Spiritual Care of the Dying: A Community Nursing Perspective

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The spiritual care provided by nurses is not obvious. The literature on spiritual care within the context of palliative care nursing is sparse and contradictory. None of the research is from the Canadian perspective. Thus, this project examined the meanings made by palliative care nurses as they provided spiritual care to people who were dying at home. This qualitative study utilized the methodology of the naturalistic inquiry. From a population of 47 Canadian palliative care nurses who provided home nursing in Kingston, Ontario, Canada, six nurses participated in semi-structured conversations about their experience of providing spiritual care within the context of palliative care. Thematic analysis of the data was assisted by using NUD*IST 5 (QSR International Pty. Ltd., 2000) software for qualitative data analysis.

Three major themes emerged: the nurses’ focus of spiritual care on the time surrounding the dying and the death; the nurses’ beliefs about spirituality, religion, and their own work; and the nurses’ evaluation of their spiritual caregiving as evidenced by the “Good Death”. The nature of the nurses’ spiritual care was of guiding, doing the unusual, relating to distress as well as relating to the one cared-for with love and friendship. The nature of the spiritual care is discussed from the perspective of caring as moral grounding and cultural imperative. Consideration is given to empowering nurses through liberating the ethic of care. What the nurses know about spiritual caregiving is looked at through the framework of the art of nursing, the nurses’ beliefs about spirituality, and the hidden work of nursing. As well, the nurses’ evaluation of their spiritual caregiving resulting in “good death” and “death with dignity” is explored.
Noting incongruence between the nurses’ personal beliefs and religiosity and what they want for their patients, the author offers the possibility that caregiving itself has become the religious expression of the nurses.

Implications for nursing encompass the education of nurses, the practice of nursing, as well as the inclusion of nursing knowledge at the policy and budgetary levels. Nursing education must change, from talking about wholistic care, to teaching how to care for the whole person by including care of the spirit in the curriculum. Nurses must end the silence regarding their work of spiritual caregiving by talking about, and documenting the care they give. Moreover, nurses who have knowledge and experience in caring for spiritual distress need to share their knowledge and start the process of mentoring other nurses into the practice of truly wholistic care. Lastly, nurses must become advocates and educators at the institutional and governing levels in order that human needs, including spiritual needs, are included in the decision making about health care policy and budgets.
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DEDICATION

I dedicate this work to my loved ones who have circled Home before me. I name them as: Jacqlyn Ann Duncan Harrington, Dessie Mary Poole Whitmore and Homer Lucien Whitmore, Mabel Lillian Wright Fierheller and Harry Seymour Fierheller, Kathleen Phyllis Whitmore Fierheller and Eldon Harry Fierheller.
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INTRODUCTION AND BACKGROUND

When an Aboriginal people do not have what they need in a particular place, they go “walk about” until they find it. (Havea, April 25, 2001)

1.0 Introduction and Background to the Study

We are born, we live, and then we die. This is the cycle of life. How we are born, live and die is as unique as the individual and as common as all of humanity. For the many: born into circumstances of deprivation and poverty, hunger and danger, the work of life is just to keep on living. For the few: born into circumstances of privilege, abundance and safety, we get to choose how we spend the days and years of our lives. From the privileged position of a white, English-speaking, educated, Canadian woman, I chose to do this study.

I begin with an introduction to the study, followed by an outline of the purpose and significance of the study. Following, I give some background information about myself; who I am, and what is important to me. My background has a direct bearing on the subject matter of the study, as well as having significant influence over the findings, and the discussion. I conclude with a short list of definitions and a brief outline of the paper.
Nurses care for people when they are born, while they live and when they die. When a person is living with life-threatening illness or disease, eventually, her/his life moves toward the dying time. Palliative care nursing, in the context of Ontario Community Care where the study is set, is nursing care of people who are terminally ill and who are dying (Duphney, Personal Communication, May, 2001). In palliative care, the focus is on providing care for comfort, and not for cure. Comfort means more than the absence of physical pain and the distress caused by undesirable symptoms of illness and disease. Moreover, nurses are to care for the whole person, that is, the physical, social, emotional, psychological and the spiritual totality of each individual person. Thus, comfort care encompasses the care for each person in her/his entirety and uniqueness. This study explores the nurses’ experience of providing spiritual care to people who are dying at home.

Spirituality is important to people, whether the individual’s spirit is formed and explored through the framework of religious experience or not. People know they have a spiritual part to themselves, religious or not. Spirituality has been a central theme throughout the recorded and oral histories of the Earth’s peoples in art, literature and music. The spirit, and things spiritual, exerts a powerful force within all people.

Nurses are theoretically educated, and practically trained, to care for people in a “wholistic” and inclusive manner. Thus, to care for a person as a whole person, providing total care requires the nurse to care for the spirit of that person. It follows that
for the nurse to care for the spiritual needs of the one cared-for, in the same way as the
nurse cares for that person’s physical needs, s/he would need to know what spiritual
needs are, how to identify those needs, as well as knowing what actions or interventions
would be appropriate to meet particular spiritual needs.

A review of literature, as well as my personal experience of teaching nursing
theory and clinical nursing, shows that most nurses are not exposed to the theory and
practice of spiritual caring during their period of education and training. Nor are they
being mentored, or encouraged, into spiritual caregiving. Moreover, in fifteen years of
teaching clinical nursing in acute care hospitals, and in such varied areas as oncology,
palliative care, surgery, medicine and gerontology, I have never once read the nursing
diagnosis of “spiritual distress” in a patient chart. Nor have I read progress notes written
by nurses about care they had given, or planned to give, to meet the spiritual needs of
their patients. And yet, throughout the same time span, I have talked with nurses who
told of praying with patients, or who spoke of knowing when the soul leaves the body of
the dying-one. I have heard nurses anguish over the suffering and spiritual pain of ones
they cared-for. I have witnessed nurses attending wakes and funerals of their patients. I
have held nurses as they cried at the death of a patient.

There is something missing. It is missing from the education of nurses and it is
missing from the written record of the care that nurses give. But, it is there in some
caregiving, and it is a part of nurses’ stories. This study explores what is missing: the
care given by nurses for the spiritual care of their patients.
The background to this study is the acknowledgement of the spiritual nature of human beings, the recognition that nursing literature speaks of caring for the whole person, but the education and training of nurses does not prepare them to provide care for the spirit. Yet, somehow, sometimes, nurses do recognize spiritual needs, and they work to meet those needs. It does not seem that they record this care, but they talk about it with other nurses.

1.1 Purpose of the Study

The purpose of the study is to explore the meanings that nurses give to the experiences of providing spiritual care for people who are dying at home. The data from this study shall be used to gain further understanding of the nurses’ experience.

1.2 Significance of the Study

Nursing research provides conflicting evidence regarding the willingness and ability of nurses to recognize spiritual needs and to provide care to meet those needs. Nursing research, or writing, on spiritual care in nursing from the Canadian perspective is virtually non-existent. Thus, this research is initiative within the Canadian context, and adds to the body of Canadian nursing knowledge. This research study

- Explores the nurse’s understanding of spiritual care when caring for people who are dying at home
• Elaborates the possible implications for nurses who provided palliative care at home
• Adds to the body of nursing knowledge regarding spiritual care

1.3 Background of the Researcher

To know how a researcher construes the shape of the social world and aims to give us a credible account of it is to know our conversational partner. (Miles and Huberman, 1994)

I begin this section with a biographical sketch, followed by four stories of personal loss written a priori to this study. These stories were written to explain my beliefs about spiritual caregiving to the study supervisor, when we first met in February 2001. I conclude with a summary of what I learned about spiritual needs, and spiritual care, in part from these four life experiences.

1.3.1 Culture and Education

I am a mature, white, English-speaking woman who was educated first as a teacher and later as a nurse. Between those two periods of formal education, I worked as a teacher of children for a brief time and a teacher of adults for many years. After diploma education and registration as an RN in Saskatchewan, I was invited into specialized training and worked as an Intensive Care Nurse at Regina General Hospital in Regina, Saskatchewan.
Following a move back to my home province of Ontario in 1987, I chose to work as a Home Care Nurse in a mainly rural area about a 90-minute drive northeast of Toronto. It was during this time and work situation that “palliative care found me”. I became part of a small group of nurses who self-taught in pain and symptom management, as there were no palliative care services or providers in the area. At the same time that I was learning about palliative care, and providing palliative care nursing to people living with terminal illness, I started to teach nursing in the RN diploma program at an Ontario Community College.

After moving to Kingston, Ontario in 1991, I began teaching nursing at St Lawrence College, Kingston Campus. Later, I took two years off from teaching in order to build a palliative care education project, write a palliative care educational training manual, and to build a palliative care information centre in another city. Following completion of those projects, I returned to the Faculty of Nursing at St Lawrence. Also, during the early 1990’s, I completed studies for a Bachelor of Arts in Health Studies at Queen’s University.

1.3.2 Personal Life

I am spouse to an ordained Minister of The United Church of Canada, and the mother of three adult children. In January 2003, I became a grandmother for the first time. My family gives me great pleasure and provides significant meaning to my life.
These familial relationships nurture, challenge and ground me, so that I can continue to do the work of teaching and, at the same time, do this research study and writing.

The Christian Church, and in particular, the theologically liberal branch of the Reformed Church known as The United Church of Canada, has been a part of my life, and I, a part of it, since my memory began. I live and work from the perspective of one who believes in God the Creator, the Lover of the Creation. I believe that we are embodied spirit, and that God’s will is that our lives have meaning and that we are called to live the Great Commandment: Love the Lord your God with all your heart and soul and strength and your neighbour as yourself.

1.3.3 Personal Losses

I am the orphaned child of two parents who died more than 10 and 4 years ago. Three of my four grandparents lived to know two of my babies. They all died many years ago. As well, my best friend, Jackie died suddenly and unexpectedly in her own home when we were both 36 years old. Her older children were at school, her husband at work and her 3 year-old child sat beside her body.

My sense of loss and grief over the deaths of my loved ones has been profound, and at times, almost overwhelming. I found the work of grieving to be very hard work. But, I worked hard, and I have come out the other side of sorrow. Some of those losses
are reflected in the following four stories. Through my stories, I make meaning of my world. My stories reflect the shape of my world in time, place and culture.

1.4.3.1 Four Stories

First Story

I am 24 years old and married to a post-graduate student. I am mother of a two year old and three month-old sons. We are financially poor, and we are living more than an hour away from family and friends. I have been experiencing upper abdominal pain since the birth of my second son. I am hospitalized for 51 days in a 6-month period.

The doctors cannot figure out what is wrong, even though the pain is at times so severe that I require morphine in order to be comfortable. Many doctors come to palpate my abdomen. I am exposed to many x-rays and fluoroscope examinations (this is prior to the development of ultrasound, computed tomography (CT), and magnetic resonance imaging (MRI) scans). I endure mid-sternal puncture for bone marrow, and a liver biopsy with no sedation. Some days, Ministers of my denomination of the Christian Church visit with each other in my room. None asks how he could help me. A childhood acquaintance is a nurse on the unit. After initial contact at admission, she never comes to talk to me. When I see her in the halls, I know she is avoiding me. She is never assigned as my nurse. My parents seldom visit, as my Mother’s attention is taken up with caring for my children and for her Father who recently had a cardio-vascular
accident. My husband is a full-time student, sole parent of two little boys, and in despair about my health. My family doctor is the only person who comes and sits with me at odd hours of the day or evening. I am moved to a private room because I cry a lot.

The decision is made that I am to have abdominal exploratory surgery. I go to the operating room believing that I am dying. I am alone, in despair and terrified. I am surprised when I wake up.

Second Story

I graduated from nursing just months ago. I have post-graduate training in critical care. I work as a primary care nurse in a 12 bed, medical-surgical Intensive care unit (ICU) in a large, city hospital. I am admitting an 85-year old woman from emergency. She has an initial medical diagnosis of bowel obstruction. Another, more senior nurse (although chronologically younger), is helping me do a “systems” assessment and hook her up to the monitors. She is sitting up in bed, alert, responding appropriately and with humour. I am sitting on the bed, facing her, and taking her blood pressure. The senior nurse has put the cardiac leads on the woman’s chest, and has adjusted the monitor. She has just turned away and is facing me.

I hear the charge nurse say, “Hey, you guys, look at your monitor!” I look at my co-worker and together we look at the monitor. There is no heart rhythm. I look at the woman’s face. She looks back at me with a quizzical look in her eye, and then a
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moment later, she curls up, unconscious. My co-worker pushes the red button on the wall to call Code 99. The team comes. We work for 90 minutes. After the Internist has talked with her son and daughter-in-law to tell them what has happened, the attempt to resuscitate is stopped.

The team leaves. I collapse down the wall and I am sitting on the floor. I don't know what happened, why it happened, or what to do now.

Somehow, I get myself together and my co-worker and I bathe her, change the bed linen and clean the area. I go to the family waiting area and sit with the family (which by now has grown to include additional family members). I don’t know how I know what to say. I recall thinking about how I would want to be treated and what I would want to hear if this woman was my Mother. I tell them everything we talked about, how she had joked with us, how she was alive one moment and gone the next. I invite them to come to see their Mom and to spend time with her.

When we go into the ICU and to their mother’s bed, I explain why I cannot take the intravenous lines out of her arm, and encourage them to touch her body and to talk to her. I step out of the curtains. After a short time, the family leaves. We prepare her body for the morgue. There has to be an autopsy. This is my first experience of witnessing death.
It takes me a long time before I believe that an act of omission on my part did not kill her. I begin my journey into exploring what it means to care for people who are dying.

Third Story

My Mother is diagnosed with breast cancer. She had a mastectomy, and has taken Tamoxefin for 2.5 years. I have not seen her for almost two months, as I have been recovering from a serious bout of hospital-acquired pneumonia. She mentioned during our daily telephone calls that she is “very tired and lacking energy.” I am finished teaching for the week, and my spouse and I travel the three hours to my parent’s farm in order to celebrate Father’s 75th birthday.

I walk into the farm kitchen and hug my Mother. I take one look at her and I know. My heart aches.

The following week, my sister phones me with the news that Mother has some liver cancer. Well, that is an understatement... Mother has a liver full of cancer.

I start to cry. My body aches and I am in almost constant pain.

She does not believe this is happening to her. She doesn’t want chemotherapy, but she consents to treatment in order to live. She is becoming more ill and weaker by
the day. She is wasting and has ascites. They drain off 1.5 liters at a time. She believes that God has abandoned her. Her distress is overwhelming her, and me.

I am her elder daughter and her primary care nurse. Her Home Care Nurse is incompetent. She never does any pain and symptom assessment, neither does she do anything else my Mom wants or needs from a nurse. She takes my Mother’s blood pressure and pulse and temperature, and then duly records the results with each visit. As well, she records “No complaints”. Mother hates her, and doesn’t want her in the house. I tell Mom to “Play the Home Care Game... if the nurse does not come, we can’t get any other services”. My Mother has her doctor write an order that the nurse is not to come more than once a week.

My Mother dies in the spirit before our eyes. Nothing the family, her doctor, her minister, or her friends do, or say, changes her belief that God has abandoned her. Her spiritual distress is overwhelming to her and to me. She leaves us in spirit before her body or mind is dead. I enter a long period of despair.

Four months later, my Mom dies, in a hospital bed in her own bedroom. I am alone with her, as she struggles towards death. The pain in my heart is so severe that I cannot breathe.

In the months following her death, I cry and I garden. I have a strong need to be with, and to nurture, living things. I withdraw from acquaintances and only see my
closest friends. It is six months before I can go back to teaching nursing. My spiritual wound heals over, but there remains an underlying abscess.

Fourth Story

It is exactly 30 years after the first story, and six years since my Mother’s death. I know that my Father’s life is fading away. I have a difficult relationship with him, and this relationship has become increasingly fractured since Mother’s death. After many months of thinking about getting some counseling, I make an appointment at a Centre run by Roman Catholic Sisters of Providence.

For the next three months, I enter into a process of spiritual direction. I share my stories. I am guided back to my childhood. I am given Biblical scriptures and literature to read. I am encouraged to use ritual, meditation and prayer. I am urged to spend time in silence. I am guided through the reflection of my stories, to discover I have a strong sense of the spiritual, yet I did not recognize the spiritual in me. I have the loving support of spouse, children and friends during this chosen experience. I have migraines and back pain that rarely leaves me. This is hard work.

During this time of spiritual work, my father’s health deteriorates and he is hospitalized. He says he is going home in a week. He says there is nothing wrong that cannot be fixed.
He is dying. He has lived his life in fear, and he is afraid to know he is dying. He ever so slowly slips into a coma. He is peaceful. I am able to sit with him, to provide comfort care for him, to be a daughter during his dying time. Few nurses speak to us. One nurse gives us support for our decision to not commence intensive medical intervention. His minister prays with him, supports the family members. My best friend drives 4 hours to be with me the day he dies. She sits in the hallway. I go to her whenever I need to do so. She is witness to the family story being lived. My siblings cannot deal with father’s dying time, and leave the hospital. Two of my adult children and I sit with him, pray for him, and are witness to his soul leaving his body. It is as if there is no time. Hours of time passed, and I am not aware of its passing. I feel at peace, calm and in the presence God.

1.4.4 Making Meaning

These are four life and loss stories that helped form my beliefs about spirit, spirituality and care for the spirit. The meanings I made were:

- To be human means having a spirit
- There is the possibility of inadequate personal spiritual resources
- Spiritual distress is real and can be overwhelming
- It is possible to be alive and spirit-less, to die in the spirit
- Spiritual distress can transform into spiritual peace
- There are ways to help some who are spiritually distressed
• Sometimes, nothing anyone does will help a spiritually distressed person
• Sometimes, a person is unable to do the work of the spirit
• Each person defines what meaning life, relationships, suffering and death has for her/him
• Christianity informs my spirituality
• Sometimes, nurses do not participate in spiritual care, even when there are clear signs and symptoms of spiritual distress

Through these stories, I share some of my losses and my beliefs about the spiritual nature of humans, the spiritual needs of persons in distress and the spiritual gifts that one person can share with another person.

1.5 Definition of Terms

For the purpose of clarity, I define terms that are shared by nursing in different countries, and thus, these terms may have differing meanings. I define these terms as they are used in the Canadian context.

Palliative Care

Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved (Canadian Palliative Care
Association, May, 1997). Both hospice care and palliative care share the same meanings, but sometimes people use the term “palliative care” when referring to care given in a hospital and “hospice care” when the care is given in the community (Ontario Hospice Association, 2002). At the present time in the Ontario Community Care system, *palliative care means terminal care*. As such, terminal care is defined as “pain and symptom management and care for the last three months of life, as defined by a physician” (Duphney, Personal Communication, May 15, 2001). For the purpose of this paper, the term “palliative care” refers to care in the community, given for pain and symptom management, and for comfort, during the last three months of life.

Community Care

Community Care is the health care service available to people who are living at home and who are living with illness or disease or disability, or who are recovering from medical treatment or surgery. The term Community Care is used interchangeably with Home Care. Home Care services *may* include nursing, homemaking, personal support, physical or occupational therapy. Home Care *does not* include provision of equipment, oxygen, supplies and medications.

Community Nurse

Community Nurse is the nurse who provides nursing care to people in their homes. The term Community Nurse is used interchangeably with Home Care Nurse.
Spiritual Needs

Spiritual needs are complex needs for meaning and purpose in life and suffering, hope and connectedness, relationship with others and a Higher Power.
CHAPTER 2

CONTEXT OF THE STUDY AND LITERATURE REVIEW

2.0 Introduction

This chapter will introduce the study within the Canadian context, and in particular, within the context of Community Care in Kingston, Ontario, Canada. Also, I review the Canadian experience of nursing and spiritual care, and the nurses’ role in spiritual care will be appraised. I end this section with the topic of spirituality and the spiritual needs of people who are living during the dying time. I close the chapter with a summary of the literature and the research question.

Literature searches were conducted in the library collections of St Lawrence College and Queen’s University in Kingston, the University of Toronto and the University of Western Sydney. As well, I utilized my personal library and that of Professor Wilkes. Further, on-line searches were conducted using OVID databases of CINAHL and MEDLINE.

2.1 The Context of the Study

The study is sited in Canada, and in particular, Kingston, Ontario, Canada. The study examines the nursing care of people who are living with terminal illness, and who
are dying at home. Thus, I expand the context of the study to include dying at home; home care, and nursing within the home care system.

2.1.1 Canada - Ontario - Kingston

Canada is a country of over 30 million people (Canada, 2001). Canada occupies the land and waters to the North of the United States, and between the three oceans of the Pacific, Arctic and Atlantic. Politically, Canada is divided into ten provinces and three northern territories.

The province of Ontario is in Central-Eastern Canada, and is a large province of wealth and resources. Ontario is the most populous of the ten provinces with a population of 11,410,046 (Canada, 2001). Ontario gained 656,000 people between 1996 and 2001, the largest growth in absolute numbers of any province (Canada, 2001). This population growth was mainly a result of immigration. Ontario’s 2001 population of 11.4 million was 38 per cent of the country’s total population (Canada, 2001).

Kingston, Ontario, Canada is a small city in the Southeastern part of the province of Ontario. It is located 250 kilometers East of Toronto, the provincial capital, and 180 kilometers South of Ottawa, the nation’s capital. Kingston sits on the northern shore and the Eastern end of Lake Ontario. At this point, Lake Ontario narrows to become the St Lawrence River that flows eastward to the Atlantic Ocean. Across these bodies of water
lies the United States. The same 2001 census shows Kingston with a minor increase in population to 114,195.

Kingston’s settlement predates the European invasions, as it has been the home of the Mohawk First Nation peoples since before recorded time. During the 17th century the French, and later the English, claimed the area as lands of their respective kings. Thus, Kingston is a historic, small, inland city. The city is home to a military base, Royal Military College, five federal penitentiaries, provincial and federal agencies and courts, as well as commercial and industrial sectors.

Kingston is an educational and medical centre with services that belie its small size. Within Kingston, there is Queen’s University, St Lawrence College, Providence Regional Mental Health Centre, the South-Eastern Ontario Regional Cancer Centre, Kingston General Hospital; a major trauma and acute care hospital, Hotel Dieu Hospital; an out-patient and day-surgery hospital, St Mary’s of the Lake; a long-term care and rehabilitation care facility, as well as a number of aged-care homes. Queen’s University has Schools of Medicine and Nursing, while St Lawrence College has a School of Nursing.

Kingston is home to a dominant white, Anglo Saxon, Christian culture. People of various racial and ethnic backgrounds and diverse religious persuasions are resident in Kingston, yet the dominant culture pervades and flavours the city and surrounding area
of Ontario. It was within this privileged, dominantly English speaking, Christian and Caucasian, city that I sited the study.

2.1.2 Canadian Health Care System

The Canadian health care system is very different from the Australian system. Moreover, all Canadians do not know how our health care system is structured. Thus, in order for the Australian, or the Canadian reader, to understand the context of this research study, some background information is provided below.

The Canadian health care system has evolved into its present form over four and a half decades. In 1947, the prairie Province of Saskatchewan was the first provincial government to establish public, universal hospital insurance (Torrance, 1981). Ten years later, the Government of Canada passed legislation that provided for federal-provincial shared funding of the costs of the provincial hospital insurance plans (Torrance, 1981). By 1972, all 10 provinces and the Northern Territories had public insurance plans that provided comprehensive coverage for in-hospital care as well as for doctors’ services (Torrance, 1981, p. 1-28).

In 1979, Justice Emmett Hall reviewed the health services in Canada (Hall, 1979). He reported that health care in Canada ranked among the best in the world, but warned that extra-billing by doctors and user-fees charged by hospitals were creating a
two-tiered system that threatened accessibility of health care. His report resulted in the Canada Health Act.

2.1.3 The Canada Health Act

In response to the concerns raised by the Hall Report, the Parliament of Canada passed the Canada Health Act (Ministry of Health of Canada, 1984). Briefly, health care in Canada is provided through right and entitlement under the Canada Health Act of 1984. This Act of the Parliament of Canada was designed to ensure that all Canadians have right and entitlement to medical care. That is, the Act provided for the care of a physician and access to an acute care hospital. In hospital, all Canadians, as needed, have the services of doctors and the accompanying support services of nursing, social work, occupational and physical therapy, and pastoral care. As well, all equipment, supplies, and medications are provided free-of-charge to the hospitalized person. This list is not all-inclusive, but rather to indicate that when hospitalized, Canadians have access to needed ancillary supplies, medications and professional services. Today, there are no private hospitals in Canada, although that may be changing as I write. Moreover, and with few exceptions, doctors are paid on a fee-for-service basis.

Nurses cannot bill provincial health care plans for services they provide. With the exception of the rare nurse who works in private practice, all nurses are paid on an hourly rate, or annualized salary, regardless of the number or acuity of the patients they
care for each day. Unionization of nurses is haphazard and inconsistent across the country.

The Canada Health Act does not ensure timeliness of care, nor does it provide for equality of service. For example, the people of the heavily populated provinces of Ontario and Quebec have greater access to medical care, increased availability of specialist physicians, easier access to specialized testing and less travel time to larger medical centres (Government of Canada, 2001). In fact, there is no equality of access to health care, nor is there equality of either the physician, or specialized treatment, for all Canadians. But, this is only some of the many shortcomings in the practiced reality of the Canadian Health Act.

