INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

ProQuest Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

University of Alberta

Accompanying the Dying:

Nurses Create a Moral Space for Suffering

by

Donna Shelley Raffin

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

Spring, 2002

National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-68615-9

Canada

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

University of Alberta

Library Release Form

Name of Author: Donna Shelley Raffin

Title of Thesis: Accompanying the Dying: Nurses
Create a Moral Space for Suffering

Degree: Doctor of Philosophy

Year this Degree Granted: 2002

D. Shelley Raffin

1736-12 Avenue N.W.
Calgary, Alberta
T2N 1J2

April 12, 2002

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Accompanying the Dying: Nurses Create a Moral Space for Suffering submitted by Donna Shelley Raffin in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Vangie Bergum, RN PhD

Joanne K. Olson

Joanne K. Olson, RN PhD

Ronna F. Jevne, PhD

David M. Gregory, RN PhD

Marion Allen

Marion F. Allen, RN PhD

Marlene Zichi Cohen, RN PhD

March 28, 2002

FOR MY FAMILY

Abstract

Palliative care nursing has a distinctive and honorable history that houses a unique and particular culture of nurses. The act and art of nursing in the obligation of accompanying the dying and creating a moral space for suffering finds itself in the hands and hearts of palliative care nurses. This research, engaging a focused ethnographic method of inquiry, brings the researcher into the culture of palliative care nurses. In this pursuit of understanding what it is like to care for dying individuals and their families, I, as researcher, immersed myself in the culture of nine palliative care nurses on a specific palliative care unit. These nine nurses were considered to be experienced palliative care nurses. The immersion was complemented by: conversations, research interviews, observations, and the writing of field notes over a nine-month period. The data consisted of the 1-2 interviews with each of the nine nurses, transcribed verbatim, and field notes reflecting the observation and conversations on the unit. Data analysis began immediately after data collection commenced. The analysis included a search for description, patterns and relationships, which have meaning to these particular nurses, and resulted in the identification of cultural themes. The study findings suggest that at the heart of the experiences of palliative care nurses lie four major themes: a calling to palliative care; the pursuit of a "good" death; surviving the health care system; and the creation of a moral space for suffering. These findings offer suggestions for palliative care nursing practice, education, and research, and reveal the importance of relational knowledge and the intention to understand suffering in the nurse-patient relationship.

Acknowledgements

First and foremost, I thank my supervisor, Dr. Vangie Bergum, for her support and her ability to inspire confidence and trust in the work. Dr. Bergum guided me through this process with intelligence, integrity, quiet humility, kindness, and her commitment to honoring the human experience of nursing. Her gift of knowing how to bring experience to words was the inspiration to do justice to this research.

I thank my committee members: Dr. Joanne Olson, Dr. Ronna Jevne, and Dr. David Gregory. Their participation on the committee, and their consultation around method and writing enriched the work, and greatly expanded my own understanding. In particular, I am grateful to Dr. Gregory for his passion and expertise in ethnographic research and his knowledge and sensitivity to the topic of suffering.

I would like to thank Dr. Marlene Cohen, my external examiner for so enthusiastically reviewing this work. Her comments were much appreciated. I would also like to thank Dr. Marion Allen, for her warmth, kindness, and support. Her expertise as a 'chair' is unparalleled.

I thank my friends and colleagues, Dr. Edna McHutchion and Dr. Nancy Moules. Dr. McHutchion, through her love and commitment to palliative care, led me to my own passion in the area of palliative care. Dr. Moules offered endless enthusiastic support and guidance. Her love of language and writing inspired me to go on. I acknowledge her time, patience, and real work of reading the study. The encouragement and support of colleagues such as Dr. Sandra Hirst, Dr Sarla Sethi, and Dr. Kathleen Oberle did not go unnoticed or unappreciated.

I thank my husband, Pavel, for his tireless patience and his gentle reminders that one day we would in fact be able to claim weekends for ourselves, and son, Peter, for his technological expertise in my own moments of desperation. My parents, Peter and Phyllis, never lost their faith and I am deeply grateful to them in countless ways.

Most importantly, I thank the nurses who so willingly, openly, and quite profoundly participated in this study. Their willingness to open their suffering up to me exemplifies their commitment and moral obligation to palliative care nursing.

Table of Contents

Chapter One: Approaching the Question: What is it like for Nurses to Care for Dying Individuals? 1
1) Origins of palliative care: The significance of nursing 2
    The need to understand suffering 5
        Emma 5

2) Purposes of the research study 9
    Assumptions and theoretical background that brought me to the question 10
    Significance of the study 13
    Proposing a theoretical framework to understand nurses suffering 14

3) Summary 17

Chapter Two: Visions of Nursing Care for the Dying: Review of the Literature 19
1) Palliative care nursing practice 20
    The Canadian culture of palliative care 21
    Palliative care education 23
    The nursing profession's response to change 26
    Workplace stresses 27
    Towards a "good death" 29

2) The importance of relationships in palliative care 31
    The nurse-patient relationship 31

3) Suffering and research 34
    Suffering 35
    Definition of suffering 36

4) The embodied experience of suffering 36
    Personhood and suffering 36
    Hope and suffering 39
    Pain and suffering 42
    Dying and suffering 44

5) The professional context of suffering 47
    Nurse as person 47
    Nursing and the moral context of suffering 48
    Professional distance and vulnerability 49

6) Summary 52

Chapter Three: Researching the Question: What is it like for Nurses to Care For Dying Individuals. 54
1) The research question/intentions 57

2) Ethnography as a research approach 58

The holistic and contextual nature 62
Reflexivity 64
Emics and etics 68

3) The research process 69
Ethical considerations 70
Gaining access to the setting 72
The participants 74
The fieldwork begins 77
Interviews 77
Observations ("Shadowing") 80
Writing field notes 81
Analysis 82
Maintaining trustworthiness 85
Limitations 89
Writing the ethnography 90

4) Summary 91

Chapter Four: Nurses in Palliative Care: A Call to Relationship **92**
1) The study context: A palliative care unit 93

2) The key nurse participants 98

3) A "calling to palliative care" 98
Nurse as person 100
Nurse Jennifer 100
Nurse Barbara 101
Nurse Muriel 102
Bringing an authentic self 103
Nurse Ruth 103
Nurse Darlene 104
Moral qualities of palliative care nurses 104
Nurse Eileen 105
Nurse Helen 106

4) The Call to relationship 108
Nurse Nancy 109
Nurse Beverly 110
Nurse Ruth 112

5) Summary 115

Chapter Five: Nursing Moments: Pursuing a "Good Death" **116**
1) Watching the events of dying unfold 117
Stepping into nursing practice with Ruth 119
Agnes 121
Freda 122
Rebecca 123
Ken 124

Coffee break 126
The bathing routine 127
Rebecca's bath 128
Agnes' bath 129

2) Ways of knowing 131
Empirical knowledge 132
Moral knowledge 134
Aesthetic knowledge 137
Personal knowledge 139

3) Ways of doing 140
Martha's journey 140
Creating a safe and trusting environment. 141
Comfort and relief from difficult symptoms 145
Rebecca's pain 147
Facilitating grief and the search for meaning 148
Fostering hope for a peaceful death 153

4) Nursing Presence 155
Nurse Nancy 156

5) Summary 157

Chapter Six: Nurses on a Palliative Care Unit: Surviving the Health Care System **158**

1) The changing context in a palliative care community 159
Entering the unit 161
Jane 161
The nursing report 163
The multidisciplinary consultation team 165
Loretta 170

2) Changing context of care 172
Facing death 175
Time as essence in palliative care 177
Rosza 182
Working in the middle 183
Gary 186
3) Summary 188

Chapter Seven: Creating a Moral Space for Suffering **190**

1) The experience of suffering 191
Enduring suffering: 194
Creating a space for suffering that is prolonged 200

2) Strengthening spirituality in suffering 205
Bert 209

Searching for meaning in suffering 211
The connection of colleagues: 215

3) Summary 218

Chapter Eight: The Continuing Conversations of Nurses Caring for the Dying 220
1) Ethnography as a way to understand 221
The theoretical framework 222
2) Themes from the ethnographic inquiry 225
Nurses are called to relationship 225
The Nurses are persons 226
The relationship is a moral commitment 226
Compassion includes intensity of self 227
The "local moral world" for these nurses is changing 228

2) Actions for self healing and harmony of nurse and patient 230
Ethical reflection of 'self' 230
A moral space 231
Suffering may not be relieved 232
Suffering can not be controlled 233

3) Changed understanding 235
Can we truly understand suffering? 235
Importance of relational (inherent) knowledge 236

4) Summations and Recommendations 237
Nursing education 238
Understanding a suffering experience 239
Nursing practice 240
Nursing research 243

5) Summary: Self-transformation and closure 245

References: 247

Appendices

Appendix A 262
Appendix B 263
Appendix C 264
Appendix D 266
Appendix E 268
Appendix F 270
Appendix G 272
Appendix H 274
Appendix I 275

Chapter One

Approaching the Question:

What is it Like for Nurses to Care for Dying Individuals?

> *Upon ceasing to try to rescue the perishing, one is then free to care for the dying. Acts of caring for the dying are deeds done bodily for them which serve solely to manifest that they are not lost from human attention, that they are not alone, that mankind generally and their loved ones take note of their dying and mean to company with them in accepting this unique instance of acceptable death of all flesh.*
>
> *(Ramsey, 1970, p. 153).*

> *Nursing is a metaphor for intimacy. Nurses are involved in the most private aspects of people's lives and they cannot hide behind technology or a veil of omniscience as other practitioner can. Nurses do for others publicly what healthier persons do for themselves behind closed doors. Nurses are there to hear secrets, especially the ones born of vulnerability.*
>
> *(Fagin & Diers, 1983, p. 117).*

What is it like to accompany the dying? In this research, I have had the opportunity to be at the side of nurses who have experienced being with the dying. These nurses work in palliative care. Historically, nursing has made many important contributions to palliative care. Since nursing's inception, nurses have cared for dying individuals who are suffering and the alleviation of suffering has been a cornerstone of a caring, compassionate nurse (Lindholm & Ericksson, 1993). Through embodied (making a conscious choice to be fully aware of her/his own body, to remain present to the patient) relationships, nurses create a moral space for suffering. Their actions stem from a moral obligation to suffer with others. The history of palliative care reveals this obligation.

This chapter will begin by uncovering the significance of palliative care nursing and the need to understand suffering, as revealed in one nurse's story. I will discuss the purposes of the research study, explore the assumptions and theoretical background that brought me to the research question, and propose a theoretical framework to understand nurses' suffering. In summary, an unfolding of the work of this dissertation will be revealed.

Origins of Palliative Care: The Significance of Nursing

Hospice or palliative care has emerged as a specialized field only within the past 30 years (Billings, 1998). The term *hospice* has sometimes been used interchangeably with the term *palliative* care, but more recently the two terms have come to different meanings (Vachon, 2001). In the United Kingdom, a hospice is a building where dying persons are cared for, but often, many of these individuals are discharged home and followed by home care programs. In the United States, the term refers to a specific programmatic model for delivering palliative care whether in hospital or in the community. In Canada, hospices are often community based, volunteer driven programs providing care in the home or free -standing hospice building (Vachon, 2001). Regardless of location or type of program, palliative care stems from the recognition that at the end of life, an important dimension of being human is the lasting dignity and growth that continues through weakness and loss (Saunders, 1967). Nurses are central to ensuring that dignity and growth are possible in the dying journey.

Nurses have always been an integral part of hospice and palliative care history. Nurses have developed models and theories for palliative practice, and have provided the leadership and organization of various hospices all over the world. In 1950, outstanding leaders such as Hildegaard Peplau and Virginia Henderson educated nurses about the importance of interdisciplinary teams, especially true in palliative care nursing. Hospice nursing, Virginia Henderson said, "was the essence of nursing" giving the lay individual the "necessary strength, will, and knowledge to contribute to a peaceful death" (1961, p. 42). In 1967, the opening of St Christopher's Hospice under the direction of Cicely Saunders occurred, and in 1974 the first hospice program in the United States was begun in New Haven Connecticut under the leadership of Florence Wald (Barnard, Towers, Boston & Lambrinidou, 2000).

The combination of scientific rigor with personal concern has been a hallmark of palliative care since Cicely Saunders founded the modern hospice movement. Upon opening the St. Christopher's Hospice, Saunders developed an education program for palliative care which embraced three broad areas: (a) the science and techniques of pain management and symptom control, (b) knowledge of psychosocial, social, and spiritual aspects of dying and grieving, and (c) self knowledge on the part of caregivers, especially related to personal beliefs about death and loss (Barnard et al., 2000). In essence, palliative care aspires to total, or 'whole person' care including body, mind, and spirit. In giving "whole person" care to the patient, the caregiver must also be a whole person.

As nurses in palliative care live a philosophy that centres around actions which promote 'whole person' care, they do not simply care for dying individuals' physical bodies, but "tend their spirit, gently, respectfully, and knowingly" (Moules, 2000, p. 4). In practice, nurses live out their beliefs, values, theories, knowledge, and experience in their actions. Actions of compassion, presence, embodiment, and respect are integrally a part of who they are as persons and as palliative care nurses. Borgmann (1992) suggested that, as in German tradition, the word *practical* is synonymous with moral, and thus practice and the decisions that govern practice and conduct within it are moral decisions. "Practice involves us morally, practically, and spiritually" (Moules, 2000, p. 5).

The nature of palliative care nursing is such that, every day, practitioners face some of the most fundamental and poignant issues confronting humanity (Perry, 1998). Nurses are invited to share in the intimate journey of living and dying where suffering is present. This sharing often entails a commitment to developing a meaningful relationship as a way to know and understand the patient's experience. The relationship, although rewarding, often places the nurse in a vulnerable position. That is nurses themselves are not unaffected.

Whenever possible, nurses accept this vulnerability as a part of their obligations to dying individuals and their families. They do not walk away from suffering of the dying, but are called to it. Obligations call to us, we do not summon them. "Obligations do not ask for my consent...something demands my response. If an obligation is 'mine' it is not because it belongs to me but because I belong to it" (Caputo, 1993, pp. 7-8). Nurses are morally obligated to enter into the suffering of others, the joys, illnesses, and the deaths, and nurses learn to accept that suffering is a part of living and dying. "There is something about suffering that stops us in our tracks" (Caputo, 1993, p. 29). In this study, I have witnessed that whenever possible, a nurse uses every layer of her/him self when invited into the personal realm of a dying individual. Near the end of the dying individual's life, I watched nurses become intensely engaged. A nurse is invited to participate with a patient at a deeper level, in trust that she or he will help to make life or death more comfortable and dignified. This invitation is a moral "call to relationship."

Nurses bear many different responsibilities and exhibit great strength necessary for coping with the innumerable pressures placed on them, and in many situations, nurses encounter 'obligation'. The sphere of obligation is constituted by "a power that overpowers them, that constrains them to take notice, and sends shudders through their flesh" (Caputo, 1993, p. 8). Nurses do not escape the eyes of those who suffer. Whenever possible they embrace the experience and temporarily become the conscious of the unconscious, a means of knowledge and confidence for those who are overwhelmed, and a voice for those too weak or withdrawn to speak. This study begins to uncover the intricacies of the nurse-patient relationship, revealing the complexities of suffering in the dying journey.

Coming to the question in this dissertation is reflected in one story from my nursing practice which exemplifies what it means to be in obligation to the dying person's suffering. The story is told to invite others to consider what it is like to suffer with dying individuals and their families in the dying journey.

The Need to Understand Suffering

The story began as I made my way down the hospital corridor to the unit where I often worked as a nurse caring for dying individuals. This journey was not a new experience, I had worked in this area for over thirteen years, caring for many individuals who died in peace as well as many who had suffered during the death experience. But today, in this relationship, caring for this particular individual, made a claim on me which I will always remember. I suspect other nurses may have a similar experience when caring for dying individuals.

Emma. On this day, one of my patients was Emma, a 68 year-old individual who was dying of breast cancer. I had met Emma a few days earlier so already I had a notion of what my day might be like. As I listened to the nurse giving morning report, I had a feeling deep in my chest and stomach that today would be different. During report, I learned that Emma had spent a restless night, fraught with periods of intense pain. Even with several doses of breakthrough morphine sulphate, Emma found little relief. The pain was reported to come on "suddenly and was not letting up". This intense non-relenting pain was new for Emma as it had previously been controlled on regular doses of MS Contin. Having learned this I began to question why this intense pain had occurred so suddenly with no relief from the medication. From other clinical situations I have known individuals to experience a "crescendo of pain" wherein pain and symptoms increase in intensity as death approaches, but it is unusual to witness pain occur this quickly with virtually no relief. I intuitively felt the need to understand more about this experience.

After report I went immediately to Emma's room. At a distance, Emma's daughter was visible in the doorway. I could see intense fear and pain etched on her face. As I came nearer, her voice was trembling, and her speech was inarticulate. I touched her shoulder and immediately she grasped my arm tightly and whispered "Please help my mom." "Please make this pain go away." My attention shifted to Emma's bed. I heard sounds of intense moaning, agonizing low-pitched screams scaling to high-pitched squeals. There was silence at the end of each breath. Cycles such as this continued and became more intense as I drew near to her side. I reached for Emma's hand, she gripped mine and would not let go. Emma's gaze was fixed and intense, her lips parched and dry as she mouthed the words "Let this end...I want to go now." "Emma", I said, "I'm going to call the doctor. I'm going to make you more comfortable." Without hesitation I left the room to page her doctor. The intensity of this pain experience told me that pills were no longer enough to "gain control" over Emma's agony.

As expected, I had to wait for the physician's call, allowing me time to reflect and gather more complete information. My maze of thoughts kept reverting back to the suddenness of this mounting pain experience. What was evoking this uncontrollable pain and suffering? Twenty minutes had elapsed (seeming like endless hours), before the physician responded. As I described the occurrence of events, portraying a vivid picture of Emma writhing in bed, I urged the physician to consider an IV drip to quickly allow Emma some relief of her misery. Hesitantly, he agreed to a small dose that could be titrated up at small increments if needed. His voice firmly projected on the phone, "Watch her respirations...she's already compromised with lung metastasis." I felt bewildered at this point wondering why his priority was not assuring a more comfortable death instead of "carefully" prolonging the inevitable outcome.

My fears and intense commitment to alleviate Emma's pain and suffering consumed my thoughts and actions. Without hesitation I started the intravenous and initiated the medication, skillfully regulated by an IMED infusion pump. Emma's daughter's words "how long will this take now" took me somewhat aback. I explained that the morphine wasn't intended to hasten her death, rather to make her rest more comfortably. In anticipation I watched. I repositioned and stroked Emma's body with lotion, helplessly doing what I could to comfort and prevent harm. My eyes followed the intravenous drip, examining the label on the intravenous bag, ensuring the prescribed drug was infusing at the prescribed rate.

An hour had passed, and comfort did not seem within reach. Once again, I titrated up the morphine drip reminding myself that not all symptoms are amenable to even the most advanced therapies. Despite this, I was left with a feeling of unease, of moral unrest, encapsulated with the pain and suffering Emma experienced. Thoughts centered on Emma's trembling body. I tried to imagine what this would be like for her. She had become quieter now, moaning vocalizations replaced with intense facial grimaces, and occasional high-pitched squeals heard at the end of the respiration. Emma's daughter, staring in stunned helplessness, rose from her chair and moved toward the window where she stood motionless, eyes fixed in deep thought. After a while, she eagerly shared how her mother had cared for her father who had died only one year earlier. "He died in excruciating pain, which didn't stop till his last breath. My mother was there for him. She never left his side."

As I sat with Emma, holding her hand, listening intensely to her daughter's story, I sensed that Emma and her daughter were reliving a connecting web experienced by their husband's/father's death one year earlier. This sense of personal suffering and emotional angst unfolded as I listened to Emma's daughter plead with me to hasten her mother's death by increasing her morphine drip so her mother, "didn't have to suffer anymore." The sense of suffering within me was a growing gnawing feeling. I could feel myself torn between divisive personal and professional values. The compelling value, "the sanctity of life" took hold and would not let go.

Based on my moral judgement and character I continued to focus on assuring comfort the only way I knew how as a nurse and as a person. The inevitable presence of technology mechanistically rooted in this living/dying experience, yet, so far removed from the individuals who were suffering, challenged my commitment of compassion. Embedded in this idiosyncratic, ambiguous human experience, I felt vulnerable and persisted to be logical and predictable in my actions. Somehow, I sensed that these actions allowed me to gain a perspective of my moral commitments to Emma. Focusing on Emma's pain/suffering was my commitment. In a sense, I suffered too.

This whole experience, lasting only four or five hours ended with the stark, yet longingly anticipated reality of Emma's death. What seemed like endless hours of suffering, was followed with intense moments of peace. My body ached from the intensity of the suffering. The suffering would remain a symbol of being a part of the dying journey a symbol that made a difference.

Purposes of the Research Study

Why do we as nurses and the nursing profession need to understand what it is like to care for dying individuals? Firstly, I suggest that nurses are obligated to understand these experiences in order to improve practice, to be able to articulate to others the effectiveness of nursing, and to understand the therapeutic value of the nurse-patient relationship. It is important for us to reflect on the meaning of our relationship with patients, and what we believe it will achieve for dying individuals. Ellis and Flaherity (1992) observed that "little has been done to unravel the complex manner in which emotion, cognition, and the lived body intertwine" (p. 3). I believe this dissertation begins to unravel this mystery. Secondly, I believe that nurses do not have the luxury of looking in on or simply overseeing the dying journey, suffering, illness, and pain. "Nursing practice situates us in the midst of the lives of people where suffering takes place" (Moules, 2000, p. 5). The obligation or intention to understand suffering is deeply an ethical one. "Obligation is what is important about ethics" (Caputo, 1993, p. 18). Beyond obligation, nurses also have a passion to understand, and this passion moves us beyond assumption, to take a look. In 'local moral worlds' or cultures of nurses who care for those who are suffering, we are as nurses, obligated as Kleinman (1992) states:

> what precedes, constitutes, expresses, and follows from our actions in interpersonal flows of experience, it is important to understand, what is most at stake for us, what we most fear, what we most aspire to, what we are most threatened by, what we most desire to cross over to safety, what we jointly take to be the purpose, and the ultimate meaning of our living and our dying. (p.129)

Thus, it is the intention of this study to explore the culture of nurses on a particular unit, caring for dying individuals, in order to get a look at their 'local moral world.'

Assumptions and Theoretical Background that brought me to the Question

In coming to the question "*What is it like for nurses to care for dying individuals?*" I held certain assumptions that informed and provided impetus for the need to understand how nurses care for dying individuals. Firstly, the literature regards palliative care nursing as rewarding, yet emotionally, spiritually, and physically taxing. I assumed that nurses who chose to stay working in palliative care, care for dying individuals in ways that inform and give a sense of satisfaction to their lives both personally and professionally. With this sense of satisfaction nurses' see the potential for growth in these experiences and find fulfilment in their work. The literature also suggests that palliative care nurses strive to reach an ideal of care (Perry, 1998), an "ideal" reached if the care experienced is meaningful and ethical. Palliative care nurses ensure that care is individualized, involving the patient and family in decisions of treatment and comfort options. This ideal also supports alleviating patients' suffering in hope that the dying is as peaceful and dignified as one would wish for one's own family. The literature describes this ideal as achieving a 'good death.' Achieving a 'good death' is, however, not always a realistic ideal. In today's health care system issues of time pressures, heavy workload, and the push to discharge patients from acute care may lead to lack of communication and fragmented care. In other words, ideal of a "good death" is tempered by the realities of a health care system under duress, which may, at times, contribute to nurses' suffering. If this is true, why then do nurses continue to work in palliative care?

Secondly, the central theoretical formulations that inform this study are relationship, embodiment, and suffering. It is widely discussed that the identities of nurses, and the effectiveness of their care for individuals, stems from the relationship developed between nurses and patients (Bishop & Scudder, 1990, 1996; Gadow, 1980, 1989; Maeve, 1994, 1998; Schroder, 1992). Exemplary nursing care occurs in the intimacy of the nurse -patient relationship (Perry, 1998). Person to person or nurse to patient relationship is an important component of learning nursing. It is in relationship that one begins to understand what suffering means to a person. It is an open and attentive stance from which to explore suffering. This stance allows nurse's to respond, or heed to the call of suffering. Heeding to the call of suffering is a moral response to those for whom she/he cares. Being in this relationship with dying individuals commits the nurse to sharing the suffering and the joy of individual patient experiences, and opens our eyes to realities of living and of dying. In this way, nursing is an inter-subjective experience (Watson, 1988).

"Inter-subjectivity subsumes the notion of embodiment"(Maeve, 1998, p. 1137). Embodiment is not a theory, or a group of theories, but a holistic way of thinking about and knowing human beings, one that is in contrast to the common Western thinking of mind and body as separate (dualism). The term "embodiment" is often cited in nursing research reports, yet there is no consensus about what embodiment really means. In this study, I will present the term "embodiment" as a moral stance in which the nurse makes a conscious choice to be fully aware of her or his own body, remaining present to the patient. Embodiment, in this sense, assumes that nurses are authentically present to patients in an attending awareness of their own bodies as it relates to moment to moment caring (Gadow, 1989; Schroeder, 1992). In other words, embodied nurses recognize and associate holistically with the experience of the other (Maeve, 1998). Embodiment does not imply however that nurses “feel” what another feels, rather nurses can be fully present to the experience of another in a means that becomes a part of their own experience. Gadow (1980) called this “fellow feeling”, a general reaching out to individuals and individual situations, an authentic transcendence of one’s self. As a dimension of the nurse-patient relationship, “fellow feeling” is a moral imperative that requires a commitment from the nurse, a commitment that simultaneously increases the nurses’ vulnerability to suffering and loss.

The assertion, however, that nurses are willing or able to commit to a relationship with every patient, is unrealistic. Some nurses, depending on their tolerance and abilities, are not willing to enter the patient's world of suffering, or to come close to the feelings of disintegration that occur with suffering. I wonder, however, if the moral imperative to care is felt by these nurses, even if they are not able to enter into the suffering relationship with another at that time.

Significance of the Study

Accounts of 'nurse suffering,' as opposed to 'patient suffering,' is an area that is now just beginning to emerge in the literature. The specific focus of suffering within the nurse-patient relationship is not apparent. Rather the literature has focused on the nurse's responses to patients who are suffering. Gregory (1994) presented the idea of social relations of suffering. The nurse has also been described as a "witness" to suffering (Kahn & Steeves, 1994), a moral agent or advocate (Gadow, 1989), a coach through suffering (Spross, 1993), as one who facilitates the finding of meaning in suffering (Perry, 1998), and as an alleviator of suffering (Lindholm & Ericksson, 1993). Responses to suffering by nurses have also been described as manifestations of a suffering state, a variety of emotions such as anger, resentment, guilt, frustration, sorrow, anxiety, and as moral distress and helplessness (Rushton, 1992; Vachon, 1987).

Suffering, however, is also a social process affecting nurses' roles and relationships. The nurse, intimately involved in the nurse to patient relationship "suffers with" the patient (Gadow, 1991; Moules, 1999). The 'nurse as person' is challenged to find meaning, to transcend her/his experiences, cope with vulnerability, resist burnout and continue to comfort and sustain the patient. Kleinmen (1992), in advocating the use of ethnography as a method for studying illness and suffering, asserted that "suffering needs to be described and interpreted as part of the lived flow of interpersonal experience in local moral worlds" (p. 129). Thus, understanding the experience of suffering must be studied within the context of the nurse-patient relationship. A nurse's sensitivity, commitment, and intention to understand suffering are central to understanding a patient's experience of dying. Emotions, commitment, intention, and value ascribe importance to human experience. "No one can help anyone without entering with his/her whole self into the painful situation, without risk of becoming hurt, wounded or even destroyed in the process" (Thomasma, 1994, p. 132). The nurse's suffering does not hinder understanding, but allows the nurse the capacities of seeing a patient's suffering. To the palliative care nurse, it seems suffering is a moral reality, inherent in their 'local moral world.'

