the hospital agree that spiritual health is as important as physical health. Individuals with a life threatening illness often seek support from chaplains and community faith leaders. Recent research in spiritual matters suggests that those who avail themselves to services that take into consideration the patient's spirituality and spiritual needs experience comfort and peace during this difficult time.

STUDY PURPOSE

Previous research conducted by the investigator confirmed the fact that a compassionate interdisciplinary team approach enhances the quality of care to end-of-life when spiritual needs are identified and attained. The purpose of this study is to gain insights and understanding into issues that contribute to *internal* and *external* experiences of suffering. In particular, the investigator is interested in learning more about what clinical interventions can help diminish or alleviate suffering or hinder this process.

STUDY DESIGN

You are being approached for possible participation in this study because your doctor and/or members of the interdisciplinary team at York Central Hospital believe you could help us gain valuable insights into your experience of being diagnosed with a life threatening illness and issues of concerns that may have caused distress and suffering.

If you choose to take part in this study, you will be asked to meet with the investigator at a mutually agreeable place, on 1 or 2 occasions to discuss your experiences and give your views and observations. The discussion could take approximately 1 hour or less and will be tape-recorded. The recording will be transcribed to facilitate analysis. There may be less formal observations or interviews within the hospital setting or in the family home. You will be involved in dialogue regarding my interpretation of your experiences to ensure accurate descriptions and conclusions.

POTENTIAL BENEFITS

Participation in this study may be of no personal benefit to you. However, based on the results of this study, it is hoped that through education and training of health care professionals, the quality of patient care will be improved so patients and families can experience a *Compassionate Model of Care.*

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SIDE EFFECTS

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WITHDRAWAL FROM THE STUDY

You may withdraw from the study at any time if you wish, no questions will be asked.

COSTS

You may be coming to York Central Hospital more often than if you were not part of the study, if you choose to meet with the investigator at York Central. If this is the case, there may be some extra costs, such as parking, which will be your responsibility.

CONFIDENTIALITY

The information that is collected as part of this study will be shared with the investigator's doctoral committee, health care providers who work in Oncology and/or Palliative Care at York Central Hospital, and hospital Chaplains. The hospital Chaplains will be asked to sign an Oath of Confidentiality. The doctoral committee and health care providers are already bound by existing confidentiality agreements. You will not be identified by name in any of these discussions.

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At all times I shall respect the privacy of patients, their family, and others in this study.

Data and information collected, as part of this study will be kept in a safe storage area.

UNDERSTANDING OF PARTICIPANTS

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I will get to keep a copy of this consent form for information and for future reference.

(PRINT NAMES CLEARLY)

Name of Family Member	Signature
Name of Witness	Signature
Name of Investigator	Signature
Date	

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APPENDIX – E

RESEARCH STUDY: PARTICIPANT CONSENT FORMS

Improving the Quality of Care to End-of-Life in Canada

A study to identify underlying issues or factors that contribute to the *internal* and *external* experiences of suffering when diagnosed with a life limiting terminal illness. From the perspectives of the patient, their family members, and professional caregivers what clinical interventions alleviate or diminish suffering (physical, emotional, spiritual or social/relationship) when implemented into patient care plans?

PALLIATIVE CARE TEAM CONSENT FORM

This consent form is part of the process of informed consent. It is designed to give you an idea of what this research study is about and what will happen to you if you choose to be in this study.

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BACKGROUND INFORMATION

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not routinely brought forward in their encounters with patients or their families once curative treatment has stopped. Individuals diagnosed with a terminal illness who are facing impending death often seek help from members of the interdisciplinary team.

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STUDY PURPOSE

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STUDY DESIGN

You are being approached for possible participation in this study because your doctor and/or members of the interdisciplinary team at York Central Hospital believe you could help us gain valuable insights into your experience of being diagnosed with a life threatening illness and issues of concerns that may have caused distress and suffering.