2.1.4 Health Care in Ontario

Health care in Ontario has undergone dramatic shifts and changes during the last decade (Greenglass & Burke, 2001). Financial deficits and cutbacks in funding from both the federal and provincial governments have resulted in mergers of hospitals as well as downsizing and even closings. One-third of hospitals beds have disappeared. The effect on nurses has received much less publicity than wait times in emergency departments, or postponed surgeries. Yet, Ontario health institutions have made over 10,000 nurses redundant. People who need medical and/or nursing care face earlier discharge from hospital, and experience the lack of adequate long-term care and aged care facilities. Moreover, they do not receive the level of home care, that they have
been lead to believe is available to them, as the government’s promises of corresponding increases in funding to long-term care and community care have yet to materialize.

Since 1996, the Registered Nurses Association of Ontario (RNAO) has been studying restructuring and the linked impact and stress on nurses. This study, “Ensuring the Care will be There: Report on Nursing Recruitment and Retention in Ontario” (Registered Nurses Association of Ontario, 2000) surveyed over 1300 Ontario nurses. They were asked questions regarding the impact of restructuring in their hospitals. As well, they were asked questions regarding their psychological reactions to restructuring, from no reaction to anxiety and depression to burnout. The study findings indicated nurses' employment roles have been dramatically altered, as has been the working environment. For example, unregulated care providers have replaced nurses, there is increasing casualization of the nursing role, poor staffing patterns, and increasing patient care loads. Nurses are experiencing emotional exhaustion, disillusionment, psychological distress, and unmanageable workloads. Moreover, nurses are now required to supervise unregulated generic workers, many of them doing the personal care work that once was the work of nurses. According to the RNAO report (2000) "The sustainability of the profession is under threat. The result is that nurses leave and recruits fail to enter the profession" (p.7). It was during this time of nursing shortage and unmanageable workloads that I did the research for this study.
More and more, the people of Ontario are finding themselves either undergoing extensive surgery on an out-patient basis (including mastectomy), or being discharged from acute care hospital unable to care for themselves, or having no aged-care facility able to admit them when they can no longer cope with living in their own home. About 15% of Canadians die at home (RNAO, 2000). Sometimes, death at home is a result of lack of access to acute-care or long-term care services and the nursing care such institutions could provide. Families are forced to cope within a system that does not meet the needs of the citizens. Sometimes, people die at home as their preference.

Sadly, there are no goals of social policy regarding death and dying in Canada (Singer, 2000). In 1991, the Cancer 2000 Task Force made 117 recommendations for increased prevalence and effectiveness of palliative care, e.g., that cure-oriented and death-denying polices be revised to include a focus on the control of suffering in both public education and fund raising (Singer, 2000). Moreover, the Canadian Senate Report on palliative care in Canada reached the conclusion that end-of-life care is fractured, fragmented, hard to access, and with too few properly trained health professionals to provide the accessible, compassionate and quality care that Canadians need (Senate, Government of Canada, 2000).

2.1.5 Dying at Home

There is a strong social movement toward “dying at home”. This social movement is not exclusive to Canada, but also appears in Australia, Great Britain, and
the United States. Some people want to live their dying time surrounded by loved ones in personalized surroundings. Thus, the health care services that any one person might require if s/he was living the last months or days in a hospital ought to be available to that same person while dying at home (Canadian Strategy for Cancer Control, 2002). Unfortunately, that is far from the reality in Canada, and in the Ontario Health Care system (Canadian Association of Provincial Cancer Agencies, 2002). Canadians have no right or entitlement to nursing care, or to home care, or to prescription drugs and/or to equipment and supplies. So, for the many people who require nursing or other supportive care when ill or dying at home, the needed services may or may not be available to meet their needs (Canadian Strategy for Cancer Control, 2002).

Particularly troubling is an American study of nine thousand patients that confirmed the widespread impression that the wishes of terminally ill people are not being respected (SUPPORT, 1995). In the first phase of the study, researchers observed the care given to patients at five medical centres and found that many of them died in moderate to severe pain. In the second part of the study, an intervention was put in place to improve communication with the family and to improve pain and symptom control. After two years, the intervention was evaluated as a failure as it did not produce any real change in how patients were treated. Although this was an American study, the findings reflect the situation in Canada.

The Senate of the Government of Canada (2000) studied the quality of end-of-life care of Canadians. The Senate subcommittee heard that many of the recommendations
from its 1995 report on dying in Canada had not been implemented, and indeed there is a crisis in end-of-life care in Canada.

"There was evidence of uneven provision of services, and disruptive and ineffective care leading to sub-standard outcomes... an absence of measures to address the situation, no increase in palliative programs, no evidence of increased funding for palliative care services, no national health strategy " (Report, Senate of Canada, 2000, pp.6-7).

The study found that only five percent of Canadians receive integrated and interdisciplinary palliative care, and although about one quarter of total deaths in Canada are related to cancer, cancer patients make up more than 90% of those receiving palliative care (pg 8).

2.1.6 Home Care in Kingston, Ontario

Prior to 1997, Ontario had a Home Care System (Lukits, 2002, p. 1). Under that system of health care delivery, a person was assessed by a Home Care Coordinator, who was employed by one of the Home Care District offices in Ontario. Nursing, homemaking, and personal support services/equipment were supplied to that individual on a needs basis for no charge. For a person, or a family with low income, Home Care provided drug benefits.
These services, including nursing, were contracted out to "not-for profit" agencies and some private supplier companies within each geographical area. Service was based on need and the availability of service providers. The Provincial Ministry of Health paid the bills, and the costs were escalating as our population aged and as acute care and long-term care facilities, with frozen budgets, could not accommodate the increasing population growth.

Then in 1997, under a change of Provincial government, a new home care delivery system was initiated at the Provincial level. In January 1997, Community Care Access Centres, generally known as CCACs, were established as non-profit corporations under the Corporations Act. Each Centre had a 12-member board of directors, chosen from a broad cross section of the respective community (Plunkett, 2002, p. 5)¹. The 34 Community Care Access Centres replaced the Home Care system. These regional centres, known as CCACs, had their own locally appointed Board of Directors, chosen from the specific geographical area. The Board had oversight of the budget, which was predetermined by the Provincial Minister of Health. Both for-profit companies and not-for-profit organizations were invited to bid on service contracts. The Ministry of Health established the criteria for selection (Plunkett, 2002, p. 5).

¹ Tom Plunkett, former Chair of the Board of Governors for Kingston General Hospital and the KFL&A Home Care became the first Chair of the Board of Directors of the newly formed CCAC.
Since conducting the research interviews for this study, the home care system has continued to change. Early in 2002, with mounting criticism of the government for inadequate funding, the province wrote new legislation. Under Bill 130, the Province of Ontario took control of the regional home care budgets and the management of those budgets (Ontario, 2002). The CCACs were forbidden to run a deficit. Moreover, the Bill provided for the dissolution of the existing CCACs and their replacement with statutory corporations. The existing Community Boards of Directors ceased to exist and were replaced by government appointees. The Provincial government pays to the CCAC what the Ministry of Health has determined to be the budget for the year. This budget is not based on either the needs of the community or on the current caseload (Plunkett, 2002, p. 5). Thus, in some areas, including Kingston, caseloads are frozen and admissions are closely monitored in an attempt to meet the budget requirements (Plunkett, 2002, p. 5). “Nursing staff have been laid-off or had their hours of work cut. The remaining nurses work under conditions that are terrible, just terrible" (Manager, CCAC. Personal Communication, January 12, 2002). “They have lost all power to meet the needs of the people. It is a very stressful environment” (Manager, Nursing Agency. Personal Communication, June 15, 2002). Exceptions are made in few cases, and “palliative care seems to be one of the exceptions when nursing services will be provided to the person who has been medically assessed as being in the last 3 months of life” (Manager, CCAC. Personal Communication, January 12, 2002).

In July 2002, the provincial government dismissed all 34 Boards of Governors and appointed all Chief Executive Officers (CEO) of the CCACs. In Kingston, the CEO
of the Access Centre resigned (Lukits, 2002, p. 1). The Minister of Health appointed all of the Board Directors, the CEO's and the Managers. The intent of such centralist action seemed to be that all decisions will be made from a central government office as well as ensuring there will be no dissent or criticism of the government policy. It was within this politicized and externally controlled home care environment that the nurse-participants to this study cared for people who were living with terminal illness.

2.1.7 Home Care Nursing in Kingston, Ontario

The Community Care (Home Care) district office in Kingston, serves the areas of the City of Kingston, and the small towns, villages and rural areas of the counties of Frontenac and Lennox & Addington. The large and mainly rural counties of Frontenac and Lennox & Addington are in the geographical areas to the north and west of Kingston. This home care district office is known as KFL&A Community Care Access Centre (KFL&A-CCAC). The CCAC provides home care assessment and coordination as well as long-term care placement of the elderly in the City of Kingston and the two counties.

The CCAC does not have any home care nurses or any other primary care providers on staff. The CCAC is an assessment and placement agency of the Provincial Government. Some of the case managers and coordinators are nurses. Others are of allied health professions, such as occupational therapy. Companies and agencies that win contracts in a bidding competition initiated by the CCAC provide the community
nursing and other allied health care services. The agencies that have the current contracts for home nursing care services in the KFL&A region are located in Kingston.

Nursing and other services are purchased by the CCAC through a bidding process where both “for profit” corporations and “not-for-profit” agencies may bid. This brokerage model is designed to provide “an impartial, inter-organizational approach to coordinating services, containing system costs, and preventing inappropriate client access and use of services.”[McWilliams, 2000 #135]² The “for-profit” companies in this part of Ontario are a mix of relatively new Canadian start-ups and branches of huge American corporations. Under the newly formed CCAC, the first contracts for palliative care nursing were awarded in the spring 2000. Hospice Kingston, which had provided specialized palliative care nursing, as well as trained volunteers, was assessed as not having met the bidding criteria (Duphney, Personal Communication, May 2, 2001). Rather than resubmit a bid, the Board of Directors of Hospice Kingston made the decision to withdraw nursing services. All the Hospice nurses were laid off (Duphney, Personal Communication, May 2, 2001).

Three agencies were successful in winning contracts for the provision of palliative care nursing in 2000. The first agency is Agency A, a privately owned, relatively new (20 year) Ontario Company. The second agency is Agency B, a not-for-profit organization that has been providing community nursing in Canada for greater

² The brokerage model is seen to be inadequate when cases or caseloads reach ever-increasing levels of complexity or with able and willing clients who wish to manage their own home health care (McWilliams, 2000b, p. 143-155) p. 147.
than 100 years and has been providing palliative care nursing in Kingston area for as long as there has been palliative care nursing. Agency A was awarded a palliative care and oncology-nursing contract for the first time in 2000. A third company was awarded a palliative care contract but declared bankruptcy before accepting clients.

2.1.8 Home Care and Pastoral Care

During my brief stay in Parramatta, NSW, Australia during February-April 2001, I learned that the New South Wales Government contracts with the Churches for provision of some of the education, social and health care services. Thus, it appears as though the ethos of the Church may be integrated within the social fabric of Australia (Johnson, Personal Communication, March 13, 2001). There is no comparable ethos in Ontario, Canada. The separation of Church and State is almost total within our society. The Churches are not invited, nor do they bid on government contracts for the provision of health care or any other social services. Nevertheless, there are some health services that are managed by Churches that continue from historic relationships (Allemang, 2000, p. 4-32).

Historically in Canada, the Churches cared for the poor, the indigent and the sick and dying. Thus, our country has a long history of hospitals and nursing care being initiated by both Roman Catholic Nuns and Protestant Churches and later, by some Jewish communities (Allemang, 2000). These are long-standing Roman Catholic hospitals, Jewish hospitals, United Church of Canada outpost medical/nursing services,
and church sponsored aged-care facilities. But today, the influence of the Church in health care is minimal. We have a very secularized health care system.

Within the acute care hospital sector, the provision of Pastoral Care services is a requirement for hospital accreditation. There is no corresponding requirement in long-term care or the home care sectors. Thus, when hospital beds were closed and health care was downloaded to the community, there was no corresponding downloading of pastoral care services or the spiritual care given by chaplains. As a result, there are no community-based health care chaplains in Ontario. I understand this is the same in Australia. As I will discuss later in this paper, hospital nurses tend to equate spiritual care with religious care and refer to hospital chaplains (Danvers, 1989; Narayanasamy, 1993; Ross, 1994). The question follows of what happens to persons with spiritual needs in a nursing care environment when there are no chaplains?

The hospital nurse’s reliance on chaplains and the lack of chaplains in home care has a potentially significant impact on the spiritual care of people who are terminally ill and dying at home. Moreover, as one community clergy suggested, “if the dying person has not had a relationship with the church prior to illness, then it is rare that a relationship is established once the person is living with terminal illness.... If a relationship is initiated, then it is usually one of crisis management”(MacKay Llewellyn, Personal Communication, January 25, 2001).
2.2 Spirituality and Nursing

In this section, I review the literature on spirituality and nursing. First, I offer the cultural context followed by definitions of spirituality. Next, I discuss the spiritual needs of the dying ones followed by a discussion on the nurses’ role in spiritual care. Subsequent, I will examine the Canadian nursing literature and assessment tools that could be used by nursing to help determine the spiritual needs of their patients. Following is a discussion on nurses as agents of spiritual care. I end this section with a summary of the literature review.

2.2.1 The Cultural Context of Spirituality

In North America, every Friday afternoon at 4 pm Eastern Standard Time, 330 million people have the option of “Discovering Your Spirit” on television. The Oprah show, produced live from Chicago, is distributed across the North American continent, and across the world to such countries as Australia. Oprah Winfrey, an African-American, and self-identified Christian woman, is a well-known celebrity who has dedicated one of every five programs to helping people discover their own gifts of the spirit as well as providing an international forum for discussion of “things spiritual”. American television also provides an increasing number of shows focused on the host being the “medium” through which specific audience members contact their dead ones and receive confirmation of continuing relationship from beyond the grave.
Thus, an awareness and discussion of the human spirit and spirituality, as well as commercial interest in the experience of the spirit and the afterlife is easily accessible to almost everyone in North America and to some who live beyond those boundaries. Things spiritual and spirituality have become part of the global and secular marketplace. The question of what has created this secularized, commercial interest in spiritual matters will not be examined in this paper. Rather, I raise the phenomenon of commercialization and popularization of the spiritual and spirituality within the popular culture of the United States, and by extension through the American domination of Canadian television and print media, within the popular culture of Canada.

This popularization of spiritual matters crosses ethnic, racial and religious boundaries. Canadians do not need to enter a church, synagogue, mosque, temple or meeting place to become aware of this en-cultured and commercialized spirituality. This popularized version of spirituality does not need religious training, education or theology. All one requires is a television and the time to watch it.

The purpose of introducing this popularized and commercialized form of spirituality is two-fold. First, I name it as a part of the Canadian consciousness. The phenomenon of secularized and commercialized spirituality is a part of Canadian culture. I suggest that I, and the nurse-participants to this study, have been influenced to varying degrees by the popularization of these forums for spirituality. As well, people who have never been involved in religion or religiosity tend to adopt some religious
beliefs/activities to their lives. Examples from a dominant Christian cultural context would be acceptance of the religious injunction to “love your neighbour”, celebrations of Christmas and Easter, baptizing children, marrying in a church.

2.2.2 The Spirituality of Canadians

Reginald Bibby is the leading Canadian researcher in the field of religion and spirituality. His extensive national surveys of adults and youth span the years 1975 to 2000 as well as a sample of 200 people (2001-2002) across the country. His research showed that “the gods are restless: secularization has been exaggerated, the Mainline Protestants and Catholics are beginning to join the Evangelicals in showing signs of revitalization, and a surprising number of adults and teens indicate they are receptive to greater involvement in the churches if they can find it to be worthwhile” (Bibby, 2002, p.4).

Even apart from organized religion, Bibby found most Canadians continue to address the big questions about purpose and suffering and life after death. Moreover, Canadians believe in God, are talking to God, and are convinced they are experiencing God. “Canadians, in large numbers, are expressing spiritual needs and interests, with many identifying themselves as spiritual” (Bibby, 2002, p. 190). The prevalent assumption is there has been a surge in spirituality since the 1980’s, and this perception has been documented by the findings. During the 1990’s, some 31% of women and 20% of men indicated an increase in their interest in spirituality. In the same survey, 12% of women and 15% of men spoke of a decrease in interest in spirituality. The net
gain for interest was therefore 19% for women and 5% for men, or about 12% overall (Bibby, 2002, p. 192-193). Moreover, age variables were taken into account in the research of spirituality. From ages 18-55+, between 71% and 74% of Canadians state they have spiritual needs, while from 66% to 75% of the same group say that spirituality is important to them (Bibby, 2002, p. 193).

Bibby’s studies included asking questions regarding what people have in mind when they speak of spirituality. The responses were coded as “conventional” or “less conventional”. The conventional category included responses that spoke of religious beliefs and meanings, while the less conventional responses spoke of “inner self or soul, peace of mind, meditation, seeking answers to the meaning of life, feeling at oneness with the earth”, to name a few (Bibby, 2002, p. 194-196).

Bibby pointed out that large numbers of Canadians do not see spirituality in the same way as most of their neighbours who are involved in the country’s religious groups. Thus, interest in spirituality among Canadians is very high among people involved with religious groups and also with people who are not religious. “More than one in two Canadians expresses spiritual needs, and those numbers are readily exceeding the one in five people who are actively participating in religious groups” (Bibby, 2002, p. 197).

In summary, Canadians tend to have increasing interest in spirituality, whether or not they are active in religious groups. Moreover, the sense of spirituality, as reflected in
the conventional and less conventional meanings shared by Canadians seem to resonate with the definitions offered by writers from nursing literature.

2.3 The Canadian Experience of Nurses and Spiritual Care

The nursing literature about spirituality and nursing originates from countries other than Canada. The literature about spirituality and spiritual care is mainly British, American and Australian. The existing literature holds to themes that are relevant for the Canadian nursing researcher, but may not reflect the particularity of the Canadian cultural context. I was not able to find any published nursing studies on spiritual care and nursing, nor was I able to discover any publications on spiritual care of the dying from a Canadian nursing perspective.

I did find one unpublished paper on spiritual assessment and nursing written from the perspective of in-hospital care (Coulson & Malo, 2000). The paper discusses barriers to providing spiritual care including: not knowing how to recognize the problems or symptoms of spiritual distress, lack of awareness, fear of not being able to handle the situation, pluralism, confusion regarding spirituality and religion, and attitudes related to illness, suffering and aging. Good listening skills, attentiveness, probing questioning, and referral to pastoral care are offered as ways the nurse can respond to patient needs.
There is a Canadian instrument to measure nurses’ knowledge of palliative care (Ross, McDonald, & McGuiness, 1996). The Palliative Care Quiz for Nursing (PCQN) is a true or false, 20-item instrument that assesses knowledge, and identifies misconceptions about palliative care nursing. The quiz focuses on physical care and does not include any concepts of spiritual care.

Coming out of the Edmonton (Alberta) Regional Palliative Care Program are two tools, developed primarily for physician use, but now utilized by nursing as well. These tools are The Edmonton Symptom Assessment System (ESAS) (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991) and The Edmonton Functional Assessment Tool (EFAT) (Kaasa, Loomis, Gillis, Bruera, & Hanson, 1997). Neither tool incorporates a spiritual assessment. Kingston palliative care physicians and nurses are now using the ESAS tool.

The College of Nurses of Ontario (CNO) governs the practice of nursing in Ontario. The College sets the criteria for becoming a nurse, and the standards of practice to be met in order to maintain that designation and privilege (College of Nurses of Ontario, 2000). CNO also develops practice documents that provide nurses with guidance and direction in their everyday practice of nursing.

One such practice document is the Ethical Framework (CNO, 1999a, p. 4). There is one definition from this document that is significant for this study.
Caring: In the literature caring is defined in a number of different ways. Caring can be considered the behaviours, actions and attributes of the nurses. Caring nurses listen to and are empathetic with clients’ points of views. Generally, caring requires recognition of clients as unique individuals whose goals nurses facilitate. Clients’ values and choices are of primary consideration when planning and providing care and the nurses personal values must never interfere with clients’ rights to receive care.

A second College of Nursing document is the Standard for the Therapeutic Nurse-Client Relationship (CNO, 1999b, p. 4). In this document, there are two definitions and a statement of philosophy that relate to this study. They are as follows:

A boundary in the nurse-client relationship is the point at which the relationship changes from professional and therapeutic to non-professional and personal. Crossing the boundary means the care provider either misuses the power in the relationship to meet his/her own personal needs rather than the needs of the client, or behaves in an unprofessional manner with the client.

Intimacy: This does not refer to sexual intimacy. In this context, intimacy relates to the kinds of activities nurse perform for and with the client that create personal and private closeness on many levels. This can involve physical, psychological, spiritual and social elements.

The Statement of Philosophy about the Nurse-Client Relationship: The nurse –client relationship is established and maintained by the nurse through the use of professional nursing knowledge and skill, and caring attitudes and behaviours. The nurse-client relationship is therapeutic; it is based on trust, respect and intimacy with the client, and requires the appropriate use of power.

2.4 Definitions of Spirituality from Nursing Literature

It is acknowledged in Western/English nursing literature that traditionally spirituality was associated with Judeo-Christian religion or non-Christian religions
(Oldnall, 1996). Nevertheless, there seemed to be consensus that in order to be inclusive of all peoples, one ought to define spirituality from both a religious and a secular perspective.

There are a number of themes evident in nursing literature concerning spirituality. Each theme is expanded in the subsequent discussion on spirituality. These themes are:

1. Difficulty defining the meaning of spirituality
2. Need for inclusive, broad definitions
3. Finding meaning and purpose
4. Relationship between Self, Other and God (highest value).
5. Life force, inner strength, ability to transcend the limitations of the physical/mental self.

There was significant evidence that it was difficult, if not impossible, to reach a consensus on the meaning of spirituality. A number of authors, who wrote from the nursing perspective, suggested it is impossible to define the meaning of spirituality as there was no single authority and because of individual interpretation (Martsolf & Mickley, 1998; McSherry, 2000; McSherry & Draper, 1998; Narayanasamy, 1991; Oldnall, 1996). The majority of published writing on spirituality focused on theorizing and conceptualizing the term within very broad definitions (McSherry & Draper, 1998; Meraviglia, 1999; Narayanasamy, 1991; Reed & Reed, 1992; Stoll, 1989). An
alternative voice suggested that the difficulty in defining spirituality is not clarifying the issue; rather it is clouding the concept of spirituality (Oldnall, 1996).

Most writers agreed that spirituality is a part of what it means to have a human spirit and to be a human being. Spirituality was seen to be a personal experience and is unique to each person. Moreover, concepts of spirituality contain notions of connectedness.

The nursing literature that included a theological perspective focused on the theme of "connectedness" as related to God and the human response to God, to oneself and others and to nature (Dyson, Cobb, & Forman, 1997; Hunter, Malony, Mills, & Patton, 1990). In theology, spirituality is concerned with "right relationships" and understandings about God as expressed through religious beliefs and practices (MacQuarrie, 1992). Oldnall (1996) summarized the definitions of other writers to form the definition of spirituality from a religious perspective as:

"the ideology of the imago Dei (image of God), or soul, existing within every person, making the individual a thinking, feeling, moral, creative being able to relate meaningfully to a God (defined by the individual) and others.... with reasons for living, and beliefs that help explain the meaning of life, suffering, health and illness" (Oldnall, 1996, p. 139).
Although Oldnall formed this inclusive, theologically-centred definition, he also considered it important to define spirituality from both a religious and a secular perspective in order to find areas of commonality, so that care of the spirit can be part of holistic care.

Spirituality from a humanistic or secularized perspective embraces a “set of acquired values that become the focus of life, and which motivate the individual toward fulfillment of needs, goals and aspirations, thus leading to the ultimate achievement of self-actualization” (Maslow, 1968, p. 25). This quest for self-actualization may encourage a person toward a spiritual quest that “exists on the human plane and is solely dependent on the individual’s ability to be self-sufficient, to succeed, and to discount negative possibilities” (Oldnall, 1996, p. 139).

But, negative events do happen in people’s lives. Hence, a definition ought to include the possibility of finding meaning within those undesirable events. Therefore, to encompass the possibility of negative events, spirituality was further defined in terms of relationships between self, others and ‘God’, finding meaning in life, illness and suffering, holding hope, being connected in relationships and with beliefs in a principal value in life (Dyson et al., 1997).