Proposing a Theoretical Framework to Understand Nurses Suffering

The theoretical background for a study includes not only an exploration of the phenomena of interest in the literature, but a specific stance towards knowledge development and how knowledge can be acquired about the phenomena. The epistemology of the present study can best be described and supported by identifying the importance of knowledge of the body (embodiment), in relation to health and illness, and the importance of relational knowledge (nurse to patient relationship), as it relates to the nurses who care for dying individuals. Early nurse theorists (Paterson & Zderad, 1988; Watson, 1979, 1985, 1988; Travelbee, 1971), (these theorists work will be reviewed in detail in Chapter 2), and nurse ethicists (Bergum, 1989, 1992, 1994; Gadow, 1980, 1988, 1989, 1991, 1999) have helped me to think about a framework for nurses caring for dying individuals who are suffering. These nurses support the importance and need for relational knowledge in nursing. They suggest that relational knowledge is needed based on the assumption that the world in which we live is knowable only to the extent that we share experiences with each other. The need to understand and be committed to listening to individuals' stories of dying and suffering is the nurses' unique moral position in the nurse-patient relationship.

Studying suffering within the context of the nurse-patient relationship has implications for all nurses as suffering is experienced in many areas of clinical practices. The complexity of suffering within this relationship is often not understood. To begin, however, it is important that we view suffering as more than symptoms, or a psychosocial response requiring a medication for its control. Rather, suffering is a human experience, a person who endures and works through the burdens of physical, emotional and spiritual trauma, where his/her humanness is threatened. The suffering of others touches the minds and souls of nurses, allowing us to face our own humanity. Enduring suffering often becomes a part of a palliative care nurse's reality.

In each palliative care journey, person to person, experience to experience, the responsibility of nursing is to assist individuals to heal, the meaning of which may be different for each person. The philosophy of palliative care involves helping individuals to find comfort, meaning, alleviation of suffering, and quality of life when cure of illness is no longer possible. With illness the objective body is brought into focus, resulting in a dualism of self and the body where the interest of the body often gets revered to the extent that there is a forgetfulness of patient as a self. Yet while illness focuses attention (of patient and professional) on the body as an object, the patient experiences self and body subjectively as vulnerability (Bergum, 1994).

Gadow (1980, 1999), suggests that dualistic thinking is harmful to humans and that the body and self should be understood in more harmonious ways. She says, the key is to "explicate a dialectic of relations between the self and the body if dualism is to be transcended" (Gadow, 1980, p. 172). The integration of subject and object body is presented in her model of *ideal modes of bodily being (*Gadow, 1980*). Primary* *immediacy; the lived body* is the usual mode or way that people understand their bodies during experiences of health. This mode has two dimensions: agency and vulnerability. The lived body is able to act, not simply to be an instrument for action; and the lived body is capable of being hurt or injured. The relationship between the body and self is unified, "the body is an aspect of the self" (Gadow, 1980 p. 174). But, when the body becomes ill, the body is known in the mode described by Gadow as *disrupted immediacy.* Agency is now diminished or altered, and the person feels a heightened sense of vulnerability. It is at this point that one becomes aware of ineptitude. *Cultivated immediacy* is the harmony (synthesis) that can be developed between the lived (subject) body and the object body when the body has come to work in synchrony. *Aesthetic immediacy* describes a new relationship between the subject body and the object body (a synthesis) that can be achieved during illness and ageing characterized by an aesthetic awareness of the body as subject.

Gadow (1989) says that nurses are important in the process of healing by bringing about harmony and aesthetic transcendence in illness. Nurses in their subjectivity, creatively and knowingly encounter the 'other', taking into account their own embodiment, and involve respectfully their patients' embodiment while providing care. The subjectivity of embodiment is a way to avoid bodily objectification of patients. Nurses increase their feelings of vulnerability as they care for and advocate for their patients. But shared vulnerability with patients is the means to overcome the gap between viewing the patient as an object or as a subject.

In a palliative care culture, nurses share their vulnerability as a way to reach the bodily suffering, of dying individuals as openly and willingly as possible. They are present to respond and enter the world of dying individuals in their suffering. Suffering is not 'out there' beyond their reach to respond. Their moral obligation is to reach suffering, to acknowledge, to give, and to intend to understand suffering. The embodied relationships of nurses to patients, are no longer an option to understanding suffering in dying. They are inherent in the moral world of palliative care nurses.

Summary

Throughout this research I have changed. Part of this change lies in accepting that new possibilities for understanding, what it is like to care for dying individuals are continuously evolving. In coming to the question, I had certain beliefs and assumptions about suffering and caring for dying individuals. I offer this discussion to explicate the changes in my own understanding of the topic, to keep the understanding open, and share the understanding with other nurses so that the dialogue will continue.

In the first chapter I have discussed the background to my question, reflecting on palliative care and wondering about the nurse's experience of caring for dying individuals. In chapter two, I delve into the pertinent literature, to affirm the importance of asking the question. In chapter three, I present my method of inquiry, and discuss how ethnography allows me to explore the topic. Chapter four introduces the reader to the palliative care unit, the key participants, and presents an understanding of how nurses are called to palliative care nursing. Chapter five explores the nurses' journeys of pursuing a 'good death' through ways of being, knowing, and doing. Chapter six uncovers how being present and sharing in dying individuals' experiences is not always easy in today's health care system. Chapter seven reveals the experience of suffering in the dying journey. Finally, chapter eight highlights the transformation in my understanding suffering that has resulted from this work.

Chapter Two

Visions of Nursing Care for the Dying: Review of the Literature

There is no profit in curing the body if in the process we destroy the soul.
(City of Hope Medical Centre Plaque, Author Unknown)

These few words eloquently capture the challenges facing palliative care practitioners today, challenges that palliative care nurses recognize. As palliative care nursing plays a dynamic and significant role in today's health care system, it is important to understand the philosophy and practices of palliative care. This knowledge has an impact on how nurses are socialized into palliative care nursing and how palliative care is explained to others.

Historically, it has been the nurse who cared for the dying, whether on the battlefield or in the trauma/medical unit in the hospital, nursing home, or hospice setting. Several factors have led to a changing palliative care context in Canada in the past few decades. One factor is a shift in the delivery of palliative care services from acute care institutions to community, hospice and home care settings. Within this shift comes a growing consciousness of cost containment and the needs of the rapidly increasing number of older adults in the population. A related major factor is the growing recognition that dying individuals require a special kind of care.

Palliative care literature is vast and arises from many disciplines such as medicine, social-work, philosophy, religious studies, and nursing. The literature supporting this dissertation focuses on palliative care practice from the disciplines of nursing, medicine, and philosophy. The following review of the literature is used to accomplish two goals. First selected studies will be presented to provide background for understanding the global context in which palliative nurses now practice. The review will show that several issues /barriers exist which impede the delivery of quality end of life care. The second goal is to explicate the importance of the nurse-patient relationship. This relationship is particularly important as nurses have a unique and primary responsibility to ensure that dying individuals experience a peaceful death. As suffering is a part of the nurse's world in palliative care, the professional context of how nurses live with suffering is explored.

Palliative Care Nursing Practice

The care of the dying is essentially the domain of nursing, not medicine (Benoliel, 1983). Quality palliative care enables nurses to return to the root of their ability to care fully for people in a holistic manner. Nurses help individuals make the transition from a sick to a dying role; they are with them throughout their journey. As economics shifted palliative services from the hospital to the community, the supportive care required by the dying individual and family became predominantly the nurses' responsibility. The following mission of palliative care developed by the Canadian Palliative Care Association (1998) will imbue the reader's understanding of the nurse's role in the continuum of care. Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support the patient and family who are living with a life threatening illness, during the illness and bereavement periods. Palliative care strives to meet their physical, psychological, social, and spiritual expectations and needs with sensitivity to their personal, cultural and religious values, beliefs, and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness or it may be a total focus of care. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team that includes the patient, and family, caregivers, and service providers. It should be available to the patient and family at any time during the illness trajectory and bereavement. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care that they are providing.

A philosophy of palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best quality of life through the relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs, and practices (Canadian Palliative Care Association, 1998).

Nurses involved in palliative care practice work in various forms of practice and in a variety of settings. They deliver care in multidisciplinary teams, in solo practice, and as advanced practice nurses. They deliver care in hospices, oncology acute care settings, AIDS clinics, continuing care settings, and in the community. The goal of all palliative care is to preserve the core philosophy and principles of palliative care by incorporating them throughout the continuum of care.

The Canadian Culture of Palliative Care

In recent years there has been a growing interest within health care to improve the care for the dying. A recent Canadian study identified five outcomes that patients and their families associated with quality end-of-life care: adequate pain and symptom control, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden on others, and strengthening the relationship with others (Singer, Martin, & Kelner, 1999). Although palliative care can be provided in any setting such as home, hospice, care centre or hospital, a recent study showed that the majority of deaths in Canada occur in hospitals (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000). Of the 201,892 deaths in Canada reported by provincial registrars in 1997, 148,145 (73%) occurred in hospital. The proportions of hospital to home deaths vary widely across the provinces and territories, suggesting that regional variations in the health care system may function as important determinants of the location of death and access to palliative care services for Canadians.

Most provinces in Canada have begun to recognize palliative care as a part of basic health care service. Some, such as Manitoba and British Columbia, acknowledge palliative care as a core health care service. Others, such as Saskatchewan, Nova Scotia and Alberta, have developed provincial guidelines for services (Alberta Health, 1993; Nova Scotia Department of Health, 1988; Saskatchewan Health, 1994). Program structures and services provided are highly variable between provinces, and within regions of provinces. Bringing guidelines to life involves integration within several existing or changing health care services, since programs include multiple levels of care, such as home care, hospice, long-term care, and acute care. Developing and providing seamless systems of care is a challenge to all members of the health care teams, including nurses.

A barrier to this seamless care is the lack of continuity of care that often occurs in the health care system today. The moment patients come into the hospital, plans are being made for early discharge. Although quality care is often provided in the home, the availability of professional care providers will depend on setting and program. Most programs do not fund 24-hour care over the long term and there are regional differences in availability of home support (Grunfeld, Glossop, McDowell, & Danbrook, 1997). Unless families are able to afford private funding of care providers, the burden of care falls to family and friends. Dying individuals discharged home without adequate support causes suffering for the patient, family, and also the nurse, who is not able to advocate for more time in hospital for the dying individual. The growing shortage of qualified palliative home care nurses compromizes the chances for quality end of life care (Grunfield et al., 1997; Latimer, 1995).

The use of acute care beds for palliative care has been well entrenched in Canada since the turn of the century (Wilson, Anderson, & Fainsinger, 1998), yet the movement toward dying at home is requiring a shift in expectations and socialization. In our current system, we have grown to expect that all funds will be covered in all localities as they are in hospital. It is difficult for nurses, patients, and families to understand paying for services at home, especially when resources are not as accessible as they ought to be.

Although there are increasing demands for home based care and care in the community because of economic situations in the health care system, there is insufficient research into the issues and outcomes of caring for family members at home (Dudgeon, & Kristjanson, 1995; Vachon, 1996; Wilson, Anderson, Fainsinger, 1998;). More research about the experience of both patients and health care providers is necessary.

Palliative Care Education

The progress towards understanding our experience of caring for dying individuals begins in education and the exposure as learners to palliative care. Many nurses describe their education as inadequate for the demands of current practice (Samaroo, 1996; Sellick, Charles, Dagsvik, & Kelley, 1996). It appears that continuing education opportunities, such as conferences and clinical education courses, have helped fill in the gaps as the body of palliative care knowledge grows (Scott, 1992).

The emergence of palliative care as a clinical discipline (or perhaps more accurately a set of clinical disciplines) has been accompanied recently by an increasing amount of literature. The scientific and clinical aspects of palliative care are more widely known and discussed than ever before. Nonetheless, there is a gap. Quill and Billings (1998), in a recent review of palliative care textbooks stated, "Much of the literature does not speak to the heart, nor do they give an adequate sense of the range of psychological, spiritual, social, and existential suffering, or to opportunities for personal growth and healing that dying presents" (p. 592).

Unfortunately, the education of nurses speaks to the lack of opportunity as well. In spite of the fact that nurses are the professionals who most often care for dying individuals and their families, research and literature is only beginning to emerge to educate nurses to effectively care for and understand the experience of caring for dying individuals. Regional councils are identifying the lack of palliative care knowledge and expertise within the health care professions as a major inhibitor of effective patient care (Scott, 1992). The inadequacy of the education system to prepare qualified professionals to care for dying individuals prompted the Senate Committee on Euthanasia and Assisted Suicide, Senate of Canada, (1995) to recommended that "the training of health care professionals in all aspects of care be increased" (p. 9). The Alberta Association for Registered Nurses (AARN) (1992) recommended that the educational needs of palliative care nurses include theory and practice related to loss and grief, symptom control, family dynamics, spiritual and cultural care, ethical issues, and community resources. The

AARN stressed the need for continuing education for practising nurses and also recommended that focused preparation in palliative care at the graduate level should be encouraged.

If student nurses are to truly understand their relationship with dying individuals, it is imperative that they learn through both didactic and clinical experience. Research shows that students learn most effectively from working with a palliative care or hospice team who role model the importance of interdisciplinary teams, the value of the presence and empowerment of nurses in their relationships with patients (Farrell, 1998; Kristjanson & Balneaves, 1995). Many studies discuss that end of life knowledge, attitudes, and skills of nurses are in need of improvement (Copp, 1994; Ferrell, Grant, & Retchey, 1993: Farrell, 1998; Field & Cassel, 1997; James & MacLeod, 1993; Kristjanson & Balneaves, 1995; Manias, Kristjanson, & Bush, 1997).

Jeanne Quint's landmark study (1967) revealed that there is little emphasis throughout the nursing curriculum on care for dying individuals. Teaching and support, in particular, were lacking in the clinical area, as nursing instructors are inadequately prepared to teach or mentor students in the care of the dying. Quint recommended that all basic nursing programs include both content and clinical experience on end of life care as a distinct and necessary part of the nursing curricula and that continuing education and service programs be offered as well.

Nursing education is only beginning to respond to the changes in societal needs, to shifts in the health care delivery system, and to the changing role of the professional nurse in end of life care. The World Health Organization (WHO) (1990) recognized the need for the development of national policies and programs for improving palliative care, and they suggested that palliative care programs be incorporated into the existing health care system. An important document from the Institute of Medicine (Field & Cassell, 1997) cites several deficiencies in end of life care and suggests that education can improve care by: (1) confirming a basic level of competence in the care of the dying patient for all practitioners, (2) developing an expected level of palliative and humanistic skills considerably beyond this basic level, and 3) establishing a cadre of professionals to develop and provide exemplary care for those approaching death. This will help to guide others in the delivery of such care, and to generate new knowledge through research to improve the care of the dying.

The Nursing Profession's Response to Change

Nursing educators are now realizing that changes in nursing preparation are necessary. In recent years several nursing professional organizations have recognized and responded to the mandate to improve end of life care. In 1997, the International Council of Nurses (ICN) recognized that nurses have a unique and primary responsibility for ensuring that nurses provide quality care that allows individuals to experience a peaceful death. The American Association of Colleges of Nursing, developed a report entitled "Peaceful Death" (1997). This report, outlined fifteen competencies that students should attain prior to graduation from undergraduate programs of nursing. The issue of certification in palliative care nursing is now at the forefront and being explored by the Canadian Nurses Association (Canadian Palliative Care Association, 1999). In many provinces, efforts to include palliative care content throughout the entire nursing curricula are underway. This is to ensure that students in baccalaureate programs, post diploma programs, and in master programs are exposed to and care for dying individuals in a variety of clinical settings. Palliative care education funds are also being established to enable palliative care clinicians to participate in skill enhancing activities such as clinical traineeships, computer module learning, and visits to programs in other cities.

Workplace Stresses

The literature cites many stresses that nurses face in palliative care practice which interfere with their ability to provide quality end of life care. An overview of stresses associated with role, work environment, and patient/ family interaction will be highlighted. The review will focus on studies conducted within the last fifteen years.

Role overload has been identified as one of the major issues for palliative care nurses working in oncology and hospice settings. The pressures of practice and work overload were associated with stress and burnout (Vachon, 1987). Initially, hospice nurses had prided themselves on having time to spend with patients. Like all other areas within the health care system, financial constraints have left hospice nurses feeling more and more stretched to give the type of care they would want to give (Vachon, 1987, 1995). Hospital and oncology nurses, in particular, have experienced difficulties with excessive demands, negative expectations from patients and families, unexpected crises, poor staffing, increased patient to nurse ratios, inadequate time, and the challenges of balancing work and personal life (Bean & Holcombe, 1993; Beck-Friis, Strang, & Sjoden, 1993; Bram & Katz, 1989).

Role conflict can evolve from a variety of situations when one's role as a team member is in conflict with what one believes may be in the best interest of the dying individual (beneficence). Role conflict issues includes: a)physician/nurse conflict regarding end of life care, b) patient/ nurse conflict regarding futile prolonged care issues of helping patients and or family members maintain control of their dying journey, and c) decisions to transfer patients from hospital to hospice primarily because of financial constraints (Coyle, 1997; Hart, Yates, Clinton, & Windsor, 1998; Kuuppelomaki & Lauri, 1998).

Nurses in palliative care often identify experiencing a 'lack of control' (reduced autonomy) in their work environment. This 'lack of control' is often related to situations that threaten the nurse's ability to practice quality nursing care, and /or to lack of participation in planning and decision making. Organizational policies and practices that limit the nurses' flexibility in implementing effective care are often expressed by hospital nurses as part of this sense of 'lack of control.'

Role strain, or having difficulties performing various aspects of one's role, is a common occurrence in palliative care, as the commitment of time and energy can be an exhausting process (Mulder & Gregory, 2000). Nurses often speak of the pressures to deliver quality care to the dying individual where time is of the essence. The nurse feels "caught" when work pressures leave little time to care (McWilliams, Burdock, & Wamsley, 1993).

Team communication difficulties have been reported in numerous studies and continue to be an ongoing source of stress (Beck-Friss, Strang, & Sjoden, 1993; Cooper & Mitchell, 1990; Munley, 1985; Vachon, 1987, 1996). Organizational factors, such as personality issues and team conflict were more commonly reported than issues with dying individuals and families, and issues related to death and dying (Munley, 1985, Vachon, 1987). Colleagues were found to be a major source of stress as well as a support. A lack of knowledge was noted to both lead to and reflect team communication problems. Nurses believed that they have the least control over issues related to dealings with others, that is: organizational factors, issues with physicians, and observing patients and families suffer (Vachon, 1987, 1995). One might think that caring for dying individuals would be the major source of stress in palliative care, yet many nurses see work environment and role stresses to be much more stressful.

Perhaps the most important reason in identifying work related stress in palliative care is related to the nurses overall abilities or difficulties in reaching an important goal of nurses in palliative care, that of pursuing a "good death." The inability to assist patients to attain this goal is often a source of nurses' suffering. While it seems logical to state that nurses need more information about their patient's desires before they can help them achieve a "good death," there is little research to draw on in pursuing this ideal. Little literature is also available about what can be inferred about a 'good death.' Important writings available from the perspective of heath care professionals and a discussion from the hospice movement may shed some light on describing a good death and the reasons for nurses suffering where a "good death" is not achieved.

Towards a "Good Death"

Much of the literature that describes what is meant to be a 'good death' comes from health care professionals' perspectives. The following discussion speaks to the notions of a timely appropriate death, one where openness and awareness of death is accepted. Lepp (1968), a theologian and psychologist, speaks of a life well spent that ends in a timely death as being part of a natural order. From this view, death, is a part of life, to be embraced with grace and dignity. Hinton (1968) in his highly recognized book *Dying*, devoted a chapter to the description of natural acceptable death. In a section entitled

'Timely Death' Hinton suggested that in order to see death as entirely appropriate (an important part of much religious teachings) helps to remove misgivings. This view has firm support from biology, as there is a biological necessity to die. The biological view has influenced some of the psychological concepts of man's nature.

Kubler–Ross in her first book, *On Death and Dying* (1969), supported the possibility, even the probability of a 'good death,' when people have their needs met and have been given proper support from their environment. She described her experience and beliefs about the purpose of death:

> We have seen the majority of our patients' die in the stage of acceptance, an existence without fear or despair. Maybe at the end of our days, when we have worked and given, enjoyed ourselves and suffered, we are going back to the stage that we started out with and the circle of life is closed. (p. 63)

In studying behaviours of dying individuals and those who have cared for them, Glaser and Strauss (1965, 1968, 1971) suggest, that a 'good death' is a form of passage in which everyone involved is aware, accepts the imminence of death, and the dying individual has resolved material and emotional concerns. Saunders (1967) suggests that the concept of a 'good death' is a most important precondition to working effectively with the dying individual. She wrote:

> The last stages of life should not be seen as defeat, but rather as life's fulfilment. It is not merely a time of negation but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and except this. (p. 64)

This discussion suggests that a "good death" is one that is timely, that we have achieved successfully and lived well. Health care professionals strive for this ideal. Many, however, have had experiences, both personal and professional, where a 'fight' or a struggle at the end of life has occurred, and where the final part of life has not been lived without pain and suffering. That struggle bespeaks a radically different journey towards death, often a journey, in which nurses partake.

The Importance of Relationships in Palliative Care

Nurses in palliative care forms key relationships with patients, families and health care teams. Within the foundation of palliative care philosophy, one of the significant aspects revolves around the concept of patients and families directing care. Issues such as dignity and quality of life can only be defined subjectively by those experiencing life transitions associated with dying. Thus nurses' relationships with patients need care that respects patients and families values, preferences and expressed needs, in the final phase of life (Gerteis, Edgman-Levitan, Daly & Debanico, 1993). Nurses value patients' autonomy, choice, respect, and dignity of worth as a foundation of their relationship. The focus of this dissertation is the nurse-patient relationship. It follows that discussion of the literature related to this relationship is necessary.

The Nurse-Patient Relationship

There are many theorists who focus on the unique relationship between the nurse and patient in their work. Early theorists, such as Travelbee (1971), and later theorists, such as Watson (1988) and Paterson and Zderad (1988), have informed the work of this dissertation. These theorists speak of the intersubjective /interpersonal nature of the nurse-patient relationship.

According to Travelbee, the nurse-patient relationship is purposefully established and maintained by the nurse through the therapeutic use of self. She defined nursing as an "interpersonal process whereby the professional nurse assists an individual, family, or community to prevent or cope with the experience of illness and suffering, and if necessary to find meaning in these experiences" (1971, p. 4). Travelbee (1971) described the commitment that is involved in the relationship.

> To expose oneself to the shocks of commitment and all that entails. It is to care and in the caring to be vulnerable, but it is the vulnerability of the strong who are not afraid to be authentic human beings. It is the ability to face and confront reality, to face reality not as we wish it to be, but as it actually exists. Nurses must possess this trait if they would help others to cope with the reality of suffering. (p.4)

This commitment is transcendence, or the ability to get beyond ones self, to perceive, respond to, and to be with the sufferer, enabling nurses to be effective and grow. Caring, "vitalizes and realizes the self, it does not annihilate it" (p.4).

In recent study of nurse-patient relationships, transcendence emerged as important for spiritual assessment and intervention (Emblen, 1992). Watson (1988) speaks of transcendence, the release of caring between nurse and patient. She notes that, the release can foster self-healing and harmony in both. She explains:

> The human care transactions provide a coming together and establishment of contact between persons; one's mind-body-soul engages with another's mind-body-soul in a lived moment. The shared moment of the present has

> the potential to transcend space and the physical, concrete world as we generally view it in the traditional nurse-patient relationship. (p. 47)

Perry (1998) speaks of a shared journey where patient and nurse together meet one another in suffering. They discover the value, worth, and strength that they can gain from one another.

The value of 'being with' the patient or providing an 'existential presence' had been noted by a range of nursing authors (Jourard, 1971; Paterson & Zderad, 1988; Vaillot, 1962). They have described the 'closeness' as a bodily presence, involving a 'being with' and not just a 'doing to.' The existential theory of Paterson and Zderad (1988) focused on awareness, authenticity, and on the emotional experiential aspects of nursing:

> Nurses experience with other human beings peak life events: creation, birth, winning, losing, separation, death. Through in-touchness with self, authentic awareness and reflection on such experiences the human nurse comes to know. Humanistic nursing practice theory asks that the nurse describe what she comes to know: the nurse's unique perspective and responses, the other's knowable responses, and the reciprocal call and response, the between, as they occur in the nursing situation. (p. 6-7)

Palliative care relationships place nurses in a position of responsibility and privilege: responsibility to commit to these relationships and privilege to encounter the humanness of life, to enrich their own lives, and to grow and gain strength and wisdom. It is through these relationships that nurses come to know the true meaning of life, death, and suffering.

Suffering and Research

Research that focuses on nurses' experience of suffering is only beginning to emerge. The majority of studies focus on the suffering of the individuals for whom nurses care. Two such studies by Kahn and Steeves (1986), and Kahn, Steeves and Benoliel (1994) have impacted my approach to studying suffering. These studies reflected the notion that suffering is the experience that motivates and guides the responses of coping and caring. Caring is a response of persons (including nurses) to the sufferer. Coping is the person's own response to his or her suffering. The caring efforts of others and the coping efforts of the self continually respond and modify each other (Kahn, Steeves, & Benoleil, 1994).

Nurses' stories presented in these two studies reveal that the clustering of themes about suffering could be interpreted as a progression of the nurses' own understanding of the suffering they encountered through their own clinical practices. "The nurses recognized their emotions in reaction to the suffering encountered on a daily basis in clinical practice and their feelings of helplessness in the face of this reality. For some nurses, it was a short difficult step from this realization to the personalization of suffering. The suffering became their own" (Kahn & Steeves, 1995, p. 9).

Other literature (including qualitative research studies) in palliative care is only beginning to note the meaning of these experiences for nurses such as the meaning of oncology nursing practice (Asplund, 1991). In recent years, a surge of qualitative inquiry has expanded the body of knowledge to include nurses experiences of caring for dying individuals (Rittman, Rivera, & Godown, 1997; Saunders & Valente, 1994) and stories of being hospice nurses (Rasmussen, Norberg, & Sandman, 1995; Rasmussen, Sandman, &

Norberg, 1997). Most recently, Perry (1998) focused her doctoral work on observing oncology and palliative care nurses who had been identified as exemplary by their peers.

These particular studies, and others in the nursing literature (Gregory & Longman, 1992; Lindholm & Eriksson, 1993) reveal the following assumptions about suffering, important to coming to the question; "What is it like for nurses to care for dying individuals?"1) suffering of others places the nurse in a vulnerable position, 2) studying suffering in the nurse-patient relationship allows possibilities for deeper exploration of the context, the self and others, and 3) the suffering of an individual deeply affects those who care for that person.

It is evident by the growing body of literature in palliative care that practising nurses and scholars are eager to understand the complexities of caring for dying individuals. We have only begun to know and understand the phenomena of suffering and the moral relationship that exists between nurses and patients in relieving the suffering of both. The following literature about the experience of suffering is important to the development of this study, and thus is presented here.

Suffering

An array of literature about suffering exists. Philosophers, theologians, ethicists, physicians, and nurses offer unique perspectives on the human experience of suffering. The literature is presented conceptually and thematically as follows: 1) definition of suffering, 2) the embodied experience of suffering: person hood and suffering, hope and suffering, pain and suffering, dying and suffering, and 3) the professional context of suffering: nurse as person, nursing and the moral context of suffering, and professional distance and vulnerability.

Definition of Suffering

While many definitions of suffering exist in the literature, no one definition of suffering has gained acceptance. Definitions that have emerged have been critiqued from many disciplines as being unsatisfactory (Cassell, 1982; Copp, 1974; Davitz & Davitz, 1975). The Oxford dictionary of English etymology defines suffering as the endurance or submission to affliction, pain, and loss. The verb to suffer means "to submit on or forced to endure the infliction, imposition or penalty of", and to go or pass through (as harm or loss) (Hoad, 1986).

A common theme noted in all the literature is that suffering is distinct from pain. This distinction, however, is not clearly elaborated so the boundaries between pain and suffering are blurred and confused. Cassell (1991) defined suffering as "the distress brought about by the actual or perceived threat to the integrity or continued existence of the whole person" (p. 24). In this definition, Cassell emphasized that suffering is experienced by persons, not merely bodies. Kahn and Steeves (1995) identified the critical components in a definition of suffering as the notion of the whole person or self, of an event or loss that threatens that self, and that the level of interaction is of personal experiences. Suffering then must be viewed as a human experience, unique to each individual in the context of their own experience.