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POTENTIAL BENEFITS

Participation in this study may be of no personal benefit to you. However, based on the results of this study, it is hoped that through education and training of health care professionals, the quality of patient care will be improved so patients and families can experience a *Compassionate Model of Care.*

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SIDE EFFECTS

There are no known side effects to participate in studies of this nature, but the discussions that will take place may trigger unexpected emotional distress. If you wish to obtain assistance in this regard, the Spiritual Care Department at York Central (905) 883-1212 ext. 7562 will provide this support. The investigator will help you obtain an appointment to see them if you wish or assist you in finding help with a counselor in the community.

WITHDRAWAL FROM THE STUDY

You may withdraw from the study at any time if you wish, no questions will be asked.

COSTS

You may be coming to York Central Hospital more often than if you were not part of the study, if you choose to meet with the investigator at York Central. If this is the case, there may be some extra costs, such as parking, which will be your responsibility.

CONFIDENTIALITY

The information that is collected as part of this study will be shared with the investigator's doctoral committee, health care providers who work in Oncology and/or Palliative Care at York Central Hospital, and hospital Chaplains. The hospital Chaplains will be asked to sign an Oath of Confidentiality. The doctoral committee and health care providers are already bound by existing confidentiality agreements. You will not be identified by name in any of these discussions.

I shall ensure that confidential information is not inappropriately accessed, used, or released directly by me, or by the virtue of my signature or security access to premises or systems.

At all times I shall respect the privacy of patients, their family, and others in this study.

Data and information collected, as part of this study will be kept in a safe storage area.

UNDERSTANDING OF PARTICIPANTS

I am signing this form to show that I have read the consent form, and that I agree to take part in the study as a participant. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in this study, I am to be kept as informed as my initial consent.

I am free to ask for further explanations about this study. I understand that Elaine MacInnis, the investigator will answer my questions. I can contact her by phone calling York Central Hospital (905) 883-1212 ext. 7561 or her private counseling office at (416) 243-2302 and she will answer any questions I have about this study.

If I feel at any time that I have not been informed to my satisfaction about the risks, benefits, or alternatives of this study, or that I have been encouraged to continue in this study after I wanted to withdraw, I can call the Patient Relations Advocate Brenda Tan at phone number (905) 883-1212 ext. 7495.

I will get to keep a copy of this consent form for information and for future reference.

(PRINT NAMES CLEARLY)

Name Palliative Care Team Member	Signature
Name of Witness	Signature
Name of Investigator	Signature
Date	

Appendix F

THE PALLIATIVE CARE TEAM: ROLES & RESPONSIBILITIES

Physicians: The *Palliative Care Physician* on the interprofessional team is responsible for the medical component of the patient's care. The physician serves as a liaison between the patient's primary care physicians and the community– based hospice palliative care programs. To be effective in end-of-life care, the physician must have a broad base of clinical expertise combined with a commitment to the philosophy of palliative care. The palliative care physician is responsible for diagnosis of disease progression and prescription of palliative treatment; maintains current palliative knowledge and is committed to ongoing communication with the team, who together will provide care for the "whole" person–body, mind, and spirit.

Guidelines for Ethical Conduct for Physician's and Physician Assistants clearly state the mandates for end-of-life care:

Among the ethical principles that are fundamental to providing compassionate care at the end of life, the most essential is recognizing that dying is a personal experience and part of the life cycle. Physicians and physician assistants should assure the terminally ill patients that their dignity is a priority, that relief of physical and mental suffering is paramount. They should always exhibit nonjudgmental attitudes and should assure their terminally ill patients that they will not be abandoned. Explain hospice and palliative care and facilitate patient access to those services. End-of- life care should include assessment and management of psychological, social, and spiritual or religious needs while respecting patients' wishes for particular treatments when possible. Also they (physicians and physician assistants) must weigh their ethical responsibility to withhold futile treatments and to help patients understand such medical decisions. [421]

Registered Nurses: The *Certified Palliative Care Nurse–Registered Nurse* on the interprofessional team incorporates the roles of an advanced clinician, educator, consultant to staff, and mentors colleagues to provide holistic care to patients and families that are coping with life limiting-terminal illness. The *Registered Nurse* has the responsibility for the patient's physical, psychological, and spiritual comfort as well as care coordination. In addition, it is imperative for the nurse to exemplify competent skills in end-stage physical assessment, disease progression, pain, and symptom management. The nurse as a teacher incorporates the important role of teaching the patient and family about their involvement in caregiving which includes medication management, equipment use, skin care, and organization of daily living. The registered nurse will have the day-to- day task of overseeing support nursing personnel who are members on the team including licensed practical nurses, certified nursing assistants, and personal support workers by facilitating communication among team members.