The final theme offered in literature is one of life force, inner strength, or ability to transcend the limitations of the physical/mental self. It may be that concepts of spirituality are broader than those offered by the previous definitions. The spirit within
each individual may be considered the 'driving force' that gives meaning to life for that person, and in doing so, helps to create a set of values and beliefs that can influence how the person lives her/his life (Murray & Zentner, 1989). Thus, what may be beneficial to one person may not be of benefit to another (Oldnall, 1996, p. 139). Moreover, it was suggested that there are two dimensions to spirituality. The vertical dimension represents the person's relationship with the Life-Force/Creator/Supreme Value and the horizontal dimension of relationship with self, others and the world (Stoll, 1989). Furthermore, religion/transcendence provides for inner strength and the ability to rise above the limitations of the physical body (Bradshaw, 1994). Thus, spirit, mind and body make a whole (Kendrick & Robinson, 2000). Defined this way, all aspects of personhood are equal, and nothing is missing (Golberg, 1998).

All of the reviewed literature was written from the encultured perspective of the individual being the primary unit in society. Thus, none of the literature spoke of spirituality or spiritual care from the perspective of cultural groups in which the extended family unit, or the entire community, is considered the social entity of highest value. Some examples of such family/community-based societies in Canada are the First Nations and Inuit peoples, and the Hutterite and Amish religious-based communities. I raise the issue of cultural norms as a caution that some social groups who hold to value systems other than individualism, and which are part of Western/English societies, have been left out of all the definitions and nursing literature thus far.
In summary, there are increasing attempts to both re-integrate spirit with mind and body as well as to broadly define spirituality from a humanistic/secular position. (Dyson et al., 1997; Elkins, Edstrom, Hughes, Leaf, & Saunders, 1988; Golberg, 1998; Martsof & Mickley, 1998; McSherry & Draper, 1998; Narayanasamy, 1991; Stoll, 1989; Wright, 1998). Moreover, there is a renewed attention on spirituality within health care (Davidhizar, Bechtel, & Cosey, 2000). Yet, the emphasis in nursing literature remains on defining spirituality, with few references regarding the experience of either receiving or providing spiritual care. There was no published literature, to my knowledge, on spiritual care in nursing from Canada.

2.4.1 Religion and the Expression of Spirituality

Religion can inform; that is, provide a form, for expressing spirituality through a framework of values, beliefs and practices. For some, religious beliefs provide answers, or at least a direction to answering the essential questions of life, death, suffering and meaning (Govier, 2000). Some people find spiritual expression inside established religious communities such as Judaism, Christianity, Islam and Buddhism. Others find meaning in less organized and or less dominant religious communities such as Wicca and Aboriginal Spirituality. Still others find life meaning and expression of spirituality in a more humanistic or secular belief system. It is important to note that within the culture of place and socialized meanings, a tradition of non-religiosity remains a religious tradition (Rutland, 1994). Thus, an inclusive perspective offers the insight of no opposing force
between the religious and the humanistic/secular. Yet, regardless of structure and form, humans find life meaning within a belief system (Rutland, 1994).

2.4.2 Human as Embodied Spirit: An Inclusive Perspective

From an inclusive perspective, I propose the concept that humans are embodied spirits, journeying at a specific time, bound to and sharing kinship. How our spirituality is lived out is as individual as each of us, and as common as our common humanity. The language we choose when defining the work of the spirit provides a window to our understanding of spirituality. The range and possibilities of meanings of human spirituality are as endless as there are individuals. Thus, any attempt to define spirituality needs to consider the widest possible interpretation in order to be inclusive of all peoples who make up our multi-cultural, multi-faith, humanistic and secular society.

2.5 The Human Experience of the Spiritual in Nursing Research

The human experience of spirituality and spiritual care in nursing has provided some useful data for nursing theory and practice (Baines, Evans, & Neysmith, 1991; Banks, 1980; Davidhizar et al., 2000; Durham & Weiss, 1997; Georgesen & Dungan, 1996; Golberg, 1998; Highfield, 1992; Jarret, Payne, & Wiles, 1999; Maeve, 1998; McSherry, 1998; Stallwood, 1975). These perspectives include the complexities of the human experience, as well as the difficulties in offering a definition of spirituality that is all-inclusive. Thus far, the major emphasis in nursing literature remains on formulating a
definition of spirituality that applies to all peoples, regardless of cultural, ethnic, religious, secular or humanistic life-view. Indeed, nursing needs to know what spirituality means; however, I suggest that spirituality in nursing means little if one restricts one's work to defining the meanings of the non-material aspect of humanity.

Rather, I propose that spirituality is like hoping. The definitions by themselves do not give insight into the living experience of being a spiritual person any more than a definition of hope tells us anything about what it means to hope. Just as hope is a meaningless term without knowing about what it means to live in hope, or to live without hope, so defining attributes of spirituality have little to do with increasing our understanding of what it means to live in the spirit or to be a spiritual person.

To be a spiritual person, that is, to exercise the work of our spiritual self, requires relationships between self, others and a Supreme Value, e.g. God,( Dyson et al., 1997; Murray & Zentner, 1989; Oldnall, 1996). The need for relationship in order to do spiritual work could be said to be a prerequisite for most people. This need for relationship does not to negate the value of meditation and/or prayer, both of which could be viewed as individualist as well as corporate acts. Human beings are, for the most part, relational beings. This need and desire for contact and communion with others, and with whatever we hold in highest value is very significant. Consequently, spirituality is explored in context of community, where there can be giving and receiving of love and forgiveness, trust and mutuality. Touch, listening and presence enable the work of the spirit (Dyson et al., 1997). The work of the spirit has the goal of spiritual
well-being. Spiritual wellness enhances one's inner resources and the "discovering of wholeness" (Dyson et al., 1997, p. 1184). It is within the community of the patient-nurse relationship and the nurse-family relationship that the nurse is offered the opportunity to explore the meaning of spirituality and spiritual care within the context of caregiving.

2.6 The Nurse's Role in Spiritual Care

A strong theme emerging from the literature is the theme of relationships between self, others and 'God'. The nurse cares for people who need caregiving. That is, the nurse cares for people who can no longer care for themselves due to injury, disease or weakness. As caregiver, the nurse is in intimate relationship with (at the least) the body of another human being. The nurse does for another person what, in normal circumstances, the person would do for her/himself. By this "doing", the nurse enters a relationship that is far from being social. The physical intimacy of nurse and the one cared-for offers both the nurse and the one cared-for opportunities "to know" one another; an opportunity rarely shared by most family members, friends, or other health care providers (VandeCreek & Nye, 1993).

One common element in discussions of nursing is indeed relationship. To nurse means to be in relationship with others. The relationship between the nurse and the nursed influences how the partnership functions (Bradshaw, 1994, p. 317). Some relationships are physical while others are emotional. Few are seen to be of a spiritual relationship, or, meeting of spirits. Nurses are professionally obligated to provide
Spiritual care (Wright, 1998). But literature suggests they often do not give spiritual care because of lack of education (Dorff, 1993), fear of invading privacy (Dorff, 1993; Carr, 1993), lack of time (Piles, 1990) and lack of awareness of one's own spirituality (Carr, 1993). Yet, Bradshaw (1994) states "spiritual care is inseparable from physical, social, and psychological care because together they form the whole" (p. 282). Moreover, Bradshaw considers the spiritual ethos of nursing as having been lost to secularization, which she characterized as "breaking the lamp" (p. 256). Nevertheless, spiritual care continues to be part of the domain of nursing, at least in theory.

The North American Nursing Diagnosis Association (NANDA) identifies spiritual distress as a nursing diagnosis (NANDA, 1996; NANDA, 1998). Moreover, there is validation of the nursing diagnosis of spiritual distress related to pain, with grief and hopelessness present for all patients in a study of cancer patients (Georgesen & Dungan, 1996). The International Council of Nurses' Code for Nurses (1973) states that nurses should promote an environment in which the values, customs and spiritual beliefs of individuals are respected. The nursing profession consistently states that its approach to care is holistic, implying that all aspects of the person are included in nursing caregiving (Van Heere, 1997). Nevertheless, there is little literature available to guide nurses to meet their patient's spiritual needs (Van Heere, 1997). Yet, both patients and nurses see the provision of spiritual care as a legitimate part of nursing practice (Bush, 1997). There seems to be too little spiritual care by nurses. There may be a variety of reasons for the lack of spiritual care in nursing. One is the lack of ability
to appreciate the spiritual needs of the persons for who nurses care (Oldnall, 1996, p. 139-140).

There are additional explanations for the dearth of spiritual care in nursing. Nursing is not providing holistic care, regardless of the common conception, as spirituality does not occupy a prominent position within the theories, education, or practice of the profession (Oldnall, 1995; Oldnall, 1996). Further, there are reasons of embarrassment, lack of qualitative nursing research, lack of literature on spiritual caregiving from a nursing perspective, nurses working from the positivist and medically dominant model, the nurses’ lack of ease with their own spirituality and lack of ability to appreciate the spiritual needs of the persons for whom nurses care (Carr, 1993; Dorff, 1993; Piles, 1990; Wright, 1998).

2.7 Spiritual Needs of the Dying

*May you be wrapped in tenderness, you my brother (and sister), as if in a cloak. (Holy Qur’an)*

In a review of the nursing literature from 1975 to 2001, with the focus on the use of spiritual coping strategies, (Baldacchino & Draper, 2001) only five of 187 articles explored spiritual coping strategies used by ill patients. Four of the studies were conducted in the USA and one in the UK. The research suggested spiritual coping strategies that involved relationships to self, others and God or Nature were able to help people cope with illness because they found meaning, purpose and hope in suffering.
This study concluded that illness results in lack-of-control feelings for people, however; spiritual coping strategies may boost empowerment and lead people to finding meaning and purpose in their illness.

When illness is life threatening and/or causes pain, suffering is compounded, and this suffering results in spiritual distress. Physical and emotional distresses are seen as defining characteristics of spiritual distress (Kendrick & Robinson, 2000). Spirituality has been cited as integral to the dying person’s achievement of transcendence and is important for health care providers to both recognize and foster (Highfield & Cason, 1983). As there are few papers on the topic, I will discuss some of the individual findings.

In one study of four patients, (Georgesen & Dungan, 1996), found the use of presence, caring, genuine concern and active listening resulted in trust being established between the nurse and the patient. After establishing trust, spiritual assessments were used to confirm grief as distress. Interventions of spiritual counseling, grief counseling, crisis intervention, cognitive reframing and reminiscence were used selectively. The outcomes were evaluated positively for all participants. They expressed increased hope, entered into a grief process, and integrated the possibility of death into their beliefs.

A pilot study in Scotland revealed 10 elderly patients described having spiritual needs at some time in their lives. Some of these patients (6 of 10) felt those needs while
in hospital. They defined spiritual needs as related to religion, meaning, love and belonging, mortality and death (Ross, 1997).

In a study of the spiritual work of the dying, a framework for understanding was developed using the concepts of remembering, reassessing, reconciliation and reunion (Derrickson, 1996). These concepts are seen to be useful for the person who is doing the work of dying in the attempt to be reconciled and transformed. The goal of the work of dying is to reach a point of comfort, if not acceptance. In writing about suffering in sickness and bereavement, Saunders (1992) writes “Life is above all about learning to love and most of us have merely begun when we die” (p.2). Later in the same publication, Saunders refers to dying as “a frightening mystery” and “a home awaiting” (p.34). She understands the role of the caregiver to be “help through silence and words” (p.34).

An American qualitative study of the spiritual needs of dying patients (Hermann, 2001) concluded that the participants viewed spirituality broadly which may or may not involve religion. Spiritual needs were also defined broadly, but focused on the meaning and purpose of life. Spiritual care was seen to be within the scope of nursing practice, and it was determined that for nurses to care about the quality of life of dying patients, then spiritual care must be given.

There are two American papers that refer specifically to Christian patients’ experiences and views of spiritual care. The first, a qualitative study was designed to
discover the essential structure of spiritual care by asking 10 Christian volunteers who received such care (Codco, 1995). The resultant theme clusters were described as: enabling transcendence of the present situation to find meaning and purpose, enabling hope and establishing connectedness.

The second paper identified prayer as central to the patients’ relationship with God. As well, the participants found meaning in their experience as defined by living God’s will. Each participant faced uncertainty and possible death in a uniquely personal way, and lived in the moment as their condition changed (Hawley, 1998).

In a study, (Bauer & Barron, 1995) of 50 community-based adults who were at least 60 years old, the researchers found the older adults wanted nurses to be attentive, respectful, caring, and hopeful. Interventions related to praying with the person, or discussing thoughts about God, were not preferred interventions by nurses. Moreover, the least preferred nursing action was helping the person explore meaning of life. The researchers did not know whether these interventions were not desirable in themselves, or whether the participants did not understand these interventions as appropriate to nursing. The findings did support the importance of caring and communication skills as spiritual care nursing interventions, which are valued by older adults.

An Australian researcher developed a theoretical model of spiritual needs in palliative care based on a review of the palliative care literature (Kellehear, 2000). He identified three sources of spiritual meaning as transcendence that are found in “the
situational, the moral and biographical and the religious” (p.149). Moreover, the findings suggested spiritual needs are complex needs that are social, psychological, and religious in nature. He noted the religious dimension may well be most significant when one is faced with suffering and dying, as it is precisely at those times when one desires to reconcile with God, or desires forgiveness from God and other people (p.154).

2.7.1 Assessment Tools

In order to respond to spiritual need, the need must first be recognized and assessed. Thus, nurses must have not only some appreciation of the significance of spiritual distress, but also some framework of assessing specific spiritual needs (Govier, 2000). However, the primary Canadian nursing texts used in schools of nursing offer little in the way of theory or practice of nursing for spiritual well-being. For example, the text: Canadian Fundamentals of Nursing, (Ross-Kerr & Wood, 2001) dedicates 19 of 1722 pages to “spiritual health” and a further 28 pages are devoted to “responding to loss, death and grieving”. Within this text, nursing of the spirit is prescriptive, as in listing the tools one must use to care for the spiritual needs of another person. The list includes active listening, encouraging expression of feelings, assessing for religiosity and cultural norms, assessing for past coping mechanisms, and using Self as a therapeutic tool. There are no tools to assist the nurse in those assessments. A second text: Community Nursing: Promoting Canadians’ Health (Stewart, 2000) fails to include any mention of palliative care or death and dying in the community.
In the School of Nursing where I have taught for 12 years, there was no curriculum on spiritual care until recently. In the 2000-2001 Nursing Theory for first year nursing students, approximately three hours of the topic was introduced into the curriculum (Yateman, Personal Communication, January 18, 2001). This dearth of spiritual caregiving in education and practice settings has been noted in Australia as well (Fry, 1997).

Instruments that could be helpful in identifying both the meanings of spirituality and spiritual distress of patients were extracted from a literature review of articles from 1967 to 1997 (Teno, 2002). Potential instruments measured: 1) quality of life; 2) attitudes; 3) religiosity; and 4) spirituality. The review of 25 potential instruments resulted in six tools and the respective assessments as valuable for identifying the needs of dying people. These tools are as follow:

1. The Spiritual Well-Being Scale (SWB) (Paloutzian & Ellison, 1982)
The SWB was determined to be an excellent tool to assess spiritual and religious commitment in a person's life.

2. Spiritual Perspective Scale (SPS) (Reed, 1986; Belcher et al, 1989)
The SPS assesses the importance of spirituality, but does not differentiate between spirituality and religiosity.

3. The Meaning In Life Scale (MIL) (Warner & Williams, 1987)
The MIL scale assesses peoples' views on how worthy their life is. It has been tested in broad groups of people including those who are terminally ill.

4. The Death Attitude Profile (DAP) (Gesser, 1987)
The DAP analyses fear of death.

5. The Death Transcendence Scale (DTS) (VandeCreek & Nye, 1993;)
The DTS examines how people transcend death and can be used by care providers to assist them to guide their patients through the time of dying.

6. The Herth Hope Index (HHI) (Herth, 1990; Herth, 1992)
The HHI assesses peoples' hopefulness. Thus, the nurse could use this index as a guide in determining ways to foster hope, or, if hope is lacking, explore for ways to draw on the individual's life experiences in order to encourage hope. Due to the direct correlation of low scores on the HHI and depression and low self-esteem, the nurse ought to assess for these conditions with any low HHI score. This scale has not been used with dying people.

Of the six scales, only the Meaning In Life and the Spiritual Perspective Scale have been used with a population of terminally ill people. None of the studies used the scales to measure the efficacy of the intervention (Teno, 2002). Thus, of the six tools that might be useful for the nursing assessment of spiritual need, none have been tested for efficacy, and only two of the six have been used with dying people.
I raise the issue of spiritual assessment tools for two reasons. First, it is recognized that nursing theorizes about holistic care, but has yet to develop and test instruments that would be useful in the assessment of spiritual need. Without spiritual assessment, it is not likely that nursing strategies will ease spiritual distress (Stepnick & Perry, 1992). Second, I acknowledge that the non-use of spiritual assessment tools in the site community is not unusual, but in fact, is usual to the practice of nursing in Canadian and other western/Anglo societies.

2.8 Agent of Spiritual Care

In order to be an agent of spiritual care, the nurse must first understand her or his own spirituality and/or relationship to God (Fish & Shelley, 1979). As stated earlier, within the more inclusive definitions of spirituality, the concept of God includes concepts of Highest Power, or Supreme Value. The individual and the community determine these concepts. Thus, it ought to follow that the nurse, within the context of a secularized society, does not have to be a religious person in order to care for the spiritual needs of the one cared-for.

Nurses witness some of the most difficult situations in life such as pain, anguish, mutilation and death (Wolf, 1999). In short, they observe terrible suffering. In one study of home care nurses who cared for cancer patients, they described positive feelings about being able to help, even though they also expressed feelings of fear, uncertainty,
shame and insufficiency (Palsson, Isovaara, & Norberg, 1995). The nurse may not know precisely which nursing interventions to use when a patient has a spiritual need; nevertheless, it is important to note that spiritual care cannot be learned from a procedure book (O'Brien, 1999). Moreover, nurses do not need religious training to meet the needs of the one in spiritual distress (DiMeo, 1991). If spirituality is seen as part of the whole, then the essence of spiritual care will not be found in theory or doctrine but rather in the fundamental capacity to enter into the life-world of the other and respond with feeling (Kendrick & Robinson, 2000).

Rather, the nurse needs to utilize her own “presence” of “being there” in a physical sense and “being with” in a psychological sense. This can be achieved by empathetic listening, reading spiritual texts, praying with the one cared-for, encouraging sharing of life stories and pictures, and acknowledging and fostering the individual’s beliefs (Davidhizar et al., 2000). However, the question still remains, how can a nurse offer spiritual care if s/he cannot articulate its defining characteristics (Kendrick & Robinson, 2000)?

One of the most striking features of modern identity is the conviction that each individual, specifically as a result of his/her particularity and unrepeatable difference, represents in some way an innovative possibility of the human spirit. What the possibility is, of course, no human being can legitimately say for another, since it is a discovery that ultimately depends on the courage one has to attend to capacities that lie not outside the self but only deep within. (DiVito, 1997, p.63).

With the possibilities of the human spirit in mind, nursing attempts to grapple with the issues of defining what is spirituality, and to a much lesser extent, examine what are
spiritual needs and what is spiritual care from the perspectives of both the patient and nurse.

Conventionally speaking, care is seen as something given to the powerless patient from the nurse who has the power to give (Ontario, College of Nurses. 1999a; Ontario, College of Nurses. 1999b). There is little acknowledgement in the literature of the capacity of the one cared-for to give, which would then support a relationship of mutuality (Kendrick & Robinson, 2000). As well, there is a lack of literature focused on explaining spirituality from the perspective of the nurse-patient relationship. By not encompassing spirituality in caregiving, nursing is not taking ownership for the holistic care theorized as part of the profession (Kendrick & Robinson, 2000).

This apparent lack of ownership for holistic care will not be addressed in this study. Rather, what will be examined is a “situation that needs to be addressed for the purposes of understanding and direction” (Erlandson, Harris, Skipper, & Allen, 1993, p.49). As previously stated, there is no Canadian qualitative nursing study focused on spiritual care. Moreover, there is incongruence in the research from other countries. Accordingly, the question suggests exploration without the boundaries of preceding theory (i.e., a priori). Rather, meaning and potential theory must emerge from the data (i.e., a posteriori).
2.9 Summary of the Literature

1. The emphasis of the literature on spirituality from a nursing perspective is on developing inclusive definitions of spirituality.

2. The literature examining spiritual needs from the patient perspective clearly demonstrates that both religious and non-religious people share the complex need for meaning and purpose in life and suffering, hope and connectedness, relationship with others and a Higher Power.

3. The literature exploring spiritual care from a nursing perspective is not Canadian, but rather originates from Australia, Great Britain and the United States. The literature is contradictory in that some literature suggests nurses do recognize spiritual needs, but may not deal with meeting those needs. Other literature suggests nurses do not recognize or care for spiritual distress. As well, there is strong evidence that little spiritual care is given by nurses.

4. Nurses are not educated, trained or mentored into care of the spirit of their patients. Moreover, nurses do not have, or use, tools that would assist them in their assessment of the whole person.
5. Nurses hold unique and intimate relationship with the ones cared-for. Moreover, nurses have the opportunity to be in mutual relationship with their patients and be agents of spiritual care.

There are no published Canadian studies of the nurse’s experience of spiritual care, or of the needs of patient’s for spiritual care. Moreover, there are no Canadian studies of the nurse’s experience of spiritual caregiving within the context of palliative care. This dearth of Canadian studies, and qualitative studies in general related to spiritual care-giving in palliative care, led me to the research question:

2.10 Research Question

**What is the nurse’s experience of providing spiritual care to people who are dying at home?**
CHAPTER 3

METHODOLOGY FOR THE STUDY

3.0 Introduction to the Methodology

After reviewing the literature on spirituality and nursing, and reflecting on personal caregiving experiences, I saw a need to study the spiritual care given by nurses to people who are dying. The purpose of this study was to learn what caring for the spirit of the dying person meant for the nurse caregivers. Moreover, I recognized the need for this study to be done in the Canadian context. I determined to study the nurse's experience of providing spiritual care to people who are dying at home. I needed to find a way to gather personal caregiving stories and to explore those stories for themes of meaning.

I did not wish to gather numerical data regarding the number of nurses who include spiritual care as part of their practice. Nor did I desire to measure the amount of time that nurses gave to caring for the spiritual needs of their patients. Rather, I wanted to hear the nurses' stories in order to understand the meaning of spiritual care as they care for dying people. Thus, the search for an appropriate qualitative methodology began.
3.1 Choosing a Research Method

Any process of formal inquiry is guided by a set of "basic beliefs" (Guba, 1990, p. 17). These beliefs that form the basis of the research paradigm are "designed to answer questions about the nature of knowledge (ontology), the relationship between the researcher and the knowledge (epistemology) and how the researcher goes about finding out knowledge (methodology)" (Guba, 1990, p. 18). The use of the qualitative research model as a strategy, through the analysis of descriptions or conversations, unveils meaning.

Guba and Lincoln (1994) described qualitative research simultaneously as natural inquiry, interpretive research, hermeneutical research, post-positivism, critical theory, and constructivism. Van Manen uses the terms human science, phenomenology and hermeneutics interchangeably (van Manen, 1990 #62; van Manen, 1998 #91). Thus, a number of qualitative inquiries, or human research methods, and terms, have developed within the qualitative research paradigm (Hill Bailey, 1997). Yet, Guba, writing in the foreword of Erlandson (1993), pointed out that naturalistic inquiry is not equivalent to qualitative inquiry, "that is, inquiry utilizing only qualitative methods" (Erlandson et al., 1993, p.10). Moreover, as will be described in the subsequent section, naturalistic studies are essentially different to other qualitative methodologies (Guba, 1990; Guba & Lincoln, 1994).
3.2 The Naturalistic Inquiry Paradigm

This essentially different paradigm, the naturalistic inquiry, “proposes a reality that is of the whole cloth... if one attempts to focus attention on certain portions of reality only, the whole falls apart as though the cloth had been cut with scissors” (Guba, 1981, pp. 75, 77-78). In other words, all aspects of reality are interrelated. Thus, it follows that in order to find meaning, I needed to look at the whole and not only at one part of the whole. Yet, Guba suggested by looking at one end of a bolt of cloth, or at one corner of a folded fabric, we can predict with some accuracy the nature of the whole piece of cloth. This analogy will hold for whole cloth, but not for cloth that was damaged in the process of weaving, or later destroyed by environmental factors. All of this suggested to me that both the process of doing the study, as well as the analysis of the data, was foundational to uncovering meanings within the data. Moreover, Guba suggested the context of the inquiry contributed to the meaning. In this study the context of place (Kingston, Home Care, the time 2001-02, health care restructuring and nursing shortages), all contributed to the development of the meaning of spiritual care for the dying. Thus, I needed to chose instruments that would capture the nuances of meanings as well reflect the context of place and time.

Guba (1981) noted, “if one attempts to focus attention on certain portions of reality only, the whole falls apart as though the cloth had been cut with scissors” (pp. 77-78). However, the naturalistic inquiry paradigm also assumed that there is not a
single reality, but rather, multiple realities (Lincoln & Guba, 1985). Continuing the analogy of reality as cloth: all cloth is not broadcloth; that is, a type of fabric that is the same from end to end. A fabric of sameness would enable one to predict the nature of the whole cloth by looking at a corner of the fabric. Rather, some cloth is a mosaic of small pieces, stitched together in a variety of patterns and images, which are gathered together to form a whole that is called a quilt. One cannot predict the nature of the quilt by looking at a corner, or at one end of the bolt. One must open up the whole cloth and lay it out in order to see how the small pieces have been brought together to make a unique and colourful quilt. Moreover, each quilt, imagined in the crafter’s mind and stitched by quilter’s hands, is never the same as another quilt.