The Embodied Experience of Suffering

Personhood and Suffering

Suffering is personal. The particularity of suffering never really allows one to know from what or where within the individual the suffering arises. Cassell (1991) stated that persons are not boundaried objects but exist in a trajectory through time with a lived past, present and an anticipated future. Thus, a person's family, relationships, culture, and social construction are a part of a world in which a person is identified and this identification in turn identifies to others (Cassell, 1991). Persons, as embodied beings, understand their bodies; they live an habitual day, have rituals, private lives and have unconscious meanings and memories that shape their behaviours in ways not always accessible to awareness. Persons also have transcendent or spiritual aspects to their beings.

Often the experience of suffering prompts people, whether or not they define themselves to be religious, to ask deeply spiritual questions, and turn to a God or a spiritual guide for solace. Even suffering for those who are avowedly religious can lead to questioning of fundamental beliefs (Anderson, 1989). It seems that answers to spiritual questions often remain a mystery beyond human understanding. Klugg (1992) discussed the direct correlation between one's theology of suffering and one's concept of God. Many Christians believe that God is infinite, all-powerful, all-knowing, and unaffected by suffering. On the other hand, some Christians believe that God is not infinite, all-powerful, all knowing, unchangeable, and is affected by suffering.

Spirituality is an inherent, integrating, and often an extremely valued dimension of the dying individual's and family's journey. Heightened spiritual awareness and concerns are a part of the dying journey (Francis, 1986; Fryback, 1993; Hall, 1997; Reed, 1987). Reed (1992) proposed that spirituality involved meaning- making through intrapersonal, interpersonal and transpersonal connections. In essence spirituality generally connotes "harmonious relationships with or connections with self, neighbour, nature, God, or a higher being that draws one beyond oneself. Spirituality provides a sense of purpose, enables transcendence, and empowers individuals to be whole and live fully" (Fehring, Miller & Shaw, 1997, p. 663).

To appreciate individual responses to suffering, it is imperative to understand the religious/spiritual views of the sufferer. Questions such as, What is the origin and purpose of human life? How is adversity related to nature? How does the individual's experience of suffering fit into the greater scheme?, help to gain a deeper understanding of our personal views of human suffering and faith. Father Robert Smith (1996) stated that what is needed is not pious talk but ordinary human courage and the willingness to probe the mysteries of human suffering.

Nurses are obligated to address the spiritual needs of dying individuals. Many nurses, however, feel uncomfortable with this aspect of care (Oldnall, 1996). There are a number of reasons for this discomfort such as inadequate education, anxiety about discussing spiritual matters, and lack of clarity about what spirituality is (Emblen & Pesut, 2001; Narayanasamy, 1993; Oldnall, 1996; O'Brien, 1999; Reed, 1992; Ross, 1996; Taylor, Amenta, & Highfield, 1995). Many nurses receive little or no education or training in spiritual care. This lack of preparation coupled with the enormity of death and the nurse's personal doubts and uncertainties may result in a reluctance to attempt to provide spiritual care, even when the need is apparent.

Various nursing models that guide nursing practice, show that spirituality was one dimension that was not viewed as essential (Oldnall, 1996). Twenty-six theories were examined to determine whether current theorists acknowledged the concept of spirituality in their assumptions and conceptual frameworks. The investigation revealed that twelve of the theories did not appear to acknowledge the impact of spirituality in the dynamics of holistic care. The remaining fourteen theories did acknowledge spirituality, however it appeared to be mentioned only briefly using implicit language. The lack of importance in addressing spirituality could be a significant barrier to assisting nurses with this responsibility (Oldnall, 1996).

Education of nurses to understand a dying individual's spirituality begins with exploration of one's own losses, grief, and fears. Such an exploration brings the nurse face to face with existential questions such as the inevitability and finality of death. Personal exploration often leads to a spiritual search for faith and or religious resources or questions. Individuals may be spiritually well grounded and not participate in religious activities. Studies have shown the benefit of having religious faith in increasing the comfort level of nurses to provide spiritual care (Kemp, 1999; Taylor, Amenta, & Highfield, 1995; Speck, 1993). Nurse educators also must provide students with practical experiences involving assessing spiritual needs. Through self-exploration, one could reflect on questions such as: What experiences and emotions has one had with suffering for self and others? What brought them courage and hope? Who did one feel particularly connected to during this experience? What practices or rituals helped one cope? Using questions such as these helps the nurse to recognize the universal nature of spirituality (Emblen & Pesut, 2001).

Hope and Suffering

Hope has long been recognized as fundamental to the human experience. A review of the literature reveals that many authors speak of hope as a virtue, as caring, and as an energy that brings life and joy (Fromm, 1968; Jevne, 1991; Vaillot, 1970). Fromm called hope "a psychic commitment to life and growth" (p. 12). Many researchers assert that life without hope is not possible (Conrad, 1985; Dubree & Vogelpohl, 1980; Engel, 1968; Limandri & Boyle, 1978; Scanlon, 1989). The affective dimension of hope encompasses a myriad of emotions. Many positive feelings such as joy, confidence, strength, and excitement accompany hope. Hope also accompanies uncertainty, fear, anger, and suffering (Morse & Doberneck, 1995; Morse & Penrod, 1999).

Hope is intimately bound with suffering in many ways (Barnard, Towers, Boston, & Lambrinidou, 2000; Fromm, 1968; Lancy, 1969). The critical role which hope plays towards the end of life takes on special meaning as death nears. Hope, in its resiliency and capacity to co-exist with suffering, helps dying individuals and their families maintain hope through the dying journey and after in the experience of loss (Gregory & Russell, 1999; Scanlon, 1989). Herth (1990), in a longitudinal study of terminally ill individuals and their caregivers, found hope increased over time. Dufault and Martocchio (1985) described hope as a "multidimensional, dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (p. 380). As a witness to suffering and hope, palliative care nurses must understand these complexities and be confident and sensitive in their efforts to address hope and hopelessness in the dying journey (Ersek, 2001).

Spirituality also increases in importance and is a critical component of hope (Carson, Soeken, Shanty, & Terry, 1990; Fehring, Miller, & Shaw, 1997; Fromm, 1968; Hasse, Britt, Coward, Leidy, & Penn, 1992). Hopefulness is associated with spiritual well being. Many qualitative studies have revealed that spirituality and spiritual practices provide a context in which to define hope and articulate ways that hope is fostered (Ersek, 1992; Farran, Herth, & Popovich, 1995; Hall, 1990, 1994; Herth, 1990; Jevne, 1991). Ways of fostering hope include practising religious beliefs and rituals, searching for meaning and purpose, and a connectedness with others. At times, suffering can challenge one's beliefs and trust in a higher being, or be viewed as punishment from God, resulting in hopelessness.

Relationships with others are an extremely important dimension of hope. The interconnectedness with others is a source of hope that cannot be overlooked. The importance is acknowledged in the literature from a variety of disciplines (Byrne, Woodside, Landeen, Kirkpatrick, Bernardo, & Pawlick, 1994; Farran, Herth, & Popovich, 1995; Herth, 1990). Nurses play a significant role in fostering hope (Byrne, et al., 1994; Herth, 1995; Hickey, 1986; Watson, 1979). The nurse supports the dying individual and family in coping with the uncertainty related to the illness, by ensuring that they have access to the appropriate resources to meet and address their spiritual needs. The nurse also helps the dying individual and family focus attention on hope for the short term acknowledging that the focus of hope is constantly changing. Of equal importance is the recognition that hope can be threatened by abandonment, discounting patient's experiences, and not sharing information openly and honestly (Herth, 1990).

To establish and encourage hope, nurses should maintain an open relationship with dying individuals and their families, demonstrating respect and interest, affirming the worth of each individual, and taking time to learn about their hope. Fostering and sustaining connectedness allows the nurse the opportunity to listen to the hope narrative, share hope stories, and create possibilities for patients to practice hope rituals. This in turn helps dying individuals sustain a sense of worth in the experience of illness and suffering (Jevne, 1991). In relation to pain and suffering, Herth (1995) states that one of the most important nursing strategies to enhance patient's hope is to strive for comfort and pain relief, and to facilitate the expression of spiritual beliefs and practices.

Pain and Suffering

Despite the attempts of many that view the human experience of suffering as a distinct entity from pain, suffering is often objectified and reduced to the experience of pain. Although pain is often present, it is neither necessary nor the sufficient condition for suffering (Cassell, 1991). Extreme suffering can take place without physical pain (such as a mother watching her dying child), and pain itself may not cause suffering. Yet, in practice, distinguishing pain from suffering can be a complex issue.

Pain, as defined by the International Association for the Study of Pain (IASP), is an acute or chronic mental or emotional distress associated with disease or other noxious stimulus causing discomfort, which the mind perceives as an injury or threat of injury to one portion of the self (to the portion of the body that has been affected) or to the self as a whole (World Health Organization, 1986). Pain is a warning, a biological alarm, counselling us to find out what is wrong and to do something about it. However, pain is more than perceiving a noxious stimulus. To become pain, according to the gate control theory, current sensation must be connected with past sensation (Melzak & Wall, 1968). Yet, suffering entails far more than pain as defined in this narrow way. Suffering entails an ability to be aware of a future and, as interpreted by the person, may be a menace to his/her integrity (Kahn & Steeves, 1986). It is the realization of a future that underwrites hope and courage as well as hopelessness and despair.

One thing that is certain, as discussed by Cassell (1982), is that suffering is a personal experience, not an external event. It is an anguish that is experienced on one level as a threat to composure, integrity as beings, and the fulfilment of intentions, but at a deeper level, as a frustration to the concrete meaning found in one's personal existence (Reich, 1989). In essence, it is the anguish over the injury or threat of injury to the self, and thus to the meaning of the self, that is the core of suffering (Cassell, 1982). It is evident from this discussion of the literature that suffering and pain are phenomenologically distinct. Suffering is a human experience broader than pain; it can include but is not limited to pain (Cassell, 1982; Lindholm & Eriksson, 1993; Spross, 1993; Steeves & Kahn, 1987).

The philosophical understanding of the distinctiveness of pain and suffering, however, continues to be fraught with difficulties in the clinical arena. Often "biomedicine views suffering as physical pain" (Gregory, 1994, p. 36) to be treated with medication. Within the biomedical view, when pain is absent, then suffering must be absent. This uni-dimensional perspective generates dissatisfied individuals, whose suffering is silenced, leading to individuals that may be cured but not healed (Gregory, 1994).

The concept of "total pain" which includes suffering, a term coined by Saunders (1967), has been a useful concept adopted by palliative care practitioners. This concept helps practitioners to recognize that the suffering experienced by an individual in pain, is derived from a variety of sources such as anger, anxiety, depression, and fearful memories of past experiences as well as physical causes. Total pain includes feelings, or emotions that require more than instrumental treatment such as medication. In this way, psychological, social, and spiritual aspects of therapy are not frills but essential components in the healing of pain and suffering. The concept of "total pain" not only shows the interrelationships that occur with pain and suffering but includes the idea that the nature of suffering is a mental anguish which erodes one's being.

Dying and Suffering

Understanding dying and suffering begins with one's own conscious reflection and interpretation on these very complex experiences. Creating a philosophical ideology for one's self encourages us to explore the question of dying and suffering. Health care professionals are challenged by suffering, as it forces them to examine the meaning of their own lives and acknowledge their vulnerability as persons.

The relationship of death to the self is a central issue in confronting our feelings about death. Confronting death through illness forces us to consider the possibility of experiencing suffering, pain, fear, and despair. Nothing less than the meaning of our mortality, the tension between our desire to live and the knowledge that we must get sick and die, is before us (Callahan, 1993).

As an embodied self, we look to nature, society and religion as guides to the living of our lives and the dying of a death. How my society thinks about death will shape the way I respond to dying and the way it supports me in my suffering, allowing me to give a voice to my struggles. All too often, with the advance of scientific medicine and other powers to control and modify nature, we have come to rely on these forces to eliminate our suffering and preserve the sanctity of life (Callahan, 1993). Rather than face suffering, it becomes easier to objectify it or attempt to eliminate it. Gregory (1994) believes that we have made suffering into something that can be controlled in order to protect ourselves.

It is time to reconsider how we have come to believe that death and all suffering are evils. Callahan (1993) offered three worthwhile perspectives. The first is that medical science has focused its attention on the causes of death, fostering the illusion that mortality can be eliminated by eradicating disease and suffering. This has led us to the belief that death and suffering is intolerable. The second perspective stems from the belief that the old-time powers of nature have been replaced by human agency. Death is no longer the plight of nature. Preventing death has become a human responsibility, and this responsibility makes it difficult to terminate treatment, and leads to a feeling of being morally responsible for direct killing. The third perspective speaks to the ultimate respect of the sanctity of life and the technical imperative to save life. Here, to save life, medicine and a fear of morality have combined to create a powerful pressure against the acceptance of death (Callahan, 1993).

The search for control of life suggests that suffering is meaningless and has no value. When something is deemed to have no merit, it may be tempting to believe we can dispose of it. Perhaps we do not clearly understand whether suffering has a purpose or not. Gadow (1991) urged us to consider that "under some circumstances suffering can be experienced as a positive though painful transition" (p. 105). Suffering may be a signal to patients and nurses that there are issues that need to be addressed. In denying the presence of suffering, we are in danger of invalidating the experiences of patients and ourselves and robbing us all of the opportunity to find meaning in the experiences of suffering and dying.

Fear and suffering has particular relevance to palliative care. Palliative care represents the antithesis to all that is valued in our society: health, success, and beauty. In palliative care, people are faced with death the fear of death and endless suffering, which is an affront to most people. This may explain why people reject being "palliative" as they fear the association of suffering. As we do not readily acknowledge suffering and dying, we also deny the voice of those who suffer. Frank (1991) identified suffering as the root issue in illness and wonders whether "society is willing to recognize the suffering of the ill as a common conclusion of humanity: if we can find value in suffering" (p. 115).

Gregory (1994) suggested that a further consequence of a health care professionals determination to eradicate suffering may be in the message we give our patients. In encouraging the belief that all suffering can be alleviated, patients tend to have faith in this knowledge. In doing this we place our patients in a very vulnerable position. We claim power over their suffering, and therefore as a result, over their experiences. Frank (1991) believed that part of the work of suffering is for patients to reclaim their own power in the professional/patient relationship. When we strive to eliminate suffering, and our patients experiences of suffering, we may inadvertently be the ones who are contributing to patients suffering (Gregory, 1994).

Suffering connects us with humanity. Humans have a moral impulse to alleviate suffering. It is a basic tenet of many religions, and is the foundation (written in the code of ethics) for medicine and the nursing profession. The virtue of compassion allows us to feel with and for another who experiences suffering. Suffering can be a great teacher, it can teach us about compassion. Compassion and suffering, as a moral response to understanding and alleviating another's suffering, is a moral imperative for nurses. Gregory (1994) suggested that we are obligated to try to understand the meaning of the experience from patients' perspective. We are obliged and encouraged to hear their voices. Gregory advised us, however, "that the cost of the journey is high because it means being exposed to one's own suffering, woundedness and grief" (p. 21). Yet it is our experience of suffering that enables us to be compassionate, and to share in the plight of another. This begins with learning what we can about our assumptions and beliefs about suffering. For some of us, as nurses, it begins with personal experience. Being called upon to be a supportive presence is sometimes a difficult moral response.

The Professional Context of Suffering

Nurse as Person

Observing nurses and patients in context is one way to understand the suffering experience. One cannot ignore that nurses bring a personal context to the suffering experience. Holding the fragility of life in their hands, as part of their everyday work, permits nurses to be themselves. This everydayness creates opportunities for nurses to face their own death as well as their patients' death. Nurses engage in the death and dying experience through a certain projection of themselves, as the meaning of life and death is considered on a daily basis. Nurses involved in the intimate journey to death "cannot hide behind technology or a veil of omniscience as other practitioners... nurses are there to hear secrets, especially the ones born of vulnerability" (Fagin & Diers, 1983, p.117). Giving of themselves, and sharing of heartfelt emotion, may be seen as beneficial to their patients, and to give any less may interfere with their ability to know and understand suffering.

Each person also embodies a private experience of suffering. Suffering evolves from a particular biographical journey through time in relation to professional experiences threatening some aspect of our personal identity. As health care professionals whose lives are embedded in the many faces of suffering, our effectiveness in caring for patients can only be enhanced from what we have learned in our own struggles to find meaning in suffering. Through interpersonal experiences in the context of our everyday lives we are exposed to religious and other cultural meanings of suffering. These meanings are often associated with certain events such as loss, death, and bereavement. We learn from our families and communities ways of responding and protecting ourselves from being engulfed in the suffering experiences. As the researcher, I acknowledge the importance of personal knowing. The holistic, reflexive nature of this study will invite conscious reflection of our own personal experiences of suffering to shed light on the nature of persons and the individuality of those who suffer.

Nursing and the Moral Context of Suffering

Patients and families assume that nurses are experts at comforting sufferers. Ameliorating suffering is frequently mentioned as a focus of nursing care, although little research has been done to develop a body of knowledge on the subject (Duffy, 1992; Kahn & Steeves, 1986; Starck & McGovern, 1992). Limited research has also been devoted to the complexities of caring for someone who is suffering, and the intricacies of the nurse-patient relationship that sets nursing apart from other disciplines in terms of suffering. Thus, a historical picture of nurses' preparation of caring for dying individuals and a discussion of their relationships is warranted in order that nurses' responses to their suffering and the suffering of others can be fully understood.

Professional Distance and Vulnerability

Nurses in practice and student nurses today are encouraged to reflect on their relationships with dying individuals, explicating the interpersonal and intimate nature of nurses' interactions with patients. When suffering is present, research shows that nurses have difficulty describing and expressing this experience (Kahn, Steeves, & Benoliel, 1994; Lindholm & Eriksson, 1993). Classic works of Quint (1967) showed that cultural values concerning death have led to a gap in the education of nurses and in turn a gap in the nursing care of the dying. Early studies by Glaser and Strauss (1965) reported that many students had little or no experience in caring for the dying. The study also suggested that many students learn by clinical experience. However, little teaching about death and particularly to the relational experiences involving intense emotions such as loss and suffering was given. Fulton and Langton (1964) discussed how society's conflicting beliefs about death contributed to difficulties nurses face in caring for dying individuals and their families. Today, more content hours are beginning to be devoted to the care of the dying in nursing curricula. Many instructors, however, continue to shy away from assigning dying individuals to nursing students (particularly in the early years of the student's experience). Many students today say they are uncomfortable in caring for dying individuals. In fact, nurses in the past have been encouraged to maintain a distance from dying patients as a means of self-protection.

The assumption that nurses practice self-protection and detachment from the dying patient allows nurses to provide better care, preventing too much involvement. Challenging this perspective, is the need to attend to patient suffering. Travelbee (1971) stated "the existence of suffering whether physical, mental or spiritual is the proper place of the nurse" (p. 159). Travelbee (1971) acknowledged the intimate character of the nurse-patient relationship and emphasized its importance to establishing authentic and effective therapeutic relationships.

The consensus from a number of nurses and philosophers (Bergum, 1994; Curtin, 1985; Gadow, 1980) is that ethical behaviour will flow naturally from the nurse-patient relationship if that relationship is understood. Much discussion in the literature has been devoted to the attribute of caring as the moral ideal of nursing (Curtin, 1985; Gilligan, 1982; Watson, 1985). It is evident that expectations that nurses have of themselves to achieve desired patient outcomes is shown in the mutual vulnerability that occurs between nurses and patients (Mayeroff, 1971; Nouwen, 1975). An example of mutual vulnerability is when nurses decide to share something intimate and personal with suffering individuals in order to provide comfort or facilitate decision-making. In this sharing nurses hope to appreciate or to have a deeper understanding of dying experiences. One wonders if nurses' suffering is a moral response to caring for dying individuals who may be suffering.

Philosophers, such as Gadow (1980), assert that nursing actions and advocacy are based on their unique knowing of patients and their moral commitments to do good and prevent harm. Gadow discussed the responsibility of "existential advocacy" as the subjective knowing of patients and moral commitments of nurses to their patients. Gadow, however, cautioned us in too closely identifying with patients, hence feeling their pain. Gadow (1980) advised nurses to maintain a professional perspective by remaining focused on the goal and appreciating the intensity of experiences for patients, without feeling the distress related to the intensity of their experiences. Gadow recognizes the possibility of "personal suffering and emotional depletion" on the part of nurses and advises a degree of emotional involvement called "fellow feeling" in which nurses "vicariously visualize their patients' emotions, but do not experience infectious identification" (1980, p 91). Gadow (1980) discussed the focus of "fellow feeling" as attention to another's feelings, and not their own, to make possible a promotion of feeling towards another's suffering. "Fellow feeling" is "a general outreaching and entry into another persons' situation, a true and authentic transcendence of themselves" (Gadow, 1980 p. 92). In fellow feeling, nurses may share the suffering of dying individuals but do not experience the suffering to the same degree as dying individuals (Gadow, 1980). In essence, fellow feeling is a dimension of the nurse-patient relationship, a moral imperative that requires a commitment from nurses and increases their vulnerability to suffering and loss.

The need for commitment, remaining focused, and vulnerable were also discussed by Reich (1989) as he portrayed the notion of true compassion, as more than pity or empathy. True compassion is more than a feeling. As discussed by Thomasma (1994), compassion involves a comprehension of the suffering experienced by another. The definition of compassion itself suggests the need to begin with the experience of suffering. The Latin components "com" and "passio" mean to "suffer with" (Pellegrino, 1993, p. 79). It means that we allow ourselves to share in that experience by putting ourselves in the place of another (Reich, 1989).

Werner Marx (1992) suggests that nurses who care for dying patients are being 'forced' to face their own mortality in ways that can open them to the need for compassionate relations with others. "Mutual facing of mortality often calls nurses and patients out of their shell of conventionality into authentic compassionate care for each other" (p. 77). Facing mortality opens the possibility of personal relationships.

In entering these relationships, nurses choose to pursue the best given their potential and context of the situation. They follow the vision of fostering the wellbeing of others. Being authentic, in this vision according to Taylor (1991), requires nurses to move to help people discover possibilities for becoming their best selves, by finding the meaning of suffering and assisting them in following that meaning. In essence, nurses focus on individuals' suffering. Taylor (1991) suggested nurses do not define themselves out of personal beliefs divorced from practice but through the meanings embedded in practice. The essential meaning of suffering embedded in practice is, in a moral sense, suffering for the wellbeing of others.

Acting out of compassion to the sufferer can be difficult. Many times nurses will observe visible signs of suffering such as crying out, facial grimacing, guarding of the body, and sometimes a withdrawn silent affect. Nurses' vulnerability is further magnified by the sense of responsibility for individuals' comfort, which is not in actuality, within their control. Patients' rights to refuse treatment (medication) to ease suffering may be distressing to nurses. Understanding the limits of their control eases their vulnerability.

Summary

In summary, an overview of the palliative care literature, including the education of palliative care nurses, was presented to provide the reader with an understanding of the global context in which palliative care nurses practice. The characteristics and embodied experience of suffering were explored. Additionally, the importance of the nurse-patient relationship and the professional context of how nurses live with suffering in their practice was discussed. The next chapter describes the method used to research what it is like for nurses to care for dying individuals.

Chapter Three

Researching the Question: What is it Like for Nurses to Care for Dying Individuals?

The encounter with ethnographic others is a therapeutic quest for meaning, a search for identity that can be considered a form of healing in the broadest sense it includes and acknowledges our subjective involvement in the creation of knowledge.
(Ellis & Bochner, 1996, p. 301)

Exploring nurses' experiences of caring for dying individuals is an intense, intimate and emotional experience. To explore this continuous unfolding human experience, the question, choice of research method, and the process are profoundly important. I have chosen to use a qualitative methodology (focused ethnography) as it allows the researcher to discover values, meanings, characteristics or philosophical aspects of individuals or groups, and collect rich and complex data. Ethnography is presented as the research approach best suited to understanding the nurse's experience of caring for dying individuals.

A focused ethnographic inquiry, asking "what is it like to care for dying individuals" may reveal cultural values and beliefs of nurses that guide their actions in caring for dying individuals. These values and beliefs I propose are embedded in "suffering with" dying individuals. This study intends to elucidate the moral commitments and actions of nurses caring for dying individuals.

This chapter begins with a brief discussion of the culture under study, and proceeds with describing the research intentions. The researcher explains the method, the research process, including ethical considerations, accessing the setting, the participants, data collection, and techniques for analysis. Maintaining trustworthiness and writing the ethnography are also highlighted.

In seeking to understand the culture of nurses caring for dying individuals, I do not intend to prove a theory about caring for the dying, predict certain causes of suffering in dying, or solve a problem about suffering in the manner of deductive approaches of natural science. Rather, I use a *focused ethnography* to describe a particular social context, culture, or "local moral world" (Kleinman, 1992, p. 127) of palliative care nurses on a particular palliative care unit. The descriptions and identifications sought were from the point of view of the individuals living in the situation, that is, from the emic perspective (Morse & Field, 1995). I (the researcher) looked for descriptions, patterns, and relationships through data collected from key participants who had special knowledge of the research topic. For this study, experienced palliative care nurses volunteered to be key participants. These key participants will be introduced in chapter 4. To maintain confidentiality and protect anonymity, names of all participants, and places have been changed. Further discussion regarding anonymity will occur under the ethical consideration section of this dissertation.

Ethnography is a way to study communities, culture, or a 'moral local world.' Kleinman (1992) suggests that ethnography deepens the study of human suffering by reframing the experience as an interpersonal process in a moral context. A focused ethnography focuses on social units or small group cultures in order to identify and understand the cultural rules, norms, and values and how they are related to health and illness behaviour (Boyle, 1994; Germain, 1993). In this study, the site is a large medical unit with a palliative care focus in an acute care institution in western Canada. A palliative care unit, although part of a large institution, is ultimately connected to a larger palliative care community.

Studying this culture of nurses caring for dying individuals, the people, place, and day to day experiences will be articulated, giving life to the realities of this particular group. The reader will see and feel the human practices of these nurses caring for dying individuals, the joys and suffering of dying, the interpersonal/intersubjective web of engagements, transformations, communications and other social realities that nurses, dying individuals and others experience on this particular unit. Although this study represents only one culture of nurses who care for dying individuals, I expect that others who read and share this work will connect and compare it to their own cultural experiences of caring for dying individuals. This may begin a conversation among nurses and others who care for dying individuals who connect in health and illness.

To obtain a sense of the breadth and depth of the "local moral world" one must understand the experiences which flow between and within that world (Kleinman, 1992). I began the study with getting a feeling for the overall sense of the unit. From exploring the place where care is provided, I carried out interviews with the key participants of the study. Actual observation, or shadow visits, with the key participants occurred in the study to explore caring for dying individuals in general, working on this particular unit, and to gain their perspectives about the larger moral world or (macro) view of the health care system. In this macro view are cultural forces that impinge on the "local moral world' of the nurses on this particular unit.

Using a focussed ethnographic approach also means that I will bring to the research my experience as a nurse who has cared for dying individuals, my self as a beginning researcher, my social history, perceptions, and prejudices as a part of understanding this culture (Coffey, 1999; Gregory, 1994). Understanding how I change and develop through this fieldwork and the analysis is an important part of this work. For "to hide this knowledge behind an unspoken veil, not to lay it open for scrutiny, is to deny my presence" (Coffey, 1999 p. 128). I need to be aware that my history, beliefs, and values as I am brought to the question and as they remain with me as I take up the question.