Nursing theories include aspects of spirituality in patient care, directly or indirectly including caring interprofessional relationships and spiritual variables.[422] One of the six essential features of professional nursing practice is the establishment of a caring relationship to facilitate health and healing.[423] The International Council of Nurses recognizes the importance of spirituality and health as clarified in the code, which states:

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[421] Puchalski, C.M., & Ferrell, B. (2010). 39.

[422] Neuman, B.M. (1995).

[423] Suggestion made by Dr. Christina Puchalski in 2007 in a presentation. Harvard Medical School Continuing Education Series. Boston: U.S.A.)

The nurse in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of each individual, unrestricted by considerations of social and economic status, personal attributes, or the nature of the health problems; the measures nurses take to care for the patients must enable the patients to live with as much physical, psychosocial, social, and spiritual well-being as possible.[424]

Puchalski, at a Harvard Medical School Continuing Education Conference attended by the researcher, asserted that highlighted in nursing codes is the importance of including spiritual care as an essential aspect of competent and compassionate nursing practice.

Nurses provide compassionate care and dignity to persons near the end of life because nurses spend more time than any other profession at the bedside and in the community with patients and their families experiencing end-of- life issues.[425] This was observed in clinical settings, on the palliative care units, and in the community with parish nurses as the primary researcher moved between these settings as part of the study.

During the course of the research, observations and conversations with nurses confirmed ethical and legal aspects of end-of- life decision making that present compelling challenges for nurses because they involve conflicts between values, principles, and priorities of care. In order to clarify ethically relevant aspects of complex cases they confront on a regular basis, nurses drew on the expertise of members of the palliative care team; the ethicist was included in a decision making framework and

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[424] International Council of Nurses. Quoted in Puchalski, C.M., & Ferrell, B. (2010). 34.

[425] Ferrell, B.R., & Coyle, N. (2008). 241–247.

process that incorporated ethical theories, clearly defined moral concepts, and an understanding of the Code of ethics for nurses. It became apparent that an ethic of caring was specifically appealing to nurses. A clinical nurse leader, during *Ethics Grand Rounds* stated:

> An ethic of caring that focuses on relationships and responsibility is one aspect of the wide-ranging fields of feminist ethics. I am a feminist who has raised issues of some of the relational inequalities that exists within most health care organizations. Caring is considered to be the very foundation of our clinical practice as nurses; caring was one of the fundamental values in the development of nursing ethics. Care for our patients mandates respectful care of the person regardless of gender, race, or ethnicity as its core principle.

As part this research project, an extensive literature search revealed that an ethic of care has not yet been adequately developed to function as a conceptual theory for the identification of "right" actions in morally troubling situations. [426] [427]

Ethicist: The *Ethicist* functions as a member of the interprofessional palliative care team and may recommend or give advice on particular ethical situations. There is an ethical dimension to all health care decisions. In clinical practice, ethical aspects of care can be thought of as falling into two general categories: "every day ethics," which comprise the general approach to patient care and professional practice and "ethical dilemmas," in which there is an added complexity to a patient's clinical situation in which one "right" course of action may be difficult to determine with certainty. End of life is a difficult time often filled with discussions and challenging decisions that must be made in the context of terminal illness. Some ethical considerations in end-of- life care.

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[426] Fry, S.T., Killen, A.R., Robinson, E.M. (1996). 41–47

[427] Davis, A.J., Aroskar, M.A., Liaschenko, J., & Drought, T.S. (1997).

Advances in medical science and technology are dramatically improving our ability to cure illness, ease suffering, and prolong life. Concentrated efforts must be taken to alleviate suffering and illness.

These advances also raise new ethical questions concerning end-of- life care, particularly around life-sustaining treatment. There are occasions when prolonging life by artificial means places onerous burdens on dying persons and their families. In face of such issues, it is necessary to maintain a balance between two important obligations. We are obliged not to intentionally kill someone; assisted suicide and euthanasia are not acceptable options**.** At the same time, we are not obliged to use life-sustaining procedures which would impose burdens out of proportion with the benefits to be gained from such procedures.