Just as each quilt is a product of stitching together multiple pieces of fabric, so I had to be aware of the multiple realities and meanings within the data. Moreover, I was, in the case of this study, the maker of the cloth, that is, the instrument of the research. Thus I set out to discover what this cloth, called “spiritual care of the dying”, would look like through discovering the meanings of the experiences of community nurses.

3.3 The Aim of Naturalistic Inquiry

The aim of naturalistic inquiry is not to develop a body of knowledge that can be generalized, regardless of time and context. Rather, the aim is to “develop shared constructions that illuminate a particular context and provide working hypotheses for the investigation of others” (Erlandson et al., 1993, p.45). Early on, I determined that the
research method would be qualitative in nature, be contextual to place and time, and include the researcher as an instrument of the research. Moreover, my experience as a nurse and as a teacher of nurses, suggested I needed to be intentional regarding those who would be the nurse-participants. These determinations are discussed later in this Chapter.

3.4 The Goal of the Naturalistic Inquiry Approach for the Study

The goal of qualitative research is to discover meaning, not truth (Hill Bailey, 1997). Indeed, the findings of qualitative research are not objective facts in the positivist or quantitative sense, but rather "subjective interactive constructions that no longer need verification in the quantitative arena" (Hill Bailey, 1997, p.19). In simple terms, constructivism means that each of us sees, and constructs meaning differently; although, a group with similar experiences may have common meanings. Differences in constructed realities are evident when people use language to communicate with each other. People who do not share a language have a very difficult time being understood. Single words, gesturing and body language are often used to get one's point across. Moreover, in the case of shared-language, often the "hearer" does not hear what the speaker intended. Even within families where people share time, space, and blood, this lack of shared meaning is all too frequently evident. Yet, for the most part, those people who share language, manage to hear and are heard.
The relationship between language and experience has significant implications for performing qualitative research (Erlandson et al., 1993, p. 24). We think in words; and words can often be misconstrued. The ability to interpret experiences and to share them with others is limited by the capacity of the constructs. Thus, the compatibility of shared constructions and the possibility of differing realities between the nurse-participants and the researcher guided the data collection and analyses.

Palliative care nurses are nurses who care for people who are living with terminal illness. These nurses share a body of nursing knowledge, and more specifically, nursing knowledge about palliative care. In palliative care nursing, the nurses share the experience of caring for people whose lives are burdened by disease or malfunction and who will die. This shared nursing knowledge and shared palliative care nursing experience provided opportunities to uncover common meanings, or differing meanings within a shared context. The concepts of constructivism (Guba & Lincoln, 1994), including the possibilities of both shared meanings and differing realities, provided the foundation for my approach to the research.

The uniqueness of each nurse was expected. "As persons, we are incomparable, unclassifiable, uncountable, irreplaceable" (Auden, 1967). Nevertheless, I was looking to see how nurses construct their ideas of spirituality and spiritual care through the common experiences of caring for people who are dying. I held beliefs about spirituality and spiritual care through my experience of caring for people who were dying, my experience of teaching palliative care in a variety of acute and long-term care settings.
and my personal life-stories. I shared in the common language of nursing, home care and palliative care. Thus, the nurse-participants and I shared both language and experience. I did not know if we would make the same or differing meanings out of our common experience of palliative caregiving. Thus, my task was to use naturalistic inquiry as the methodology to explore the unique experiences of individual nurses in order to discover shared or differing realities of spiritual caregiving.

3.5 The Research Task

The research task was to explore the personhood of the nurse as s/he lives doing spiritual care of persons who are dying. How does the nurse see her/himself as a provider of care of the spirit for palliative patients in her/his care? What does it mean to care for patients who are in spiritual distress? Does the nurse’s sense of her/his own spirit make a difference to the care s/he gives? What motivates a nurse to do palliative care for years? The research was guided by the aim of developing shared constructs, accepting the possibilities offered by the potential for multiple realities, and with the goal of discovering meanings, not truth. The research approach of the naturalistic inquiry helped me to answer the questions.

3.6 Trustworthiness of the Study

Guba (1981) examined the implications for research that is situated within the assumptions of the naturalistic paradigm. While he accepts both relevance and rigor as
important in research, he considers relevance to be of paramount importance. Rather than rigor, Lincoln and Guba (1985) suggested the credibility criterion as the most important aspect for establishing the trustworthiness of a study. The naturalistic study must meet the standards by which it may be judged (Erlandson et al., 1993, p.131-160). These standards must establish trustworthiness, and enable authenticity. That is, the final product must establish that this study is worthy of consideration and attention. In order to meet these standards, techniques must be used in order to establish each aspect of the naturalistic inquiry’s trustworthiness. The techniques that I used to establish the trustworthiness of the study are listed below:

- Persistent observation: Defined as the persistent attention to accuracy of the text and to clarify meanings within the context of the interviews.
- Reflexive triangulation: A method of verifying and/or validating data when working with the possibility of multiple realities.
- Referential adequacy of the materials: The determination to make available those materials that provide the background information to the study.
- Thick description: The full description of everything that is pertinent to the study.
- Purposive sampling: The determination to gather data from a population most likely to inform the study.
- Audit trail: The determination to make all pertinent data forms and analysis available for evaluation.
- Ethical considerations: The process by which the study participants and the data are kept safe and anonymous, and the study is ethically designed.
The relevance of these standards of trustworthiness is explained in the appropriate sections of the description of the study.

3.7 The Study

3.7.1 The Position of the Researcher

The researcher was very much a part of the study. I proposed the research question, developed the format of the inquiry, designed the questions, introduced the study to the agency gate-keepers and the nurse population, collected and analyzed the data, and considered the meanings of that data.

3.7.1.1 Researcher as Instrument

The researcher was indeed the instrument of the study. That is, I maintained that I was as much a part of the study as the sample of nurse-participants. This naturalistic inquiry paradigm included analysis of the data and the discovery of emerging themes from the data. I, the researcher, performed the analysis and discovered the emerging themes. My beliefs and knowledge were instrumental to the analysis of the data, and theme development, of the study. I did not set-apart, or bracket, my own understandings of spiritual care, or my experiences as a palliative care nurse. Bracketing was defined as “setting aside all prejudgments and her (or his) experiences” (Cresswell, 1998, p.82).
Instead, I contributed my experiences of spiritual care in palliative care and explored the meanings of those experiences in a partnership with the nurse participants. Together, we were co-researchers and co-learners. This mutual influence is affirmed within the naturalistic paradigm (Erlandson et al., 1993, p.15).

3.7.1.2 Researcher as Partner

Erlandson (1993) stated “the researcher establishes a partnership with the stakeholders in the study, a partnership that requires a free and honest exchange of the separate constructions of all participants and in return offers opportunity for growth and empowerment. The implementation of the partnership builds authenticity into the research (p. 160). In order to form this partnership and to offer each of us the opportunity for growth and empowerment, I claimed the authority of my own experience in exactly the same way that I was encouraging the nurse-participants to claim the authority of their own experience.

I acknowledged the danger of bias and reactivity, but the danger of being insulated from, or not hearing the stories that hold the relevant data was greater. I determined that telling some of my stories (written during my initial work with the study supervisor in Australia, February 2001) would bear witness to my beliefs and values and personal experiences of loss and death. I told my stories, a priori to this study. Thus, in order for this study to be relevant, the “whole cloth” must look different from my portion of reality.
3.7.1.3 Researcher as Reflector

I determined to keep a reflexive journal during the time of the study. The contents of this journal do not form a part of the data. Rather, the journal was kept as a personal aid so that, at any future point in time, I would have a written record of my work and how I was feeling about that work at any point in the process.

When I was in Australia working with the study supervisor (February-April, 2001), I began journaling in the form of email to family and friends in Canada. I shared and recorded my work and my reactions to being both in a different place and commencing, what was for me an important piece of work. I continued this method of recording once back in Canada. But then, I was sending email to Australian friends and to the study supervisor. As well, I began a written record of field notes following each of the participant interviews. The purpose of these field notes was to track the affect and emotional responses of both the participants and myself during our conversations. In addition, I recorded data that was not available on the audiotapes, such as body language, site of the conversations and total length of time of the meetings. I later determined that these field notes were of limited value and the notes did not form part of the data.
3.7.2 Selecting the Site

The research sites were the two agencies that have contracts with the Community Care Access Centre to provide palliative care nursing in Kingston, Ontario, Canada. The first agency, Agency A is a private Canadian-owned company. The second agency, Agency B is a not-for-profit organization that has been providing community nursing in Canada for more than 100 years. Although Agency B has been providing palliative care nursing in the Kingston area for as long as there has been palliative care nursing, Agency A was awarded a palliative care and oncology nursing contract for the first time in 2000. Recall (Section 2.1.7), that the community-based not-for-profit Hospice was assessed to not meet the bidding criteria of the CCAC on the first round of bid submissions, and withdrew palliative care nursing service to the community during the months prior to beginning work on this project. The Hospice’s withdrawal of services was relevant to this study in that it decreased the population of community nurses who were providing palliative care. In addition, I interviewed one nurse who provided leadership in the area of palliative care nursing in this community, but who did not work for either of the two site agencies. The information from this interview forms part of the background information of this study.
3.7.3 Accessibility to the Site

Accessibility to the two agency sites and the credibility of the research was made easier by the fact that I am known for past work managing a palliative care education project in Kingston area as well as authoring a palliative care training manual which continues to be used in Ontario. Thus, even if a contact person did not know me personally, my name was recognized. Accessibility was gained by contacting the Directors of Nursing (and through them, the Executive Officers) at both agencies.

I decided there could be a richer mix of nurses and experiences by using two community agencies instead of one agency as a result of the differing histories, type of organization and length of time providing palliative care nursing. Moreover, prolonged engagement with the participants to the study allowed me to develop the kind of relationship that allowed for openness, mutuality and sharing. It was anticipated that such a relationship would result in a wide scope of data, shared meaning of the data, and enhanced ability to produce thick description and accuracy of the data.

Prolonged engagement was met by spending a significant time in the field. This meant keeping open both the research interviews in terms of length of time, and avoiding analyses of the data early in the process. Prior to the nurse-participant interviews, I conducted one "expert" interview in June 2001. Recall from Section 2.1.6 that the Health Care and Home Care in Ontario were in a state of enormous change,
and accompanying tensions, during the time frame of this study. Thus the purpose of this “expert” interview was to gain background information on the current state of palliative care nursing in the community. I arranged a one-hour appointment however, interestingly, this interview took just under four hours. This lengthy conversation provided an “initial signal” that some nurses wanted to talk at length about caregiving in the context of home care and palliative care.

I made no attempt to analyze the data early in the study. Nevertheless, I did review the content of particular interviews in preparation for the later interviews. This was done to clarify statements or concepts made by the previous interviewees. On a second review of the transcripts, read in the order of the interviews, it was apparent that I did ask more clarifying questions later in the interview process.

3.7.4 Population

The research was designed as purposive sampling in order to gather data from self-motivated, and volunteer, nurse-participants. That is, there was no attempt made to survey all nurses who provide palliative care. Moreover, the study was designed to capture the experiences of nurses whose workplace does not include pastoral care workers as part of the care team. Thus, the focus was on interviewing home care nurses.

The study was designed to capture the experiences of home care nurses who care for people who are most likely to express spiritual needs. As the literature
suggests, people who live with life-threatening illness or who are dying have many spiritual issues and needs. People who know they are dying tend to seek their final answers to spiritual questions about the meaning of life, love, friendship, pain, suffering and death (Bergen, 1991; Newshan, 1998; Vachon, 2000). I reasoned that if nurses were to have experiences of providing spiritual care, it would more likely occur when caring for people who were dying. In June 2001 the population of home palliative care nurses was 47. All the nurses were female.

Agency A had a core group of 13 nurses who cared for people who are dying at home. These nurses are not part of a dedicated palliative care team. They are generalist nurses who work full-time or part-time. They carry a varied caseload that includes any referred patient as well as patients who have cancer and/or are living with terminal illness. They perform visiting nursing (day or evening visits) and shift- nursing (in the home for 8-12 hours at a time).

Agency B had a dedicated palliative care team, as well as nurses who do some, or all, of their work as shift nurses in the home. The combined group varies in number, but in June 2001 stood at 34 nurses.

Materials available to provide background information on palliative care nursing in the community consisted of site organization brochures and admission data forms. There was no access, or need for access, to patient charts since the major material
comprising this study was the personhood of the participants, and their willingness to share their stories of spiritual caregiving.

3.7.5 Access to the Sample

I now discuss how I accessed the nurse population by arranging for the interviews, and engaging with the nurse-participants.

3.7.5.1 Arranging for the Interviews

The first contacts for the study recruitment occurred in December 2000 and January 2001. The purpose of these initial meetings/conversations was to introduce myself, present my research proposal, ask for advice and support, gather background information on the current home care situation and to determine whether or not the agencies would approve access to their staff nurses. In all cases, the managers were very enthusiastic and supportive. The first contact occurred before leaving for Australia and before the research question became concrete. Arrangements were made that I would contact them again on my return from Australia.

Second contacts were at staff meetings attended by nurses who provide home palliative care nursing (the prospective research participants). These meetings were held in May and June 2001. These meetings were arranged following my return from Australia at the end of April 2001. At one agency, there was a new manager responsible
for the Palliative Care Team who was not from the Kingston area. She had been briefed regarding the project, and expressed keen support. At both agencies, arrangements were made for me to have time on the agenda of the May staff meetings. Subsequently, one agency requested my time with staff be pushed back to their June staff meeting.

3.7.5.2 Engagement with the Nurse Participants

The third contacts were at two (palliative care nursing) staff meetings, one at each of the community agencies. These meetings were the last gathering of staff before September. My purpose at the meetings was to introduce the study and to introduce myself. As well, this was the one opportunity I had to personally invite participation in the study. I hoped to build credibility for both. At the meetings, I spoke of my personal background as a home care and palliative care nurse, as well as my present work teaching nursing at the St Lawrence College. I introduced the study and spoke of some of the findings of my literature search. I stated that there were no Canadian studies of nurses and spiritual care. I handed out prepared packages of print materials including background for the study, ethics approval, possible interview questions, information for the participants, a demographics sheet and a consent form.

Neither meeting was well attended. I was told it was due to heavy workloads. Thus, for many potential nurse participants, the information package (Appendices 1-5) left for each, in their respective mail slots, was the only information they received about the project. I invited telephone calls or emails to answer any questions. No nurse
telephoned or emailed to me to ask questions about the project. However, the nurses were asked how they would like to contact me if they chose to participate in the study. At both sites, the nurses decided, if they chose to participate, to leave the completed demographics form and signed consent in the provided envelope at the front desk of their workplace. I would telephone weekly to find out if any envelopes were left for me.

3.7.6 The Interviews

Following is the interview schedule, setting up the interviews, the location of the interviews, the format of the interviews and engagement in the nurse-participant interviews.

3.7.6.1 The Interview Schedule

I found that getting started was not straightforward. The politics of Community Care in the province of Ontario, the stresses of inadequate staffing, and the changes of supervisory and nursing staff during the time of the research interviews led to time delays and missed appointments. The initial meetings with the palliative care nursing teams took place in May and June 2001. The individual nurse interviews were held during (July-September 2001) the summer months in Canada. By August 2001, I was fearful that there would not be an adequate number of volunteer subjects to reach saturation of data. Saturation is defined as “finding information that continues to add until no more new information is found” (Cresswell, 1998, p. 56). Nevertheless, by early
September I had verified that I had reached saturation of data. Finishing the interviews in September was fortunate timing, as by October, nurses were being laid off from both agencies due to the freeze on new admissions at the CCAC.

3.7.6.2 Setting Up the Interviews

The volunteer nurse-participants set the interview schedule. Each left the signed consent in a sealed envelope at the front-desk of the respective agency. After retrieving the envelopes, I telephoned to arrange the time and place of meeting. The envelopes were returned over a period of seven weeks. Meetings were arranged within a week of my telephone call to each nurse volunteer.

3.7.6.3 Location of the Interviews

The interview locations varied. The volunteers chose the location for our meeting. I offered my home to each of the participants. One conversation was held in the participant’s home during the evening. One interview took place at a worksite (not a patient’s home), during a lunch break. A third interview was in a public library at the end of her workday. At the request of four participants, the remaining conversations took place in my home, either afternoon or evening.
3.7.6.4 Format of the Interviews

The research interviews were designed as semi-structured audio taped interviews. Questions (Appendix 3) were developed which formed part of the Ethics Approval documentation. Emergent design resulted in few questions asked by the researcher and significant story telling by the nurse participants. In fact, the emerging design of the interviews took place at the beginning of the first interview. This change in the interview was supported by both my own experience as a nurse and teacher as well as by Lincoln and Guba (1985), who stated that "design provides for certain broad contingencies without, however, indicating exactly what will be done in relation to each" (pp.226).

Following initial conversation and time for relaxation into the process, I asked the first nurse-participant to define spiritual care. She told me that she didn’t have a definition. I then asked, “Tell me a story that will help me to understand what you mean by spiritual care.” I asked few questions. The nurse told story after story of caregiving for the spiritual needs of her patients. In fact, there was a point in the conversation when I thought the interview was over, and I shut off the tape-recorder. Some minutes later, the nurse told me to turn it back on as she had another story that she wanted to tell me. The first interview/conversation lasted 90 minutes.
This format, of easing into the conversation, then requesting, “tell me a story” was the primary format followed for all the seven interviews. Nevertheless, in later interviews, I asked more questions in order to confirm or clarify data that I had heard in previous conversations. Those questions were contextual, and did help me to clarify whether or not I was hearing shared meanings or separate realities.

3.7.6.5 Engagement in the Nurse-Participant Interviews

The interviews, which were conversations, lasted from 45-90 minutes. In five of the seven interviews, the meetings did not end at the completion of the taped interview. The nurses stayed and continued in conversation about community nursing and, in particular, about palliative care nursing. I was conscious of the continuation of these conversations, and monitored the content to determine if there was information being given that ought to be included in the data of the study, and thus audio-recorded. I determined there was no continuation of the conversations about spiritual care, but rather, the talk was about the politics of home care. Thus, the research data consisted of the tape-recorded conversations.

3.7.7 Data Analysis

Data analyses, described in more detail below, consisted of transcription of the tapes, analysis of the text, attention to the text, theme development and added strategies to ensure credibility of the method.
3.7.7.1 Transcription of the Tapes

There were seven nurse-participant interviews audio tape-recorded. The sixth interview tape was of such poor quality that it could not be transcribed. Previous to this sixth interview, I questioned if there was saturation of the data with the fifth interview. Thus I held the sixth interview to confirm my beliefs. The sixth interview tape was of poor quality. As a seventh nurse had volunteered to participate in the study, I held the seventh interview. After that last interview, it was clear that saturation of data had been reached. Thus, there were six transcribed tapes, and the analyses of the data were from those six transcriptions.

Transcription of the data was completed in January 2002. The length of time from the final (seventh) interview to the finished transcriptions was five months. This lengthy time was a result of difficulty in finding a skilled person who had the transcription equipment available to her. As a medical transcription program is offered at St Lawrence College where I teach, I found a graduate capable of doing the work. Finally, in June 2002, after my teaching commitments were over for the academic year, I commenced the work of analyzing the interview transcripts.
3.7.7.2 Analyzing the Text and Theme Development

The interviews were coded using NUD*IST 5 (QSR International Pty., Ltd. 2000. La Trobe University, Victoria, Australia) a software program that was designed to assist with the qualitative analyses of data. The text of each interview was read and coded to themes as they emerged.

By September 2002, I had coded the six interviews. After discussion with the study supervisor, and in response to the continuing deterioration of the community nursing work environment during the time of this study, there was no attempt made to meet again with the nurse participants to share themes or to request a response to those themes. In October 2002, I returned to Australia for two weeks in order to spend time with the study supervisor to firm up the themes that emerged from the text and to write up the findings.

3.7.7.3 Attention to the Text

The study interviews were not held in the field, that is, in the homes where the nurses cared for people who were terminally ill. This study was designed as nurse-participant interviews that took place away from the “work-place”. Thus the concept of persistent observation needed to be redefined for this study. In this study, persistent observation
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might more accurately be defined as persistent attention to accuracy of the text and to the meanings within the context of the interviews.

Furthermore, I contracted out the work of transcribing the audiotapes. This was done to ensure data accuracy. Nevertheless, I was required to edit some of the text, as the person transcribing was unfamiliar with some medical/nursing terminology and with some profession-based expressions used by nurses, such as “snowed”, “PICC lines”, and “astrocytoma”. In some instances, I referred back to the original tape for clarification. In other cases, I recalled the conversation, and edited accordingly. This editing of the printed texts had a positive effect by providing another opportunity for detailed recall of the conversations prior to commencing the coding and sorting of data.

The original research design included having the nurses’ review their own interview following transcription. In the information package and during the interviews, the nurse-participants were offered the opportunity to read their verbatim transcripts, in order to clarify content and to add/delete from the conversation. No nurse participant requested to do this transcript review. Thus, there was no member checking of the data.
3.7.7.4 Added Strategies Ensuring Credibility of the Method

Trustworthiness as Validation

A controversial issue within qualitative research has been concern around the value or “trustworthiness” of interpretive research findings (Hill Bailey, 1997). As discussed previously, the goal of qualitative research is to understand meanings, whether they are shared or multiple realities. Thus, some researchers have re-conceptualized the issue of trustworthiness as validation. This validation may, or may not, result in agreement with meanings. Validation allowed the opportunity to reassess the analysis in order to determine whether there is quality to the meanings.

Determining quality of the meanings helped to establish trustworthiness of the study. One method for determining quality is called triangulation. There are three forms of triangulation validation that are referred to as respondent, comparative, and reflexive triangulation (Walsh, 1998, p. 231). Respondent validation consists of showing the themes to the research nurse-participants and seeking verification in which the nurses recognize a relationship between findings and what they said and did. Because of the likelihood of multiple realities, and due to the continuing deterioration of the workplace (the study sites), I determined to find an alternative strategy to meet the obligation of validation/verification of the data.
One alternative method of triangulation compares two different kinds of data from two sources to see if they corroborate each other. As evidenced by the literature review, there were no other comparable studies in Canada. Thus, there was no comparable setting or findings with which I could make a comparison. Moreover, the thought of verifying the nurses’ stories with the families of the deceased raised ethical issues. An alternative would have been to conduct a verification study using a different population of nurses, however, time and financial resources did not permit such a study. As well, Walsh (1998) points out, this type of verification has the problem of “limitless exercises attempting to replicate what were in fact multiple realities” (p.232). There was a need for a type of triangulation that would account for the possibility of multiple realities, would meet the obligations of ethics and would be cost and time effective for the study.

Reflexive Triangulation

Reflexive triangulation seemed to have value as I was working with the possibility of multiple realities. Reflexive triangulation is a more subtle form of triangulation in which one shows “confidence in our knowledge but not certainty” (Walsh, 1988,p. 232). This confidence in knowledge involves the view that reality is independent of the claim that the researcher makes about it. Thus, reflexive triangulation demands the fulfillment of certain criterion for the findings of the study (p.233). Examples of question or criterion are:

Do the findings sound plausible?
Considering the nature of the community nurses' work in caring for persons who are dying, do the findings sound credible?

Do the findings have validity considering the circumstances of the research and of the characteristics of the researcher?

The trustworthiness of the study was established by findings that account for multiple realities that sound plausible, credible and fit the circumstances of the research and the characteristics of the researcher.

Thick Description

Validation can occur only if the reader has the ability to imagine her/himself within the context of the study. Thus, it was essential that I write a detailed and engaging work. This work included thick description of everything that was pertinent to the study. I refer to the description of the setting and the context of the study, methodology, the analysis and themes developed from the data.

As the research was being done in a society and a health care system that is not well known to the Australian reader, I have included additional descriptions of the Canadian Health Care, Home Care in Ontario and in particular, Home Care in Kingston, Ontario.
Audit Trail

Interview questions, notes, documents, email letters, journal keeping, as well as the original audiotapes and transcriptions were made available to the study supervisor. This criterion for developing an audit trail was used to both validate the data and the process of the inquiry. For example, I worked half a world away from the supervisor. We carried on our discussions, critiques and analyses of the work as it progressed, mainly by email and some telephone conversations. Only during two brief visits to Australia (February-April, 2001 and two weeks in October, 2002) did we work together in shared space. Thus, early on, one of the audiotapes was mailed and two of the transcripts were emailed to the supervisor in their entirety along with my initial attempt at analysis. Her responses sometimes enabled me to gain clarity about future directions, and at other times, encouraged me by responding that “I was on the right track”. On my return to Australia in October 2002 I shared with her the six transcripts as computer files and hard copy as well as my coded data. Thus, an audit trail was laid and always available to the study supervisor.