The Research Questions/Intentions

The research centers on the broad question: What is it like for nurses to care for dying individuals? In exploring what it is like for these palliative care nurses to care for dying individuals, I (the researcher) am interested in understanding the experience from the nurses in the context of the nurse/ patient relationship. The day to day experiences of these nurses as they cared for dying individuals on this unit, their inner thoughts, feelings, pains, fears, pleasures and a sense of moral commitment that are integral to this particular culture or 'local moral world' is what the researcher is seeking to understand. In particular, I am interested in knowing about the suffering that these nurses experienced. Related questions are: What is their personal perception of suffering? How do nurses perceive suffering through their clinical experiences? How do nurses explain their moral commitments to alleviating suffering? How do nurses effectively carry out their work and work through suffering? As previously discussed in chapter one, the central theoretical formulations that informed this study and the research question are relationship and embodiment. As this research focuses on the nurses' experience in the nurse – patient relationship, the researcher acknowledges that further study will be needed to focus on the patients' experience.

This study calls for a method that allows for rich detail that conveys the context and humanness of the nurses' experience. In a sense, this study could have aspects of a greater search for what it means to be human. As we search for meaning in our own experiences and in the experiences of others, we gain a deeper grasp of what it means to live in this world. The best way to capture these experiences is through the study of voices and actions of those connected in the experience, those connected in the culture in which care occurs for dying individuals. The researcher must become immersed in this culture of palliative care nurses as they care for dying individuals. In order to do this, one must in a sense become a part of the culture.

Ethnography as a Research Approach

Ethnography, as a research method, is committed to describing the social and cultural worlds of a particular group (Emerson, 1982). It seeks to discover social or cultural knowledge that people use to organize their behaviour and understand their experience (Germain, 1986). As discussed by Morse and Field (1995), ethnography is a means of gaining access to the health beliefs and practices of a culture which allows the observer to view phenomena in the context in which it occurs. Simply stated by Gregory (1994) ethnography "is a research process in which the investigator closely observes, records, and engages in the daily life of another culture" (p. 51). Agar (1980) explained that the meaning of ethnography is ambiguous; it refers to both a process (the methods and strategies of research), and to a product (the written story). To "do" ethnography, researchers study a culture, observe its member's behaviours and listen to them, and also produce 'an ethnography' that is a written text. In doing ethnography, researchers hold a particular philosophical position which determines how data will be collected and analyzed. Muecke (1994) described the four major ethnographic schools of thought as: 1) classical, 2) systematic, 3) interpretative, and 4) critical.

Classical ethnographies, according to Muecke (1994), strive for comprehensive descriptions of peoples' material constructions and perspectives. The people under study share a common culture. The overall description reconstructs the raw "facts" into simpler more common terms and categories such as ties, belief systems, and rituals. A classical ethnography is the product of extensive periods during which the researcher resides with the community being studied, observes and documents in direct participation with the people in the community. The classical ethnographer typically relies on a few persons from the group, for more intensive interviewing over the extended period of time. Other voices that are a part of the culture are noted, but not relied upon for the basis of the data, as are the few key participants.

Systematic ethnographies aim to define the structure of the culture rather than to describe a people and their social interaction, emotions, and materials. In essence, a good systematic ethnography presents a reliable schema of the typical way that the people under study organize their knowledge. The overall aim of systematic ethnography is to discover "the native point of view" (Spradley, 1980) and to learn the "cognitive maps" that shape the natives' behaviours as members of a particular group. This aim is achievable through rigorous semantic analysis, where the primary data are folk taxonomies of words and naming units, and contrast sets of terms (Muecke, 1994).

Interpretative ethnographies propose that ethnographic analysis should discover the meanings of observed social interaction. Interpretative ethnographies follow the beliefs of Max Weber and view ethnography as naturally analytic and interpretative rather than methodological (Wolcott, 1992). This school of ethnography provides "thick description" of human behaviour as it is embedded in its cultural context (Muecke, 1994). Geertz, in his interpretative ethnography *The Interpretation of Cultures* (1973), states that good ethnographic description renders the people "accessible, setting them in the frame of their own banalities, it dissolves their opacity… and brings us in touch with the lives of strangers" (p. 14).

Critical ethnographers view ethnography as a fiction, an intervention created by the interactions between the ethnographer and the informant, who together are considered to be co-authors. This stance is in opposition to classical ethnographers and ethnoscientists that view culture as "out there" to be discovered. Critical ethnographers propose that ethnography is wholly interpretative and that each ethnographer could create different accounts with many different possible readings of one culture. Critical ethnographers hold that the ethnographer is inevitably a participant throughout the text and its construction, and that ethnography is subjective, reflecting the stance, values and awareness of its transcribes. Critical ethnographers are fundamentally concerned with rhetoric, with the form of description; they view both the writing and reading of ethnography as a creative processes (Muecke, 1994).

In nursing, *focused* ethnographies are becoming more common than classic ethnographies because the research motive is to develop nursing knowledge and practice (Muecke, 1994). Focused ethnographies are time limited, more delineated, yet context based studies within a fairly discrete community or organization. Like the classic model, focused ethnographies typically derive from the fieldwork and conceptual orientation of a single researcher (Muecke, 1994). Germain (1986) distinguished *macroethnography,* signifying broad, long-term studies of a complex society, from *microethnography,* focused studies of "the sub units of social institutions or even a single family" (p. 147). The topic of focused ethnographies is chosen or problem identified, before the researcher begins data collection.

Focused ethnography was chosen as a method for this study as it allowed the researcher an opportunity to explore palliative care nurses in the context of a palliative care unit which has a culture of its own. Focused ethnography suited my research because I arrived at the research question from specific assumptions, questions to be explored, and a focus on nurses caring for dying individuals, which allowed me both breadth and depth. A large nursing unit and a variety of individuals (both professionals and lay patients) served as the focus of the study, yet the bulk of information would come from nine key participants who had expert knowledge of caring for dying individuals. The goal of this research was identification and description of the 'local moral world' of these nurses caring for dying individuals (Kleinman, 1992), allowing for theory generation in the context of discovery, as contrasted with studies that are theory testing in the context of verification (Germain, 1993).

Focused ethnography allows for multiple data sources where the search is for themes, patterns, meaning, and understanding (Germain, 1993). In this study, data sources included observations and interviews. Data were collected through the techniques of participant observation (shadowing observations of nurses), and structured and unstructured interviews. This combination of participant observation and interviews increased the validity of the collected data (Chenitz & Swanson, 1986; Germain, 1993) and provided for a full rich description.

In "doing" ethnography (with the exception of critical ethnography), whatever school of thought is upheld the central aim is to understand a way of life from an insider's perspective. Researchers set out to grasp the "emic" or the "native's" point of view (Spradley, 1979). More importantly, Spradley (1979) emphasized that "rather than studying people, ethnography means learning from people" (p. 3). Agar (1980) discussed hallmark characteristics of ethnography as: a) the holistic and contextual nature of ethnography (fieldwork); b) reflexive character of ethnography; c) the use of emic and etic data; and d) the end product (text) called ethnography. In the following paragraphs, the first three characteristics are discussed through the lens of the ethnographer participating in the research process of nurses caring for dying individuals.

The Holistic and Contextual Nature

The use of the ethnographic approach provides nurse researchers with the opportunity to explore the holistic/contextual nature of society and explore the routine and daily lives of people. A central tenet of ethnography is that individuals' behaviour can only be understood in context, that is, not separating the elements of human behaviour from their relevant context of meaning and purpose (Boyle, 1994). Hammersley and Atkinson (1983) reminded us that the context includes far more than the physical environment as "any account of human behaviour requires that we understand the social meanings that inform it" (p. 9). Boyle (1994) suggests that the ethnographer needs to do more than describe behaviour. Rather, the ethnographer "must understand why the behaviour takes place and under what circumstances" (p. 162).

"Field work" is the hallmark of ethnographic research. Essentially, all ethnographers share the conviction that for the description of culture, the researcher must spend time in the field and become part of the culture (Fetterman, 1983). Cultural knowledge requires an understanding of the people, what they do, what they say, how they relate to one another, what their customs and beliefs are, and how they derive meaning from their experiences (Goetz & LeCompte, 1984; Spradley, 1980). In ethnographic research, understanding is often gleaned through participant observation and/ or interviews. Participant observation is necessary as it combines participation in the lives of people understudy with maintaining some professional distance that allows for adequate observation and recording of data. Data provide the baseline of meaning and the contextual data for the ethnography as described below.

In this study, through the exploration of nurses' experiences I (the researcher) entered intensively the nurses' world of caring for dying individuals. Using conversations with nurses as a means to understand the experience, I explored the moral commitments, meanings, beliefs, and values found in their stories. In addition, a "shadowing" of the nurses (known as participant observation) for observation of nurses in the context of caring for dying individuals occurred. Field notes written after participant observation experiences describe nurses' behaviours and actions, as well as dialogue between nurses and patients in context. A great deal of time needs to be devoted to gathering the kind of data rich enough to create a "picture of the whole". Hughes (1992) stated that, in ethnography, "the goal of inquiry is rounded, not segmented understanding, it is comprehensive in intent" (p. 443). Through analysis of the data, an effort was made not to separate the data gained from the nurses' stories and from their actions/dialogue in practice, rather, to embellish the stories they told, and to explore in depth why and how their stories unfold in practice.

Reflexivity

Ethnography has a reflexive character which implies that the researcher is part of the world they study (Boyle, 1994). Nurses conducting ethnographic research must accept reflexivity as part of the research-design. The study of culture requires an intimacy with the participants who are a part of the culture. Intimacy was gained through the process (described above) of both observation and interview. It is the interface of the two that leads to the reflexivity described by Anderson. Anderson (1991) shows that fieldwork is inherently dialectical: the researcher affects and is affected by the phenomena she/he seeks to understand. "Meaning is not merely investigated, but is constructed by the researcher and informant through active and reciprocal relationships and the dialectical processes of interaction" (Anderson, 1991, p. 116). Reflexivity therefore leads to a greater understanding of the dynamics of particular phenomena and relationships found within cultures.

Reflexivity, however, poses many challenges for the ethnographer in gaining and maintaining trust with the participants both initially and throughout the research process (Kaufmann, 1994). It takes time and effort to feel a part of the culture being studied. Reflexivity describes the struggle between being the researcher as an outsider and becoming a member of the culture (Morse & Field, 1995). Through this type of participation researchers must realize that they alter the culture as subjective members of it. I (the researcher) came to realize that we are ourselves, and our subjectivity becomes entangled in the lives of others. The subjectivity of myself as a researcher and my interest and involvement in their lives, was like another lens or analytical filter through which experiences of caring for dying individuals could pass. I also reminded myself that I was not only a part of the data collection but a part of the analysis as well. This whole notion of the 'researcher as self' yields much controversy in the field of ethnography.

The necessity of constructing a false identity is an underlying theme in the writings of the ethnographic experts (Hammersley & Atkinson, 1983; LeCompt & Preissle, 1993), because they feel this protects the researcher from being too subjective. The researcher is cautioned to stand back from social and political issues and is expected to have no personality. Spradley (1980) states "the less familiar you are with a social situation, the more you are able to see the tacit cultural rules at work" (p. 61). I argue that constructing a false identity would result in putting a veil between the researcher and the researched, and that findings are more accurate when the researcher becomes directly, personally and existentially involved in daily life.

Yet, it is evident in fieldwork that the researcher needs to balance being one's personal self with the role of researcher. Lofland and Lofland (1995) propose that the researcher needs to be at a certain distance to be able focus with any clarity. Everhart (1977) described the blurred vision that can result from being too close: "Saturation, fieldwork fatigue and just plain 'fitting in' too well culminated in a diminishing of critical perspective, events were escaping me, the inquisitiveness had been drained from me" (p. 13). I suggest, however, that reflecting honestly and openly in stressful research events has helped me to retain integrity and develop insight and awareness of myself as a person and as a researcher.

Establishing credibility in the setting is where the ethnographer first begins. Lipson (1991) contended that when doing ethnographic research, the researcher may be of similar background to the group being studied. Lipson discussed further that there are many similarities in the skills between using oneself in ethnographic research (researcher as instrument) and practising clinical nursing. A clinical nurse has good interviewing skills, listens carefully, is an astute observer on several levels simultaneously, and interprets several levels simultaneously. These skills enhance rapport and trust in clinical nursing just as they do in ethnographic research. Germain (1993) added two more advantages to the use of the nurse as ethnographer in a health care setting. The nurse is accustomed to entering different subcultures for clinical experiences and the nurse knows the language of health care.

The researcher however must be appraised of the danger of "going native". Researcher bias may develop from too much rapport with one particular person or one particular sub group. By identifying too closely with some participants, the researcher may develop flawed conclusions (Hammersley & Atkinson, 1983). In this study site I (the researcher) have, through other professional community service, had limited contact with a few members of the unit (only one of which was a key participant). I was aware of the focus of the unit but had limited understanding of the day to day operations and ultimately the culture that shaped the nurses' experiences and the care that they gave. Thus I felt comfortable with being the researcher on this unit, as I was aware of the possible ways bias could be introduced, which in itself is a factor in preventing bias.

The initial period of entering the setting is always awkward, as the researcher is an outsider, a stranger to the group. Authenticity of the researcher is of extreme importance. The desire to become familiar with the norms and values in the setting, the rituals and practices, and the nurses who cared for the dying individuals demonstrated my intention to be a part of the culture. I also came prepared with certain goals and aspirations, yet was open to many possibilities. This demonstrated the flexibility and openness needed in order to become an accepted member of the culture.

As the researcher in this study, I come with a parallel background to the participants in this study. I have had previous experience (4 years) as a community hospice nurse, and over 20 years of experience as a nurse in various acute care, intensive, medical/surgical units, where I cared for dying individuals. Having a masters degree, with a clinical focus in palliative care nursing, and experience in teaching palliative care to undergraduate and graduate students, I hold an understanding of palliative care nurses that gives a foundation from which to investigate this culture.

Junker (1960) describes four levels of participant observation according to the amount of involvement the researcher has in the setting. The four levels on a continuum of the most involvement with the participants (participant only) to no involvement with the participants (observer only). During the course of the data collection the researcher may use all four types of observation. In this study, I took the role of 'observer as participant,' that is my time was spent observing and interviewing as researcher, with minimal time in the caregiver role. These roles will be explained and described in the data throughout the study, as well as in the description of "shadowing observations" later in this chapter. It is imperative however to make clear the extent and limits of any involvement. As a participant/observer, I (the researcher) let the nurses involved in the study know that my primary role was to observe, but that I was willing to assist them in their care when they were present. In their presence, I felt welcome and became comfortable in being a part of the culture.

Emics and Etics

Emics and etics are terms used in ethnography, and are directly related to the above discussion of reflexivity. The emic perspective (the insider's view), which focuses on the informant's perspective of reality, is key in understanding and accurately describing situations and behaviours (Spradley, 1979). The etic perspective (the outsider's view) focuses on the researcher's abstractions /scientific explanation of reality. What becomes problematic in ethnographic research is the polarized epistemological presumptions related to the emic or etic meaning (Omery, 1988). Diverse trends in anthropology have been known to adopt assumptions leading to the exclusive use of either the emic or the etic orientation. It is felt that this results in potential loss of data and therefore of a comprehensive understanding of the culture under study (Omery, 1988).

Hammersley and Atkinson (1983) noted that a combination of emic/etic perspectives provides deeper insights than are possible by the informant or researcher alone. The two views, side by side, produce a "third dimension that rounds out the ethnographic picture" (p. 63). It is important to remember, however, that the emic perspective may not always conform to the etic viewpoint. Most ethnographers agree that both views help the ethnographer develop conceptual or theoretical interpretations (Boyle, 1994), and thus most employ an eclectic research style which integrates both epistemological assumptions (Punch, 1985). The study of nurses caring for dying individuals adopted this eclectic research style.

As previously discussed, I (the researcher) entered the informants' world through interviews and observation as nurses cared for dying individuals. The interviews, both formal (structured) and informal (during observation or spontaneously on the unit), intended to capture the perception of nurses living the experience; to show the reality of their experience within the culture. I explored and described the cultural beliefs, values, and experiences verbatim from the members of the culture.

I (the researcher) then took an etic perspective, or view of the outsider. On completion of each interview, and or observation, I reflected on the experience and documented in the form of "field-notes." In addition to recording explicit details of a situation, I recorded personal insights of others in the context. The primary purpose of this etic approach was to make explicit the interrelationships among the various systems and subsystems in the group under study, generally through an emphasis on the contextualization of data (Boyle, 1994).

In engaging in this eclectic style of research, I (the researcher) was open to possibilities of seeking understanding from many perspectives and developing comfort in the ambiguity of the research process. Honouring the nurses' perspectives from interviews and the observations that occurred in the context of caring for dying individuals resulted in a thick description of the nurses experience (to be discussed later in this chapter) (Geertz, 1973). On another level, my own understanding of the experience was being transformed as I wrote the copious field notes. Unconsciously, I learned to trust myself, to trust that what I was capturing was what I saw and heard. Ultimately, I knew that I had to learn to accept the uneasiness of doing research in this way as the experience was always changing and evolving.

The Research Process

To begin this research experience, the landscape is sketched for the reader to enter into the world of the participants and the researcher. This detailed description of entering the nursing unit and my initial impressions reveal the culture of the unit. In essence this revelation will capture the notion of receptivity as I began to immerse myself into the culture of the nurse's experience of what it is like to care for dying individuals. Included in the landscape is a portrayal of: gaining access to the setting, introduction of the participants, and analyzing and evaluating the data. I begin with a discussion of ethical considerations of the study.

Ethical Considerations

Ethical approval to conduct this study was obtained from the Health Research Ethics Administration Board, University of Alberta, and the Conjoint Medical Ethics Review Board, University of Calgary, where the research occurred (see Appendix E). Informed consent, confidentiality, anonymity, and an evaluation of the risks and benefits were ethical considerations discussed with each of the individuals prior to their participation in the study.

All participants received information about the nature of the study prior to setting a time to meet (see Appendix C). Consent was gained with each nurse and/or individual or family member prior to initiation of an interview/shadowing observation (see Appendix F and G). Each nurse/dying individual was informed of their right to withdraw from the interview/observation if they saw the need to do so. Formal interviews were held at a location/time convenient for the nurse. Most often this was at the nurse's home, although some nurses preferred the interview to be at work at a time when they were not scheduled to be on duty.

The interviews/observations with nurses all added richness to the study. The passion, sincerity, and dedication of these nurses were portrayed in the release of many emotions during our conversations. On occasion, when nurses became tearful, I offered to stop our discussion. I wrote in my field notes;

> It was evident that she was very passionate about her nursing career. She spoke several times of the "need to make a difference" in the lives of patients and families. She did not want me to turn off the tape recorder, she would wipe her eyes and continue to talk. I was concerned with the anxiety these conversations would surface, however, she stated she was "glad to finally be able to say her piece. Nurses often don't get an opportunity like this." I offered the name and phone number of a counsellor if she needed support after our conversation.

I worried about stirring up the emotions of these nurses, however, at the same time I felt a sense of rapport, of trust in our relationship that these conversations were mutual and important. During the periods of shadowing observations, this sense of rapport and respect for privacy continued. Tears and laughter were shared but I was never asked or felt the need to end the observation because my presence led to discomfort. As a nurse and a researcher, I felt honoured to be a part of the culture of caring for dying individuals.

I was also alert to the feelings of dying individuals having a researcher present in the intimate moments of dying. I understood and respected the vulnerability of these individuals and made sure that they were aware that I would leave at any time if my presence made them uncomfortable. I found that all individuals demonstrated a willingness to participate in this study, in order to help others, particularly those who were dying. "It was a way to return something for all the help they were currently receiving" (personal communication Mr. K).

It was also possible that I (the researcher) could have observed or heard something that was unethical, or represented inappropriate nursing practice. That did not happen. If it had happened I would have reviewed the problem with my thesis supervisor not directly involved with the agency or the study in order to determine the best handling of the situation. If there had been a situation of moral crisis or one compromising patient safety, I may have chosen to bring up the situation to the attention of the unit supervisor immediately rather than at the end of the study.

In the data collecting process, all information was treated confidentially. Anonymity in reporting was assured and is provided through the use of pseudonyms for the institution, the unit, as well as the persons referred to in any way. When it was appropriate for the researcher to introduce myself I (the researcher) told participants that I was a graduate student doing a study of nurses caring for dying individuals, and that I was also a nurse. I answered any questions posed about the research or my role, and also explained that the data would be handled in a confidential manner.

Gaining Access to the Setting

In selecting the site of study, I considered whether the site would allow me the opportunity to observe the research topic, maximizing the intensity of the phenomenon (caring for dying individuals and suffering) to be studied, and the frequency in which it occurred. I chose the unit where I knew the focus was caring for dying individuals and where the caregivers of the unit were well respected within the larger palliative care community.

I initially contacted the unit supervisor, and arranged a time to meet with her and discuss the possibility of doing a research study on the unit. In meeting with the unit supervisor, I submitted a proposal of the research for the supervisor to examine, explained the purpose of the research, who might be involved in the study, the role of the researcher and how I might go about collecting the data. At this time, we discussed access rules which included: the frequency and comings and goings of the researcher, how I would identify myself as a researcher, what data sources I might access on the unit, and the range of participant observation activities that I might be involved in. The unit manager expressed enthusiasm for the study and was confident that many of her staff would be enthusiastic as well. Ultimate approval to access the unit would come from the chief nursing officer, whom the unit manager agreed to contact. Less than two weeks later the unit manager contacted me with approval access the unit for the study.

Beginning the research was both a stressful, and exciting, time for me. Upon being accepted to do the study on the unit, I had felt a sense of acceptance and genuine interest from the nursing unit managers and nurses themselves. This was evident at an initial meeting that I had arranged to explain the study to nurses on the unit. The purpose of this meeting was twofold. First, to explain the background, purpose, and who might become involved in the study, and secondly, to begin to recruit the key volunteers who might be interested in participating. Because the study focused on nurses, I indicated that key participants would be registered nurses but explained that all members of the unit were in essence an important part of the study. The nurses were interested in knowing what their role would be as well as my role as researcher. I left information letters for those who might be interested on the unit.

Prior to beginning actual data collection I spent time on the unit to get to know the participants who at the same time, got to know me as the researcher. This time included engaging in social activities planned on the unit, such as the welcoming social gathering for a new social worker on the unit. During this first period on the unit my goal was to ask general questions about the unit structure, routine, and above all to listen and learn about the values and beliefs of the group. I found that clarity of the research was important for all individuals to know. I considered that I might be approached by individuals not involved in the study, as discussed by Morse and Field (1995), and was prepared to easily and quickly answer the question "What are you researching?" with a one line answer. My answer was clear… I was interested in nurses' experiences of caring for dying individuals. If they proceeded to ask more questions, I would provide them with greater details about the study.

The Participants

Many terms exist to describe people who provide information to the researcher. The term *informant* comes from anthropology (Morse, 1991) and has been used to identify those persons who become the sources of information for the researcher. Some nurse researchers feel that the term *informant* has negative connotations and prefer to use the term *participant* (Boyle, 1994). Morse (1991) stated that the term *participant* is commonly used in qualitative studies and that it designates the most active role of the persons who are being studied. In this study, as nurses (and others) were actively involved in helping me to learn about their culture and actively controlled the research process, the term participant was thought appropriate for this study.

All persons, employees or clients who were connected with the unit were part of the culture, and therefore participants. Yet the focus of the study was on nurses caring for dying individuals, and these key participants were nine nurses who volunteered to be interviewed and participate in "shadow observations" (these nurses will be introduced in detail in chapter four). In considering key participants many ethnographers advocate selecting the key participants based on what they know (Fetterman, 1983; Germain, 1993). After receiving approval to begin the study, I elicited the unit supervisor's opinion as to whom she felt might be best suited to be a key participant (based on the criteria of being an "experienced palliative care nurse"). An "experienced" palliative care nurse was defined as a nurse with five or more years practice experience. The unit supervisor acknowledged that many of the nurses on the unit could serve as key participants. She also felt that there would be many that would want to be involved in the study, and that choosing could be difficult. Thus the researcher decided that the nurses should volunteer to be key participants in the study.

Originally, as the ethnographer, I was seeking a non-random sample of five nurse participants who were presently caring for dying individuals on this particular palliative care unit. Nurses who volunteered agreed to being interviewed and observed while caring for dying individuals. Inclusion criteria for participation was as follows:

- Registered Nurse who cared for dying individuals on this unit
- Registered Nurse who spoke and read the English language
- Registered Nurse willing to share their experiences of caring for the dying.

Recruiting the nurses into the study was surprisingly easy. I was overwhelmed with the enthusiasm of the nurses. In recruiting, I attended one staff meeting (where 12 nurses attended) to present the intentions of the study. A recruitment letter and sign up sheet was left on the unit for interested participants to sign up, or contact me personally for more information about the study. Within a week, seven individuals had signed the sheet and in the following two weeks another four individuals became participants. Due to personal reasons, two individuals later withdrew their names from the study. Overall nine nurses were key participants in the study agreeing to be interviewed and participate in shadowing observations. One nurse was interviewed only.

More nurses volunteered than I had originally thought I would interview/observe. Having this many nurses interested, I felt honoured and encouraged to obtain their perspectives. I was aware that the number of participants in qualitative research varied among methods and individual studies. Morse (1991) suggested that ethnography needs approximately 30-50 interviews, although she did not state how many participants were needed to gather these interviews. During this study approximately 40 interviews (including both formal and informal as well as shadow observations) with key informants were counted (see Appendix H). Data from members other than the key participants on the unit was not counted as interviews but were considered in the discussion of this culture. Germain (1993) however discussed the importance of richness of the data rather than the number of interviews or events. The importance of any sample is determined by how accurately the key participants portray the full context of the culture as well as to what extent they are able to answer the research questions.

The Fieldwork Begins

The interviews and observations took place over a period of nine months from mid October 1998 to the first week of June 1999. This was a longer period than I had anticipated due to many circumstances (time conflicts, presence of appropriate dying individuals). In the beginning, I averaged 1-2 days per week, approximately 5-hour days on the unit. From February to June I spent 1 day a week, and sometimes 2 days every other week doing "shadow observations." These days were shortened to approximately 3 hours a day, of being immersed in the culture of the unit. This time frame was flexible to allow the researcher to fit with the nurses' schedules.

Interviews

Each key nurse participant was formally interviewed (tape-recorded) at least once, and informally contacted a couple of times individually as the experiences unfolded (see Appendix H for information). Informal interviews/conversations were not taped but were recorded as field notes. Informal interviews included nurses who called me at home, those who would engage in conversation while I was on the unit, often taking the form of impromptu discussions sometimes focussed but often serendipitous. One nurse participant chose to write some journal notes which she shared with me. Other important informal interviews/conversations took place during nursing conferences, during shift report, or during shadow visits. All these sources of data were important to understanding the culture of nurses' caring for dying individuals.

The formal interviews with each key nurse participant were conversational in nature. The term "conversation" is used to more accurately describe the actual process used; it implies more of a discussion that is dialectical in nature. As Bergum (1989) wrote "like an interview, the conversation has a central focus, but it is not one sided" (p. 48). Rather than one particular person (the researcher) asking the questions, a dialogue of openness to discuss a particular topic encouraged the nurses to speak about their own experiences. The nurses needed little encouragement and often spoke of their experiences in the form of a story.

The majority of the more formal conversations (those that were tape-recorded), occurred in the key nurse participants homes, lasting an average of two-and-a-half-hours. In these conversations, I always began with the "business" of the research project included reviewing the information letter, discussing ethical considerations, and signing the consent form. Biographical data (Appendix B) was also obtained to allow for a more detailed description of the nurses.

The beginning of the conversation focused on the "nurse as person." I explained to each nurse that I believed that as a person they brought to their nursing experience a rich background, and history of life experiences, that were "lived" as they cared for dying individuals. Their personal backgrounds helped me to understand, on a deeper level, their experiences. To focus the conversation, I would often ask them to "tell me what it had been like for them to care for dying individuals," and this would often lead to a lengthy conversation. I did have an interview guide in case the interview was needing to be more structured (see Appendix D interview guide). Most often, however, the nurse addressed these questions without my prompting.

In telling their stories, the nurses often appeared intense, sometimes passionate. Often little interruption by me was necessary, except to prompt for clarity or to "tell me more." There were times in the conversation where critical junctures occurred. The nurse would lead the conversation down one path. As suggested by Morse and Field (1995), I tried to keep track of these junctures and revisited the paths that had been left untouched. From almost all sessions, I came away feeling honoured to be a part of these nurses' experiences. I felt a need to know more. The nurses appeared eager to share and contribute to the study. I wrote in my field notes:

> The nurse appeared very comfortable, attentive and willing to share her stories. She sat in a relaxed position, made eye contact and was very focused on the conversation. In fact, I noticed that she did not touch her tea until after the conversation was ended.