Dying persons are to be provided with care, compassion, and comfort. A person receiving care should be given sufficient pain management to lessen pain and suffering, even if such pain management could shorten life, though not intentionally. The goal of such care is to alleviate suffering while minimizing the potential side effects of medication.[428]

The palliative care team would like to believe in a “good death” and family units that are functional, articulate, cohesive, and able to adapt to changing situations. [429] Unfortunately, throughout this study observations establish this is not always the case; there were numerous times when consultation with the ethicist for professional intervention was required to assist families have a meaningful discussion and make

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[428] *Health Ethics Guide*. (2000). Catholic Health Association of Canada. 54–55.

[429] Fisher, C. (2003). 257– 264.

difficult decisions when family members had conflicting views. Certain patterns of practice were witnessed during family meetings to facilitate the application of ethics and enhance patient autonomy and participation in the ethical decision-making process. The team applied an *ABC Model*, *"A Framework for Ethical Discernment."* *A* – Observe. (1) Identify the problem; (2) Acknowledge feelings; (3) Gather the Facts. *B – Deliberate.* (4) Consider alternatives; (5) Examine values; (6) Evaluate alternatives. *C – Act.* (7) Articulate the decision; (8) Implement the plan as agreed upon.[430]

It is important that resources be available to promote sound ethical decision-making by all persons entrusted with the care of patients diagnosed with a life-threatening illness. This responsibility is frequently facilitated by the ethicist. The ethicist or ethics committee may advise on particular ethical situations, promote education on ethical issues, and, where appropriate, review and recommend organizational policies.

Social Worker: *The Social Worker* functions as a member of the interprofessional palliative care team with expertise in end-of-life care; however, as von Gunten and colleagues note, the discipline of social work is often poorly understood.[431] Social workers have extensive knowledge and expertise in psychology and family systems. This was confirmed over the course of this study by observing the social worker on the palliative care unit as she worked with patients and families through numerous social problems associated with a life-limiting illness, disability and impending death. The social worker's code of ethics requires that a social worker must include spirituality when

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[430] *Health Ethics Guide.* (2000). Appendix 1.

[431] von Gunten, C.F., Ferris, F., Portenoy, R., & Glajchen, M. (Eds.) (2011). CAPC *Manual: How to Establish a Palliative Care Program*. New York: Centre to Advance Palliative Care.

making an assessment. Similar to other professions, social workers are challenged to meet this recommendation due to lack of available spiritual assessment tools.

Social work interventions in general involved two types of related services: for example, referrals to community services as determined by physical and social needs of the patient and resources available; or emotional support including family counseling and, after death, bereavement counseling. As a result of findings midway through this study, awareness was raised for the need to provide anticipatory loss and grief counseling. The social worker in combination with a colleague from Richmond Hill Hospice and the spiritual care volunteer on the unit facilitated a Tuesday afternoon *Anticipatory Grief Support Group* on the unit for families of patients. Unfortunately due to lack of government funding, support for bereavement services related to complicated grief or other related grief needs were not offered after the patients' death, within the hospital setting.

For social workers, counseling is often the work they often find very rewarding and important, especially in end-of-life care. Many professionals are familiar with the social workers' instrumental interventions but less knowledgeable about their expertise in counseling. Thus it is particularly important for social workers to clarify their roles on the interprofessional palliative care team.[432]

Professional Chaplain: The *Certified Professional Chaplain* in hospitals and other health care settings offers spiritual care to all who are in need. The spiritual aspect of care is significant in end-of-life care. Puchalski states that in the move to

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[432] Ajemian, I. (1994). 17–28.

care for the "whole person" particular attention must be given to the spiritual domain and identify patient's religious and spiritual needs and resources while carefully respecting each individual's religious or spiritual orientation. "Whether particular individuals view themselves as religious or spiritual in the past, being hospitalized with a serious, potentially life threatening illness more often than not will prompt an existential crisis."[433] Puchalski asserts that asking for information about one's spirituality and assessing spiritual needs requires sensitivity and is a primary role of the professional health care chaplain:

> With specialized training, the hallmark of the certified health care chaplain is their integration of theology and the behavioral sciences…their ability to correctly assess and provide appropriate spiritual care in an interfaith and pluralistic milieu…the health care chaplain is involved in the total care of the patient, implementing a model of spiritual assessment, describing one's plans of care, and demonstrable outcomes…has the expertise to discern ethical issues relevant to end-of-life care, to conceptualize and communicate theologically the meaning of the crisis experienced by persons in the setting in which one's ministry is practiced…they understand the religious and spiritual language and world view of patients they encounter, and provide spiritual support appropriate to the patient's clinical and spiritual context, including emotional and spiritual support for patients who may view themselves as agnostic or atheist.[434]

These relationships are based on trust and respect for the individual; they uphold the code of ethics and standards of professional practice of their certifying chaplaincy

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[433] Puchalski, C. (2006). 123.

[434] Ibid., 121–123.

organizations.[435] Professional chaplains demonstrate a deep commitment, sensitivity, and respect for the diverse ethnic and religious cultures found in North America. [436]

Spiritual care professional chaplains recognize clients to be any patient, family member, staff, or student to whom they provide spiritual care. They have specialized education to mobilize spiritual resources to provide quality of care to help patients find hope and healing when cure is no longer a reality. They maintain confidentiality and provide a supportive context within which patients can discuss their concerns. They are professionally accountable to their religious faith group and the employing institution.

Community Faith Leaders and Spiritual Counselors: Community spiritual care professionals are trained to work with people of all faith traditions and beliefs. They may have a variety of titles, among them clergy or faith leader, spiritual counselor, pastoral counselor, or pastoral care worker. As adjunct support to patients and the hospital palliative care interprofessional team, community spiritual care providers are qualified and grounded in a religious tradition but do not evangelize; they approach the dying person in an open way that is nondenominational, nonsectarian, and all inclusive. Care may be provided by the spiritual care professional in coordination with the patient's own clergy/faith leader (if part of the person's life). The goal of end-of-life care is to support the patient and family. There are various spiritual interventions that can include prayer,

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[435] Chaplains having met the standards for certification can be certified by several professional Organizations including, the Canadian Association for Spiritual Care (CASC), the Association of Professional Chaplains (APC), the National Association of Jewish Chaplains, and the National Association of Catholic Chaplains.

[436] *White paper – Professional chaplaincy: Its role and importance in health care.* (2001).

singing, rites, and rituals as deemed appropriate including assistance in planning and preforming funeral, or memorial services. [437]

Complementary Therapist: The complementary therapist on the palliative care unit is a registered nurse who worked at St. Christopher's Hospice is London, England. Drawing on her knowledge, theories, expertise, intuition as a nurse, and certification as a therapist in various complementary therapies, she uses appropriate interventions in the context of the patient's needs. Her position on the interprofessional team is part of a research pilot project examining holistic integrative therapies; the results verify positive benefits for dying patients, and her research will be published in the near future.

Dying patients spoke of being deprived of nurturing physical contact such as touch; various forms of touch are considered to be holistic/integrative modalities.[438] [439] Modalities used with patients on the palliative care unit include but are not limited to:

Therapeutic Touch: Therapeutic touch is a specific modality of centering intention while the practitioner moves the hands through the client's energy field for the purpose of assessment and treatment. Developed by Kreiger and Kunz, it is grounded on the philosophy that universal life energy flows through and around us, and any interruption in this free flow of energy leads to illness. The goal of this therapeutic intervention is to balance and repattern the body's energy so that it flows more efficiently to promote health and prevent disease. The practitioner scans the client's energy flow, restoring order and balance to the ill system. This approach is also an effective complementary care approach for facilitation of the body's natural restorative processes, thereby

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[437] von Gunten, C.F., Ferris, F., Portenoy, R., & Glajchen, M. (Eds.) (2011).
[438] Credit, L., Hartunian, S., & Nowak, M. (1998).
[439] Dossey, B. (1995a). 429–454.

accelerating healing, promoting relaxation, reducing pain and anxiety, and treating chronic conditions.[440]

Massage Therapy: Many terminally ill patients in the study found massage therapy beneficial in making the physical and mental adaption to a lifestyle that has become increasingly bedridden. The practice of manipulating the patient's muscles and other soft tissues with the intent of inducing physical and psychological relaxation, improvements in circulation, relief of pain and sore muscles can reduce symptoms and improve the individual's sense of well-being.