3.8 Ethical Considerations

All of the previously mentioned methods that were used to validate this study would be meaningless if ethical considerations were not taken into account. The study was referred to as Protocol No. HE 01/047 and it received approval by the University of
Western Sydney Human Ethics Review Committee on May 9, 2001. Unlike the situation in Australia where there is a need for multiple ethical review applications, I held to the Canadian standard of receiving ethics approval from the educational institution that was supervising the research. The Ethics Approval from the University of Western Sydney was accepted by the management of the site agencies and by the nurse-participants.

The issue of confidentiality arose. To show demographic details of the individual nurse-participants would make each easily identifiable within this relatively small palliative care community. Thus, demographic data was grouped and not made available as individualized data.

Both prior to the interviews and during the interview phase of the study, I made arrangements for a trained and experienced counselor to be available to any participant, should she become distressed. The provision of a counselor was never required.

The safe storage of tapes and transcripts was maintained by keeping all data sources in a locked filing cabinet in my personal office. These data source materials were shared only with the study supervisor and the transcripts were shared also with the associate supervisor.

Ethical considerations of confidentiality, anonymity, informed consent, safety of the participants and safe storage of information about the study were maintained throughout the study. The validity of the study was not compromised by breach of ethical
consideration. The trustworthiness of the research was determined through the process of validation (Polkinghorne, 1988).

3.9 Limitations of the Method

There appear to be three limitations to the method. However, as there was no attempt to generalize the findings, the limitations fit the paradigm. These limitations are:

1. Dominant mono-cultural nature of the Kingston community
2. Small size of the sample
3. Sample participants were all female

These limitations will be further discussed in Chapter 5.
CHAPTER 4

STUDY FINDINGS

4.0 Introduction to the Study Findings

In this chapter, I present the findings of the study. First, I discuss the demographics of the sample. Next, I name the focus of the nurses’ spiritual care. Following, I offer the major themes and the minor themes found within the stories of the nurses’ spiritual caregiving. The findings are described under the appropriate theme with supporting quotes from the nurses.

4.1 Demographics of the Sample

Due to the nature of the community and the small size of the palliative care nursing population, the ethical consideration to maintain confidentiality would be compromised by individualized demographics data. Thus, I provide a summary of the demographics of the sample.

Each of the six participants was a RN. The College of Nurses of Ontario registers two classes of nurses. The Registered Practical Nurse (RPN) has the limitations of practicing within the context of stability and predictability. The Registered
Nurse (RN) has no such limitations on the scope of practice. Although both classes of nurse work in the home care setting, I invited only RN’s to participate in this study. I did not want limitations to practice influencing the experiences of the nurse-participants.

The six RN participants were all female. They were aged 31 to 55 years, with a median age of 46.5 years. They had been nursing between 4 and 32 years, with two of the seven participants having less than 9 years experience, and five of the sample having more than 23 years experience. They had been working in community nursing for as little as 5 months and for as long as 12 years. Their palliative care nursing experience ranged from 5 months to 25 years. Three participants had more than 10 years experience in palliative care nursing.

The nurse-participant's academic background in nursing ranged from Diploma in Nursing to Master of Nursing, with 3 of the 7 having university education. All participant’s had extensive and on-going continuing education and post diploma/degree training in such areas as oncology certification, intravenous therapy, pain and symptom management, central line care, wound management, stress reduction, meditation, patient-controlled analgesia pumps, and psychiatric care. Some have attended palliative care conferences.

The participants had a varied and broad experience in nursing. Their experience included outpost nursing, rehabilitation, cardiac, neurological and nephrology, labour
and delivery, pediatrics, ambulatory care, hospice and cancer clinic, surgical and medicine as well as psychiatric nursing.

Thus, the sample consisted of six Registered Nurses (RN's) who were mature women, with a very broad background of experience and knowledge in nursing. They had a varied academic background, but all were active participants in continuing nursing education. There was a wide range of palliative care nursing experience, with the majority of the sample having greater than 7 years providing palliative care nursing in both acute care and community care settings.

An alias name was given to each of the nurse-participants in order to protect their identity. These alias names are Barb, Liz, Pam, Alex, Shirley and Maria.

4.2 Perspective of Spiritual Care: Death and Dying

The palliative care nurses’ perspective of providing spiritual care was on death and dying. Each of the stories spoke of caring for a person who lived their final days and who died. In some stories, the nurses gave background information regarding the beginning of their relationship with the one cared-for. But, the focus of the stories was always on the time and events surrounding death. Each of the stories of spiritual care was a story of care given during the terminal stage of illness, and in particular, the time surrounding dying and death. First, I present the study findings as an outline of how the
nurses focused on death. The outline is presented in Table 1. Next, I will expand on each of the ways in which the nurses focused their spiritual care on death and dying.
Table 1: Perspective of Spiritual Care: Death and Dying

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<tr>
<th>Themes</th>
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<td>The Nurses’ Focus of Spiritual Care Was On Death</td>
<td>Relating to Distress</td>
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<td>Purging</td>
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<td>Family Relationships</td>
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<td>Walking Beside</td>
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<td>Loving to Death</td>
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<td>The Nurses’ Beliefs</td>
<td>Definitions of Spiritual Care</td>
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<td>Religion and Religiosity</td>
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<td>Sharing Own Beliefs About Death and Dying</td>
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<td>The Nurses’ Evaluation of Spiritual Care As “Good Death”</td>
<td>A Good Death</td>
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<td>Comfort</td>
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<td>No Family Conflict</td>
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<td>Importance of the Dying</td>
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4.3 The Nurses’ Focus of Spiritual Care Was On Death

The focus of the nurses’ spiritual care was centred during the time and on the events surrounding the dying and the death of the ones for whom they cared. This focus on the dying time was evident in each of the stories. There were no stories of providing spiritual care “just to help someone through the day”. Nor were there any stories of providing spiritual care for someone who was living with a life-threatening illness, and who survived/ was surviving. In every story, the one cared-for died.

The nurses’ spiritual care was focused on the dying time as the most significant point of spiritual intervention. There were six minor themes related to this focus on death. These minor themes are: relating to distress, purging, pain and symptom management, family relationships, walking beside the dying one, and loving the person to death. I will discuss each of these minor themes in turn.

4.3.1 Relating to Distress

All the nurses in the study discussed relating to the distress of the one cared-for during the terminal phase of a life-threatening illness. The following comment typifies the nurses’ reaching out to relate to the distress of the one who was dying.
It was our way of reaching out and being with her in her suffering, in her struggling, because her pain was spiritual and because it caused her so much grief that the expression of that grief caused her too much pain, she couldn't do it. And so I guess it was our need to be able to just go in and not leave her alone and her husband did what he could but he couldn't stay and he left and so (this other person) and I spent what little time we could, just spending, and she did not really want people with her but I guess she trusted us enough to be able to do that and that distress was very difficult. [Barb]

Another emphasized how sometimes the nurse was the only other person in someone's life. The person depended on the nurse to help him/her resolve issues.

Some don't even have relationships with anybody but they come to their own terms with what they feel is their beliefs and as long as they are to terms with that and it seems to be an ongoing process to, and some people that I look after just do not have any part from anyone else. They just have their nurses and they depend on their nurses and themselves to resolve any issues that they have. [Liz]

The same nurse considered her observational skills and her willingness to raise issues with the one cared-for as instrumental in helping relieve the distress of the dying one.

"I'm afraid, I'm afraid, I don't want to die with issues unresolved. I wonder if I have done anything to offend God? What is going to happen to me after I die?" Just those kinds of statements, or just the fear in their eyes, or anytime there is fear we don't know what it is until we ask them. "You know what is happening, I see something in your eyes, you look afraid, what is making you afraid?"

Then they say, "It's the pain. It's leaving my family. Should I clean my record? Have I hurt people's feelings? I feel guilty." Everything just kind of spews out as things go and if you have good communications and sometimes if you don't have good communications things just come to you anyway. [Liz]
Another nurse told how she advocated for increased visits so that she could manage the distress of the patient and the family.

_This family is in distress. I need to provide support... I need to increase visits. I need to see this family once a week. There’s a lot of distress there’s a lot of pain there’s a lot of unresolved things they need to work through._ [Pam]

One nurse acknowledged that some spiritual distress could not be relieved. “We could manage her symptoms but we couldn’t manage her spiritual distress.” [Barb]

Two nurses shared how relating to the distress of their patients impacted their personal lives, and threatened their own well-being. For one nurse, caring for the distressed patient caused physical exhaustion. “I could barely stand it and I would leave exhausted every time.” [Alex]

The same nurse provided an account of what amounted to continuous, around the clock, nursing care. “I get a good three hours sleep in between. I run home, sleep, they phone, I go back in. And I went in Friday about five in the morning...” [Alex]

Another nurse spoke of her emotional reaction of jealousy towards what appeared to be a “normal life”, as well as her physical and mental exhaustion due to the stress of palliative caregiving.

_I can remember times; there were times in my life I would drive home from working and I would see someone walking their dog and I would be very jealous of them because I had a dog but I was really, really tired. So tired that I physically couldn’t get myself out to do that and nor could I let my mind rest._ [Shirley]
4.3.2 Purging

The nurses were actively involved in purging as an important aspect of the spiritual care of the dying person. The term “purging” comes from the nurses. Other terms used that conveyed similar meanings were “cleansing”, “opening the flood-gates”, “settling things with families”, “mourning losses”, “talking”, “opening up”.

The nurses defined purging as spiritual work. The purging sometimes took many months. “I think maybe that’s what that year of telling me their life story is about... you know its purging and cleansing and so on and so forth. ...You know, when somebody sits there and purges their life on you, this is spiritual work.” [Alex]

Purging also included life review and the use of photos as a means of reviewing the life of the patient. “Oh, yeah. Oh, yeah. Because when we sat on that bed and we are going through these photo albums and I have never seen these pictures before, I knew what that was and I knew when that happened.” [Alex]

Another nurse told of encouraging the patient to talk about re-establishing values. This encouragement included staying with the patient and holding him as he cried.
We didn’t talk about God; we didn’t talk about anything like that except he needed to talk about re-establishing his values…. He had to talk about what was important in his life and how I could tell that he was just close to crying so everybody left but I stayed behind and he looked at me and he said I have a short time to live. … I stood there and I held him as he sobbed. [Barb]

She reflected on what she heard as intense and poignant. “I have just listened to one of the most intense detailed poignant discussions of my career.” [Barb]

Initiating the conversation appeared to be an important aspect of helping the one cared-for to begin the process of purging.

And sometimes people’s flood gates are overflowing and they haven’t said anything and then all of a sudden it occurs to them, or you just keep a little gentle nudge as you form the relationship with the people and then kind of go from there. [Liz]

The nurses discussed the goals of purging as cleaning up, and moving on.

“When they do come to the point where they are terminal or palliative it’s still the same. You know they are trying to go through everything, clean up all situations and they’re still going through it as the same person. [Maria]

I could see how they had moved on and she took over more and as he died. [Barb]

There was acknowledgement that sometimes the nurse could not help the dying one, even if there was a good relationship between them. They named the person’s lack of feeling safe, deep-rooted fears, family dynamics and interference from other people as blocks to purging or resolving issues.
If you have a good rapport with the client they feel pretty safe with you usually, and then they usually open up. If they don't feel safe with you, and they don't feel safe with anybody, depending how deep rooted their fears and concerns are. Sometimes they just don't resolve issues and sometimes it's too big to resolve anything because of the family dynamics with the client, the client to the family, family to the client and how many people are stepping in all the time. [Liz]

The nurses understood purging as a challenge to keep the dying one comfortable, a challenge they could not always meet. “My challenge is to help them to keep them comfortable but if they don’t want to talk about it or if they don’t want to deal with it that’s okay cause I’m not going to change them.” [Barb]

Purging was an important aspect of the spiritual care given by the nurses in their efforts to decrease the distress during the time of dying. In order to do the spiritual work of purging, the need for pain and symptom management was held to be a directly related aspect of spiritual care.

4.3.3 Pain and Symptom Free

The nurses’ shared their meanings about the relationship between physical pain and spiritual distress. The nurses clearly understood this physical/spiritual relationship. Moreover, they acknowledged the importance of the role that they played in relieving the pain and distress.

One nurse described the inter-relationship of spiritual peace and pain management.
"To me it would be judged, number one, whether or not the person is comfortable. Number two is pain management. Three, their whole spiritual being needs. Because I think first and foremost, I don't think you can separate the spiritual peace from the pain management because I feel one will defeat the other if they are not met." [Maria]

She described the need for empathy and understanding of chronic pain and how chronic pain feeds depression and insomnia. "I feel there is an extreme need for empathetic people and people who understand chronic pain and all that goes with chronic pain; depression and insomnia, how one feeds on the other." [Maria]

She stated her goals of spiritual care and pain management. "I believe with everyone it (spiritual care) does matter and my ultimate mandate through it all is just to get people to the goal that they are not afraid, issues are all resolved and pain is under management." [Maria]

The same nurse understood spiritual pain and physical pain to be interconnected in such a way that without one, there cannot be the other. "I mean you can't do one without the other because without spiritual healing, like I said before, I believe the pain itself will escalate." [Maria]

Another nurse expanded on the interconnectedness between spiritual pain and physical pain.
Well, I think spiritual distress can exacerbate physical distress. You know, sometimes people can feel very guilty about what's happened, you know, in their pasts. They may have unresolved conflicts. ... They might be really angry that this has happened to them. They might feel like they have done something to bring this on, like they are being punished or they have been forsaken. They may feel very isolated from friends and people that they thought were friends and they may just feel terribly alone. [Shirley]

A third nurse shared her previous death experiences with the one who was dying in order to give reassurance that she would manage the pain.

I think the role is of reassuring and they ask me what it will be like when they die and I try to be, I tell them nothings absolute and nobody's the same but I try to give them a breakdown of it, what goes on. And, um, I find pain on the last day is never an issue, we have either medicated them so well or they are just in the calm before the storm thing. [Alex]

The same nurse emphasized what she meant by managing pain. “You know, my thing is, when I say pain free, I mean pain free.” [Alex]

There was evidence that the nurses knew the cared-for could not think about spiritual issues when they were struggling with pain and nausea and vomiting. “You know, I don't think that you can really think about or have that individual think about their spiritual issues when they are in pain or just struggling with nausea and vomiting.” [Shirley]

Another nurse explained the connection between pain management, comfort, sleep, feeling better and dealing with issues.
So we talked about morphine and we talked about breakthroughs, and we talked about all this. I said look you take the medication, it is going to make you be comfortable, you are going to get some sleep, you are going to feel a little better, then you can deal with all this stuff that you are dealing with. [Barb]

The same nurse spoke of managing pain in order to give control back to the patient so that he could deal with the issues that overwhelmed him.

“He was quite overwhelmed with some of this but he had to be in control so we got his pain under control because it was still a bit of a problem, and he went home for Christmas and New Years. (He) had a lot to deal with.” [Barb]

Thus, the nurses were very intentional in managing pain, and in particular, managing pain so that the person could have the chance to do the spiritual and psychosocial work they needed to do before death.

When they do come to the point where they are terminal or palliative, it's still the same. You know they are trying to go through everything, clean up all situations and they're still going through (it as) the same person. I think they are all traumatized majorly and they all go through whatever stages they go through as things progress. I mean obviously if there is pain out of control and things like that we get it under control as quickly as possible. [Liz]

4.3.4 Family Relationships

Cleaning up situations often meant healing relationships. The nurses were very deliberate in their meaning of spiritual care as including helping the one cared-for to work toward healing relationships. As the following verbatim show, this is not always
possible. “But you know, (she, the patient) barred her mother from coming to her home while she was sick and while she was dying. Because she (the mother) was such a toxic woman. “[Alex]

Another nurse spoke of how, at the time, she was unaware that she made the way easier for a man to be open and talk about his preparations for death with his family.

*By my ability and his trust in me, as the caregiver, as the nurse, as the friend, to share for the first time his plan to prepare for his death and I’m thinking that the hard part will be with the emotional part with his family but I really didn’t realize that it was with me and I was truly moved by that.* [Barb]

4.3.5 Walking Beside

There were two images of walking beside in the meanings the nurses gave to spiritual care during the dying time. In both cases, the walking was not “with”, but rather “beside” the one cared-for.

The first image was not of an easy walk, but rather a deliberate choice to walk beside, because she was needed to be there. There was a sense of responsibility to the one cared-for in the posture of walking beside.

*There have been bumps over the years. I think I’m not the first person to probably say that, but I think that in some ways I see that people really need me to be there. To travel along with them and I don’t mean travel in front of them, or behind, but just beside them.* [Shirley]
The second image of walking beside was described in terms of intimacy, acceptance and to be a witness on the journey.

_That I think is why we use the term intimacy because that was such a privilege to be the witness... That's another part of it, to be that non-judgmental person that can just walk with walk with you, ... but it is a walk and it doesn't matter which direction you go but you are side by side._ [Barb]

4.3.6 Loving to Death

The final aspect of spiritual care as focused on death was love. All the nurses did not share this aspect of love in palliation. But, for those who did, the meaning of love in the dying time was powerful. These two nurses believed that their relationship with those for whom they cared was one of loving to death.

One nurse described how the experience of spiritually caring for one who was dying changed her own sense of being. She included love, physical care and comfort as aspects of her spiritual caregiving. She understood care of the dying to include preparation of the body forever.
To me spiritual care is its, its when someone's end stage and in the process of dying, something happens to me and I can walk in and I can see this person actively dying and I, I can feel warmth in my eyes and I'm, I'm smiling at them and my thing is to love them and care for them and make them as comfortable as possible. Then when they pass away I have beautiful death experiences and the families, they're just like "wow". Afterward then I have to prepare the body forever they're gonna go, because I don't know where they're going, you know, and ah maybe one day I'll find out. [Alex]

Loving to death was not limited by unlovable qualities of the one cared-for. Nor did the attitudes of family toward the dying person influence the love and care given by the nurse. The nurse was unshaken in her attitude of care and love in death.

We had one client I guess she was a horrible, horrible person and she was so palliative and her family, uncles and cousins and aunts they had to tell me what a horrible, thieving, conniving, lying and I said, "Whoa, that's none of my concern right now. All I can do is give her good care right now and love her because she is dying, you know". [Alex]

The same nurse recognized that sometimes the nurses were the only people who loved the dying one. "You know. I want that person, when that person is dying they are dying with love. Even if it's their stranger-nurse. I want them dying with love cause when this one woman was dying the only love she was getting was from her nurses." [Alex]

The second nurse compared the love between two lovers to the love between the nurse and her patients. This kind of love did not have to be a love of passion, but it did have to be an emotional love between two people: the one caring and the cared-for.
Love is when partners go off in different directions, but is always side-by-side, and maybe that’s what it is to love between two people, not necessarily a love of passion. A love of two people does have to be an emotional love, the emotions were there but it was still there in a therapeutic relationship. [Barb]

Loving and caring create transformation. This loving to death was part of the spiritual care of the nurse’s death work. The nurses believed both they and the ones they cared-for were changed as a result of loving. “And just going in and caring, I don't know, just, you know, just something happens in loving.” [Alex]

4.4 The Nurses’ Beliefs

The nurses spoke of their own beliefs about dying. Their beliefs included definitions of spiritual care, spirituality and religion, and their own beliefs about dying. In some cases, they questioned whether or not they would receive the kind of care that they gave to the ones they cared-for. As well, there were strong indicators of hidden work found in the belief systems of the nurses. This hidden work was named as charting and labour.

4.4.1 Definitions of Spiritual Care

The nurses offered few definitions of spiritual care. For the most part, they let their stories speak to their beliefs about spiritual care as part of palliative care nursing.

One nurse understood spirituality to have a vertical dimension of relationship to something greater than we (A Higher Power), as well as relationships to other human
beings. "Spirituality is having a vertical comprehension in terms of a relationship because there is something greater than ourselves... and it's anything from relationships to other human beings." [Shirley]

Early on in her conversation, a second nurse found it quite difficult to define spiritual care.

I don't know that I do, sometimes I think it is just a common whatever occurs to you at the minute and it comes out of your mouth. You follow through on because you think this is what this person needs. I don't really pick a specific category to put anything in. Everything is just the overall need of the client and their family. [Liz]

Toward the end of the conversation, she offered this definition. "Everything is just the overall need of the client and their family. To me it is just the overall well-being of a person and their soul and their spirit." [Liz]

A third nurse gave this definition.

To me spiritual means certainly not only religious it's totally depended upon what a person believes. Whether it be God or a symbol just whatever their belief is in. It's also to me it means that basically whatever the person feels within themselves should be acknowledged and met prior to death. [Maria]

4.4.2 Religion and Religiosity

Religion and religiosity were not evident in the personal beliefs of the nurses. There was only one subtle reference to holding a religious faith. Nevertheless, the
nurses gave significant meaning to connection with a religious community, and in particular, to the value of seeing a clergyperson for the one who was dying.

Of the six nurse-participants, only one nurse expressed holding personal values about the importance of faith to her sense of well-being. "I'm not religious, but I have a strong faith and I know that if I don't nurture that part of me I get narky. [Barb]

Although this nurse describes herself as "not religious", she has a friend who is a nun, and she believed her work in palliative care to be "her ministry".

My friend, who is a nun, tells me this is my ministry and I think, ah, this is my ministry. But I honestly believe that I am called to, and I don't say this, I don't do it on a conscious level but I know that when the voice inside tells me I need to be somewhere I follow that voice. [Barb]

In contrast, one nurse expressed lack of belief in the role of religion in her life.

Well, I don't really attend church. I guess I just have a fairly positive outlook on life and death and dying. I guess my biggest concern would be how would I handle the situation if it were me sitting or lying in that bed. I try not to focus on that very often because that just takes away from the focus that you are supposed to be having at that particular time. If it comes to my mind, I always just hope that I might be as wise as that person in that bed in front of me. [Liz]

The nurses did not express personal connections to either a religion or to practices that encompass religiosity. Nevertheless, the nurses expressed strong beliefs about the value of connection to a religious community for the ones who were dying. In
particular, they placed high value on the inclusion of a clergyperson into the spiritual
care of the terminally ill person.

The nurse believed connection to a religious community provided comfort and
strength during the time of dying.

I guess for the most part or for some people, I think for the most
part, they are in comfort for the priest and the minister or people from the
church to be there. For people that are truly religious, they get a lot of
strength from that. You know, and they know that when it is time for going,
they are going somewhere. I think they get a lot of comfort. [Alex]

The nurse initiated the conversation with the one who was dying regarding
seeing a minister. She understood this contact to have value for both the patient and the
family.

I said, I don't know what your religious background is, but I sense
that you fear death and perhaps it would be a good time for you to decide
whether or not you want to see a minister of whatever religious faith you
are. I came out of the room and I didn't realize but his family had a
monitor system and they thanked me for doing that. They weren't
necessarily a religious family but they thought that that would mean
something to him. [Maria]

As well, the nurses initiated the contact with a clergyperson, even when they
were unsure of the religious background of the one cared-for.
Nurses will call ministers. Some nurses call their minister and (she) will say, “I have this client and I don’t know what flavour they are but they need something”, and often that is the beginning of a relationship. Then the minister will go in and somebody from an organization will go in and see them and hitch them up with some support service through their church or whatever. [Pam]

Nurses believed that people who are dying wanted to see someone from a religious community, regardless of prior interaction with that community.

But I tend to believe that ... regardless of their interaction with the church in prior years when someone is getting to the point of death they want to see someone. Whether it be the fear, whether it be that finally they are realizing their next journey and that there must be some Super Being. [Shirley]

Another nurse believed people who are close to death want to see a minister, as the minister is God’s representative on their behalf.

It is almost as though the clergy, whatever religious denomination you are, are not called in if they are people who do not attend church regularly, or are not involved in the church community. Until towards the very end when the patient realizes just how close they are to death. Basically I really believe that some people feel that as long as they have seen a minister once they are safe. [Shirley]

Nurses also held beliefs about religion sometimes having a negative impact on the peace and comfort of some dying people. The negative impact was related to fear of dying and prior loss of connection to a religious community. “The people who are afraid are the people who I think probably haven’t been to church in thirty years.” [Alex]
As well, the negative impact of religion was related to guilt and pain during the dying time. “You know, they’re confessing left and right and centre. Um, I think that for some Catholics there is a lot of pain involved with dying and being Catholic.” [Alex]

Or, they expressed ambiguous feelings about the role of religion in the lives of the ones cared-for.

*Religion to me, I have varied religious backgrounds in my clientele and everybody deals with it differently, you know. Roman Catholic’s, Protestants, Presbyterians, you know, everybody seems to deal with it on their own way. Lots of times people have just given up on God and spirituality and sometimes they are spiritual and they don’t even realize they are. Some people keep in touch with their ministers, other ministers come and do home visits and so forth. I think sometimes people believe as long as they can get to the end, as comfortably as possible and with as much satisfaction as possible then they seem relatively peaceful.* [Liz]

One nurse understood spirituality to include, but not to be restricted to religiosity. As well, she made the connection between peace, lack of fear and the need for the nurse’s acknowledgement of the person’s beliefs.