Not all interviews were calm and smooth. There were instances where the nurse was overcome with emotion. These emotions stemmed from their love and dedication to providing quality care to dying individuals. Although the conversations were focused on their experiences, I felt that I was involved as well. Their stories were of interest to me; there appeared to be a sharing of common concern and experience. I also felt validated myself as a researcher as many expressed interest in my work. They were thankful that finally "someone was interested in the nurses' voices." This one to one interaction with each participant was the beginning of many more conversations which unfolded during the "shadowing" experiences or unprompted on the nursing unit.

After each formal interview I recorded my immediate thoughts (sometimes written, sometimes by talking into a tape recorder). My thoughts included information about the location of the interview, a description of the environment, overall content of the interview, and key words or phrases that were repeated by the key nurse participant that stood out for me.

Observations ("Shadowing")

In ethnography, as discussed by Agar (1980), there is always an emphasis on direct personal involvement with the people in the study. The nurses in this study helped me (the ethnographer) to learn their basic beliefs, fears, hopes, and expectations of caring for dying individuals. Observing the nurses individually, as they were directly involved in caring for dying individuals, occurred. Numbers and lengths of observations varied on an individual/situational basis. I arranged (by appointment) to spend at least one observation day with each key nurse participant. During the day I remained with the nurse for the entire day (her eight-hour shift). I was also present on the unit many other days where I did not have an assigned nurse to shadow, but instead floated from nurse to nurse (if they were key participants). Generally, I was free to wander to which ever key nurse I judged valuable for data collection. The staff were often voluntarily useful in pointing out events they thought would be helpful for the research. For ethical reasons (outlined in the ethics proposal), I did not shadow others nurses who were not key participants as they were directly involved in patient care. I did however informally have discussions with them.

In shadowing the key participant nurse, I assumed the role of "observer and participant" (Morse, & Field, 1995). At the beginning of each 'shadowing' experience I explained to the nurse and to the individual or family member for whom the nurse was caring (and who also gave me consent), that my role was primarily to observe. I would not initiate care but would assist, for example, in turning or bathing an individual. Initially in doing these "shadowing" observations, I was a bit nervous and very conscious of not getting lost in the detail. I wanted to strive for quality in the data I collected. This process began with establishing reciprocal trust between myself and the participants. I always began by engaging in establishing rapport through conversation. Often it began with who I was when I was not a researcher, or how the dying individual was feeling that day. When I felt comfortable, I would "absorb" as much of the experience as I possibly could. Occasionally I would leave the room and jot down actual verbal/non-verbal exchanges or salient points that captured the essence of the experience. When it was feasible, I would ask key participants about their perceptions of events and their feelings about them shortly after the event. Remaining focused for a long period of a time was mentally exhausting, and I was conscious of when to stop if I felt my mind was wandering. Upon leaving the visit, my thoughts were often spinning, and I tried to capture my thoughts on the way home by talking into a tape recorder. The essence of each shadow visit was captured in field notes as described below. Overall field notes of shadow observations and informal conversations amounted to 522 pages of hand-written notes.

Writing Field Notes

Focused ethnography makes abundant use of field notes which contain not only a passive account of the facts of the event, but also an active process of sense making of the researchers feelings, and interpretation of what they see and experience during the participant observation (Emerson, 1982). From previous experience in a graduate level course I (the researcher) obtained beginning skills needed to record detailed field notes.

Over time, the experience of writing field notes became a process that assumed ritualistic behaviours. As often as possible, the notes were written on the day the 'shadow observations' occurred. Processing my field notes immediately after each visit was time consuming but important as it allowed for ongoing review of the data, and assisted me in establishing goals for subsequent visits. I would write at home where it was quiet and my time was uninterrupted. I would use the short descriptions obtained during data collection and the tape recordings I made in the car to help me reflect on the detailed observation in a sequenced order as it unfolded. These notes became the beginning of my "ethnographic notebook." I organized the note book to include three columns on a page consisting of: 1) observational (actual details or descriptions, of interactions, behaviors, events portraits of subjects), 2) analysis (my initial sense of what I saw, heard, felt, uncovering of relationships between the participants, events, and interactions), and 3) interpretive notes (looking for meaning in the data and using the literature to clarify, and/or challenge my perceptions). The notebook was created in this way to avoid mixing what I saw and what I heard from what I thought. Although these notes were generally written at one sitting, they were reviewed and reconstructed to enhance the description/detail. When I began the research, I can recall the overwhelming, confusing feeling of how much detail to capture in all its complexity. I quickly learned that extensive notes were needed to create a "thick description" (Geertz, 1973) to make explicit the cultural patterns and relationships among the nurses and dying individuals for whom they cared. Thick descriptions helped me to explore the underlying meanings of these experiences.

Analysis

Data analysis occurs simultaneously with data collection (Germain, 1993), begins early in the data collection phase, and continues throughout the research. As the ethnographer develops ideas, she /he tests them against the observations made, and ideas are altered and then re-tested. Tesch (1991) discussed that "the main purpose of this type of analysis is to achieve deeper insight, to search for commonalties across the study, participants or sites, to explore uniqueness, and to interpret the meaning of the discovered patterns" (p. 319). The analysis process in a traditional approach to ethnography uses data from participation and interviewing, a back and forth process.

I began with the interviews. Each interview was transcribed by a secretary. I reviewed each transcription while listening to the tape, correcting, filling in missed words, and obtaining an overall sense of each transcript's general meaning. I wrote memos on the sides of the transcribed pages, and initially I would ask myself what individuals were saying about themselves and their experiences of caring for dying individuals. How do they describe it? Was their suffering in their experiences?

As I conversed with more nurses, and had more exposure to the nurses caring for dying individuals, my memos became more focused as I looked for recurring expressions and ideas. I began to ask myself what the suffering was like. What were the nurse's moral commitments to understanding/alleviating suffering? What issues/concerns were arising? As I developed ideas, from the transcribed interviews, I watched for them in the 'shadowing observations,' and recorded my thought in my fieldnotes. I was aiming for a deeper insight, searching for commonalties across the participants, exploring for uniqueness and interpreting the meaning of discovered patterns. I had all this data and needed to pull it together. I started to 'code' the data.

Codes are labels assigned to units of meaning (Germain, 1993). Units of meaning occurred in words, sentences, and sometimes paragraphs of raw data. Coding of the data started broadly and then became more focused as it progressed. I modified the analysis process, as outlined by Burnard (1991), for sorting and sifting or 'funnelling' the data to a smaller number of thematic groupings (see Appendix I for an example of 'funnelling' the data).

I began again with the first few interviews, where a first level of coding began. I began to notice words that were reoccurring, words that were describing the nurse/patient relationship, the qualities of palliative care nurses, and the environment in which they worked. The words compassion, connection, presence, 'calling' to palliative care nursing, suffering and good death were repeatedly used. At the end of the data collection the list of words was very long.

Already, I had begun to develop thematic groupings or categories by using the previously mentioned words as headings, but now was able to list other words or subheadings, or related category codes. As the analysis continued more categories were developed or regrouped until major categories were identified, with a few words or outliers that did not appear to fit with any of the emergent categories. I did not discard this data, but rather used the words to test the rest of the data, or strengthen my understanding of the prominent categories. The goal from identifying these categories was to identify patterns from the data (Boyle, 1994; Germain, 1993).

Throughout the process of collecting the data, I explained to key participants that I would ask for their verification that the data that I was collecting was appropriate and accurate. This process is to enhance the validity of the list of categories (Burnard, 1991: Morse & Field, 1995). I also memoed for myself questions to ask the participants for further verification. Germain (1993) suggested that the major portion of the work of the interpreter is completed after the researcher leaves the field. I did return to the field three months after the data were completed to check with a few of the key participants their thoughts on the final list of categories I believed to be accurate. The majority of authentication occurred during data collection itself.

Maintaining Trustworthiness

Objective measures of scientific reality and validity are not appropriate for works with experiential, aesthetic, and artful intent (Eisler, 1981; Sandelowski, 1991, 1994). They take us too far away from the "artfullness, versatility and sensitivity to meaning and context that mark qualitative works of distinction" (Sandelowski, 1991 p. 161). Scholars suggest that evaluation of qualitative work be based on the adherence to the underlying philosophical assumptions of the research tradition such as ethnography.

Explicit standards for assessing trustworthiness or scientific merit of ethnography have changed over time (Germain, 1993). Bruyn (1966) cited six criteria imperative for subjective adequacy of ethnographic methods which include: 1) the time a researcher spends with a group, 2) place or actual observation of subjects in their everyday lives, 3) social circumstances or the variety of social settings, roles and activities witnessed, 4) the understanding of language, phrasing and sentence structures in daily use, 5) intimacy of the encounters, and 6) consensus or "confirmation in the context" that the meanings interpreted by the observer are correct. Traditional criteria for ethnography include a qualitative interpretation of the quantitative terms *validity* and *reliability*. The following modifications by Sandelowski (1991) will be used to discuss trustworthiness for this study.

Validity is the primary criterion of 'good ethnography' (Germain, 1993). In ethnography, validity is how accurate the instrument (the researcher) captures the observed reality and portrays this reality in the research report. In this study, I strove to discover and interpret cultural meanings of nurses caring for dying individuals, rather than how to know "truth" (Aamodt, 1989; Boyle, 1994). This discovery is a way of presenting "subjectivity," and analyzing the ways in which human beings make sense of the meanings of their worlds. The researcher's job becomes one of reporting and interpreting the perspectives of the informants as clearly as possible. This subjectivity in ethnography is enhanced through the researcher as self, reflexivity, and immersion in the culture. The researcher observes and then records cultural data. More than observation, the researcher becomes a part of the cultural scene and assumes a reflexive character, being a part of, rather than separate from, the data. The researcher explores self - awareness as a source of insight, implying that the researcher must be conscious of the role as researcher and aware of one's own internal state (Aamodt, 1989). In this study, through the use of memos, I attempted to note my biases and on more than one occasion discussed these biases through consultation with other researchers and when appropriate with the informants themselves. Establishing trust with the informants was key. As previously discussed, the lengthy immersion into the culture, (over a period of nine months), allowed trust to be possible and time to strengthen my observational skills. These measures enhanced my sensitivity, perceptively, informed value judgements, and knowledge as a researcher.

Transferability or *fittingness* occurs when findings fit other contexts as judged by readers, or when readers find the report meaningful in terms of their own experience (Germain, 1993). In this report, thick description and verbatim quotations from nurses, will allow other nurses to recognize the value, importance, and meaning of nurses suffering in caring for dying individuals. The knowledge generated in this study provides exemplars of suffering that add clarity, complexity, and/or challenge the assumptions about suffering presented in the literature. Ultimately this knowledge will lead to an appreciation and understanding of the complexity of these nurses' experiences of caring for dying individuals. In essence, I do not pretend to bring forward *the* truth but rather *a* truth.

Credibility explores whether the findings are believable or representative of the 'real world' of the participants, and is enhanced by the ethnographer's direct and repeated involvement in the culture (Boyle, 1994). The researcher must be with the participants for a sufficient time to build trust with them and to achieve the purpose of the study. The acute care facility was selected for this study because the researcher had knowledge of the agency and had experienced a past professional relationship with some of its members. Even though staff within the agency had changed, history of a previous professional relationship, which was positive was remembered by a few key participants.

Building trust was a developmental process. As a researcher, I built trust with the key participants by attending staff meetings, by explaining the study and by sharing my interest in palliative care nurses. I perceived that trust developed as I was encouraged to provide information at discharge rounds and team conferences.

Validation of the data was obtained from key participants during the data collection process. Agency documents such as letters from clients, and agency evaluation forms were further evidence to support the categories. My field journal, was reviewed, by a colleague for evidence that biases were made explicit. These measures enhanced the validation process and increased the credibility of the findings (Germain, 1993).

The technique of peer-debriefing was also used by the researcher to establish credibility. The purpose of the debriefing was to keep the researcher 'honest'. The debriefer posed questions to me regarding the meanings and values asserted in the analysis and interpretation of the data. She suggested a re-examination of the data for one category in particular. She challenged me to examine the meaning of compassion to mean more than an emotional identification with the other. The debriefer also helped me to clear my mind of feelings and emotions that may be clouding the analytical process, as she knew that I had strong feeling about the ethics of "justice" in allowing dying individuals the right to choose where they will die. She suggested I needed to look further at the macro level of the health care system to understand the allocation of resources. The debriefer, having had experience with doing ethnography, was familiar with the back and forth process of analysis. She encouraged me to continually memo questions and to check these out with the key participants.

Credibility of the findings was also checked close to the end of the study after data collection had been completed. The debriefer encouraged me to re-check with the participants that I was using the correct terminology of the major categories that best suited their language as palliative care nurses. I also confirmed with the unit supervisor her opinion of the final categories, as I had had several conversations with her throughout the process of the research. This technique, known as 'member checks' (Morse, 1991), was also performed with some of the key participants in phone conversations.

The greatest risk of focused ethnographies is that the boundaries of their focus unknowingly exclude what is relevant (Muecke, 1994). In this study, I purposely allowed the scope of the study to be broad. The research question: *What is it like for nurses to* *care for dying individual?* allowed me to begin in a non-directed way to capture the fullness and complexity of this experience. Although I was interested in understanding 'nurses suffering', the study was not limited to this concept alone. I allowed myself, as a researcher, to remain open both in the interviews and shadow observations. I allowed the emerging data to guide my questioning and tried to observe in the 'local moral world' of the nurses caring for dying individuals. To capture this experience was indeed a challenge. The use of verbatim quotes in reporting the data and maintaining credibility as described above is what I aimed for.

Limitations

It is the custom of ethnography to choose participants who best exemplify the topic under study (Germain, 1993). In this choosing there is richness, but something is always excluded. This study honours the perspective of the experienced palliative care nurse. The "novice nurse" who may have a different perspective is not included in this study. There is a particular homogeneity to the participants in this study. All of the nurses from this culture are female, are not people of color, are all from similar economic backgrounds, and they are all Canadian born and raised.

As is the usual case with a focused ethnography, the number of participants was limited. The findings and interpretation of this study are bound by the context and time of data collection. The very thing that adds merit to this research is that which restricts it. Ethnography is the study and honouring of this particular culture of nurses. In this study of these particular nurses there are rich, vibrant, and expansive opportunities for understanding. It is the depth of these particulars that offers the strengths which surround this research, but it could be argued that the research is constrained by its lack of breadth.

Limitations from this study may also stem from my abilities as a researcher to interpret the experience of what it was like to care for dying individuals from the conversations I have had and the observations that occurred. To capture the essence of this culture and write it in a way that is interesting to others is a challenge, a challenge that poses the risk of losing the richness of the experiences these nurses live.

Writing the Ethnography

The purpose of writing an ethnography is to share with people what has been learned and to attempt to make sense out of the cultural patterns that present themselves. Ways of reporting the ethnography vary among ethnographers and the audience for whom they are writing. An ethnographer may choose to report in a natural history, chronologically or spatially, or choose to organize information based on significant themes (Omery, 1988). Describing those themes involves a report of the actions, interactions and getting a feel for what is 'going on here'. The description is enhanced by presenting critical events, rituals, and or roles.

The report of the data in this study is organized around the following four major themes: 1) A call to relationship; 2) Pursuing a 'good death'; 3) Surviving the health care system; 4) Creating a moral space for suffering. Under each major theme are sub-themes that portray the patterns, making linkages between ideas. In discussion of these linkages, critical events, roles, and rituals are explored. I have chosen to write the work in this way, as it allows the reader an opportunity to experience the unfolding of nurses' journeys as they care for dying individuals.

Summary

In this chapter I have discussed the method of *focused ethnography* as the one best suited to study what it is like for nurses to care for dying individuals. I have presented the culture under study, reviewed the research intentions, and described the research process from ethical considerations to analysis of data. Finally a discussion of maintaining trustworthiness and writing the ethnography was presented. In the next chapter the presentation of the study findings begins.

Chapter Four

Nurses in Palliative Care: A Call to Relationship

> *When both care provider and care receiver are co-participants in caring, the release can foster self- healing and harmony in both. The release can allow the one who is cared for to be the one who cares, through the reflection of the human condition that in turn nourishes the humanness of the care provider. In such connection they are both capable of transcending self, time and space. Neither stands above the other.*
> *(Watson, 1985, p. 132)*

Nurses often speak of the privilege they have to share in the intimate journey of living and dying with their patients. To share in such a special relationship, where high regard for the whole person and their being in the world is paramount, is often the ultimate goal of human life. Sharing in this journey of searching for wholeness when an individual is dying is not always peaceful. Suffering, pain, and loss are often a part of the journey. I have often wondered why nurses choose to partake in this journey. Is there a special kind of nurse that is best suited to be on this journey? One might speculate that nurses are "called" to palliative care. Being "called to care" in this study, is a willingness to be in significant relation, to be responsive to others, to be in spirit together, and in human existence together. Throughout the study I consciously wondered what kind of a person is drawn to those who are dying, who are suffering, who are searching for meaning in living and in dying. What calls them to this relationship?

The purpose of this chapter is to begin to present the findings of my research into nurses caring for dying individuals. In the writing of this dissertation, I will highlight the conversations with nurses and others (their words verbatim) by indenting the text. Each observation will also be highlighted, by identifying the nurse that I observed. I will begin by discussing the study context and exploring the palliative care unit where this study occured. In this chapter I will also introduce the key participants who care for dying individuals on this study unit and explore the qualities that these palliative care nurses embody. Finally I will describe the reasons these nurses came to be palliative care nurses, answering a 'call to relationship' with those who are dying.

The Study Context: A Palliative Care Unit

The context for this study was a medical unit in an acute care setting located in a growing city in Canada. The noted 'specialization' of this unit was palliative care. Patients who were admitted to the acute care facility with a 'palliative care' diagnosis were sent to this unit if a bed was available. Patients in other areas of the hospital who were 'palliative' were often transferred to the unit. This unit is one of the few units in acute care facilities offering palliative care services. At this time, money for palliative care in the province was only beginning to surface.

As previously mentioned, I had a professional relationship with some of the members on the unit from my time spent as a community hospice nurse. Upon entering the unit, the intention of my initial was to gain a sense of what the unit was like. To do this, I informally spoke with several individuals who worked on the unit (social worker, unit clerk, unit supervisor, nurse clinician). I felt that to fully understand the nurses' experiences it was necessary to understand the norms and values of the total system from their perspective. Initially, I spoke with the unit clerk, a long standing member of the unit staff. She was welcoming and suggested places on the unit that I might want to "hang out" to get a good sense of the overall ambience of the unit. During this time, I observed the surroundings, the day to day functioning of the unit, and sought out background goals and philosophical beliefs about the unit as well as demographic information about the nurses who worked there. As these conversations were informal, I did not tape record them. I did, however, record fieldnotes. The following accounts reflect my initial experiences on the unit.

> It was my first day and I arrived ahead of the scheduled time for day shift report. Rather than just dropping in at any time during the day, I wanted to begin my role as a researcher, as a "nurse" did, listening to report, preparing to start the day well informed of the progress of each patient.
>
> The unit manager began report and introduced me by name. She explained for those who were not aware, that I would be spending a lot of time on the unit "doing research." She encouraged her staff to dialogue with me at any time, voicing their questions and concerns, and to "make me feel a part of the unit." She explained to her staff that initially I would not be spending time with anyone in particular, rather I was gaining an initial sense of what the unit was all about.
>
> Report revealed that the unit was a very busy, hectic place. It was clear from report that various "medical types" of patients were cared for on the unit. Although the "focus" was palliative care, the unit was busy with many other complex medical situations. It became clear as I spent time with the nurses that this "mix" of patients was not conducive to "good" palliative care.
>
> As I wandered around the unit, the setting at first seemed very cluttered with all types of medical equipment such as wheelchairs, stretchers, scales, carts of linen, blood-pressure machines and so on in the halls.

Among this clutter, however, was a sense of organization. Each piece of equipment had its place, stowed neatly in a corner, or pushed against the wall. Another striking feature of the environment was the beautiful art, strategically hung on the walls. Examples included reproductions of Monet, Van Gogh, prints of the Renaissance period, philosophical and religious citations, and art with a palliative care message such as Robert Pope's painting "Caring and Hope." There were also photographs of patients who had died on the unit. These pieces portrayed the special association and significance of their palliative care focus and love for the dying individuals for whom they had cared.

The living space itself also portrayed a sense of comfort. In particular there were areas for patients and their families. A lounge positioned away from the nursing station was decorated aesthetically in varying shades of green. Large couches and comfortable chairs, smaller tables and chairs where one could do crafts, a television, a stereo, and a gourmet coffee machine enhanced the comfort of patients and their visitors. The view from the window, encompassing the entire room, was a large body of water, and sky, far-reaching and endless. The blue sky and stillness of the water evoked an invitation for reflection. Although there were four individuals in various places in the room, I was overcome by the feeling of peace and the powerfulness of silence. Entering the room I felt a need to sit and stay awhile. I watched the individuals, two of them patients, who were sitting watching the water. One patient was in a reclining chair, wrapped up in blankets had her eyes closed. She was not sleeping; periodically she would open her eyes, sigh and close them again, deep in thought. Two visitors, sitting close to one another on a love seat, were sipping coffee. Aware and respectful of the silence, they whispered to one another, then also would stare into the stillness of the water.

Another area for families was more private but an equally comfortable room, with all the amenities (phone, kitchen nook, comfortable seating) needed for lengthy stays when remaining with their loved ones. It was an area where families could go to rest or socialize with other families also experiencing the potential loss of a loved one. The room was also used for private discussions and counselling of family members.

Wanting to observe the actual patient rooms, I spent some time with one of the nurses who was caring for a palliative patient. When I entered the room, Mrs. W appeared to be resting comfortably under a down quilt. I noticed the patient's room to be less busy looking than the hallway. It was tidy and an attempt had been made to make the atmosphere more like home. Pictures of Mrs. W's family, greeting cards, and drawings were on a bulletin board, the bureau, and on the windowsill. Palliative care patients were encouraged to bring belongings from home that conveyed their individuality and love for life. The room had been rearranged to meet the patient's needs, however, it was spacious enough for the nurse to provide care. At one point I noticed the nurse actually pull over a chair to sit and be at eye level so she could be attentive to Mrs. W's needs. Before leaving the room the nurse turned on some music from a portable CD player in the patient's room. Upon discussing the room with me, the nurse conveyed that she "wished the art in the hallways was also present in the patient's rooms." The environment and the way the nurse delivered care led me to believe she was very open to many possibilities of caring for dying individuals.

There was also another small family room that was off the unit with comfortable seating/couches for the family to rest. Although this place was accessible to anyone from other units, I often noted the room to be empty, and would go there to record field notes. When the door was closed, I noted others would respect the privacy and not enter the room. The general surroundings of the unit also suggested that the nurses and staff on the unit were a very close family. In the staff room there were several written announcements of upcoming social gatherings, births of children, letters of thanks from a staff member who was helped through a personal crisis. There were also professional portraits of the staff together on three different occasions. These photos were on the walls in the hallways, a part of the other significant art. The placement of the photos, visible to all visitors, portrayed the staff's willingness to share their lives with others. Surrounding these pictures were plaques with the names of individuals who had donated money to the unit for the purpose of purchasing special electronic beds. These beds were yet another symbol of attempts to enhance the comfort of patients on the unit.

Overall, this environment, although part of a very busy acute care institution, was decorated to be as comfortable, attractive, and peaceful as possible. The surroundings, atmosphere, and collegiality of the staff facilitated a presence of caring that offered comfort and respect. It afforded opportunity for living one's illness in comfort and peace until death. This is the essence of a palliative care philosophy.

The Key Nurse Participants

Ten nurses met the requirements and volunteered to be key participants in the study. Nine participated in interviews and shadowing, One nurse participated in the interview only. They were all women who have an average of 21 years of nursing experience. These nurses have worked in palliative care from 6-20 years with an average of 13.8 years. Three of the nurses have baccalaureate degrees, 2 in nursing, and 1 in a related field. Two of these nurses are pursuing graduate education. The average age of the participants is 53.6 years.

All of the participants are or have been married, and all have children. Eight of the key participants have older children in high school and or university. Two of the participants have children in junior high school. Seven participants work full time hours (12 hour shifts), and the remaining three, work permanent part time (eight hour shifts). The key participants will be introduced in the remaining text of this chapter, to allow the reader a beginning sense of them as persons and what brought them to palliative care.

A "Calling" to Palliative Care

Most of the nurses in this study came to palliative care because they wanted to give of themselves to others and grow as a person themselves. They expect and desire that personal closeness will be the 'core' of their work with dying individuals and their families. They hope that in view of their own suffering, religious beliefs, and sense of self- confidence as persons, they will be able to give of themselves. Ultimately, for whatever reason they were "called" to be palliative care nurses, there was a search for possibilities that foster human well being. *Nurse Barbara* said, "we do this kind of nursing because it brings us closer to who we are as people." Barbara shared her beliefs about working in palliative care.

> In this work, there is a 'peace' that occurs, there is a beauty with it, and there's an end to suffering. It's not gross, it's not a bad thing, it's a sad thing. We have a ritual on the floor that says you have to wear waterproof mascara, because we cry lots. You get close to people. Sometimes it's a pretty rough death, but there's a release when it's done. It's not bad.

The notion of "calling" is likely not unique to palliative care nurses, however, it is evident in this study that palliative care nurses have intense desires and commitments to enter into relationships with dying individuals and their families, and give of themselves. These relationships allow nurses the opportunity to know and understand the dying individual's experience, to foster their professional responsibilities of striving for a "good death", and empower dying individuals and their families to live the journey that they desire. *Nurse Nancy* reveals her 'call' to relationship:

> The attraction for me is being able to talk to patients and families. I have some strong feelings of how palliative care should be for the importance of families, like, what they want should come first. It's their journey, it's what they want. The appeal for me is helping families make that happen,

> and making the whole experience go the way that they would envision it to go.

A call in the life of a palliative care nurse is an everyday experience requiring passion, direction, and a sense of well being on the part of the nurse. The ability of the nurse to sustain this passion and direction is inherent in knowing oneself.

Nurse as Person

As palliative care practice connects us with humanity, searching for meaning and the deeper questions of life, so is the palliative care nurse searching for finding one's self. To be with others in an ethical way, one needs to understand the other person as well as self. In understanding self, the values, the beliefs, one can begin to understand the other.

Each nurse's story of understanding self was unique in this study, but all revealed the interwoven nature of past, present, and future experiences. They all shared the importance of having a comfortable relationship at home with their own families, having leisure time that is fulfilling, and having worked through their own death anxieties as precursors for understanding self. I felt that getting to know each nurse as a person was an important part of understanding their experiences in the context of caring for dying individuals. I chose to do this in their first informal interview, where I asked each one of them to tell me a bit about themselves as 'person' that brought them to being a palliative care nurse.

Nurse Jennifer. I first met Jennifer at her home, and was struck by the many pieces of unique china, pottery and art she had throughout her home. The environment was ripe with personal history and culture. I sensed that she was a very artistic person and she mentioned during the interview that she was interested in other cultures, native cultures in particular.

The beginning of the interview was tense for Jennifer. She remarked that she was not in the habit of "talking about herself." I explained that I wanted to know more about her as a 'person' and as a 'nurse.' Interestingly enough, she mentioned several times throughout the interview that "personal life experience" was extremely important in feeling comfortable and "authentic" in giving care. After the initial period, she appeared very comfortable, attentive, and willing to share her stories. She sat in a very relaxed position, made eye contact and was very focused on the conversation. I noticed that Jennifer did not drink her tea that she made until after the interview was over. Repeatedly she spoke of "those who care, must care in the moment, and be there for the patient's needs." Jennifer's powerful ability to focus made me feel very welcome, and wanting to share more of her experiences.