Reiki: Reiki is based on Buddhist teachings using a hands-on touch to support and intensify energy in the physical, emotional, intellectual, and spiritual areas of one's life. The philosophy of Reiki contends that a person is vitalized by a vital energy that comes from a universal life force. Universal and individual energy are aligned and balanced through the application of gentle hands-on touch to energy pathways of the body. Reiki body work is *not* massage. The touch is gentle and aims not to manipulate tissue but rather to transmit universal life force to the recipient.[441] Learners of Reiki must themselves receive an attunement by an expert Reiki master in an initiation ceremony so they are attuned to the energy transfer process. In the complementary therapist's pilot project, students work with palliative care patients under the guidance of a certified Reiki therapist; observations of their work indicated positive outcomes as confirmed by patients.

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[440] Kreiger, D. (1997).
[441] Abrahams, E. (1999).

Aromatherapy: Aromatherapy is the offshoot of herbal medicine in which aromatic plant extracts are inhaled or applied to the skin as a means of treating illness and promoting beneficial changes in mood and outlook. Though aromatherapy and herbal medicine use many of the same plants, in aromatherapy the plants are distilled into oils of exceptional potency.[442] Sharing an office with the complementary therapist who uses aromatherapy in her practice, I have come to a deep appreciation of the benefits of these oils when rubbed on the skin or inhaled to promote relaxation and other therapeutic effects. Observations of the process reveal no treatment should ever involve more than a few drops of oil. Aromatherapy is also used in the relief of pain (lavender and capsicum) and is most useful in the enhancement of mood, increase in vitality, and relaxation.[443]

The significance and benefits of various complementary therapeutic approaches recognized by Giasson and Bouchard [444] were identified by patients in conversations with the researcher as part of this research study. They spoke of their experience of being nurtured and cared for; a boost in self-esteem; increased motivation to receive and give attention to self and others; a sense of energy and increase in mobility (e.g., range of motion or hand grasp); temporary relief from loneliness and isolation; decreased feelings of abandonment through interactions with staff; and a calming reassurance and support.

Palliative Care Volunteers: The palliative care volunteers fill a very important role in providing hospice care within the hospital setting and in the community. In this study volunteers had diverse backgrounds; they are men and women of all ages and walks of life, even high school teenagers were trained as junior hospice palliative care volunteers.

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[442] Allison, N. (1999). Guided Imagery. 71-73.

[443] Robbins, J. (1999). 5–17.

[444] Giasson, M., & Bouchard, L. (1998). 393–398.

All volunteers are provided training to varying degrees. Volunteers that work directly with clients must complete a minimum 30-hour hospice volunteer training program and pass police background checks before being matched with a client.[445] Specialized volunteer roles may include bereavement volunteers who work exclusively with grieving families and friends or those who sit at the bedside during the dying process. The scope of volunteer's duties is all-inclusive, depending on the patient and family needs and quality-of-life goals. The most common role is working with a single patient and family in providing support through companionship at the bedside and offering respite time for the patient's family. Observations of volunteers on the palliative care unit validate Ajemian's remarks:

> There is often a major gulf between the professional world of the institution or health care program and the community it serves. Volunteers bridge this gulf, bringing a special dimension of community support to the program and reminding health care professionals of the particular needs of that community.[446]

The *Spiritual Care Volunteer* provides emotional and spiritual care support for patients and families on the palliative care unit on Tuesdays; she attends palliative care rounds, and her insights and observations are valued and incorporated into the patient's care plans; she helps facilitate the Tuesday afternoon *Anticipatory Grief Support Group* with the social worker and her colleague from the local hospice for families of patients on the unit. Observations and feedback from patients and families clearly affirm the value of such services and programs on the palliative care unit.

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[445] Ontario Hospice Palliative Care Association.
[446] Ajemian, I. (1994). 17–28.