*To me spiritual means certainly not only religious. It’s totally dependant upon what a person believes. Whether it be God or a symbol, just whatever their belief is in. It’s also, to me it means that basically whatever the person feels within (her/himself) should be acknowledged and met prior to death. It’s basically so that they are at complete peace within themselves on dying, and my aim, although you can’t always reach this goal, is to try and make it so people are not afraid.* [Maria]

The one nurse who expressed having a personal faith recognized that some people’s prior life experiences were so painful that they never find peace, even in their dying time.
But when it's in existential angst some people have to die that way because that's how they lived and if they don't face the issues in life they're not going to face them in death and I'm not there to change that and that's okay. [Barb]

4.4.3 Sharing Own Beliefs about Death and Dying

The nurses shared their own beliefs about death and dying. The nurses did not share the same meanings about death and dying. Yet, for some nurses, what they believed about death and how they believed they would die were two different stories. The meanings of death held a positive connotation for the nurses.

One nurse described her changing beliefs, her interest in the dying process, and her sense of "being a witness".

I have totally gone from the one extreme to the other because now I'm totally intrigued with it because I really, really believe it is another journey. It's just another part of your life and certainly with some things I've witnessed it's certainly backed up that way. [Maria]

A second nurse described the difference between the anticipatory grief and the reality of the death for family and friends. She believed the death occurrence was a spiritual experience for her.

And everybody you know, nine out of ten times, everybody just sits back and is amazed at how cool this was, and this anticipatory grief leading up like "Oh, my God the moment this person dies, it's going to shatter me." But everybody's sitting back going "wow". And that's a spiritual thing for me. [Alex]
A third nurse differentiated between a spiritual perspective and a human perspective. She understood each to be “the call of the soul”.

*I think of my second person, the one that died a short while ago. We connected at a level that was not from a spiritual perspective. It was more of a human perspective but yet it was I believe it was the call of the soul.* [Barb]

Another nurse described her belief that the whole process of dying was a spiritual experience for both the family and for the patient. Moreover, she valued this time as being very important.

*And another thing that I should have mentioned, that I was just thinking of, as far as the spiritual needs of the patients, I did mention as far as settling things with families and what not, but I think the whole process of death is spiritual both for the family and the patient. It’s a time for them to all get out what is necessary and hopefully their questions will all be answered by the appropriate personnel involved. Everyone can have no regrets and no guilt. This to me is pretty important, for sure.* [Maria]

One particular nurse shared her beliefs with her patients about what happened after death.

*But you see, even then you know, I get a lot of questions about what happens to me afterwards. I tell them I don’t know but ah, and I am quite honest in telling them my beliefs. I say I am not sure exactly what to believe in, so I believe in a little bit of everything cause that way I got myself covered.... Yeah, playing it safe. But, but I really believe, who knows for sure, but what I go back to is that the spirit lives on and just finds another house to live in and so on and so on. You know I believe in that sort of thing.* [Alex]
As well, she used the power of her own beliefs in an effort to shorten the time of dying for a child she cared-for. "Then I'll just sit there and go why aren't you going and then I'll call on all my little angels and say will you get down here and get her." [Alex]

This same nurse shared her concerns of not being cared-for when it is her own dying time.

Oh just make it quick. Yeah, I don't know, I do this and I watch people die and think it is all great and groovy and beautiful and I say to my friends "When I am sick and dying will you take care of me?" And they say "Okay." And I always turn to their husbands and say, "Will you change my diapers?" And they say "Nnnno." [Alex]

She knew that the care she gave was unusual, and she did not believe she would be cared-for the same way that she cared for others. These thoughts caused her to question how she would end her own life.

But ahh, I don't know. I don't think I will have what I give or I will have what I see. You know, I think I will be alone. I don't know. I think before I get to any real suffering I will probably end it. Probably I don't know. But I don't know who I would call on. [Alex]

Another nurse spoke of her fears of dying, as loss of loved ones. "What would scare me the most? Leaving everybody I love." [Liz]

Even though a nurse despairied about being alone and not cared for when it is her dying time, she held beliefs about life after death.
But, but I really believe, who knows for sure, but what I go back to is that the spirit lives on and just finds another house to live in and so on and so on. You know I believe in that sort of thing. [Alex]

4.4.4 Hidden Work

The nurses’ work of spiritual caregiving was mostly hidden work. That is, there was no written record regarding the work that the nurses did in providing care to meet the spiritual needs of the ones cared-for. Moreover, the nurses gave many hours of unpaid labour in their work of caring for those who were living the last days. The two sub-themes of hidden work are charting and unpaid labour. This minor theme of hidden work concludes with the nurses’ acknowledgement of the price they pay for the work they do.

4.4.4.1 Charting

One nurse told how she charts. “I would chart but I would chart it globally. I would chart “support given, issues related to personal growth, death and dying issues, relationship issues”. [Barb]

The same nurse explained why she no longer charts praying with her patients.

It wasn’t a problem to start with, but my boss was very uncomfortable with the spiritual component and she said “I knew you’d be upset”, but I said “I’m livid” because I said, “I bent over backwards to make sure that I’m not putting my views on anybody else, but you or nobody else is going to tell me I can’t practice nursing in the way that I meant to practice”. [Barb]
I used to chart that I have prayed with a patient, I don't do that anymore, people are uncomfortable with it and so I usually chart support given related to personal spiritual issues, so leave it at that. [Barb]

Another nurse writes “good discussions” and other non-specific notes. “I write things like “good discussions”... Sometimes I write "client very distressed and teary over blah, blah, blah" you know, "options discussed" and stuff like that, but no ... Then it is "pain and symptom management, supportive care". [Alex]

A third nurse spoke of what she charted. “I use emotional. I use the diagnosis pain and symptom management, then if there is other pain, emotional support."[Liz]

A fourth nurse told of her charting. “I would probably be more apt to use emotional distress.” [Maria]

A fifth nurse spoke of what she read in the nursing notes of other nurses as well as what she used as her nursing diagnosis.

Comforting the patient and reassurance, support care, usually it is something nice... some sort of interaction with the client around a spiritual activity but that's rare quite honestly... They don't call it spiritual care... they will call it emotional distress... and my diagnosis is always alteration in comfort. [Pam]

Finally, a nurse summarized the way that palliative care nurses record the spiritual care that they give. “It's couched in other language.” [Barb]
Another explained the difference between what she read in the nursing notes and how the nurses communicated with each other about the real issues and the actual care given by the nurses. “Very rarely do they document it in detail, it will be in support given and they just leave it at that. But, when they talk, you find out what the support is.” [Pam]

4.4.4.2 Labour

The nurses gave many hours of unpaid labour. Sometimes, they did not recognize that the time they gave was work time.

And, and we were called in there all the time, around the clock... I get a good three hours sleep in between, I run home, sleep, they phone, I go back in. And I went in Friday about five in the morning. [Alex]

The same nurse spoke of caring for another patient.

But they phoned me at home, at four in the morning, so I just stayed through and then Donna came in and they just phoned and said, “Do you guys need food, do you need this, do you need that?” And ah, I don’t know, I wasn’t leaving. [Alex]

Other times, the nurse decided what the one cared-for needed, gave the care, and waited to see if they would get paid or not.

And I looked at the RPN and she goes, “I’ll be staying all day.” And I phoned the office and said, “We’ll be here all day. Today’s the day, and you tell CCAC whatever they want to hear, I don’t care.” [Alex]
You know if, you want to pay me, pay me, you know like, if it's not in the plan of care, oh well. [Alex]

The same nurse did not recognize all of her nursing care as work. She did not consider talking to the patient on the phone for an hour during her weekends off to be work.

I mean there is time; there is time on your weekends off and stuff that you phone and check up to see how they're doing. I don't consider that putting in an hour when you talk to the clients for an hour or so. [Alex]

Nor, did she think going to be with the bereaved family after the death of the loved one was labour.

Or going over to see a client, you get a bereavement visit afterward but you get "a visit" and sometimes I think that these people you know they don't have other people to talk to and so on and so forth. [Alex]

When asked how much time she gave as unpaid labour, her response was "none". [Alex]

Three nurses spoke of times when they attempted to respond to patient needs outside of work hours.

I said, "Well, I did go and see you or drove by your house but there were a bunch of cars" and he said," Well, you should have come in". [Barb]
I phoned this morning, being my day off, but I have a patient who is in a crisis... I mean being a day off didn't mean a thing to me because I felt it was necessary to do that. [Maria]

We never left the patient's home without saying, “Look if anything comes up or if you have the smallest question I want you to ring us because there is no sense in worrying about it overnight because it might be something really easy we can answer”, and most phone calls were relatively easy. [Shirley]

One nurse explained that nurses “bend the system” as well as giving of their own time in the care of their patients.

They'll utilize the system, they will bend it not break it, just bend it to provide what's there and I think ... they volunteer, some of them will volunteer. Some of them will just bill for x number of visits but be there for more and they do that to some point --- and I have had some of them say I was in that home for x hours, but you know my time slip will say this. [Pam]

Two nurses verbalized their reasons they give unpaid labour.

These are all things that I feel you must follow through in primary nursing, you must, for the patient, and for yourself if you have any belief that you are a good nurse. [Shirley]

There are also things that I don't think the office totally understands the extra hours involved and there truly is a lot, a lot of emotional issues that you are an advocate for the patient, an advocate for the family, a liaison between the people that paid for your visits, a liaison with the doctors, you are out there on your own. [Maria]
Finally, two nurses explained the personal costs to both nurses and the ones
cared-for when nurses work with poor pay and too many assigned patients.

They get frustrated, they get angry, they have a right to be... They
try to be very politically correct in what they do and they worry that they
have screwed up somehow and they get frustrated with the 300 kilometers
on their car and the price of gas going up. They wonder how they are
going to manage this. [Pam]

They (Community Care) are not going to get nurses with insight for
this type of care unless they are experienced and when you can go to the
hospital and almost make double the amount of money it is not right.
[Shirley]

4.5 The Nurses’ Evaluation of Spiritual Care as “Good Death”

The third major theme in the spiritual care given by the nurses was their
evaluation of the spiritual care they gave. They evaluated their care as successful if the
person died in comfort, with no family conflict, and with pain and symptoms under
control. Moreover, they held high value to the importance of the dying itself. This
importance was evidenced by two sub-themes: “being there” and “doing the unusual”.

4.5.1 A Good Death

A nurse reflected about the topics of conversation when palliative care nurses got
together.
And that's when they will also talk about the people they have lost over the past and they'll talk about what went well with it, what went badly with it, how it was easy or hard. And usually under easy or hard, the personal feeling of this was a good death or a bad death and I thought that death was peaceful or how they felt about it and how they internalized it. It comes out and they start ruling it back to where they are and sort of in a spiritual sense of where they are. [Pam]

One nurse is very clear about her beliefs about a good death. "It was beautiful. It was so beautiful. I think that, that is probably the most beautiful experience. It was, that day was beautiful, everything leading up to that was horrible." [Alex]

4.5.2 Comfort

The nurses described spiritual care in the context of providing comfort during the dying time. Comfort was tied to pain management, management of adverse symptoms, as well as acceptance of the ending of life and spiritual peace.

One nurse describes her hope for comfort for the patient as well as for the family.

The family has to live and what your hope is in the whole thing is for comfort and some sort of peace with the patient, with what's happening to them, which is easier said then done but that's what your hoping for. [Liz]

Another nurse summed up her goal of providing for comfort. "You try to make everybody's comfort level with the situation as easy as you possibly can. [Shirley]"
The same nurse speaks of seeing and listening as ways to be attentive to the underlying messages from the one cared-for.

"To me it's almost like watching a child and I don't mean that in any lesser meaning than that, but just listening to what words they are using, you know sometimes people will say things like, "Oh, I'm fading away", and if you just take that for what it is you know you could get into diet, "Well I will bring you some Carnation instant breakfast tomorrow", you know you are off and running.

But if you can just sort of listen and ask them to say "What are you telling me when you are saying those words?" and I think that you will get a clearer picture and they feel like they are fading, I think they are fading, fading away out of this life and they can talk to you a little bit more about that. [Shirley]

The nurses understood blocks to comfort and peace. These blocks were "past losses not mourned" and "fear of dying".

"And I think the best example of spiritual distress in the past is if people have to mourn a lot of losses that they've had in the past, that reflect the past. [Shirley]

I think most of them are pretty prepared, but for some of them its fear and its not fear of dying its fear of how they're gonna die.... [Alex]

Sometimes the past horrors of war and deprivation are blocks to comfort for the one dying.
Spiritual Care of the Dying: A Community Nursing Perspective

But there are some people, and you find some people that grew up in the war and know there’s a lot of people that were prisoners of war and people will share those kinds of feelings and sometimes that angst is tough and it’s hard to lodge that. It becomes a challenge then to get those symptoms under control. [Barb]

One nurse believes palliative care nurses are committed to caring from a philosophical understanding of “Total Pain”. “People that you meet in the same area of care try very, very hard to meet that total pain philosophy.” [Shirley]

Lastly, a nurse summed up how complex and difficult it can be to provide the care she wanted to provide, to both the dying one and the family members. She pointed out that in a situation of conflicted needs, her primary focus was on the one living in the dying time.

And whether in your mind you agree or disagree with anything that’s going on, you still have to put your feelings aside and deal with what that person wants and that is what I do. Every person is individual, every person has different needs, everybody in their family is different with different history, different problems, different concerns and its wild. We met in a big home, with a big family, the amount of needs and everything but initially when it comes down to it my focus is the client, then the family. [Liz]

4.5.3 No Family Conflict

The nurses evaluated the care they gave toward the goal of a good death by how much or how little family conflict existed at the time of death.

One nurse believed that people could change when faced with their own death.
I think that people can change, people who perhaps have had a rough life or who have been very selfish people. I think their whole persona can change when they are faced with the fact that they are going to die and obviously to some people it really does not seem to matter from what they say but I don't believe that either. [Maria]

Another spoke of healed relationships.

Ya, let me tell you that the next day she's up beside him. The relationship was totally different, there were letters on the wall, not a lot but everyday there was a new letter. I was invited to read them, we never talked about anything like that again, again a different place and time, but they had moved on. [Barb]

A nurse expressed amazement at a person timing their death when it was convenient for family members. She valued this story as helping her to gain in wisdom and insight.

That just amazed me. I mean that has to be the most unselfish death. I could not believe it. So I really find rewards in this work, like I really find that you gain wisdom and just see a totally, totally varied, so much insight into people and their deaths. I really love it. [Maria]

The same nurse summarized her understanding of a good death. She defined the good death as one of peace, comfort, families together, no regrets, all the loose ends tied up.
It's basically so that their complete peace within themselves on
dying and my aim although you can't always reach this goal is to try and
make it so people are not afraid. Whatever that might take, whether it
involves giving them piece of mind by having the minister come in or a
lawyer to help them with their financial decisions or whatever or helping
get families together that have parted for a long time. Just whatever it
takes so that the person dies without any regrets, just all loose ends tied
up. [Maria]

4.5.4 Importance of the Dying

The importance of the dying, both before and after the death, was a major theme
within the spiritual care given by the nurses. There were no stories of providing spiritual
care to persons who did not die. As stated earlier, the nurses’ spiritual care was focused
on death and dying. In particular, the stories told by Alex and Shirley spoke to the
importance of the dying time. This emphasis on the importance of the dying contained
two sub-themes: Being There and Doing the Unusual.

As well, the minor themes carry a suggestion of the nurses’ attempts to develop
rituals around dying and death, rituals of presence and body care. These rituals have
been long missing from mainstream Canadian culture, hidden away in hospitals and
funeral parlours. Taken together, these sub-themes inform the importance of the dying:
both before and after the death.
4.5.4.1 Being There

One nurse told powerful stories related to being there during the time surrounding death. These stories spoke of attentiveness and intimacy, commitment and helping the family understand what is happening.

When one young woman was dying, the nurse stayed awake so the husband could sleep. There was attentiveness as well as physical intimacy and sharing between the nurse, husband and the dying woman’s best friends.

I would just sit there at night and say to her husband “go to sleep”, and he’d go to sleep. It was a very strange thing, he’d wake up and say, “You’re always there when I wake up”. I said, “Yeah, pretty odd. And ah, we played a lot of music and when her sisters came down. And her two best friends were there and we hung out on the bed, they had a great big bed and had a lot of chairs around.” [Alex]

Later in the story, the nurse had gone home for a couple hours sleep, only to be awakened by a frantic telephone call. She returned to the home, and found the dying woman in distress. She encouraged the loved ones to give the dying one what she wanted, then helped them to reconnect to the dying woman with intimacy and sharing.

She keeps screaming and pulling her oxygen off. I said, "Then stop." I asked her sister to go get the candles, and so we lit the candles and had her chants and all her other classical music.

... And then some scented candles and some incense.
Again everybody piled up onto the bed, everybody had a limb or a piece of skin, doing memories, the photo album and so on and so forth. And that was it. [Alex]

A second story told of the dying time of a five-year old girl. This story contained the same sense of attentiveness and commitment as well as the nurse’s continuous assessment regarding the comfort of the child. She offered comforting images to the parents.

Basically, Friday came, they phoned me again.

I got a good three hours sleep in between. I run home, sleep, they phone, I go back in. And I went in Friday about five in the morning. And ah, she’d just gone into the coma.

So I looked at her and I looked at mom and dad and I said, “I’ll be staying all day. And I phoned the office and said, “We’ll be here all day. And, we stayed all day and it was a quarter to five that evening that she passed away.

This little five-year-old when she was going, she started the moaning probably about an hour before she went.

I got down on the floor and I looked at mom’s face and I said, “Can you hear that?”

She said “Yup.”

I said, “Can you think back to when she was a little baby and she was sleeping and she was making that rhythmic breathing noise? That’s what she is doing right now.”

So you know when she did other things, then I would reassess it and when I was sure, I would reassure them that that’s not pain.

So I think that’s my role there. She was in the middle of them (her parents lying on either side of her) all day, and I even got a picture of mom passed out with her.

And even dad would look at me, and say, “Why isn’t she dead? “

I said, “She is waiting for something”.

And then the grandparents showed up and she was dead a half an hour later. [Alex]
She sums up her commitment to being there during the dying time. "I commit myself a lot to my patients, that when it's the end I'm there. [Alex]

She plans for the future dying time of another child. She will be there, even if it means sleeping in her car.

But this little boy when it's his time, there will be no one else in there. If M... is doing clinic it will just be K... and I and we will do around the clock if we have to. You sleep in the car; you do what you have to do. [Alex]

4.5.4.2 Doing the Unusual

Two nurses shared stories that spoke of doing the unusual after death. These stories are unusual within the context of Canadian dominant culture, and in particular, within the context of the Canadian health care system. Moreover, the standards of practice within Canadian palliative care do not include caregiving the body after death. These stories suggest rituals of presence and bodywork that are hidden, or absent, from the current Canadian nursing death practices.

This story told of care given after the death of the five-year old girl child. Two nurses participated in this unusual care.

So, (the other nurse) picked the baby up and went into the bathroom, cleaned the baby up, and ran a bubble bath.
Mom came in and she was just like, "Oh my God."

She said, "I'm gonna get my bathing suit on."

I said, "Okay."

We were probably in there for about an hour, cleaning her up and then we took her out to Mom and Dad's bed. Moisturized her, cut her hair, got her dressed and laid around in the living room until about 11:30 at night. And it was beautiful.

And I said to her when we were in the tub to, I said, "Do you want a picture of this?" Because they're a real picture people. And she kinda looked at me and she said, "Do you think?" I said, "Yes". [Alex]

The same nurse told a second story of caring for the body of a young woman to meet the woman's standards of personal care during her life. As well, she advocated for the woman's care, even after death.

I gave her a bath and we changed her and, um, what about lipstick and I said, "We're going to do her full face." Because she always wore makeup, she would be mortified to leave the house without it.

Then we phoned (the funeral parlour), they came over and I got into it with the guy at (the funeral parlour) the week before over my immediate next-door neighbours. Their father was my client. I got into it with (him) over his makeup. He looked horrible it looked grotesque. And they do this thing at (this funeral parlour), they stretch the mouth out, it looks horrible.

So they showed up and I said to the (funeral) guys "Do you see her face?"

They say "Uhuh."

I said, "Don't touch it okay."

She was being cremated anyway.

But I say "Don't touch it, let her go out like that." [Alex]

Another nurse told a story of unusual care given after death. This story was focused on calming the fears of a dying man; even long after the nurse knew that he is dead.
I remember one man, talking about spiritual distress. You know he was terribly worried that he would be declared dead, but not really dead. And he had this terrible fear about being buried alive essentially, and actually I was with him and his wife when he died.

Before he actually died we talked about his fear and you know I tried to really reassure him that I was well aware of what his fear was and that I, with his permission would prep that to all the nurses caring for him, so that if I wasn't there at that moment in time that they would be still aware of that.

And we talked to his doctor who was most likely going to be the doctor declaring and plus I told him that we would stay with him an extra longer time after he died.

It would be absolute, and he seemed to be okay with that. [Shirley]

The nurses who provided unusual care during and after death explained why they did so. They valued the care they gave, and knowing when not to do what would cause distress to family members. “But nice stuff like that, just caring for the body afterward. You know, and caring for the body and knowing what you have to do, and sometimes when you don't have to do stuff.” [Alex]

Thus, the nurses' stories of spiritual caring spoke of their desire to make “a good death” for the one cared-for and for the family members who have more life to live. Moreover, they worked to make a good death for themselves. They understood that they did not have to do it, but they understood this work to be care for the soul, both for the one dying and for themselves.

My thing is care of the soul and care of the body and caring for the soul is helping somebody make decisions you know that will be less hurtful to their soul. You know. And it may seem like it will be more painful ... but in the end it will be more calming for you. [Alex]
Lastly, a third nurse summed up how she evaluated the spiritual care she gave to ultimately get the cared-for to a good death.

*I believe with everyone it does matter and my ultimate mandate through it all is just to get people to the goal that they are not afraid, issues are all resolved and pain is under management.* [Maria]
CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

5.0 Discussion

In the discussion of the findings, I focus on the nature of the spiritual care given by the nurses, what the nurses know about spiritual care and why they gave spiritual care. I expand on each theme in turn. Following the discussion of the findings, I talk about how the experience of doing this work has changed my practice of nursing. After a summary of the findings, I address implications for nursing, then the limitations of the study. I conclude the section with recommendations for further research.

5.1 The Nature of Spiritual Care

The nurse-participants provided spiritual care to the patients. The nurses' spiritual care was focused on the dying time as the most significant point of spiritual intervention. Wilkes (1997) observed the same emphasis on the dying time in her literature review of good death and palliative care nursing. Within this study, there are six minor themes related to this focus on death. These minor themes are: relating to distress, purging, pain and symptom management, family relationships, walking beside the dying one, and loving the person to death. These minor themes define what the nurses meant by spiritual caregiving.
The nurses’ spiritual care was focused on the short time left for the patients, the dying time. Their spiritual caregiving encompassed relationships to Self, Others and a Higher Power, making meaning of life and suffering, healing relational wounds, and preparing for the journey after death. They provided this spiritual care through acts of presence, listening, encouraging, managing pain and symptoms, working to ease distress and healing broken relationships. Thus, the nurses’ work of spiritual caregiving falls within the broad definitions of spiritual care as provided by nursing literature (Bradshaw, 1994; Bush, 1997; Cairns, 1999; Coulson & Malo, 2000; Davidhizar et al., 2000; Dyson et al., 1997; Fish & Shelley, 1979; McSherry, 1998; McSherry & Draper, 1998; Oldnall, 1996). These findings are contrary to Highfield and Cason’s (1983) findings that nurses had limited awareness of spiritual needs and problems. As well, there was no indication in any of the stories of spiritual abuse. Spiritual abuse is the act of making a person believes that s/he is going to be punished in this life, or in an afterlife (Purcell, 1998).

5.1.1 Spiritual Care as Guiding

The nurses acknowledged the role they played for family and loved ones as the dying progressed and death occurred. Their previous death experiences helped them to be confident that the event of death would not be as traumatic as some loved ones believed. Thus, they were able to act as guides and interpreters during the journey to death. They understood this time of dying to be a spiritual experience for the nurse, the
dying one, and loved ones. The literature regarding such guiding is contradictory. In one study that described nurses’ behavioral intentions toward the dying, Waltman and Zimmerman (1991) surveyed 372 American nurses. They found the nurses were highly likely to do general nursing care of dying patients, but were much less likely to openly communicate with dying people or their families. They concluded that the need for open communication was not being adequately met by nursing staff. On the other hand, an Australian qualitative study demonstrated that nurses expressed their palliative caregiving as dealing with death, making connections, building interpersonal relationships, and being involved in issues (Taylor, Glass, McFarlane, & Stirling, 1997).