Nurse Barbara. Barbara welcomed me into her home, by making me some tea and encouraging me to make myself at home. Thinking that I was to come a half-hour later, she was "still making herself presentable", on which she placed great importance. As I prepared my tape-recorder at her kitchen table, I was greeted by her dog. Before we began she shared some special events that were happening in her family's life.

At the beginning of the interview, Barbara voiced her eagerness to discuss a profession that she was very proud of. Her expressions and stories also revealed the passion she had for palliative care nursing. She recalled her nursing career, and stated the most fulfilling years of her practice have been in "coming to palliative care nursing". Many times, she voiced the importance and closeness of her colleagues making a profound difference in the love of her work. She also spoke of the importance of being oneself and the need to respect other's values and wishes in their dying journey.

Nurse Muriel. Muriel welcomed me into her home, the atmosphere warm, comfortable and immaculate. Her home was decorated for Halloween, a special time for the neighborhood community, of which she was very much a part. Muriel's surroundings were also filled with many family memories, ranging from handmade crafts to family photos. She had many snapshots on her fridge and she stated they were "there for her children to acquaint themselves with the lives of their relations, as did not often see them."

Muriel's warm, personable, and compassionate nature was evident as we conversed. She commented on how "pleased she was that someone cared about the nurse's suffering". She was without a doubt a very caring person, with an overwhelming sense of duty and moral commitment. Her ultimate goal as a palliative care nurse was to comfort and alleviate pain and suffering, ensuring that the patient's and family's wishes/ needs were respected. She believed that a sense of control was the patients/families, not hers. It was also evident that she was willing to go the 'extra mile' to make sure this happened. She stressed, throughout the interview, that the nurse needs to put aside her own values in order to meet the patient's needs. She stressed that she was a "giver and not a taker".

Facing death on a daily basis creates opportunities for nurses to face their own death. Therefore, nurses engage death through a projection of self, as the meaning of life and death is considered on a regular basis. Nurses understand death/dying not as objective onlookers gazing at meaning from afar, but through a situated understanding of self gained from being meaningfully engaged in caring for the dying individual. *Nurse Jennifer* shared her experience:

> I've learned that life experience contributes to being a better nurse. I've also worked a lot on myself. I've gone to retreats and done those kinds of things that made me more aware of myself, and made me more comfortable with being myself. There was sort of an "aha" moment after I had been to a retreat, that I didn't have to be this professional nurse that couldn't be emotionally involved at all. It was OK to be involved you know as a nurse. I realized that you didn't have to hide behind a corkboard. You could actually go and sit, and be yourself. It was certainly a lot more emotionally draining that way, but I also felt more fulfilled.

In a sense, finding one's self is a search for authenticity, a search which is ongoing, as a way of life, and as a way of being with others.

Bringing an Authentic Self

Nurses, in their call to being with others, search for an authentic self. Searching for authenticity means being true to oneself, accepting responsibility for one's choices and being willing to make choices directed by one's values, personal identity, and life goal. Bringing an authentic self to being with others helps persons to discover possibilities for becoming their best selves, given their situation. *Nurse Ruth*, shared her beliefs about bringing an authentic self:

> Not all nurses are able to be authentic with dying individuals. Being authentic does not happen over night. Knowing one's values about dying requires constant reflection that does not happen upon graduation from

> nursing school. Life experience and a personal understanding about what death really entails is the only way one can really be authentic. Helping someone explore personal intimate meanings of life and death is not a task which can be memorized, but rather must be experienced from the depth of one's soul, to reach within and find personal meaning. The connection that is experienced in searching for intimate meaning is what entices nurses to work in palliative care. You have to want that connection to be an authentic palliative care nurse.

In this study, bringing an authentic self, means that nurses help others to care for their own being. In the face of their dying, nurses help others to discover meaning in their life, encouraging and assisting them in exploring that meaning in both the present and future. An authentic self for both nurses and dying individuals cannot be socially derived but must be inwardly generated. *Nurse Darlene* expresses her feelings of being authentic:

> I've cared for so many young women, 38, 42, and we've seen them from the diagnostic stage to death, sometimes for a very short period of time. I recognize how precious and vulnerable we are, and that there is a plan out there somewhere, for why I'm here. I wouldn't say I'm a religious person in that God has a plan for us. I don't know why, but for some reason, there is an explanation as to why this experience is happening to both of us. These experiences force us to look at our beliefs about life and death regularly. Patients look at you, the nurse, to help them sort out these experiences.

Moral Qualities of Palliative Care Nurses

The moral sense of nursing practice invites us to enter authentically into relationships with dying individuals and gives us ways of caring for their well being. There are many moral qualities or characteristics that are inherent in the culture of palliative care nurses. A discussion of these qualities within the culture of palliative care nurses is important here to enrich the understanding of their "call" to relationship. Two qualities revealed throughout the study of these nurses were compassion and courage. These qualities will be discussed in detail throughout the dissertation but warrant a foundational discussion here.

Compassion, or suffering with someone, is a quality that is a natural part of being human. As humans we all have the capacity to feel with others, to enter into their predicaments, and share their emotions. However, palliative care nurses who are able to be authentic in their relationships with others show compassion that involves more than informed feelings for others. Their feelings are not just passive. In having compassion, these nurses are moved to action. In acts of true compassion there is an affective aspect (feeling with others), a cognitive aspect, (having particularized insight into the situation of others), and a conative aspect where individuals are moved to act on behalf of others.

Nurse Eileen. The initial visit with Eileen emanated compassion in every sense. When I arrived at Eileen's house she was busy baking muffins for her colleagues at work. Her baking was a way to show her gratitude to them for the support they gave her last evening. "It's just one way I can show my appreciation for their understanding".

During the interview Eileen was very passionate about the need to make a difference in her patients' lives. She spoke of advocacy for those individuals being sent home to die, the need for nurses to go that "extra mile," to push the health care system to "bend" so dying individuals have the resources they need to ensure peace and comfort. Eileen saw her role as speaking up for the patient to stay in hospital, until those resources were available. "I'm willing to speak out, to keep making noise if others don't seem to be listening. Nurses consider what it would be like for them if they were faced with a similar situation in their family. "It's our moral way that allows us to question what doesn't seem fair."

It is evident in this study, that the quality of *courage* is also important. Courage, derived from the Roman word *corati,* means to act with heart, spirit, intention, purpose, bravery, and valour (Hoad, 1986). Courage makes risk taking possible, carrying one beyond safety and security. But it is not blind. It is courage informed by knowledge, past experience, and by a trust in one's own and another's ability to grow. For example, courage may be required when collaborating with other members of the team if they are pursuing care that the nurse may deem not in the best interest of the dying individual. On a busy medical unit, palliative care is sometimes regarded as less important than curative or life prolonging treatments, and courage may be required to convince other members of the team that dying individuals deserve respect, dignity, and the right to choose other alternative measures of care in hospital. It takes courage for the nurse to stand up to others on behalf of the patient and their family. On an observation visit I watched *Nurse Helen* approach the physician with courage and compassion.

Nurse Helen. Helen was caring for Bill, a gentleman with multiple myloma, a disease that is reported to be common in individuals between the ages of 40-60. Bill was 32. Usually in this disease the malignant cells infiltrate the bone marrow, "often causing excruciating back and bone pain." Bill had been unresponsive to chemotherapy treatments, the malignant cells were "spreading like wildflower", and the oncologist gave him no hope of going into remission. The chemotherapy was stopped, but the family was searching for other treatment options. Bill's back pain was getting worse. Two weeks of trying different pain medication regimes was not working. Without warning to the health care team, Bill consulted the advice of a herbalist, and began to take herbs. The nurses on the evening shift notified the physician who refused to give an order for Bill to take these herbs. Not wanting to go against the advice of his physician, but knowing that he had limited choice, Bill asked Helen to phone the physician again. Knowing that the physician was coming in that morning, Helen chose to speak with him in person. "I know that this physician is not going to change his mind, but I feel obligated for Bill, to speak to him face to face."

The physician arrived some time later. I watched Helen approach the physician. Consciously the nurse stood by the physician speaking to another physician. Helen spoke: "Dr. Todd, I was wondering if I could speak to you about your patient, Bill. Bill is wanting to try these herbal remedies." Dr. Todd gave the nurse little time to explain Bill's situation. "I will not write an order that I do not agree with. If Bill chooses to take these herbs, I guess that is his decision, but I do not see it as being in his best interest." "Dr. Todd," Helen exclaimed, "what other alternatives can you suggest for Bill? If this gives Bill hope, is that not in his best interest?" The physician paused, looked at Helen, and walked away to Bill's room. Helen sighed, shook her head, and walked away. Later she checked the chart. The physician did not order the herbs. Helen, in a disappointed voice, spoke out loud, "I guess Bill doesn't have the physicians support, but he has mine."

In giving authentic care, *Helen* courageously spoke out for Bill. Out of a desire to be a caring, moral person, Helen supported Bill. She knew this was important to Bill, and that it gave him the hope he needed to work through his suffering in this illness experience.

The Call to Relationship

Palliative care nurses are called to relationships with dying individuals and their families on a journey that is often uncertain. They are present to share many emotions such as joy, fear, intense pain, and suffering, and they view this relationship as essential to their personal and professional fulfillment as nurses. This call to relationship is a call to responsibility, a responsibility to "suffer with" the other, to be responsive and sensitive. This responsiveness and sensitivity allows the nurse to be open to the face of the other. The face of the other is a moral connection to relationship. In seeing the face of the other we understand a special sensitivity and sensitiveness to situations. The following, reveals *Nurse Barbara's* sensitivity to the face of the other.

> Those who suffer often don't say anything. You have to look at their face, they just have to hold onto your hand. You know that gut feeling nurses get, well it's that gut feeling. It's a lot of stuff... it's something you feel something you see. I don't know how you can tell. It's just there. It's the clues that they give you. We don't have to ask if we don't know. We just touch. It's what nursing is all about.

Moral life in caring for a dying individual evokes deep emotions. The journey of living and dying is full of paradoxes and contradictions. A dying individual may experience weakness in body, but strength of spirit, in fears but also in joy, in apprehension but also in faith. A nurse shares in these experiences. Her/his relationship intensifies because of the emotions shared between the nurse and dying individual. Emotions call a nurse to a heightened sense of being. Emotions allow the nurse to show her/his relational being. The nurse who has a sense of genuineness most times understands the call in a moment. Emotions can themselves be a source of knowledge. Emotions for a nurse can be an embodied knowledge of rituals and practices that are often unspoken, tacit, and taken for granted.

The following exemplar from *Nurse Nancy* uncovers the moral role that emotions play in this relationship. The face to face relation with this individual opened a moral space, a space for sensitivity to suffering. It is not to argue that the care the nurse provided did not require a high degree of professional skill in her responsiveness. Rather the nurse's sensitivity to suffering gave her knowledge of what was important at that particular moment.

> We had a patient who was bleeding profusely. He had esophageal varices and whatnot; and we were just trying to keep him comfortable. I suctioned him and that made him bleed more, but if I didn't suction him he couldn't breathe. I didn't want to leave him alone. I was holding his hand and basically directing someone to go and get the morphine. I didn't want to leave his room. Even though he wasn't aware that we were there, I just stayed. And I think I actually prayed. I know the nurses were getting frustrated because we couldn't stop the bleeding. We were all just focused on doing whatever we could to make him comfortable. I felt privileged to be there for him even for the short period of time I spent with him.

It is evident in this situation that *Nancy* was present to the face of the other. Emotions did not get in the way of providing good care for this individual. A feeling of fulfilment came from her moral response to the other, a relationship in which professional activities were performed out of responsibility and compassion.

In observing/shadowing other nurses, I noted that personal closeness, sharing of emotions, being present with individuals, and knowing who they really are as individuals, was most important in their relationships. I sensed that nurses were most fulfilled when professional care was carried out of a moral sense and out of a face to face relationship with dying individuals who confirmed the moral worth of their care. *Nurse Beverly* shared her perspective:

> There are lots of positive experiences that we have with patients. Especially those where you're able to get close to them, to find out what they consider are important in their lives. You work out a real closeness to them. A closeness that allows you to ask questions like, What do you think is going to happen to you when you die? People usually respond by saying I have a place to go, I'm going on a journey.

Often in their discussion with me, nurses would say things like, "Nurses, because they are nurses, do whatever has to be done" or "As a nurse, you do it all because you're the one who is there to do it." But it seems that many nurses do not recognize that as they are "doing" their care, their moral sense of valuing personal care comes out of their relationships with patients. I witnessed this several times. For these nurses who I will call "authentic nurses", their professional practice came out of their being in a way that expressed both the requirements (competent doing) of professional practice, and a particular way of being, face to face with others, expressing who they are as people. Their roles are fulfilled when their care is affirmed.

In a shadowing visit with *Nurse Barbara* we cared for Lillie, an 87 year-old lady with *non-hodgkins lymphoma*. Lillie, admitted 3 weeks earlier with pneumonia and hypoxia, was now not responding verbally. She had O_2 on a 4l/min, her respirations were deep and laboured and her skin was cool to touch. Barbara came over to Lillie and stroked her head. She immediately assessed her respiratory rate and checked to make sure she was not experiencing any pain. She repositioned Lillie so that she was in a more upright position to breathe. The physical touch Barbara performed seemed to create an atmosphere of familiarity. It made their relationship seem close very quickly. She stood there for a long period, watching Lillie's face. Lillie reached out to grab Barbara's hand.

The physical motion and emotional expression of touch is reciprocal; it affects both the person initiating the touch and the person being touched. Touch can reach past technological treatment allowing the patient to reach out of the solitude of suffering. The use of touch for Barbara was obviously an authentic expression of her moral sense of being with Lillie. In observing Barbara I could see that she authentically knew whether to touch or not to touch Lillie, she knew whether to take her hand or place a hand on her shoulder. Barbara came up to Lillie's face instead of addressing her from the foot of the bed or the doorway. She stood close, making physical contact and talking directly to Lillie. She made her presence known to Lillie even when she was performing technical care, and Lillie responded by grabbing her hand.

The nature of the nurse-patient relationship is such that touching is both inescapable and acceptable. Touch is powerful. I often noted patients open their eyes, slow down their breathing and relax, reciprocate by clutching the nurse's hand. It appears that touch causes the dissolution of boundaries between two persons. When they have difficulty knowing what to say, nurses often use touch, the silent expression of being present in the fullest sense of the word. The nurses in the study all agree that touch needs to be genuine to be effective. In essence they believed that patients know when you are not authentic, and that they can feel your hesitation.

At one time or another, I noted all nurses in this study being called to relationship, and choosing to enter into and fulfil their relationships with patients authentically. They did so through expressed emotions, closeness, and face to face presence that fostered wellbeing. The moral sense of nursing practice invited them to enter authentically out of a desire to be compassionate, caring persons and excellent practitioners. This desire is seldom recognized as extraordinary; rather it is seen as the essence of nursing care. The human potential to care, like the human potential to be authentic, cannot be classified or characterized as a single "thing" nor can it conform to classifications. It cannot be boxed, packaged, or delivered on command. Sometimes there are situations that just happen, that stifle the nurses' ability to be able to give as caring nurses. On the unit there were occasions that I noted which prevented the nurses from being caring, and authentic. For example there was a period on the unit where there were three deaths within four days. Not only was the physical care difficult, but there were grieving families whose demands had the potential to "put you over the top."

Nurse Ruth. The day after this event I was shadowing *Nurse Ruth* who reflected on the cascade of losses experienced the day before as she cared for Hilda. Hilda was an 82 year old lady with cancer of the bowel. Hilda's tumour was inoperable and several treatments of radiation had been tried to reduce the size of the tumour. The treatment did not work and Hilda was now experiencing severe diarrhea, making her very weak. Because of her weakness, Hilda needed to use the commode chair for each trip to the bathroom. Hilda preferred to use the commode chair rather than the bedpan, as she did not like the odour to remain in her bed. "They try really hard to keep my bed clean, but sometimes the bed pan spills, or I'm not wiped clean enough." As I watched Ruth I saw the anxiety and frustration etched on her face, as this was the seventh time that we had assisted Hilda to the bathroom. As the day wore on, Hilda became weaker, and we were almost lifting her onto the chair. Ruth noted that Hilda was much weaker today and she was anticipating soon that we will not be able to help Hilda to the bathroom, as she so desired. Ruth reflected on the three deaths that happened in the last few days as she commented, "My God, Hilda is losing ground quickly, I'm not sure I can handle another death this soon, especially not a traumatic one."

Hilda was not Ruth's only patient, in fact she had three other patients who "seemed to need her a lot today." Her beeper was ringing and no one seemed to be helping to answer her lights. I sensed the hurried time as we helped Hilda off the toilet for the ninth time. Hilda was heavy this time, her feet and legs large and swollen, and she did not move with ease. Ruth grabbed the tissue to wipe Hilda and Hilda insisted on wiping herself to make the process even more difficult. What was Ruth to do? She did not intend to strip Hilda of her independence just because she was in a hurry. Yet it was becoming more difficult, even unsafe, as Hilda stood up each time to wipe. Ruth and I looked at each other and waited. As Hilda signaled, we moved her back to her bed, which was not an easy ordeal. Hilda was heavy, her feet did not move in tandem, her body flopped heavily back onto the bed. In a hurried motion, Ruth hurdled her legs up onto the bed. Hilda screeched in pain. Ruth took a deep breath and did not say a word. We positioned her as comfortably as possible and left the room.

I watched Ruth pick up speed as she raced to give the medications to her patient next door. The patient firmly reminded her that he should have received these "an hour earlier." Passing the pills to George, she knew he was in pain. She promised earlier before she was called in desperation to Hilda's room that she would bring him something for pain. You could sense the frustration on Ruth's face, the anguish on George's face. "What am I to do?" she muttered.

As we left George's room, we met face to face with Hilda's daughter. "My mother needs to be up in the chair", she exclaimed. "I told you yesterday that we are expecting her sister to visit and I want her to be up, not in bed when she comes. Has she been up at all today? She looks like she hasn't even had her faced washed." I watched Ruth's face go redder and redder, as she replied "Your mother has been up several times today. In fact, she has received more attention than any of my patients. Yes, your mother has been well cared for."

The many trials and tribulations of Ruth's day did not allow her to speak in a caring authentic manner. Her words spoke of frustration, of loss, of the burden of heavy physical and emotional care that she has provided for all of her patients in the last few days. Demanding families are often grieving for their own losses. Loss, heaviness, and grief were a part of the unit that day. These burdens had an impact on all those who are a part of the life of the unit. They will not last but they were present that day.

Summary

In this chapter the presentation of findings about nurses caring for dying individuals was initiated. A description of the study context and an introduction to the key participants was presented. In essence, the findings uncovered nurses as persons; and revealed their authenticity, moral qualities, and reasons why they came to be palliative care nurses, a "call to relationship" with others.

Chapter Five

Nursing Moments: Pursuing a 'Good Death'

> *Sometimes there is a dramatic beginning to this journey when patients are formally diagnosed with a terminal illness or informed that their disease has spread and is incurable. Other times, patients gradually become aware that they are losing their battle against disease and are facing death. Both the patient and family are on this journey. The patient's journey ends with death, hopefully a peaceful death but the family journeys further, grieving losses and searching for meaning after the death. In this journey nurses strive for a 'good death.'*
>
> *(Nurse Nancy)*

Palliative care nurses, like many other nurses, hold very high expectations of themselves. The journey towards death is an intense, memorable, and important part of the dying individual's life and the lives of many others. Palliative care nurses acknowledge their commitment and responsibility with great intensity. They exhibit a deep personal commitment to support and respect the dignity of dying individuals and their families and the personal choices of these individuals. In pursuing a 'good death,' their practice is focused upon being present for people who are journeying towards death. *Nurse Darlene* stated "Nurses strive to make a difference, to ease the suffering, to help them on an emotional and spiritual level rather than just the cafeteria is here, the bathroom is there and here is the telephone."

Nurses in this study are present to foster comfort for the whole person and their families. Life, for these nurses, is sacred. While they may have different views about how another's life should end, they all agree that life should not be prolonged unnecessarily, and that the dying process should be open (shared by all members and accepted). Difficult pain and suffering that is prolonged, is not part of a 'good death. In the complexity of the dying journey a 'good death' does not always occur naturally. Rather, assisting patients to a 'good death' requires the skill, compassion, and courage of dedicated health care professionals who remain along side the dying individuals and their families.

A 'good death' is difficult to define, as it is as complex and unique as the life from which it is an extension. The goal of this chapter is not to define a good death but to reveal nursing moments that are a part of this nursing culture that strives for death that could be described as 'good.' The chapter begins walking along side *Nurse Ruth*. Focusing on one nurses experience in no way suggests that this represents a 'typical day' of a palliative care nurse, but rather draws the reader into the nursing culture, routines and practices of this particular unit. Pursuing a 'good death,' requires good nursing care and is predicated in nurse's ways of being, nurse's ways of knowing, nurse's ways of doing, and nurse's ways of giving and receiving (nursing presence). These characteristics were uncovered through many experiences of dialogue and shadow visits with several of the key participants. In essence, nursing presence is the key to facilitating a 'good death.' The presence of the nurse is supportive and empowering. As discussed in the previous chapter, nurses who are 'called' to palliative care develop relationships with the patients in their care. These relationships lead them into the journey towards death.

Watching the Events of Dying Unfold.

I enter the nursing unit in great anticipation today. Last evening I called the unit to confirm that *Nurse Ruth* is scheduled to work the day shift. The unit clerk confirms that Ruth is working and remarks, " the unit is busier now than it has been for months. You will have countless opportunities for learning lots tomorrow." I am excited about this and sleep very little during the night, wondering what will I face.

I enter the nursing unit and find a quiet subdued environment. The lights are still dim and no one is at the nurse's station. It's 6:50 AM and not one person is at the desk. Usually at this time, nurses are deep into their charts, completing the narratives of their shifts, as well as all the other facts and details pertinent to their patient's care. The desk is full of charts, and the trolley carts which nurses use to carry supplies from room to room appears full of supplies, not neatly piled but in disarray. It seems that the nurses have experienced a busy night. They are no where near ready to go home. What does this mean?

The report room is also quiet, but for a different reason. There are four nurses already present in the room, preparing for their day to begin. Ruth, whom I will be shadowing today, is present and she greets me, offering me a chair. She remarks that she is here early today "to get a head start. If today is anything like yesterday, I will need all the help I can get." The nurses are busy writing up their 'nursing sheets,' a sheet where they will record pertinent details on each patient as the day unfolds. How important is it to have this nursing sheet? I note that each nurse creates her sheet in a unique manner. I watch some nurses fold their sheets in half, and create templates where they will record certain data they know to be important. I watch Ruth pull data from the kardex, and from the patient's record. She is ready to take in all she can about the patients since she has seen them last. Ruth is ready to 'nurse.'

Ruth has four patients. Three of these patients are *"supportive care"* only, the legal way physicians tended to write a *"no code"* order. This formal language is used on the kardex, and in the chart, however nurses tend to use the word *palliative* more. Ruth told me. "Perhaps, this is because comforting and nurturing are more a part of our role than others. We feel good about comforting others."

Ruth's patients were in rooms 1, 2 and 4; rooms 1 and 2 are semiprivate rooms and room 4, a private room. Ruth also had one empty bed, which she anticipated would "not be empty for long." From Ruth's 'nursing sheet' and from report, I felt I had learned a lot about each patient. I knew however that in reality I knew very little. Although Ruth had cared for each one of these patients the day before, she comments on the importance of taking in all the data you can, as "things change quickly around here, and I never take anything for granted."

During report, the night nurse revealed her judgements and comments on her assessments of how patients are doing. This report uses many language forms. Lab values, detailed physical assessments, as well as the human interactions between nurse and family, nurse and patient. Understanding the complexity of these experiences is important to nursing practices. The night nurse knows that each word is important, and yet 'one word' can mean a whole lot of things, making a very complex experience vividly clear. "He's *stable* for now, the night nurse reports but I'm not sure how long he can *rally*, the *chemo* is killing him." Nurses consumed a multitude of data specific to each patient. How do they take in all this data for each patient and keep it straight I wonder?

Stepping into Nursing Practice with Ruth

Before we leave the report room Ruth goes over her patients with me. She shares their diagnoses, their relative status, the nursing care they will need, and her priorities for the morning. Ruth knows that to be organized is key if she is to "keep her head above water." Having an empty bed means there's the likelihood of an admission so she wants to keep her day as organized as possible so she is ready for this probable admission.

We then check the doctor's order sheet on each patient for "something new," but the physicians have not been in to write orders yet. At this moment, things are quiet. Ruth explains that although the morning is busy with tasks, "sometimes you are able to devote quality time to being with patients with the curtain drawn. Giving the patient a bath allows you to focus on them only. Although registered nurses have allowed nurses aides to take over this work, I still continue to do some of this work myself. I consider it an important aspect of being with the patient." As we leave the desk area, I sense that this quiet will leave us. We embark on what awaits us.

Ruth introduces me to her patients as a "nurse researcher who is studying about nurses on this unit and their experience of caring for patients." I am impressed that she asks each patient "do you mind if she is with me as I care for you today? She will explain her study for you later in more detail." I asked her later how she decided to introduce me in this way. She replied:

> Patient's deserve respect and have a right to know who you are, and your role for being with me. I read in your papers that you gave that you would be obtaining consent from the patients. Many of these individuals are too ill for a lengthy explanation from me. I knew that you would explain the study to them. I also want them to feel comfortable knowing that you are a nurse, and that you were not a new student learning the ropes. They need to understand that you are not green that you have knowledge, and are there with the purpose of gaining knowledge that may improve their care.

It was clear to me that she felt comfortable having me there in my role as a researcher and that my purpose for being there was important to her as well. Ruth was making a way for me helping me, to "gain entry" into a new place, to negotiate my role, and making me feel comfortable in my role. I knew that there might be nurses who are not as comfortable with a stranger, especially a researcher who normally is a "faculty member," and who is not always in practice at the bedside. As the study progressed and the nurses learned of my background, they recognized that I know how to "nurse." Somehow that made a difference to them. It was to be my saving grace.

Ruth initially visits each patient, inquires how they spent their night, provides necessary care at that moment, and plans with them their nursing care and treatment for the day. Ruth and I enter the room of Agnes, the first patient we greet that morning. Ruth knows Agnes well as she has cared for her over the past week

Agnes. Agnes, ninety-four years old, was admitted ten days earlier with dehydration and abdominal pain. Agnes also has cancer of the lung that was diagnosed two years earlier. From the chart I find that Agnes had the flu one month ago and periodically since then she has experienced nausea and vomiting. Over this period, Agnes has not tolerated solid foods. The physician and nurses are concerned that Agnes is much weaker and seems unable to meet basic needs of nutrition. Four days ago a palliative care consult was initiated and Agnes was placed on the waiting list for a hospice bed.

This morning Agnes is very sleepy, her sleep was interrupted several times because of the nausea, and now she is experiencing abdominal pain. Ruth's assessment suggests that nausea and abdominal pain are the major priority at this moment. She notes that Agnes does not appear comfortable and that instead of attempting to eat breakfast another hour of rest would likely be in her best interest. Ruth turns her pillow over and straightens the draw sheet underneath her. After feeling and listening to her abdomen with the stethoscope she covers her tightly and places a fresh cold washcloth on her forehead. She reattaches her call bell and plans to leave to get her some medication for pain and nausea. Before leaving, Ruth assures Agnes that she will be back with the medication. Making sure that Agnes is comfortable is Ruth's priority.

Freda. In the bed next to Agnes is Freda. Freda is eighty-five years old and is waiting for placement in a long-term care facility. I note on my 'nursing sheet' that Freda is not a "supportive care" only patient. Freda was admitted one week earlier with congestive heart failure and urinary tract infection. Freda is sleeping soundly, and because she is deaf, she hears very little without the aid of a hearing device. Ruth is careful not to disturb her as she gently lifts the covers to inspect the edema in Freda's legs and feet. Ruth explained that the swelling has decreased remarkably since Freda received intravenous Lasix. Ruth looks to me to ensure that I know the drug. I nod as she is talking and she continues. Freda has a foley catheter which Ruth checks, and a saline lock for her intravenous Lasix medication. Ruth explained that Freda requires 'total care' and that her family cannot manage her needs at home any longer. She tells me that today much of her physical care will be done by the nurse's aide. I note however that Ruth takes an active part in making sure Freda is comfortable. I marvel at Ruth's ability to carry out an assessment without waking the patient.

As we leave the room Ruth reminds me that she needs to get Agnes something for pain and nausea. Ruth however stops at the next room, to meet her next patient. Making an initial assessment of each individual is important to her because "it helps me to establish priorities. I want to know how each one of them are doing first thing."

Rebecca. As we enter Rebecca's room she is awake and alert. She greets Ruth with a smile and she reaches her hand out to encourage Ruth to come to her. Rebecca is seventy-three years old. She was admitted to the unit a few weeks earlier. When Ruth and I reviewed the charts prior to visiting each patient, Ruth discussed that 'palliative care,' does not mean immanent dying. Rebecca is a prime example, having suffered many reoccurrences of cancer, several treatments and different cancer therapies over the last five years. Rebecca began with cervical cancer, had radiation treatment, a short remission, more therapy, and then a remission for a few additional years. Rebecca has come back now to receive more radiation treatment, but this time she is weaker and unable to care for herself. She is now waiting placement for the palliative care unit in a nearby long-term care facility.

These last couple of days have been difficult for Rebecca, as she has experienced burning, frequency, and pain on voiding. The physician suspected a urinary tract infection, and she is being treated with antibiotics. In the last few days her symptoms have been especially severe and this morning is no exception. Ruth assesses Rebecca's level of pain and inquires about her voiding patterns, and the amount of fluids she is drinking. Ruth's knowledge of "radiation cystitis" helped to direct her questioning. Together Ruth & Rebecca discuss the need to make her more comfortable, and Ruth tells Rebecca what her vital signs are as she does them. She checks her intravenous site, the amount of fluid in the continuous infusion and the medication bag hanging. The infusion at 125cc/hour does not help the urinary frequency Rebecca is experiencing, but this IV is necessary as she is not drinking well. Ruth asks to look at Rebecca's perineum. The worried look on Ruth's face connects with the pain that Rebecca is experiencing as a result of radiation treatment. Together they agreed that a foley catheter might enhance Rebecca's comfort, while healing her scarred and red urethra and vulva begins to occur. In the meantime, "more pain medication is warranted to take the edge off the pain" Rebecca agreed. Rebecca was at the centre of planning. There was a shared approach to planning care. Rebecca processed it all, and Ruth engulfed it all. Both were concerned about Rebecca's comfort.

Ken. The final patient visited, only because of room sequence, was Ken. Ken was resting soundly. He did not arouse, or open his eyes when Ruth came into the room. Ken was seventy-six, and had been present on the unit for close to a month now. Ken has abdominal cancer and newly diagnosed ***hepatocellular*** cancer. Upon admission, Ken was very jaundiced and had an ilieus. He experienced severe abdominal pain which was not controlled and, thus, was started on a pain medication regimen. His pain seemed to be under control although Ruth noted that this last week he had become very drowsy and his pain would escalate to a point where nothing could relieve it. Then he was restless and very agitated. Ruth assessed that he had been over sedated and notified the physician who immediately ordered all narcotic sedation to be stopped. Ruth's knowledge of narcotic sensitivities helped Ken to recover. Yesterday, she remarked was "the most alert he has been for days."

Ruth touched his shoulder. Ken opened his eyes and sighed when he saw Ruth. She checked his intravenous and asked if he was experiencing any pain. She felt his abdomen and watched his facial expressions. Ruth knew that Ken was reluctant to share his discomfort with others. At this time, Ken denied any pain and he appeared to be symptom free at rest. Ruth spoke with Ken about being up more today, and perhaps trying some solid food for breakfast. Ruth sensed that Ken was anxious and she assured him that they could plan his activities one step at a time. Ruth was paged to the desk and she left quickly, promising to be back soon. Ken closed his eyes and I left the room.

As I approach the desk, Ruth is taking a phone call from Rebecca's husband who is inquiring about how she is doing. She then prepares morning medications and pain medication for Agnes. As all of her patients are elderly, they each have a multitude of medications. As well, palliative care patients may be on preventative medications to counteract the side effects from high doses of opioid analgesics, the nausea that occurs from the cancer disease process, and cancer therapies such as chemotherapy and radiation.

While Ruth prepares the medications she is interrupted several times by phone calls, one is from the diet kitchen inquiring about Agnes's diet, another is from the pharmacy, and another is a nurse who needs help to turn a patient. After administering morning medications to each patient, she prepares the patients for breakfast. She pays particular attention to both Agnes and Ken who have recently been experiencing difficulties with maintaining adequate nutrition.

Ken, having experienced opioid toxicity, required parenteral hydration, as he was too drowsy to take oral fluids. Preventing dehydration and the potential for further complications of delirium was important. Ken was re-hydrated with an intravenous solution of normal saline, at 100cc/hour. Today, he is alert enough to begin to take oral fluids. Ruth will have to assess, over the next day or so, how much oral fluids he can tolerate in order to begin the process of decreasing and eventually discontinuing intravenous fluids. In addition, she will monitor Ken's urine output, blood pressure and mental status.

Agnes's nutritional status is of extreme concern to Ruth. The nausea and vomiting has persisted and is only temporarily relieved by medication. Agnes has only managed very little (less than 300cc's of fluid per shift) in the last few days. Intravenous therapy is not an option for Agnes if she is to be transferred to Hospice. Presently the team is considering ***hypodermoclysis*** for administration of anti- nausea drugs and possible hydration instead of the injections that she is presently receiving. At this point the multidisciplinary team agrees that they should continue to hydrate Agnes.

Coffee Break

I have several questions to ask Ruth but I know that coffee break is a time for Ruth to connect with her co-workers and happenings outside of work. These nurses lead busy family lives and feel the stresses that prevail with shift work. They struggle with trying to find time to plan social events with one another. Being a particularly close unit, their times together are important outlets which give them satisfaction and strength in their work.

Ruth introduces me to those individuals whom I have not formally met, and explains to them why I am with her today. Without hesitation they are interested in learning what the study is about and how I can see it benefiting nursing practice. They are pleased that at least the voices of nurses will be heard, but are sceptical that it will truly make a difference to nursing practice. They look forward to hearing the results when it is done. Coffee proceeds with discussion of happenings on the unit and life in general. Ruth looks at her watch. It's time to go back.

The Bathing Routine

On our return to the ward, it is time to provide undivided time and attention to our patients as we engage in a bathing routine. The type and extent of the routine is different for each individual depending on the patient's needs, energy, and desires. The bath is important for both patient and nurse. A bath contains certain outward gestures on the part of the nurse, gestures that can be replicated, gestures that carry with them therapy and health giving actions. Yet through these actions bathing reveals an inwardness, and the immediacy of human touch. Caring, respect, dignity, and devotion can all be felt by the patient through her/his touch. The nurse gathers information through her hands, eyes, nose, ears, and a third ear that listens for what is not said, the body sounds not heard, and absences in the conversations. During the bath the nurse processes and forms judgements about the needs of her patient.

Ruth explains that in order to devote her time and her presence to the patient in a meaningful way, she shares her baths with the nurses aide, one day being with one patient the next with the other.

> I cannot give myself fully to a patient if I am rushed. It's not the task itself that is important, it is the direct contact, the relation, and the ability to judge and make a full assessment. If it is done with care, patients usually relax, open up, and allow you to enter into their world. If it is rushed, it may as well be just for the sake of checking it off your list.

Through her initial assessment this morning, Ruth decided that "we will bathe Agnes and Rebecca today."

Rebecca's Bath. Rebecca is presently receiving external radiation treatment for recurrence of cancer of the cervix and vulva. The area on her upper pelvis and lower abdomen is marked. This area cannot be immersed in water or washed with soap. While soaking in a tub would likely be the most soothing and would afford the highest degree of cleanliness, it is not possible.

Rebecca is also very weak. The measurement of oxygen saturation in the blood is an important physiologic measure in determining the overall physiologic status of an individual. Earlier Ruth measured Rebecca's oxygen saturation level at 89%. With exertion, her levels have been known to drop to as low as 84%. Bodily exertion of moving to a tub or shower may be too strenuous a demand for Rebecca. At present Ruth recognizes that the energy Rebecca can expend is minimal, thus her bath must be a passive one.

Ruth decides that a bed bath is the safest for Rebecca. To cleanse her perineum without washing away the radiation markings, Ruth decides to apply luke-warm moist compresses to the perineal area that she will leave in place for much of the bath. The marked site where external beam radiation is performed has developed a skin condition that has progressed from dry desquamation (where the skin becomes dry, itchy and flaky) to moist desquamation (where the skin has begun to peel and become painful and weepy).

I watch Ruth as she begins to wash Rebecca. She is efficient but not rushed. She encourages Rebecca to wash her own face, offering the cloth to her several times as the warm water on her face makes her refreshed and offers a healthy glow to her pale, ashen looking skin. Ruth then washes Rebecca's legs and feet with slow relaxing strokes towards her heart. Rebecca's eyes close and her breathing is deep. Ruth carefully assists Rebecca on to her side where she washes her back and buttocks. After drying and applying lotion she turns Rebecca again on to her back. At this time she changes her bath water and cloth. She now begins to focus on Rebecca's lower abdomen and perineum, the area most painful and tender. To this point Rebecca has been calm, relaxed and serene. To maintain this calmness Ruth must also remain calm, approaching Rebecca in a caring gentle manner. I watch her begin squeezing water from the cloth onto Rebecca's abdomen, not rubbing with the cloth to remove the markings. She squeezes the tepid water allowing the air to dry most of the water, finishing with gentle patting with a soft towel. The area remains red and weepy.

The act of bathing for Ruth is "nursing in its finest form." Ruth is present, committed and absorbed. This is not a routine task to be done, but an act that is caring and requires skill and judgement. Ruth enacts her skill in a way that drew me to be with them. The pain I expected Rebecca to experience did not occur. I witnessed and felt a serene flow of caring in this bathing. There were no mechanistic actions. The bathing was a work of art, a caring for Rebecca that enhanced her dignity. I watched Ruth's absorption as she artfully carried out each action, attending to Rebecca's body, knowing the areas that may be sensitive or painful. Rebecca's body is familiar to Ruth. There is an immediacy to this act of nursing.

Agnes' Bath. The nursing act of bathing Agnes is also enacted with care, skill, and judgement. The knowledge and skill required to bathe Agnes is not as complex as bathing Rebecca. Agnes will be bathed in a whirlpool tub. Sitting on a bath chair she will be simply lowered into the tub. Agnes can participate in her bath, having the ability to bathe the upper portion of her body. What is important to Ruth is that her presence with Agnes will allow her the opportunity to talk to Agnes about her next transition to a hospice facility. Although Ruth was present at the time when the physician explained his thoughts on relocating Agnes to Hospice, Ruth had not had the opportunity to hear Agnes' feelings and thoughts about this transition.

Ruth has prepared the bath and Agnes is lowered into the tub. Agnes is clutching a basin as she continues to feel nauseous. Looking into Agnes's eyes, Ruth gently lifts the basin from her hands. "I'll keep it right here," she says, "if you need it let me know." Agnes hesitantly allows Ruth to move the basin close by where she can see it. Not rushing, Ruth allows her to soak in the tub. She stands and faces Agnes and asks, "do you have a sense of what has been planned for you in the next little while Agnes?" I noticed that Ruth used the words "planned for" and wondered if this wording was used deliberately. Was this Ruth's belief that Agnes was involved very little in the planning? Agnes replied, and their conversation was open and honest revealing important feelings and emotions.

> I know that I am going elsewhere for the rest of my life. I know that it is not home and it saddens me. I'm too old and too weak to argue. I guess I can only hope that it is a place where I am wanted and that they will take good care of me. I have to trust my family. I hope that they will not let me down. Ruth replied by saying; "I know that this move cannot be easy for you. I want you to know that you do have a say on how the move should go, what your needs and wishes are when you do move. Your nurses here

at the hospital will help you to voice those concerns to the doctor. We are here for you."

Agnes smiled but did not speak.

The experience of this bath was much more than the actions to cleanse in a physical bodily sense. Ruth's care and relation through the act of bathing helped Agnes to express her feelings and voice the emotion she faces in this transition. Ruth's presence was a way of symbolizing her care and concern for Agnes as a person. The act of bathing was a medium for this understanding to unfold.

After the bathing was complete Ruth and I had a chance to sit down for the purpose of charting. The events of the morning were rolling in my head. I had so many questions but I asked Ruth about the kinds of knowledge that she needed to be a nurse on this unit. Other nurses joined the conversation. As the conversation continues, it is evident that knowledge on this unit is far more than facts and textbook knowledge. I have witnessed and nurses have spoken about knowledge in many forms. As a nurse and an academic, what instantly comes to mind is Carper's (1978) *Ways of Knowing*. The following is a compilation of many experiences with nurses on this unit enacting "nurses ways of knowing."

Ways of Knowing

Nursing is both a science and an art. Ruth's act of bathing certainly showed this. The bath involves specific knowledge of the body and its systems, as well as knowledge of complex technologies and procedures to ensure the safety of patients. It also involves a sophisticated understanding of human relationships and behaviours, how to attain information from patients, and one's understanding of the patient as a whole person. How a nurse creates the balance of the science and the art is influenced by the nurse's values and beliefs, and she must recognise these as the impetus for developing a philosophy for the pursuit of good nursing care.

The seminal work of Carper (1978) identified four patterns of knowing held to be most valuable in the discipline of nursing: empirics, aesthetics, personal knowledge in nursing, and ethics, moral knowledge in nursing. The interconnectedness of these patterns was uncovered in my shadowing of Ruth on this day as she and other nurses strive to know a 'good death'. These patterns, as I describe each one separately, serves only to illuminate the importance of all knowledge used by these nurses.

Empirical Knowledge

Empirical knowledge is empirical, factual, descriptive, and helps the nurse to identify the patterns of behaviour associated with normal and critical events, principles and laws governing life status and processes. Empirical knowledge of the dying process is of utmost importance when creating possibilities of a 'good death'. This knowledge assists the nurse in identifying and addressing factors contributing to pain and suffering in the dying individual and the family. The nurse in palliative care requires special knowledge to alleviate discomfort from a multitude of symptoms including, pain, nausea, vomiting, dyspnea, fatigue, and constipation, only to name a few. Empirical data can help the nurse identify the cause of the symptom, measure the quality and intensity of the symptom, and recognise and assess the multi-dimensional aspects of the symptom. In essence, empirical data cues the nurse about presentation, causes, and approaches, to and interventions for preventing further symptoms or controlling present symptoms. Ruth's knowledge of the symptoms and ability to assess for radiation cystitis is a prime example.

Most importantly, this type of knowledge allows the nurse a good sense of the dying process, offering both descriptive and prescriptive knowledge.

Particulars of a situation obtained from empirical data is a part of clinical expertise related to recognizing patterns of the illness, including the pace and expected events which may occur during the dying process. The nurse is able to read the signs of changes taking place. These signs cue the nurse to predict future events. Predicting future events prepares the patient and family, reduces anxiety, and fosters a sense of wholeness and serenity for both patients and families. Empirical knowing is essential at this time in the dying process.

I observed this knowledge of empirics and commitment to a 'good death', as I shadowed *Nurse Barbara*. Barbara was caring for Willy, an 86 year-old lady who was in the final stages of dying. I learned from report that Willy had a restless night because of her laboured respirations. Barbara explained that Willy was "hypoxic" from consolidated lungs. Upon entering the room, we noted that Willy was positioned in high fowlers, 0_2 on @4 litres via nasal prongs. She was experiencing air hunger, laboured breathing, and apneic spells lasting 15-20 seconds. Barbara immediately suctioned Willy, repositioned her higher, suctioned again, initiated humidity, suctioned again, repositioned, and vigorously pounded on Willy's back to release the secretion. Finally, she suctioned a mucous plug. These actions were completed in rapid succession with little deliberation. Without words, Barbara picked up on my look of bewilderment. She explained that normally she would not be so "aggressive", however in this situation she felt it was only fair that Willy's husband be updated of her condition. In other words, Willy was "saved" to allow more time for her husband to be present at this critical time. Barbara felt uncomfortable, not knowing how much Willy's husband knew of her changed status overnight. Her empirical knowledge of the dying process that guided her actions and her commitment to both Willy and her family was evident.

Dying in the presence of loved ones, family, and/or others is a ritual that is not taken lightly on this unit. Standard practice, whenever possible, is that "no one dies alone." From their experiences of families not present at the death of their loved ones, *Nurse Darlene* gained the belief that:

> Some families need to be there and some do not. It's kind of important to know what they want, what they can do, and what they can handle. I will often say to families, it's a practice on this unit if your mother/father takes a turn, and that we feel the end is near, it is our practice to call and let you know.

Their empirical knowledge of the dying trajectory helps them to develop practices and standards of care.

Moral Knowledge

Moral knowledge in this study is foundational to who the nurse is, and how she relates to others. It is the ethical component focusing on "what ought to be done" based on the primary principle of obligation, embodied in the concepts of service to people and respect for human life. Moral knowing is enacted, and the nurse discovers this knowledge in her relationship between the patient, family, and others involved. Discovering the "good" is embedded in the relationship with others. Nurses in this study respected, and allowed individuals to make their own decisions. They enacted relational practices such as sensitivity to timing, listening, and attending to the context of the situation. The knowledge needed to 'do the right thing' is not only known by philosophical positions or principles but must be discovered in understanding persons, both self and other. It is relational knowledge. *Nurse Nancy* stated:

> Nurses are able to sense when dying individuals and their families want to talk about intimate, personal issues. I don't go in with an agenda. I let them lead the way. I'll ask them, you know, 'How are you doing emotionally?' 'What's it like?' 'How are you holding up?' It has to be the right moment for them to talk on a deeper level, to actually talk about what their experience means. It's these types of conversations that help us really to know what the 'right thing' for them is.

To understand the dying journey, nurses gather knowledge that is constructed through understanding the person. Nurses rely on the perspective of the "other," this perspective places the condition (disease) within the individual's framework of meaning. The experience of the 'disease' is lived by that person, and the data comes from within, rather than analyzed from without by the nurse. Knowledge for ethical care then is found in that particular experience at that particular time. Nurses value these moments, as an integral part of the nurse/dying individual's relationship. These moments involve mutual respect, engagement, mutual thinking, embodiment, uncertainty, vulnerability, and freedom (Bergum & Dossetor, 2002).

In this relationship, ethical knowing is often equated with beneficence, to doing what is good in a particular situation. Nurses in this study adopted a caring orientation, a moral ideal through situated engagement. Decisions were made and actions carried out through collaboration with all members involved. An effort was made to help dying individuals and their families become clear about their wishes, by helping them discern what they valued and what they imagined their dying experience would be.

Situated engagement was portrayed as I shadowed *Nurse Nancy*, as she cared for Mr. K., who had been admitted three weeks earlier with cancer of the colon and metastasis to the liver and lung. Mr. K was admitted to palliative care because his wife (who was legally blind) could no longer care for him. At this time, Mr. K. was grappling with the issue of where he should be to die. The palliative care team was preparing for Mr. K to go to a long-term care facility. Mr. K, however, was wishing to return home with his wife. There were many internal family issues that would not favor a decision for Mr. K to return home. The moral dilemma of what was best for Mr. K was arising, as Mr. K's wishes to go home were not favored by his wife, or his wife's sons, who were not willing to assume a supportive role. His alternate wish was to remain in hospital. Financially, however, this was not feasible.

As the context is unveiled, I watched Nancy apply her expertise of questioning and facilitating dialogue to fully understand Mr. K's experience. I noticed that she spent long periods allowing Mr. K to reminisce about his past. Nancy stated:

> You can tell when patients desire your attention, they keep talking even when you are busy doing other things. This is a clear message that they have something on their mind. This message tells me that a deeper sense of personal meaning for this experience is being sought out. This personal meaning is a story waiting to be told.

For Mr. K, talking about the past, increased his ability to cope in the present. Reminiscence that validates personal sources of meaning, capabilities, and strengths may lead to enhanced self esteem. Reminiscence, for Mr. K, may have been a positive process in the context of another difficult life experience, a general way of coping with losses. Reliving past memories opens a space to work through losses, subordinating unpleasant thoughts, and re-establishing a more secure self-identity based on past experiences. Reminiscence also helped him to relinquish the past to some extent as he adjusted to the reality of loss.

The action orientation of ethical knowing for *Nancy* is related to her moral obligation to Mr. K. Nancy, in her commitment to doing what is good for Mr. K, uncovered his values and wishes. Through situated engagement a decision was made. Mr. K agreed that, for his family, and his wellbeing, a long- term care facility would be best. Nancy helped him to make this decision.

Aesthetic Knowledge

Aesthetic knowing is essential knowledge that adds to the understanding of the dying journey for individuals and their families. It is the conscious molding of the raw experiences of life into something that is important, meaningful, and has the potential of enlightening us in some way. Artful practices and rituals in dying on this unit can be viewed as art forms. Although what is under our control seems often very little in the dying journey, the parts of experiences over which we do have control can be judged and I would contend are often judged for their aesthetic qualities.

As a form of knowledge, aesthetics is knowledge related to artful nursing practice, how the nurse is in this situation. Aesthetic knowledge is only comprehensible when context of the situation is understood. The nurse is able to perceive and envision what the patient needs, and creatively transform this knowledge into a sense of significant relationships and wholes. In shadowing *Nurse Barbara*, I felt that in her many experiences of caring for dying individuals she embraced aesthetic knowledge that was difficult to explain.

I asked myself why she was able to sense the 'right time' to call Willy's husband. She had not looked after Willy for quite some time. How did she know differently from the nurses on night shift to call when Willy's situation had not significantly changed since that time. Barbara, for some reason, attached significance to Willy's breathing pattern and the look on her face as a sign of impending death. Although the outward physical assessment signs of Willy's breathing had not changed dramatically (for example; respiration rate was similar, the quality remained labored but was not worse), Barbara detected a change in Willy's demeanor; she described seeing Willy's eyes as 'accepting,' she seemed less restless, and more at peace. This perceptive ability of Barbara has been honed and developed over many years of palliative care experience. Although she could not explain to me why she "knew to call", she commented that over the years she did learn to attend to and trust her inner experiences.

Aesthetics requires engagement in the moment. Through the process of engagement, interpreting, and years of nursing experience, she creatively acted in a way she envisioned to be 'good' for Willy and her family. This perceptual sensitivity in the moment, revealed her actions of calling Willy's husband, and will likely affect how she perceives meaning in successive situations.

Ruth's aesthetic acts of bathing Agnes conveyed her concern for Agnes's feelings about her transition to hospice. Presence and compassion are seen to be important modes in the aesthetic pattern of knowing. The expressive and creative and empathetic perception of Agnes's situation however, would not have been transformed into a sense of the whole, without referring to personal knowing.

Personal Knowledge

So much about palliative care is about creating a personal journey in concert with dying individuals and their families. Nurses on the unit creatively orchestrated and learned the rhythm of each personal journey they encountered. What is aesthetically pleasing to one dying individual and family certainly may not be pleasing to another.

Personal knowing involves knowing of the self in relation to another human being, and the ability of the nurse to engage with that human being as a person. *Nurse Beverly* told me in one of our interviews that:

> Caring doesn't come naturally. Some people do it better than others. I feel that it's a gift, and people give these gifts in different ways. Usually it comes from knowing one's self, from within, for the love of someone. It's that wanting to know them as a person.

Beverly's statement suggests that in knowing the self, the nurse can authentically respond to another. In sharing in the relationship with a dying individual, the nurse engages in the relationship as it unfolds. The expressive dimension is the self as authentic (privately known) and disclosed (revealed to others) in relationship. Beverly spoke of how moment to moment "knowing the patient" is how self is revealed.

> Being with a dying person is not always easy. There are times when you just have to be there, and just listen. You don't have to say anything. You don't have to do anything. Sometimes people like touch. Sometimes they don't. It doesn't have to be holding hands. It can be something as simple as

> a rub. You know, if they're looking tense a little neck rub or back rub helps. You don't have to say, 'Can I rub your back?' It just sort of happens in the moment. It's not a planned thing I guess is what I'm saying. You just know when it's right.

It is evident that all types of knowing (empirics, moral, aesthetics and personal knowledge) are necessary in the practice of these nurses. Important aspects of these nurses' being, in caring for the dying individual are knowing oneself, the patient, and the particulars of the dying individuals experience. It is all these ways of knowing that promote wholeness and integrity in caring for dying individuals. With experience, nurses develop knowledge about the dying process, and feel competent in their ways of doing, as they pursue a 'good death.'

Ways of Doing

Nurses perform the 'doing' of palliative care with the ultimate goal of a peaceful death, helping to create and maintain wholeness and serenity in the dying journey. To meet the goal of wholeness and serenity, nurses in this study supported the dying individual and their families in focusing on living. Many nurses told me that their goal centered on whom that person was in their life, helping them to die peacefully, but also to live until they die. Focusing on living paved the way to pursuing a 'good death'. Nursing practices of creating a safe and trusting environment, alleviating difficult symptoms, facilitating grief, searching for meaning, and fostering hope for a peaceful death are shared by nurses, patients, and families.

Martha's Journey. About 10 minutes prior to our scheduled time for lunch, Ruth and I got a call about the new admission. "Apparently she is on her way from another hospital outside the city and will be arriving to the unit within the hour," the unit clerk informs us. We learn little about the patient except that she is "palliative." The timing of the admission is "typical." "What to do about lunch? If we leave and take our allotted time she will arrive. If we wait and begin the admission process when we get back, we will never leave on time." Ruth decides that we will eat our lunch in the room just off the unit. We will see the ambulance transport team when they arrive and be able to be back quickly.

Creating a Safe and Trusting Environment

Caring for dying individuals may mean being in the midst of life's most existential experiences. The journey, often uncertain, is created by a tension between "ideal" and "real" nursing practice. It means pursuing all that is good, harmonious, and beneficial in life and death, and opening up oneself, especially if unanticipated, to the foul, dissonant, and meaningless nature of that same life and death. It is in these experiences where nurses struggle to maintain and build a trusting relationship with dying individuals and their families.

Martha arrived on the unit just shortly after we finished our lunch. We greeted her at the elevators and walked back to the unit in tandem. One did not have to ask any questions of Martha to know that she was not well, that she was placing her trust and faith in Ruth and others on the unit to "do good." Martha was pale, the color of dry wall paste. As we moved her from stretcher to bed, I felt her warm damp skin. Moving caused her to become very short of breath and she shivered as we uncovered her body. She was literally bruised from head to toe. Ruth and I glanced at each other. I could feel my breath in my throat, my heart quickening. Ruth and the paramedics were especially gentle upon lifting Martha the rest of the way from stretcher to bed. Martha was weak; added exertion would not be beneficial to Martha. We covered her and raised the head of her bed, making sure she was relatively comfortable before moving outside the room to receive report from the paramedics.

Report was brief. Martha traveled "in a stable condition, was 'palliative,' and her husband was soon to arrive in his car." The paramedics went back into the room to wish Martha well. Before returning to the room Ruth perused her chart. "Oh my gosh" she exclaimed as she reported her platelets to be "7." Reading further, we found that she was receiving chemotherapy and radiation treatments initiated only a few weeks earlier. "She's immunocompromised and we have placed her in a semi-private room. Why were we not made aware of this prior to her coming?" Ruth, without delay, asked the unit clerk to put a call in to the physician. Ruth was beginning to create a safe and trusting environment for Martha. I asked Ruth to tell me how she was feeling.

> When you are caring for a dying individual you really put pressure on yourself to do the best you can for that person. With palliative patients you always have in the back of your mind, the fact that there are not going to be many more tomorrows. You know that you are not going to have many opportunities to go back and give the kind of care you really wanted to. The peaceful endings, yes, you have them in your memories, but the ones that come back to haunt you are left with feelings of guilt and despair. You are always on your guard to do the best you can.

On return to Martha's room we greeted her husband as we entered the room. Upon shaking hands and acknowledging his presence, I sensed that John (Martha's husband) was very concerned and worried for his wife's safety. He quickly stated, "we were just discharged from this hospital two days ago and here we are back again. We should have never been discharged." I could sense his frustration, anxiety, and loss of trust in the health care team. Ruth sensed this as well, so she conveyed that her plan in the next little while was to ensure Martha's comfort. She explained the admission procedure and assured John that Martha's comfort was primary. If she was not up to answering questions at this time, only pertinent questions would be asked now. Ruth also assured John that the doctor had been contacted of Martha's arrival to the unit and she will be informing him of Martha's condition.