5.1.2  Spiritual Care as Doing the Unusual

There was strong indication that the nurses worked to do whatever the dying person defined as necessary or important to his/her life, even to the point of doing the unusual; such as sitting with a body long after death just to make sure he was dead, or doing the hair and makeup of the deceased one, as she would want it done. As well, two nurses helped a mother to bathe in the tub with her dead child. I did not find any literature that supported these unusual acts of caregiving after death. I use the term ‘unusual’ to mean unusual within the norms of the dominant Canadian, English-speaking, Euro-centric nursing culture.
5.1.3 Spiritual Care as Relating to Distress

The nurses spoke of relating to the distress of their patients, whether that distress was of spiritual and/or physical pain, grief, unresolved family conflict, or being alone and without significant others. They acknowledged the physical and emotional exhaustion such relationships created as well as their desire to have a "normal" life. Such demands increase the nurses' vulnerability and lay raw their own life experiences of grief, loss, and for some, abuse (Hall, 1996). Yet, these nurses willingly entered into the brokenness of their patients. The nurses viewed their willingness to initiate the conversation as an important aspect of helping the ones cared-for to begin the process of purging. The value of purging was in the cleaning up, healing broken relationships and moving on towards a good death. The nurses acknowledged that sometimes they could not decrease the distress of the dying.

There was a common belief in the circular interrelationship between spiritual distress and physical pain, and the nurses understood the significance in the role they played in relieving this distress. They clearly identified the necessity to control pain and unwanted symptoms so that the person would be able to deal with issues and do the spiritual work necessitated by living with terminal illness and approaching death. Palliative care literature on pain and suffering supports these beliefs (Latimer, 1998; Newsham, 1998; Baines & Norlander, 2000). Their caregiving was holistic, in that the nurses did not delineate bodywork from spiritual or social or emotional work. They
clearly understood that the human being is more than the sum of parts, and that what affects one part affects all. Kendrick (2000) supports the belief that spirit, mind and body are one, while Goldberg (1998) refers to the holistic nature of a human being as all together.

These nurses shared the image of "walking beside" the one cared-for in the meanings they gave to spiritual caregiving during the dying time. This walking beside was a deliberate choice taken from a sense of responsibility for the patient. Moreover, the walking beside was seen as intimate, accepting and being a witness to the journey of the dying time.

5.1.4 Spiritual Care as Love and Friendship

The final aspect of spiritual care as focused on death was love. All the nurses did not share this aspect of loving the patient, but for those who did, it was a powerful image of loving to death, and even beyond death. One nurse spoke of her care of the dying one as including preparing the body for eternity. This loving to death was not limited by the lovable qualities of the patient or the attitudes and relationship between patient, nurse and family members. As well, there was recognition that for some patients, the nurse was the only caring person in the dying one's life. This loving care was described as emotional love that can create transformation, and within the loving relationship, both the caregiver and the ones cared-for were changed as a result of the loving.
Throughout these stories of spiritual caregiving, the most significant concept was that of "care". This care was relational and centred on the well-being of the patient. Unlike the professional standard of nursing care as empathy (College of Nurses, 2002), these nurses cared in a profoundly personal and interpersonal way. Their caring was not just of concern, or beneficence or dedication. Some nurses understood care in different ways (Kuhse, 1997). Yet, all the participants' caring was emotional, and powerful and for some, loving. The loving was described as "loving to death". Bevis (1981) identifies nurse caring as "a feeling of dedication to the extent that it motivates and energizes action to influence life constructively and positively by increasing intimacy and mutual self-actualization." (Bevis, 1981, p.50), while Wilkes and Wallis (1998) refer to a model of nurse caring-compassion as "a momentary pinnacle of professional nurse caring that they are striving for but which not all necessarily achieve (p. 587).

The caring relationship as love and friendship has been described in nursing literature. One intriguing image of this caring relationship is of "the dance of compassion" (Cooper, 2001, p.185-187). Compassion is at the core of caring (Wilkes & Wallis, 1998). Cooper believes the dance starts with recognition of suffering, and the dance requires the one caring to move toward that suffering, and not turn away. Younger defines this as entering into the suffering with the patient (Younger, 1995). Suffering separates the sufferer from others, in part because the experience of suffering is very different from the experience of observing the suffering. Thus, the one caring must be the one to make the move toward the one suffering. The dance of compassion also includes the caregiver as feeling the pain of the suffering one, and having the desire to do something
about the suffering. The nurse being advocate and acting without judgment accomplishes this. Moreover, the one caring needs to have “the ability to accept both the light and the dark of the experience” (Cooper, 2001, p.186), as what has happened to the patient could be the experience of the caregiver.

The nurse-participants exhibited compassion as love and care for the totality of the person cared-for. This compassion and love and/or friendship were evident in these nurses’ relationships with the ones cared-for. The nurses agreed that caring has an emotional component that characterizes the nurse-patient relationship. In fact, it could be said, caring as constructed by some of these palliative care nurses was the kind of caring that was previously defined by the “loving care within families”. It could be argued, “the central task that nursing took upon itself was the translation of "love" into the public domain” (Dunlop, 1994, p. 30). The findings suggest caring in nursing is in the process of being reconstructed as loving care by some palliative care nurses. It is interesting to note that this reconstruction is taking place back in the home.

5.1.5 The Underside of Loving Care

There is an downside to this construct of caring as familial love. At the same time as including a sense of love in the meaning of care, the term brings with it all the negative connotations associated with the historic feminization of caring. The history of the caring work of women has been the unpaid labour of female family members and the underpaid labour of non-family members (Ehrenreich & English, 1978; Schwartz,
1993). As Dunlop (1994) points out, it seems no accident that “cure” is associated with
the higher status, predominantly male occupation of medicine that “jealously guards the
term” (pg 29), whereas, “care” is relegated to female dominated, lower status
occupations (such as nursing), and low-status male and female occupations such as
gardener, farmer, cook, cleaner. For example, women care for the children, the elderly
relatives of herself and her male partner, or other relatives, the poor and homeless (as
in soup-kitchens and refugees). Thus, caring is not seen as a set of practices, but rather
the thinking, feeling way of being that gives rises to activity (doing something or
refraining from doing something). This loving care given by women is the history of
families and health care and education and social welfare in Canada. [Baines, 1991
#238] Consequently, the emergent construction of caring from a nursing perspective
becomes the work from below, that is, from the least powerful in the system.

There is little reason to doubt that caring is profoundly shaped by the social
structures of the institutions of care. And, as stated earlier in Section 2.1, our institutions
of Home Care do not hold to policies and guidelines for caregiving based on the needs
of the patients. Rather, our home care services are predicated on meeting a centralized
pre-determined budget that is based on political agendas. Under such conditions, there
are enormous pressures on the caring relationships between the home care nurses and
the ones cared-for. Benner (1984) sums up by stating, “The demands of nursing are
large ones. The pains, risks, and dangers encountered are sometimes great and cannot
be experienced without personal cost” (p.208). For nurses to accept such a personal
cost, there must be some counterbalancing benefit to the work of home palliative care
nursing. This benefit could come from what has been historically known as caring for the sick and dying out of religious conviction.

5.1.6 Spiritual Care and Religion

Within any cultural context, people who are non-religious tend to appropriate at least some of the norms of the dominant religion. And, conversely, religions become encultured. In Canada, the dominant religion is Christianity. Thus, the Christian injunctions to “love your neighbour as yourself” and “care for the unfortunate among you”, imperatives shared with all world religions, enters the moral framework of even the most non-religious. The value of caring for self and other is found in the most secularized of Canadian society.

There was little evidence that the nurses worked from a religious value of caring for the sick and dying. Rather, there was a significant incongruence regarding the meaning of religion and the clergy. The nurses identified themselves as not being religious or part of a religious community. Yet they held high value for the role of clergy in the lives of their patients. Specifically, they seemed to support the patient’s beliefs that the clergy’s visit to the dying one somehow directly represented God’s coming and making all things well. This powerful belief in the role of the religious in the lives of their patients was not transferred into having meaning in their own lives. They made meaning for their own lives outside the framework of conventional religiosity.
Beliefs about the clergy’s role in easing the distress of patients have been found in nursing literature which examines the spiritual caregiving of hospital nurses (Dyson et al., 1997; Elkins et al., 1988; Golberg, 1998; Martsolf & Mickley, 1998; McSherry, 1998; McSherry & Draper, 1998; Narayanasamy, 1991; Stoll, 1989; Wright, 1998). These researchers found that hospital nurses refer to pastoral care and chaplains for spiritual care of their patients. As in the literature, the study nurses encouraged reconnection with the church or clergy for their patients, but this did not translate into similar beliefs for their own lives. Moreover, these nurses did not rely on ministers or priests to provide spiritual care, but they did recognize the value for the patients when they had a relationship with a minister and/or a faith community.

One possibility for this incongruence was the nurses made caregiving itself their religion. Spirituality seems to be dependent on another, either a God-force or a substitute god-force, such as wealth, work, and friends, or caring for another. Thus, caring in itself can become either a surrogate religion or occur because of religious beliefs and values (Rutland, 1994). With religion defined as a framework for expression of spirituality, then caregiving could be defined as the religion of these palliative care nurses. Moreover, within the construct of caring as religious expression, the care for the spiritual needs of the patients became the spiritual work of the nurses. Thus, spiritual caregiving of the ones cared-for was both the object of care and the means by which the nurses discovered their own spiritual selves. In this way spiritual care was both the caring relationship itself, and it was the vehicle by which the nurse met the needs of the
patient and of herself in the sense of transcendence and meaning of life. This caring was of supreme value to the nurses.

5.1.7 Caring as Grounding and Imperative

What is it that both compels and enables nurses to give care as "loving to death", with intimacy and mutuality, regardless of the personal cost or the un-lovability of the one cared-for? Nell Nodding (1984) attempted to give caring a transcultural and trans-historical meaning by grounding caring in the universal memory of being cared for. She traced one stream of human caring as "the longing to maintain, recapture or enhance our most caring and tender moments" (p.101). Further, she suggested another stream of caring as being "the natural sympathy human beings feel for each other and this natural sympathy enables them to feel the pain and joy of others" (p.104). Thus Nodding gave both a "nature and nurture" source for caring. Nodding's work provided a basis for understanding care, but she did not provide the ethical framework around which such caring could be built.

There has been any number of theories of moral development and the accompanying ethics of how humans find meaning in life (Freud, 1925; Mead, 1974; Kohlberg, 1987). Yet, Gilligan (1982) pointed out, "a problem in theory became cast as a problem in women's development, and the problem in women's development was located in their experience of relationships" (p.7). Gilligan's (1982) work on women as moral agents became pivotal to understanding the concept of morality as centred
around relationships and responsibility. Thus, the moral dilemma for women becomes "how to lead a moral life which includes obligations to myself and my family and to people in general" (p. 21). Moral problems arise from conflicts in responsibilities rather from competing rights (p. 19). Moreover, responsibilities include both self and others (p. 147), and because people in relationship often have competing needs, women living from an ethic of caring have to choose between those competing needs, or else they have to redefine the question. For many women, faced with competing needs between themselves and others, the socially defined and culturally imposed injunction to self-sacrifice determines the needs of the Other take precedence over the needs of the Self.

5.1.8 The Cultural Imperative of Self-Sacrifice

The concept of freedom of choice is important, particularly for women, and most particularly for a profession of mainly women who "work from below". Unlike the existentialist position, which posits that regardless of circumstances, each human has the opportunity and the right to choose her/his meaning of life (Frankl, 1984), Gilligan (1982) acknowledges the sociological view that women are encultured to an ethos of self-sacrifice which complicates women's development by "pitting the moral issue of goodness against the question of responsibility and choice" (p. 132). Thus, the ethic of self-sacrifice is in direct conflict with the ethic of caring.
5.1.9. The Ethic of Self-Sacrifice and Unacknowledged Labour

The ethic of self-sacrifice could be pivotal in the way the nurses gave away some of their labour. The nurses spoke of sleeping in their car, taking telephone calls at any hour of the day or night, spending hours on the phone with family members, leaving their bed for the patient’s home as soon as the call came, staying in the home around the clock when death was imminent. All of this work was either not identified as labour, or it was seen as labour that the CCAC managers could decide to pay for or not. In either case, the labour was given, and recompense may or may not follow.

By these acts of “always being available” to the patient and their family, the nurses saw themselves as being good nurses by meeting their own self-defined standard of care. Moreover, their personal relationship with the one dying compelled them to be available day and night. However, these individual nurses did not carry the sole responsibility for the care of the patients. They had co-workers. I suggest the ethic of self-sacrifice was being pitted against the ethic of caring, in that, the moral issue of what makes a good nurse was superseding, or being confused with, the ethical obligations of relationship and responsibility. Moreover, the home/community care system feeds off these nurses who provide care, not as workers, but as moral agents; acting on the relational and responsible imperatives in the meaning they make of their lives and work. Meanwhile, the health care structures that control how nurses work
"remain above the strife, and deficiencies are located in uncaring individuals" (Dunlop, 1994, p. 29).

5.1.10 The Ethical Imperative to Care

The nurses spoke as if they had no choice. They were obligated to give care. This resonates with Maeve’s (1998) naturalistic inquiry of nine palliative care nurses. She described how moral practice issues were dominant in the nurses’ meanings as they were able and willing to confront the dilemmas of their patient’s lives. Moreover, by helping the patient’s work through their issues, the nurses incorporated these understandings into their own personal and professional lives. Maeve understood the nurses’ work of palliative caregiving to be the working out of moral issues in community with their patients (Maeve, 1998). Yet, Maeve’s study differs from this study in one significant way. Maeve’s nurse-participants sometimes experienced negative relationships with some patients, whereas there was no indication of any negativity in relationships with patients in this study. On the contrary, one nurse spoke of the fact that she was there to love an unlovable woman to her death. This suggests the nurse pre-determined the quality of the relationship she would have with the patient, and this relationship was independent of the qualities of the terminally ill woman. It could be said the nurse chose the quality of the relationship a priori.
If nurses believe they are free to choose, the moral imperative of the relational morality ought to be “the injunction to care, a responsibility to discern and alleviate the real and recognizable trouble of this world” (Gilligan, 1982, p. 100). Cooper (1989) proposes that Gilligan’s ethic of care provides nursing with a framework of moral deliberation that demonstrates compatibility with nursing’s historic and philosophical underpinnings of relational caring. Moreover, Cooper believes Gilligan’s ethical paradigm supports the value of caring as a moral activity (Cooper, 1989). The dilemma then arises concerning how the nurse, who experiences both the ethical imperative to be in relationship and responsible to suffering and dying patients, finds mutuality and enrichment for herself?

5.1.11 Liberating the Ethic of Care

A Canadian feminist theologian offers a response to this dilemma. Marilyn Legge (1992) believes an ethic of caring that is liberating must be shaped by women who are doing their utmost to claim their own power, and who are learning to recognize the potential in relationships with others who share the human experience of problems and possibilities. These relationships enable interconnectedness with all humanity, and move each person in the relationship toward a future in which all persons can be whole (Legge, 1992). The nurse-participants claimed their power to care for the spiritual needs of the ones care-for, and in this way, they claimed wholeness for their patients and for themselves. As well, they claimed their power to manage the pain and symptoms of disease and decay in order that their patients could experience a “good death”. It is
within the ethic of caring, shaped by nurses who claim their knowledge and power, for
the holistic well-being of their patients, that nurses and the ones cared-for both move
toward transcendent wholeness in loving care relationships. In this movement toward
transcendent wholeness, the nurses cared for the spirits of the ones cared-for and for
their own spiritual selves.

5.2 What The Nurses Know About Spiritual Care

The findings reflect what the nurses know. I have grouped their knowledge under
three headings: the art of nursing, spirituality, and hidden work. I expand on each in
turn.

5.2.1 Art of Nursing

The nurses spent a lot of time in palliative care on meeting the physical needs of
the dying one. This caregiving involved a lot of direct physical contact with the skin of
another person, and because of this closeness, there is opportunity for an intimacy
rarely shared between people. Some nurses believe that the skin symbolizes a physical
and psychic boundary. But for other nurses, the skin is not the "where the person ends"
boundary (Wolf, Giardino, Osbourne, & Ambrose, 1994, p. 107). Care of the skin is one
of nursing's tasks, and part of the identity of nursing. Moreover, this care is private work.
Thus, nursing's bodywork gives "both access and opportunity to enter the lifeworld of
the patient and to enter the sacred spaces of human existence" (p. 111). Within these sacred spaces are found the spiritual aspects of human beings.

When the nurse enters this sacred space of human existence, s/he enters with the personal knowledge of an awareness of the self and the other in relationship. To enter the sacred space implies that the nurse is aware of the totality of what it means to be human. Holism implies if the parts are separated the whole no longer exists (Wilkes, 1997, p. 115-125). Thus, when a nurse understands the relationship between her/himself and nursed as a sum total, then holistic care can be given and received.

When people are dying, time is running out. They may have many issues not yet resolved, and the nurse needs to be there with them and for them. Sometimes, nurses are not needed to "do", but rather, to "be". When nurses can help from their own life experiences of feeling alone, or at a loss, or afraid, then there can be a sharing of humanity. It takes courage to give spiritual care because it entails examining one's own fears, darkness and losses (Cooper, 2001). Given these challenges, responding to the spiritual needs of patients is complex and complicated. These nurses acted as both physical presence and as people in relationship, sharing in each other's experiences. The emphasis in spiritual care lies in relationship, not on knowledge (Lancaster, 1997). This relationship has been defined as "unconditional positive regard" (Rogers, 1961). It was with this sense of unconditional positive regard that the nurse-participants cared for each patient, regardless of their lovable qualities or the length of the relationship.
5.2.2 Spirituality as Reciprocity and Mutuality

The nurses entered into spiritual caregiving as both reciprocal and mutual experience. They spoke of caregiving as privilege. Most nursing literature does not speak of reciprocity and mutuality in the nurse-patient relationship. Indeed, the Standards of Practice of Nurses in Ontario (College of Nurses, 2002) holds no acknowledgement that the nurse-patient relationship offers the possibility of reciprocity and mutuality. Yet, the caring literature (Roach, 1987), as well as literature focused on spiritual caregiving (Kendrick & Robinson, 2000; Zerwekh, 1993; Ronaldson, 1997) acknowledges reciprocity and mutuality. As well, the shared relationship “energizes action to influence life constructively and positively by increasing intimacy and mutual self-actualization” (Bevis, 1981, p.50).

Both reciprocity and mutuality are very much part of transcendence as the way of caring made evident by extending oneself for the good of another (Kendrick & Robinson, 2000). Transcendence is defined as the experience of going beyond the limits of lived human experience (Zerwekh, 1993). It is of note that the "mother of the hospice movement", Dame Cicely Saunders (1992) defines resurrection as "a sudden lifting of the load of longing and pain.... the loss is transformed into a gain" (Saunders, 1992, p.71). Thus, Saundar’s use of the religious concept of resurrection could be seen as pivotal to the growing in transcendence as defined by Zerwekh. Hence, reciprocity and mutuality are critical to the experience of going past known human experience, to
the place of transcendence and resurrection. Good spiritual care may mean "the successful ability of all of us to transcend the ordinariness of everyday life, and to gather meanings in the unseen world of the spirit" (Kellehear, 2000, p. 154).

5.2.3 Hidden Work

The study found that the nurses hid work in two ways. First, they gave labour and time with no recompense. Moreover, sometimes they failed to understand that the time they gave was really working time. They disregarded the hours of phone calls, sleeping in their cars, going out to the patient’s homes at all times of the day and night as extraordinary and/or working time. When asked, they declared that they were always paid for the work they did.

Second, the nurses’ work was hidden from other nurses, and from other health care providers and auditors, by the acts of omission in not recording the work of spiritual care in the patients’ progress notes (the chart). As well, they never used the nursing diagnosis of “spiritual distress”, not did they include spiritual caregiving in the written plan of care. In one case, the nurse’s rational for such action was the reprimand she had received from her superior. Yet, the nurses also disclosed that they used code words and phrases that other nurses understood to mean “spiritual issues”. Thus, there were secret words and phrases that only the palliative care nurses understood to mean something other than what it read. There was no indication that all the members of the
palliative care teams did understand. Thus, what the nurses know stays inside the profession, indeed, possibly inside a particular group within the profession.

The hidden work of nursing was explored to find out why nurses’ work stays inside the profession (Wolf, 1999). As well, Wolf’s research included why nurses should make their work known outside the profession. Examples of hidden work were identified as the work of knowing how, knowing the patient, bodywork, comforting work and helping people to die a good death. The nurses to the study hid their work of knowing how to ease distress of spiritual pain, knowing the stories of hurt and pain that were told in the purging, their acts of comfort for the patient by entering into loving relationship, and the details of how they helped people to die a good death. As a consequence, all of their work remained hidden, even inside the profession.

Wolf (1999) declares that nursing work remains hidden because of nurses’ continuing low-status as compared to physicians. This analysis suggests that nurses have internalized the beliefs regarding their low-status, and act as if they what they do and what they know is not of high value. As well, nurses contribute to the devaluing of their caregiving by not speaking of “their caring work and knowledge and skills” (Cooper, 2001, p. 94). The profession of nursing loses with the loss of stories of everyday, hidden nursing work. At the same time, the institutions of care, driven by budgets, will not value care as long as nurses keep their work hidden. These stories of hidden work, once told, “Would help nurses to understand each other’s work-life and assist them to create communities of care”. [Wolf, 1999 #188] Moreover, the nurses’
disclosure of their hidden work would give other nurses both role models and the
professional permission to bring their own work to light.

5.3 Why The Nurses Gave Spiritual Care

The nurses gave spiritual care with the goal of the patient being able to
experience a “Good Death”. This good death was defined as the patient dying in
comfort, with no family conflicts, pain and symptoms under control and with the nurse
present and willing to do the unusual for the one who has died.

5.3.1 Good Death

A “Good Death” is not a moment frozen in time, but rather a continuum of
complex interactions, reactions, planning and responding. When considering death as a
process that takes time, “the Good Death is not a single event but a series of social
events” (McNamara, Waddell, & Colvin, 1994, p.1501). Kellehear’s (1990) examination
of dying people found 1) the social life of the dying person, 2) the awareness of dying,
3) the personal preparations, and 4) public adaptations, and 5) saying goodbyes, were
the five key elements of the Good Death model. The nurses in this same study included
all five elements in their beliefs about good death.

In a study of in-patient hospice and community-based hospice services in
Western Australia, McNamara (1994), interviewed 22 nurses. The nurses found
challenges to the "Good Death" ideals they shared. These challenges were identified as 1) encroachment of medicalization into the palliative care ethos of comfort care, 2) lack of consensus about the impending death among family members, 3) lack of agreement on what a Good Death means, 4) patient compliance with nursing goals and routines, and 5) ritualization of Good Death by nurses recounting stories where the family were all in agreement and the patient complied with what the nurse judged to be the best course of action (McNamara et al., 1994). Indeed, nurses expect patients to be compliant and dependent (Kellehear, 1984).

The nurse-participants in this study were clear and consistent about their meaning of "Good Death". They may have had issues about medicalization of terminal illness, or doctors not providing the medications they wanted for the pain and symptom management of the terminally ill patients. But, there was little indication that these remained issues at, or near, the time of death. The nurses were in charge, exerting their knowledge and power, as they managed the dying time.

Nurses do not like "Bad Deaths". As the converse of "Good", nurses would identify "Bad" as being beyond their control. Thus, a bad death would mean pain or symptoms not managed, institutional policies interfering with the kind of care the nurse want to give, lack of cooperation by doctors, over-medicalization of the death experience, lack of acceptance of the death by the one dying or by family members, the patient or family not being cooperative with, nor dependent on the nurse, or the patient not dying quietly and cooperatively. Nurses identify bad death as one that lacks dignity.
5.3.2 Death With Dignity

Palliative care theorists offer romanticized ideas about death with dignity when they hold to notions of a “good death”, or even a “good-enough death” (McNamara, Waddell, & Colvin, 1995). In palliative care practice, culturally appropriate behaviours are designed to make death meaningful. Maintaining dignity is central to that care (Street & Kissane, 2001). Yet, “dignity is socially constructed, individually perceived, embodied, and relational” (p. 99). In our society, with notions of a right or wrong way to die, the dignity of the one dying and the promotion of dignity by health care professionals seem to be very important.

Dignity is found in relationship, as it requires both nurture and support between people as they interact with each other. Thus, loving care for the person who is terminally ill or dying can hold up the value of that person, even as the body decays or fails to sustain life. By caregiving with love, the nurse can be a role model for family members who may find it difficult to maintain familial relationships in the face of disease, decay, unpleasant odours and less-than-private bodily functions. Yet, nurses may not always be positive influences for the family and the dying one. Rather, by holding to the primacy of a belief that death is “good” if it is neither too quick or too slow, and that the dying-one accept her/his impending end-of-life, then “nurses can add burdens on the very ones they are caring-for” (McNamara et al., 1994, p. 1506). Consequently, the nurse, by holding to the hospice standard of comfort by giving holistic care, may not
realize that s/he could be adding a burden and not be comforting as desired. If the goal of such loving care is a "Good Death", then it ought to be the person dying, or if unable, the primary family caregiver(s) who determine the defining characteristics of that goodness. Nurses need to be aware of their own beliefs about "Good Death", in order that they may accommodate any differing meanings the patient and/or family may hold. Families look to the one dying to "set the tone", and thus reflect their background (Kellehear, 1984, p. 8). By being open to differing meanings, nurses can best provide for the comfort of the ones cared-for.

I add a caution regarding nurses looking to the dying one to set the tone. The process of disease and decay can, and often does, cause personality change. As well, individuals who were demanding of others when strong and healthy may continue to be demanding in weakness and illness. Moreover, home palliation can be prolonged, increasingly complex, and demanding (Vachon, 2000; Senate, Government of Canada, 2000). Some ill people are very demanding, and the expectations of the family caregiver(s) may become extremely onerous over time. Even with Home Care services, the heavy work of family caregiving remains the work of (mainly) female family members (Aronson, 1991; Baines et al., 1991; Senate, Government of Canada, 2000). Consequently, the nurse must be aware of the care-load and who bears the responsibility for that care within the family system. It may be that the nurse is the only person who can protect the health and well-being of the primary family caregiver. Facilitating cooperation and sharing the workload between the patient and all the family members can give protection to the primary caregiver.
Palliative care nurses do comfort work that is intentional and results in people being comforted and able to die peacefully (Wolf, 1999). Being with, being there, and walking beside signify active presence so that the nurse can do comforting work and be a comfort to the ones cared-for. The nurses placed high value on their physical and active presence with the one dying. Presence, as the opening up of oneself to another, is “the highest level of human caring” (Cooper, 2001, p. 213). Nursing presence requires openness, receptivity and the availability of the nurse and the one nursed (Patterson & Zderad, 1988). The ones dying and the loved ones were very open to the presence of the nurse, and the nurses placed high value on her presence as a way to facilitate “Good Death”. The nurse’s presence, as an opening up of oneself, is important and essential to the spiritual care of the patient. The encounter creates intimacy. And in this intimacy, “the cry of loss may not expect or want as answer but only a silent listening” (Saunders, 1992, p.2).

5.4 Theory and Practice of Care

There have been efforts to develop theoretical models of nurse caring. Wilkes and Wallis (1998) developed a model of caring in nursing that attempted to integrate compassion as the core of caring with a number of caring actions specific to nursing. They define compassion as “to love, to have and share feelings, to be a friend and to be concerned for others” (Wilkes & Wallis, 1998, p. 587). Their study examined the changing attitudes about caring exhibited by nursing students as they progressed
through their studies at two Australian universities. The results suggested professional nurse caring was directed toward the patient, and was "ethically oriented towards a moral obligation to care, and included respect and love for others, allowing both the cared and the carer to grow" (p. 588).

The ethical obligation to care comes out of the socialized role of women and daughters and mothers (Aronson, 1991). As well, the ethical obligation to care is transferred as pivotal to the nurse as a health care worker (Pellegrino, 1985). Moreover, for the nurse, this obligation to care is facilitated by the development of special relationships with the patients (Wilkes & Wallis, 1998). This special relationship must include respect and love for the other, and must allow both to grow as moral beings (Frankena, 1983; Gilligan, 1982).

It seems culturally appropriate that female nurses would be over-represented in the work of palliative care nursing. Historically, in Western societies, women have done the work of birthing (midwives and female family members), growing to adulthood (mothers and grandmothers) and caring for the dying (nurses and female family members) (Chappell, Strain, & Blandford, 1986). In the 20th century, the patriarchal medical establishment took over birthing and hid it away in hospitals. After the Second World War, the same thing happened to death. It too became lost to the community and families. Yet, in both cases, it continued to be the silent work of women who did the work of caregiving in birth and death.
But now, as we enter the 21st century, the work of birthing is returning to midwives working both in hospital and home. And, as more and more people opt to live the dying time at home, increasingly, nurses are doing the caregiving of the dying ones in full view and in concert with families (Iverson, 1993). The nursing work that has been hidden and silenced is coming out, into the community, through the witness and work of family members. Hence, the community now has the opportunity to bear witness and participate with nurses in loving-care of the spirit, as well as of the body, of their loved ones.

5.5 Nurses’ Own Spirituality

I find it difficult to reconcile a concept of care as “natural sympathy” with “loving to death”. It seems to require a stretch of the imagination and does not ring true. Thus, I suggest moral meaning, and the nurses’ own spiritual work, as the enabling and driving force behind the loving and compassionate care they give to the ones cared-for. An understanding of the spiritual self enables nurses to give holistic care (Ronaldson, 1997). Yet, some of the nurses in this study seemed ambiguous, or lacking in clarity, about their personal spirituality.

Perhaps nurses are called to more than “presence” in order to provide spiritual care. Good spiritual care may mean “the successful ability of all of us to transcend the ordinariness of everyday life, and to gather meanings in the unseen world of the spirit” (Kellehear, 2000, p. 154). It is in the everyday-ness of sharing our humanity that we
connect in the spiritual dimension of life. And, this is spirituality as transcendence. The stories that the nurse-participants shared in order to explain what they meant by spiritual care were stories of embodied spirit meeting embodied spirit. The relationships were ones of mutuality, and transcendence for nurse, patient and sometimes, for loved ones.

The stories of spiritual care were the stories of journey.

*If* *life is a journey, then, it is not a pilgrimage but an odyssey in which one leaves and returns home again... each step may be a circling back, a remembering... progressively we understand or know ourselves and our world differently with each movement of the circle, but there is no necessary end point* (Keen, 1992, p.392).

Murray and Zentner (1989) provide a definition of spirituality that attempts to be universal and comprehensive. They state spirituality is "a quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose, even in those who do not believe in any god. The spiritual dimension tries to be in harmony with the universe, and strives for answers about the infinite, and comes into focus when a person faces emotional stress, physical illness or death" (Murray & Zentner, 1989, p.16).

For nurses who care for the dying, we can be liberated, and the work-load become lighter,

When we acknowledge that spiritual needs are at the very heart of our humanity, and that to deny them will not only cause spiritual distress but may exacerbate physical and emotional problems, such as pain and fear.
We cannot justify our lack of involvement. By doing so we risk denying our patients their passage to wholeness and healing. ... By drawing closer to them, in some mysterious way we are brought to a new understanding of truth, love, and spirituality; we too are healed” (Rogers, 1961, p.213).

And, in the healing, we too journey home again.

5.6 How the Study Changed Me

This study has changed me in a number of ways. First, it has changed my practice of nursing. I did not document spiritual care as a nursing diagnosis, nor did I document my nursing actions to help ease the spiritual distress of patients or their family members. Thus, all of my work of listening, encouraging life-review, exploration of dreams, visual imagery, hugging, comforting, praying, and walking-beside has not been recorded. The knowledge, comfort level and skills that I have in helping people who live with life-threatening illness, or who are dying were shared with my students in clinical practice. Yet, I never spoke of spirituality and spiritual care to my students or my peers. Nor did I teach my students how to do a spiritual assessment, or how to document the specific interventions they used to encourage spiritual comfort.

This study has changed me as a cohort of nurse educators. After a tentative start, I now enter into conversations with my peers about spiritual care in nursing. I have found some of my peers to be open and engaged in the conversation. In an effort to raise the level of that dialogue, I purchased the Australian film documentary, Losing Leila; the story of the birth and death of a child. Once this writing is finished and
submitted, I will host a “Wine and Weep” evening to encourage dialogue and hopefully initiate change in the approach to our teaching of nursing.

In my practice as a nurse educator, I am more deliberate in teaching about spiritual needs as well as encouraging interventions the students can take to modify the distress and empower the ones they care-for. I expect documentation of those actions and evaluation of the care they give to meet spiritual needs. I am trying to role model the best of nursing that is evident in the findings of this study. I have not yet introduced a spiritual assessment tool. I recognize the work of this project, and the contribution of the nurse-participants will mean little unless I continue to teach and speak and write on the subject.

Lastly, this study has changed me as a person. Doing this work of designing the study, listening to the nurse-participants, relating to new information and people and places, making meanings of what was spoken and writing up the project has been both hard and satisfying work. But, more importantly, the work gave me two years of being focused on spirituality and spiritual care.

My mind and heart are filled with stories of wonder and grace and the transformational power of love and care. I share one of those stories, my fifth personal story, as I near the end of this study.
5.6.1 A Fifth Story

Betty was my husband’s Aunt, and for many years, she cared for him as his Mother. Betty lived in an in-hospital palliative care unit during the last three months of her life. During Betty’s dying time, she transcended the limits of her physical life, and as a result, she transformed the lives of all who cared for her. This 80-year-old woman, who was dying of metastases of thyroid cancer, knew each of her 45 nurses by name, and she encouraged stories of their families and work. She had a mother-son relationship with the surgeon who had operated on her a few years prior to this time. Their relationship so mutually loving that he continued to visit her in palliative care and indeed, remained active in her medical care to her death.

Betty gained in understanding during her dying time. She grew to know, in some unexplainable way, what each of her many children and other family members could do for her. Moreover, she knew what she could do for them. Thus, each person in the family had a role to play in her caregiving, and she clearly and gently asked for what she needed from each of them. My role, as a “daughter-in-law and nurse” was to hear her stories of pain and regret that she believed would be too painful for her children to hear. As well, I held the role of patient-advocate and translator. I advocated on her behalf with the professional caregivers and I interpreted the medical language and meanings to her family members.
Betty was not a religious woman, yet she spoke of dreams in which there was always a “Phoenix Rising”. She led yoga classes for other patients from her wheelchair. She asked her children to decorate her room with flowers and music and a talking toy parrot. She had one son bring her Perrier water by the case. She wrote poetry about the nurses who cared for her. She kept a diary so that her children would have a record of her life in palliative care after her death.

Less than two weeks before her death, on hearing a person crying in the next room, she struggled out of bed, got into her wheelchair and went to see the person. This woman was suffering from unmanaged pain and the isolation from her home and family. Betty wheeled herself to the nursing station and told the nurses what she had learned and what the woman needed from them. The neighbor’s pain became tolerable and the nurses spent an increased amount of time in her room.

After Betty died, five of her nurses came to the wake and funeral. About a year later, I met the Palliative Care Nurse Coordinator from Betty’s unit at a conference. She spoke of how they continue to reminisce about Betty and what she meant to the nurses.
5.7 Making Meaning: Spiritual Caring as Quilting

Martin Buber (1970) refers to the “I-Thou” relationship, as a very special encounter with something mysterious, awe-inspiring and transcendental. These are the privileged moments of human existence, and are quite distinguishable from the ordinary moments of daily life and the mundane hours of the work of nurse caregiving. The “I-Thou” relationship cannot be sustained in all of the work of nursing. But, for those places and times when we have these special encounters we are blessed. Each of us circles home. The ones we care for have much to teach us, and much to share. The stories of the palliative care nurses’ experiences of spiritual care are stories of that recognition. Thus, the meanings the nurses made of their spiritual caregiving were stories of care given, and received, in differing ways. The cloth made of these meanings is a pieced quilt, with shades of colour and pattern that differ from edge to edge. Each nurse pieced her own block of pattern, and as the blocks were stitched together, they formed the complex pattern of the quilt. Opening the quilt allows us to appreciate the patterns and colours of spiritual care given and received by this group of nurses.

5.8 Summary of the Discussion

The spiritual care of the nurses was focused on the dying time as the most significant point of intervention. The nature of the care was loving and compassionate, and reciprocal. This loving-care is an emerging construct that is outside the professional
standards of nursing in Ontario. There is a downside to this emergent construct of loving care as it reflects the cultural obligation of women to care as wife, mother, daughter, and grandmother within the socially defined family system.

Caring has meaning as nurses (and women) make moral meaning of their lives. Nurses, as mainly women, are moral agents who understand morality as centred on relationships and responsibilities. Nurses do their caregiving work within a cultural imperative to self-sacrifice. This self-sacrificial work results in their labour being unacknowledged and unappreciated, sometimes even by themselves.

The nurses work from an ethical imperative to care, and nurses who claim their power of knowledge and relationship can liberate this ethic of care.

The nurses know spiritual care involves the art of nursing, and they share a sense of spirituality that includes reciprocity and mutuality. Yet, because of the cultural context of their spiritual caregiving, they continue to hide their work.

The nurses gave spiritual care so that their patients will have a Good Death. This good death includes concepts of comfort, healed relationships, and dignity. The nurses entered into the relationship of loving care with a base of both theory and practice, neither of which they learned or experienced during their primary nursing education.
The nurses gave spiritual care as part of their own spiritual work. Through their work of palliative care given in loving care and with an emphasis on the holistic nature of the care needs of the ones cared-for, the nurses make meaning of their own lives.

Nurses can be changed by the experience of spiritual care giving, and by the work of others, in their loving care of the ones cared-for. I have been changed by the experience of hearing and working with these stories.

5.9 Implications for Nursing

The project followed the research philosophy of the interpretive paradigm in the study of the meaning of lived-experience. The purpose was to seek a fuller understanding of the experiences of spiritual caregiving by palliative care nurses. Until and unless the interpretive approach continues to be utilized in the study of nursing, there can be no critical theory approach. And, until there is critical theory approach, there can be little “critical self-reflection coupled with action and change.... (That is) overtly political and is directed towards personal and social transformation” (Wilkes, 1991, p.232). Before nursing can change, the interpretive approach to research will assist the documentation of the unknown in nursing practice. In the knowing, the inconsistent, the ambiguous, the incongruent and the absent will be named.
Knowing the construct of nurses' spiritual caregiving has implications for the practice of nursing, for policies in the workplace and the profession which affect the provision of holistic care by nurses, and last, but not least, for the education of nurses.

5.9.1 Practice of nursing

The practice of nursing needs to look hard at what is missing, and then work to change that practice. Most nurses are not doing spiritual care. The literature is clear about that fact. Yet, this study has shown that some nurses, regardless of lack of assessment tools or theory or role models, do practice spiritual care in the loving care that they give for the well being of the whole person. They may not be able to give inclusive, neat definitions of spirituality, but they are willing to transcend the limitations of the profession, and the cultural norms of nursing, to ensure comfort and healing for themselves and for the ones cared-for.

5.9.2 Policy

A growing concern with the human sciences designed to shape social policy is that they overlook life-world, meanings, practical knowledge (skilled know-how), transition, and experiential learning. For example, in health care, the goal is to design a health care system based on systems analysis and economic incentives and patterns. Consequently, the system is designed and controlled based on treatments and procedures that can easily be counted and priced.
Caring practices, healing relationships, and attentiveness that prevent illness (and suffering), and complications are not easily counted and tend to get marginalized as the focus intensifies on treatment techniques and procedures. But this economism is parasitical on the skilful ethical comportment of health care practitioners with notions of good about what is required to adequately care for particular patients. [Benner, 1994, p. xix].

The only way that the needs of human beings will become paramount in policies that affect nursing, and the ones who we care for, is for nurses to become part-of-the-solution. To become part-of-the-solution means that individual nurses and groups of nurses must become increasingly vocal and active on the committees and agencies that set health care and palliative care policy.

5.9.3 Education

As nursing educators, we must change what we teach and how we teach it. The empirical, theoretical and medicalized model of nursing has ensnared us. We rely on measured outcomes and increased educational requirements for entry-to-practice to increase the professionalism of nursing. Thus, nursing education, as it is now practiced, consists of teaching nursing theory, anatomy and physiology, pharmacology and psychomotor skill building. We need to teach a more holistic nursing that includes identifying spiritual needs, utilizes assessment tools and role models spiritual care interventions as part of the curriculum. But, more importantly, we need to include the art of nursing, and as educators, we need to share our own struggles and humanity as we role-model holistic care that includes spiritual care.
5.10 Limitations of the Research

There are three limitations of the research. These limitations are the small size of the sample, the fact that the sample consisted of only female nurses, and the monoculturally dominant nature of the site community. Nevertheless, the limitations were not limits of the methodology. The study was not designed or intended either to be generalized or to develop theory. The methodological goal was to determine the meanings that a sample of palliative care nurses gave to their experiences of providing spiritual care to people who were dying at home. The sample consisted of women. Yet, most Canadian nurses are women. Within community nursing and palliative care nursing, women are even more over-represented. In Kingston, there are no male palliative care nurses working in home care, although there are a few in hospitals. Thus, the fact that only women participated in this study is representational of the home palliative care nursing population. The sample size was small as befits the naturalistic inquiry methodology. The dominantly mono-cultural nature of the site community adds a definite limitation to the study findings. Canada is an extremely multicultural country, but the areas of most significance in that multiculturalism are large cities like Toronto, Montreal and Vancouver. Kingston is quite representational of Canadian small cities, in that it is home to many peoples of the world, yet it continues to have a very dominantly white, Anglo, and Euro-centric cultural. Whether these meanings could or would be very different with a sample of a very different Canadian nurse population remains to be seen.
5.11 Recommendations

The major recommendation of any study is to encourage further research. As this study is the first of its kind in Canada, it is essential that I encourage others to follow on the work. It would be most interesting to follow on this research with similar studies in a large metropolitan area as well as in a rural area. Moreover, I recommend a longitudinal and attitudinal study of nurses’ spiritual caregiving pre-and post educational process. This education would encourage discussion of spiritual needs, provide spiritual assessment tools and develop nursing care planning for spiritual distress. Moreover, it would provide a forum for team-building and mutual support within the nursing community.

I hope this work is judged to be of a significant standard to tickle the curiosity of other nurse-researchers. I am one quilter, and this is the design of the quilt I have made.
POSTSCRIPT

This project has changed me as a person. I started with the notion of continuing my formal education, challenging my capabilities, and doing something that might have some value to nursing. In the process, I have traveled half-way-round the world twice, I have met wonderful, kind, dedicated, giving people who welcomed me into their world, encouraged my flagging spirits, shared their humour, showed me small wonderful corners of their land, introduced me to new wines and food and thought. I have learned from people who look through different eyes, and all of this has expanded my horizon. My world is larger and richer.

I went “walk-about”, and I found what I needed.

Dianne Iverson

February 2003


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W.B.Saunders.


APPENDICES

Appendix 1: Cover Letter

Dear Community Palliative Care Nurses:

My name is Dianne Iverson and I am asking you to be involved in a research project. I am a research degree candidate working toward a MN (Honours), University of Western Sydney, Australia.

Some of you may know me through my work as the initiating Coordinator and Trainer for the KFL&A Palliative Care Education Project. You may have read the Palliative Care Education Resource Manual that I wrote in 1996. Others may know me as a Nursing Instructor at St. Lawrence College where I have taught since 1990.

You may not know that I have worked as a Home Care Nurse, and more specifically as a Palliative Care Nurse. From 1986-1990, I was one of 4 nurses who introduced pain and symptom management, and the principles of palliative care for persons living with terminal illness in Victoria County. In 1997-98, as Pain and Symptom Management Coordinator for Toronto, I built the Palliative Care Information Centre of Toronto. Both my nursing experience and my experience as a daughter caring for terminally ill and dying parents have brought me to this particular project.

Nursing research provides conflicting and sparse evidence regarding the willingness and ability of nurses to recognize spiritual needs and to provide care to meet those needs. There is little nursing research or writing on spiritual care in nursing from a Canadian perspective. The purpose of this project is to analyze the experiences of
registered nurses in providing spiritual care to people who are dying at home.

Following are some of the value and benefits of the project:

For the nurse participants involved in the project, the major benefit will be the opportunity to identify and reflect on your personal experience and practice of spiritual care, as well as the belief that you have contributed to nursing knowledge.

For terminally ill people who are dying at home, the major benefit will be receiving palliative care from nurses who have identified and reflected on their spirituality and future caregiving.

For the profession of nursing, the project will provide knowledge of nurses’ understanding of spiritual care and help in the development of future education and research theory.

For society, the study will add to the body of knowledge of spirituality and care of the spirit.

I invite you to join with me in this research project.

Dianne Iverson Dip Ed., RN, BA
Appendix 2: Background Information

Project: Spiritual Care of the Dying: A Community Nursing Perspective

Researcher: Dianne Iverson: Faculty of Nursing, St Lawrence College, Kingston, Master of Nursing (Honours) graduate student, University of Western Sydney, Sydney, NSW, Australia

Supervisor: Dr. Lesley Wilkes: Professor of Nursing, Clinical Nursing Research Unit, University of Western Sydney/Wentworth Area Health Service, Penrith, NSW, Australia

I am requesting you to participate in a project hoping to:
- Explore the nurse’s understanding of spiritual care when caring for people who are dying at home
- Determine if there are factors that help/hinder in spiritual care
- Consider the possible implications for nurses who provide palliative care at home
- Add to the body of nursing knowledge regarding spiritual care

Participation will involve a semi-structured interview where you and I will be in conversation about the experiences of providing spiritual care for dying people. The interview will be audio taped. The interview will not be a series of questions, with me asking, and you answering. Rather, we will share a conversation. There are topics I will want to cover, for example: experiences of spiritual care, spiritual distress/comfort, does the workplace help/hinder spiritual care, what do nurses know about care of the spirit and how do they know it, what life influences led you to this work?

If at anytime you wish to terminate the interview, you may do so. You may wish to complete the interview at another time, and that can easily be arranged. If you find any aspect of the interview distressing and require access to a professional counsellor, this will be arranged for you. If you agree to participate, I ask you to sign a consent form, and enclose it with the demographics sheet in the envelope that is provided. I will collect the sealed envelopes one week following our meeting time.

During the interview, I will ask you to suggest names of nurses who will be able to provide additional information, or who will have a different point of view.

Following the interview, a verbatim transcript of our conversation will be made. I will ask you to review the transcript for accuracy and clarity of meaning. You made add or subtract parts that you believe need to be changed. You do not have to review the transcript. It is your choice.

After the interviews and the transcripts are completed, I will invite you to review the themes that appear from the conversations. You do not have to participate. It is your choice. I will be happy to send you a summary of the research findings at the completion of the study if you wish.

- Consent is voluntary; you do not have to participate in this study. You may withdraw participation at any time during the study.
- Data will be stored for five years in a locked filing cabinet in the researcher’s office and in password-protected computer files.
- Confidentiality and anonymity will be maintained. Only the researcher and her supervisor will have access to demographic data. All participants will be assigned a pseudonym (another name), known only to the research nurse. Therefore, you will not be identified by name in any publications.

This study has been approved by the University of Western Sydney Nepean’s Human Ethics Review Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Human Ethics Officer, UWS Nepean, Kay Buckley, telephone (02) 47360169 or email to kbuckley@uws.edu.au. Any issues you raise will be treated with confidence and investigated fully, and you will be informed of the outcome.
Appendix 3: Interview Topics Form

INTERVIEW TOPICS FORM

The content of this form is for the information of the participants in the research project: Spiritual Care of the Dying: A Community Nursing Perspective.

The interviews will be in the form of a conversation. We will meet in a place and at a time of your choosing. During our talk, I hope we will cover some/all of the following topics. I ask you to give some thought to one or more stories from your nursing that will help me to understand your views and experiences of spiritual care.

Tell me a story about caring for someone who was dying.

What made this experience meaningful for you?

In what way did this experience change/not change how you give care to others?

Are there things about your work situation that are helpful/not helpful in providing for the spiritual care of your patients?

How do you know when someone is in spiritual distress?

What relationship (if any) is there between spiritual distress and physical pain?

How/where did you learn what is helpful in easing spiritual distress?

How do you recognize spiritual comfort?

What have you learned about yourself in nursing dying people?

What will affect how long you do palliative care nursing?

How do you care for yourself?

What does spirituality mean for you?

Can you suggest ways nursing education might change so that other nurses would learn what you know?
Appendix 4: Demographics Form

DEMOGRAPHICS FORM

The purpose of this form is to collect information about the participants for the purpose of this study. This information will be treated as confidential and will be accessed by the researcher, Dianne Iverson and her supervisor, Dr Lesley Wilkes.

Data collected on this form will be coded in all written and verbal presentations. You may choose a pseudonym (another name) for yourself, or you may have one chosen for you.

Name: __________________________ Age: _____ Gender: _____

For the purpose of this study, what name would you like to be known by?

______________________________

How long have you been nursing? ______

How long have you been nursing in the community? ______

How long have you worked in palliative care nursing? ______

What other kinds of nursing have you done?

________________________________________________________________________

Is nursing your first occupation? ______

If not, what other work have you done? ________________________________

What is your highest academic training in nursing? ________________________

What additional academic training do you have? __________________________

What courses/workshops/conferences in nursing have you attended during the past 5 years?

________________________________________________________________________

________________________________________________________________________
Appendix 5: Consent Form

CONSENT TO PARTICIPATE IN RESEARCH

I, ____________________________ hereby voluntarily consent to participate in the research project entitled Spiritual Care of the Dying: A Community Nursing Perspective.

This research project is being conducted by Dianne Iverson.

I have read and understood the written and verbal information provided to prospective participants in this research project. I have agreed to participate on the understanding that I may withdraw from the study at any time. I am aware and agree to the interview being recorded on audiotape.

I understand that the findings from this study may be used in future research and may be published. I have been reassured that any information from this study concerning myself will be treated with confidentiality.

I understand that should I become distressed during the interview and require further counseling, I will have access to an experienced counselor.

NAME: (please print) ____________________________

SIGNATURE: ___________________________________

DATE: ____________________________

WITNESS NAME: (please print) _________________________

SIGNATURE: ___________________________________

CONTACT PHONE NUMBER: ___________________________

PREFERRED CONTACT TIME: ___________________________