It is evident that creating a safe and trusting environment is foundational to pursuing a 'good death.' The dying individual and family must sense that safety and trust are inherent in their relationship with the nurse before nursing care can be perceived as meaningful. Later in a private conversation Ruth expressed the following to me:

> The big thing is trust. I would tell my patients, I'm right here if you need me. Just call. I'll be checking on you every little while. They knew that I was going to be there and that made all the difference. Trust is an important part of the relationship, because you can't be always there.

Moral agency in nursing is partially bound up with our willingness to promise and to hold ones self to promises made. Ruth communicates her commitment to being there for Martha and her husband. Verbalizing her commitment, and following through, fosters the trust in their relationship. Reassurance that there is always someone close by reduces anxiety and fosters trust.

> Respect means letting the patients know at all times who is in charge of their care. I will go back, before I leave and say I'm leaving. I always let them know the name of the nurse who's coming on after me. If I'm not coming back the next day I will tell them when I will be back, and that I will be thinking of them. I don't sever the relationship just because the shift is over. They need to know that they matter to me as a person, and that I care about them.

Ruth kept her promise to Martha and John that day. She completed the most important parts of the nursing history, took Martha's vital signs, and administered Morphine and Maxeran for Martha's pain and nausea. Less than half an hour later the physician came to examine Martha. Martha was transferred to a private room before we ended our shift.

Honesty and openness must also be practiced for trust to occur. I noticed that Ruth was open with John, providing him with any information that she knew about Martha's condition. I asked Ruth how she knew how much information to give families about their loved ones. She said that although it is impossible to know how much patients really want to know, patients and families will guide you, in how much information they will listen to at any given time. Nurses, she said "need to watch for nonverbal cues, as to the amount of information they take in."

Patients and families may choose to deny the reality of impending death. It is the nurse's duty however, to ensure that the information has been disclosed and is accessible to the patient at any time. The nurse is careful to balance hope with reality. Ruth stressed the importance of preparing the patient and family for what it might be like when death draws closer.

> One of the things that I find very important is to tell people what they can expect in the dying process. Most of the time, detail is what they need to put their mind at ease, especially the breathing, how it's sometimes noisy and awful for them to watch. If it's really distressing, we sometimes give the patient some medication but mostly, the family, they just need to know what to expect.

By being truthful, Ruth offered the family knowledge, comfort, and a sense of control to act in a way that they feel is appropriate for them. Awareness and acceptance or some reality of an impending death is imperative for a 'good death' to occur.

Comfort and Relief from Difficult Symptoms

One of the most common characteristics for a 'good death' discussed by the nurses on the unit is freedom of pain and difficult symptoms. *Nurse Helen* stated "given the resources and the philosophy on this unit, we don't like to see our patients in pain. We have a large pool of resources. There is always something that we can do to make it better." Nurses on the unit felt morally compelled to address pain and suffering and, to the best of their abilities, relieve it so that patients can regain some control over their bodies. If patients are severely distressed by symptoms, it will be difficult for them to concentrate on any other aspect of their journey. Nurses see a good death as one in which the dying individual is comfortable, alert, and pain free. Nurses have expertise in making this happen. *Nurse Muriel* expressed her beliefs about efforts to relieve pain and symptoms on the unit.

> On our unit, we have a lot of knowledge and experience in managing pain and symptoms. We are given a lot of latitude to properly assess and titrate analgesics until the patient is comfortable. Most nurses give everything they can within their limits to achieve comfort. Giving means more than pills though. It means hot baths, soothing music, and relaxing massage. It evens means putting on makeup to hide that gastly grey colour. Looking good fosters hope that feeling good may be just around the corner.

I observed Nurse Muriel bathing Frances, a dying individual, who was experiencing labored respiration's.

The bath was intended to comfort not only Frances, but also her husband who was soon coming to visit. Muriel was concerned that Frances was clean and comforted for her family to see. During the bath, care was taken to avoid causing added pain and suffering. Long smooth relaxing strokes were used. Frances' bed was not put flat, and she was not positioned in any way that would compromise her breathing. Muriel knew the position where Frances felt most comfortable and she took extra time and care to make sure that comfort was achieved. After the bath, she wrapped Frances in several warm blankets. Her calm focused attention to Frances was comforting in and of itself. Never did she give her the impression that her time schedule was tight, that she had four other patients waiting for her care. Muriel was able to give great comfort to Frances and her family from the aesthetic and empiric act of doing the bath. Muriel recognized that symptoms are complex and must be managed creatively. Addressing emotional and spiritual issues also needs to take top priority.

Rebecca's Pain. We entered Rebecca's room to find her clutched and curled up in pain. Rebecca has been waiting in need of pain medication. She is not one to ring her call bell. Instead she lays silent, the pain now consumes her. Ruth goes near to Rebecca's side she feels her pain. Ruth asks with sorrow in her voice "why did you not call me?" Rebecca replies, "I knew that you were busy and that you would come when you had time." Rebecca conveys her trust in Ruth, but Ruth knows that Rebecca's pain is immediate and all consuming. Ruth moves closer to assess Rebecca's abdomen. She feels, listens and kneads her abdomen like dough.

Ruth has an integral understanding of body knowledge. Rebecca describes the sharp pain as when she voids. She tells of her urinary frequency and burning, and says the pressure is great and not going away. Ruth asks, "how much do you void at one time?" "What does it look like?" "Is there blood present?" Ruth suspects that Rebecca may be experiencing "radiation cystitis." Without delay she leaves the room and quickly returns with pain medication. Ruth closes the blinds, places a cold cloth on her forehead and refills Rebecca's water jug. "It's important to drink as much as you can, but right now it's most important to rest and let the medication work." Immediately after leaving the room she puts a call in to the physician.

The palliative nurse is a facilitator for patients and families who are managing symptoms. The nurse must assess the strengths of the individual and family encouraging them to draw on resources that have worked in the past. She considers all aspects of the individual's pain experience, including physical, emotional, and spiritual needs. When necessary, she provides support for their limitations to enhance their ability to live through this difficult experience. *Ruth* speaks to me about the importance of support and encouragement in this experience.

> Sometimes I can sense an underlying force that is not permitting the medications or other interventions to work. There's an emotional, family, another physical reason, there's just something. There's just something blocking them either accepting treatment, or letting go. I usually try to find out what it is that's not right for them. Dying individuals are so sensitive, they sense others discomfort to their pain, and they hold on to this feeling, and they don't release their pain and suffering in front of others. I try and engage them in conversation, and let them know that if they are really willing, there is always something we can do to help.

Facilitating Grief and the Search for Meaning

It is a challenge to see into another persons' dying journey with real clarity and understanding. Yet, on this unit, I witnessed how nurses, accompanied individuals through their grief, and sought to understand and create knowledge related to the meaning of these experiences. The search for meaning is seamlessly woven into these nurses caring interactions with dying individuals. *Nurse Jennifer* reveals this experience:

> For me, I remember feeling this profound relationship with a dying individual that was both emotionally draining yet fulfilling. I didn't even know the man. It was the end of my shift and they asked me to be with him until his family or someone could come. He was at the end of his journey, bleeding profusely and there was nothing we could do to stop it. It was a horrible way to die and so just being there was all I could do. I'm

> not sure how aware of my presence he was, but he was seeing things that were not visible to me. I tried to focus on what it was he was seeing and I remember at one point he grabbed my hand and I could actually feel his fear. I don't think I moved a muscle the whole time I was there, I think I just sat and prayed, that what I was giving him was comforting and allowing some meaning, some sense of this horrible experience. I know I went away feeling like I made some difference. At one point his children came in, leaned over their father, and kissed him on the cheek. It was very upsetting to watch this because I was there at his side and I had to move away quickly, they wanted to rush in and rush out. Their visit was brief, just a few minutes, but that's all that they could be there for. They ran out of the room crying. That was very upsetting and so after they left, I knew for him, that I would stay.

In this situation, both the patient and the family are grieving losses that are past, present, and future. Individuals need to acknowledge their grief in ways that are most comfortable for them. Jennifer was present to encourage and give permission for the expression of feelings related to loss. This shared pain and vulnerability among all, helped to lift the heavy weight of grief. The significant relationship that she shared, and the meaning that the family took from this experience, allowed the possibility for understanding this man's suffering.

The impact, which nurses on this unit have on the dying individual's and family's grief experience is profound. The family may not remember the nurses' names, but they do remember the nurses' actions. *Nurses* in their stories revealed to me the "little things" that made a difference to the families' experience of grieving.

> One nurse took time to answer the questions of an elderly gentleman who didn't understand why his wife's feet were so blue and cold; one took a young man outside on a stretcher for one more breath of fresh air when he was having great difficulty breathing in his room; others prayed with the family until the chaplain came, gave gentle reminders of the path that laid ahead, or greeted the family member at the door to prepare them for how their mother looked that day. In another situation the nurse cried with the family when the moment of death finally arrived.

These are the nursing actions, the "little things" that families remember. When families return to the unit to visit, to say thanks for support, these are the moments that the nurses remember and cherish.

Nurses, in their interviews, talked about how palliative families, in their grieving journey, are often living "in limbo". The nurses' role is to help prepare the family for the separation that death will bring, and to assist them in maintaining a cohesive family unit in the present. While grieving losses is an important task on the palliative care journey, no one can tolerate an unrelenting encounter with loss. Nurses encourage patients and families to take a break from grieving. One practice nurses encourage to counterbalance grieving is creating memories.

Every person wants to feel significant and believe that they will be remembered when they pass from this world. Patients and families on the palliative care journey, are often reminded that life is short; nurses work at helping them to create memories that will last after the individual has died. *Nurse Helen* shared how she helped in creating these memories.

> I've encountered many similar instances where I have gone in the room and the family is sitting there not knowing what to say. I feel really good when I am able to say to families, You know, he knows you're here. He is able to hear your voice, and feel your touch and feel quite rested that you are here. I encourage them to talk about the past, about fond memories that they have had together. I tell them, its okay to laugh and to cry together, it's just okay. They just need your support and guidance.

Nurses on the unit also participate in helping to create memories, by suggesting ways that patients can leave reminders of their life behind or by providing assistance with fatiguing activities so that patients can conserve energy to spend on priorities that will leave a legacy. Celebrations and rituals are appropriate ways to create memories. Memories impart an understanding, an understanding that is shared. *Nurse Beverly* shared one way that dying individuals are remembered on the unit.

> Many families have donated monies to our bed fund. We purchased specialty beds for palliative patients on the unit. The dying individual's name is engraved on a plaque on the wall so their contribution is recognized. We encourage family to keep in touch. Some families choose to become volunteers on the unit, to help other dying individuals and families.

In observing and spending time on the unit I was reminded that a life threatening illness may provide an opportunity to view things differently, to alter priorities, to generate new ways of living, and to assign new meaning to the experience. I recorded in my fieldnotes that:

> Patients and families on the palliative journey tended to review their life and try to integrate their experiences, to make sense of what is happening to them. Dying individuals focussed on living and acknowledging death. Focusing on living involved helping the patients to make sense of their illness and prognosis; it also involves helping them to live until they die.

Acknowledging death however also means talking openly about death when patients and families want to do so and respecting those that choose to maintain control of their emotions and not to explore their feelings. *Nurse Nancy* remembers:

> I remember this client who we had for a long time. He refused to have anyone with him through the dying journey until near the very end. Finally he allowed us to call his family from far away and they were there for him when he died. There were in fact several of them. Even though the family was not able to reconcile their differences before this man died, we all felt good that somehow we were able to make a difference, even if it was not an outward obvious difference. The nurses were able to feel the patient's peace.

Fostering Hope for a Peaceful Death

Palliative patients and families need hope at every stage of their journey. As I shadowed Ruth, I watched how her presence, her gestures, and her ability to create a safe and trusting environment, instilled hope in the dying journey of the individuals she cared for. The immediacy of hope was enlivened as she cared for Rebecca.

Rebecca. Ruth had already prepared Rebecca both emotionally and mentally for the insertion of a foley catheter. Rebecca was aware that physically, the pain of inserting the catheter into the vagina and past the raw and tender vulva was unavoidable. Rebecca entrusted her very self, and body, to Ruth's knowledge and skill of inserting the catheter. Prior to, and during the procedure, Rebecca felt Ruth's support through her presence and her gaze of concern. Prior to beginning, Ruth spoke of the future, the potential for the relief of pain, a hope that Rebecca may have periods where pain does not consume her every thought, and her every move. Through calmed and deepened breathing Ruth helps Rebecca relax, and helps her to use the breathing to ease the pain, as Ruth slides the catheter into it's proper place. Tears flow from Rebecca's eyes. Ruth quickly attaches the catheter tubing, and moves away the sterile field. She holds Rebecca's hand, and breathes with her through the pain that lingers. Ruth speaks again, her words, "the worst of the pain is over" is comforting to Rebecca. In holding, and in silence, hope is instilled.

Hope, is also conveyed by our language, comforting, and encouraging words. *Nurse Nancy* demonstrated this in her conversation with Mr. K about being transferred to long term care to die.

> I can understand how moving to a long-term care facility at this point in your life might be difficult for you. You feel safe and comfortable here and have important values and beliefs that you cherish. Moving must only seem like we really are not considering what is best for you. Your needs are important to us, so lets consider some of the possibilities that may be open, and of benefit to you at this facility.

Conversations, such as these, acknowledge Mr. K as a person, consider his needs, and convey hope for future possibilities important to his life. I noticed that nurses on the unit speak of hope in connection with the past, present, and near future. When Ruth spoke with Agnes, she stressed the importance of living in the moment, and hoped for compassion, pain control, and not to be abandoned by those who would care for her. Nurses hope for an end to suffering.

Nurses on the unit help patients see possibilities. Nurse Muriel stated "you've got to have the belief that something good lies ahead. It is not denying reality. Realistic hope can help the dying person face reality, while it can also help them to go on living." Muriel suggested that a way of fostering hope is to encourage the expression of feelings and facilitate coping.

> It's the tiny little things that make a difference. It's sometimes the second that you took when you were at your wit's end, with many things happening, to hold somebody's hand, listen when they have a story to tell,

> or do something that you thought was ludicrous at the time, but you did it because you knew it was important to the person. That's what people remember and that's what it's all about.

The mutual goal of all who are a part of the palliative care journey is a peaceful death. From the discussions and observations, I have come to believe that peace on this unit is viewed as multi-dimensional, including freedom from distressing physical symptoms, mental security, and spiritual serenity. This holistic harmony in death is the goal of the palliative care journey. Patients and families move toward peace when they accept situations that cannot be changed, forgive themselves and others, experience a sense of connectedness and belonging, have a sense of perspective regarding themselves and life events, and trust in a power greater than themselves. Nurses practice with the belief that serenity can exist even in the presence of overwhelming circumstances. Their goal is that dying individuals are comfortable with self and others, and feel a loving presence.

Nursing Presence

As the patients and families work at the tasks that are part of the palliative care journey, on this unit, the nurse's presence supports and empowers them. Nurses on the unit are not overpowering, they allow families time and space to be with their loved ones. As described earlier by Ruth, nurses develop trust with patients and they know that their role is to be there for the patient as the possibilities of allowing the patient and families to make choices present themselves. A most demanding and deeply human aspect of caring is the expressive art of being fully present to another person. *Nurse Ruth* portrayed this in her act of bathing Agnes. She explained:

> One of the things that I really value in nursing is learning about people, knowing who they are as people. That's important in the relationships that you establish with patients in whatever kind of care that you are giving. I like to spend time with patients. It doesn't matter what you're doing, just to be there. Whether you're giving them a bath, doing their dressing or whatever, it's your presence, you're just there with them. I've learned through experience how to best use those moments. It's giving the most you've got during the time you're there. You learn how to really focus on them.

Ruth values true presence as unconditional loving in a non-routine way and of being with as she bears witness to changing health patterns of persons and families. The power of true presence is evident when persons and families express that they feel understood and supported. Observations with ***Ruth*** as she inserted a foley catheter revealed that true presence is not just caring, but a union of caring with a nurse's expertise. Nurses in their caring relationships, raise questions, draw on stories of experiential and theoretical knowledge, formulate hypotheses, and remain open to the situation from the patient's perspective.

Nurse Nancy shows the skilled role of nursing presence in caring for Mrs. D, who had undergone palliative surgery for biliary obstruction. Mrs. D, knowing that the surgery was not as successful as they had hoped, was asking Nancy what she could expect in the near future. In addressing this question, Nancy asked Mrs. D if she had any fears about the future, "fears that you will experience pain and suffering, and that this will be hard for you and your family." I sensed that this was a difficult question for her to ask. I noted that she moved in close, maintained eye contact, and touched Mrs. D several times. These types of questions explored Mrs. D's evolving personal meaning. Nancy used presence and her expertise to hear this.

Nancy, through her presence, way of questioning, and ability to consciously establish relatedness, gave meaning to what may have been a seemingly meaningless intervention. Presence fostered her ability to share in another's experience. This involved being emotionally and spiritually present to the other. Nancy's presence meant to un-conceal, to be aware of tone of voice, eye contact, affect, and body language, to be in tune with her patient's messages.

Summary

This chapter, written through the lives of Nurse Ruth, and others, revealed the values, routines, and practices of this nursing culture. Pursuing a 'good death' was presented in ways of being, knowing, doing, and giving and receiving (presence). Nursing presence throughout this study has been lived by these nurses as they accompanied the dying individuals and their families'. Excerpts from observation and interviews with these nurses have explicated nursing presence through touch, attentive listening, reflective responses, respect, knowledge, and commitment.

In essence, the nurses presence on these journeys with dying individuals and their families is supportive and empowering, involving nursing practices such as: creating a trusting environment, managing difficult symptoms, facilitating grief and the search for meaning, and fostering hope for a peaceful death. True presence is a moral commitment, a commitment to accompany dying individuals and families on their journey, assisting them in reaching the goal of a peaceful death.

Chapter Six

Nurses on a Palliative Care Unit: Surviving the Health Care System

The system doesn't deal with individuals they just deal with numbers. There is no story to them, it's just a brute fact that they have to go elsewhere to die.
(Nurse Eileen)

The philosophy and goals of palliative care presented earlier in this dissertation are easy to state. Realizing them is not as easy. Palliative care aims to achieve the best quality of life for patients and families when the patient's disease is not responsive to curative treatment. Making this transition, from curative to palliative care, patients and families journey towards a "good death", a death that is peaceful. Nurses' accompany patients and their families on their journey, and their presence is supportive and empowering.

Living the realities of this journey is also not always easy. One is brought face to face with institutional limitations, human foibles, problems of giving care in teams, and cultural challenges within these teams. Dying, even with the best possible care, can be difficult and messy. Yet despite these difficulties, much can be done, and is being done to make dying more comfortable and humane. Nurses are motivated to enhance their knowledge, skill, and understanding of the dying journey to bring greater comfort to those who entrust their care.

Early in this study it became clear to me that the culture of this palliative care unit has changed over the last five years. Nurses live this changing culture and are faced with "surviving" the health care system each and every day. In this chapter, the reader will come to know the nurses in practice on the unit and the patients for whom they care. To understand the context of dying in this particular culture ('local moral world'), one must look at the world that encircles this unit. In an interview, one nurse voices a scenario that captures a common voice, a voice that articulates the changing culture in this palliative care community.

The Changing Context of a Palliative Care Community

The changing context of palliative care was affecting this culture in ways I was to discover. With each interview and observation, I sensed that that many of the palliative care routines and practices on this unit were changing in a manner that these palliative care nurses did not always embrace. I began to wonder if the goals and restructuring of palliative care services were meeting the needs of dying individuals on this unit as well as they ought to be. During the interviews, the nurses voiced concerns about the changing context of palliative care locally and the impact that these changes have had on the unit. Here is *Nurse Helen's* perspective of how palliative care has changed.

> In our society we are accustomed to believing that health care is only related to recovery or wellness. It seems to me that this mindset has evolved with the "fight to beat cancer". In cancer care there has always been a focus on cure. Nurses are also trained to believe this. Our downfall begins with nursing education when we do not help students to understand that excellent end of life care is integral to nursing. That we as a society have not failed but that it is our responsibility to ensure that individuals at the end of life have a peaceful death.
>
> Not very many years ago I remember how working on this unit allowed us to be a part of providing care that focused on meeting these goals.
>
> When someone with cancer, for example breast cancer, was readmitted to hospital with metastasis for a second time, we started the process of

> palliative care. We understood that this person is dying. Our nursing goals would shift to keep this person comfortable. We would treat her bone pain, ease other symptoms such as shortness of breath, provide support to her husband and children, and involve them in helping her live towards a peaceful death.
>
> As a team we would have acknowledged that a more peaceful death might be at home, but if this was not possible we would allow her to remain in hospital with us. Our goals would be to ensure that her treatment was, whenever possible, not invasive. Her family and friends would be there to comfort her. Nursing goals would also consider her family's needs during and beyond her death. You see we would have helped her reaffirm this important phase of life, and support her as a person who has choices over her remaining life. Unfortunately now those choices to remain with us here in hospital are no longer an option. Instead, the dying individual becomes a target for discharge preparation. We look to whatever other possible place to provide care. No one is arguing that home surrounded by loved ones is the best place to be, but when the resources and the support are not there dying at home becomes a burden, not a peaceful phase of life.

The shift to community care has left many hospital-based clinicians feeling that no one is listening to their concerns and that they are not appreciated for their efforts. The goal of actualizing patient choices, including the right to die in a hospital setting, is often no longer a choice for dying individuals. Patients are sometimes transferred to hospice or palliative care programs at home primarily because of economic considerations.

In chapter five a 'call' of palliative care nurses was discussed, as a way to fulfil their intense desires and commitments of entering into relationships with dying individuals and their families. These relationships between patients and nurses were fostered by personal and professional responsibilities in striving for a 'good death' a journey that embodies meaning and peace. Nurses in this study shared several exemplars of these related moments (discussed throughout the dissertation). These are moments that continue to be valued by nurses today, but are not always given the time and space to happen. The reasons nurses originally came to work in palliative care are being threatened in today's health care context.

Entering the Unit

I enter the unit to find the doors propped wide open. The sign on the door "please keep doors shut" sends a message that something is not quite right. The doors are never open, there are too many confused patients that wander away from the unit and get lost. Why are these doors open?

Jane. Jane's room faces you directly as you enter the unit. Her door is open too! Jane is visible to anyone who wishes to look. Jane is vomiting. It is a violent throwing up right down to the depths of her stomach. You can see her struggling, reaching for the basin, the call bell, clutching her stomach tightly. The noise is horrifying and can be heard well before you enter the unit. The nurse hears it too. She runs from the room down the hall to help her. I drop my things to help.

In a fluid movement the nurse grabs a towel and face cloth which she strategically places on Jane's head. The nurse is at her side. Jane is shaking the smells, the loud retching, the undigested frothy fluid streaming into the basin does not bother the nurse.

The nurse faithfully waits, and her body cringes when Jane grasps for air, her diaphragm moving up in a violent action. I watch the nurse close her eyes briefly, take a deep breath, and hold Jane's shoulders tighter. The vomiting seems to have subsided now. The nurse raises the head of the bed more, positions her pillows, replaces the wash cloth on Jane's forehead, and leaves quickly. Her beeper is ringing, another patient is in need.

Jane's chemotherapy treatments have not put her disease in remission this time. Her condition is considered "grave." Although Jane is "palliative," she will not be remaining on the unit to die. Plans are being made that as soon as she is "stable" she will be sent home. It did not "used to be this way!"

As I walk towards the nurse's station I can feel the "buzz" in the air. There are several nurses standing at the desk, around the patient care manager. They are staring at the board in front of them that lists the rooms and the patient's names. The board is full and the nurses are discussing where they are going to put a patient that is presently in emergency. The patient is a palliative care patient, one of "their" patients' that has been readmitted in "poor pain control." I sense that this patient is special to them and that they are desperately wanting to make room for their person. The nurses plead with the unit manager, that "there has to be a way, we've got to find a room."

Above this focused concern one can hear screaming. John is in bed in front of the nurses' station. He is attempting to climb over the side rails, and is calling "Help! Help!" The nurse goes to John, holds his hand, and strategically lowers his body back into the bed. "The nurses are busy now John, but we are right here. How about I get you a tea biscuit?" John, for a brief moment seems to settle, but soon the screaming comes again. I find out later that John is a 'medical patient' waiting for transfer to long-term care facility. Yet is it possible that John will stay longer on the unit than Jane, who clearly needs palliative care?

The Nursing Report

The nurses gather into the 'nurses conference room'. There are at least twelve chairs around a long table, filled with staff nurses, the unit manager, and the unit clerk to "listen" to taped report. Yes, taped report. My first reaction is "how antiquated, every other unit uses a report board." Conversations with the nursing unit manager revealed that several discussions have occurred about whether or not to change this ritual. The reason to change is related to the lengthy time nurses were taking to record their report, as well as the time it took to listen to report. For a trial period the use of the report board was implemented. But the nurses were not convinced that report was more efficient, and they did not see the change as beneficial to their work on the unit. I wondered how this could be. Other units I've worked on as a nurse have found the 'report board' much more efficient.

It did not take a long time to understand the significance of "taped report" on this unit. Taped report was much more descriptive, and comprehensive, then board report. Taped report allowed the nurses to do what palliative care does so well, to not only understand the dying individual but also to understand the lives of others involved in the dying individual's life. The taped report allowed nurses to gain a more holistic sense of this dying individual as a person. I also sensed that hearing the nurse's voice describe her experience of what the dying individuals experience made report richer and more complex. Here is the morning report in which the nurse discussed Lillie, 82, admitted with hypoxia/pneumonia several weeks earlier.

> Although Lillie spent a quiet night, her evening was anything but quiet. The evening shift was very traumatic and exhausting for both Nurse Barbara and Lillie. At bedtime, mouth care prompted bleeding that did not stop for 25 minutes. The nurses were with Lillie as they applied pressure and ice until the bleeding stopped. They did not leave her side. Her oxygen saturation level dropped to less than 80 at times, and she was choking and grasping for air. After some IV sedation, humidified oxygen, and many warm blankets, they were able to settle Lillie.

The intricacies of the nurse-patient relationship, and the detailed description of the nurses' care would not have been possible with board report. Taped report is much more personable, and humane, allowing the story to unfold as it does. *Nurse Muriel* described her thinking about taped report:

> Taped report is much more akin to the philosophy of palliative care. We have stories of people's lives that we have to tell. Board report does not allow you to tell the whole story, the story of the dying individual's family, all those everyday life experiences which are impacting on the way this individual is dying right now! Knowing these things from report allows you to look at the family and think gee, you know they are stressed beyond; without taped report you can't appreciate it and you don't have the time to read the charts.

Nurse Beverly pointed out this important point about board report:

> It breaches confidentiality as far as I'm concerned. When you write these sorts of things out everybody has access. Some of the boards you can see

> from the desk. Visitors standing at the desk waiting to be helped, can see the board, if they have good enough vision. It's just not right.

Taped report continues on the unit. It's a ritual the nurses will fight to keep.

The Multidisciplinary Consultation Team

The multidisciplinary consultation team is an important part of the expert delivery of palliative care to patients and their families. The team is able to provide consultation of pain and symptoms, counselling, grief support, and co-ordination of care to create the possibility of a peaceful or 'good death.' A team of physicians, nurses, social workers, pastoral care, and a pharmacist are present in the hallway on the unit to do "rounds." Usually they walk around to see each patient in need of a 'consultation', or in order to review their progress. Today they are here to focus on Stanley. The group standing huddled around the physician, are waiting for an important team member, Nurse Jennifer, Stanley's 'primary care nurse.' "Where is Jennifer?" Dr. Capers bellows to the unit clerk at the desk. The "units going crazy," she replies, "she's around here somewhere, I'll try and find her. "Jennifer to the desk, Jennifer." Jennifer put the light on in the room she was in. "It's Jennifer and I'm sort of tied up here." Can you find someone else to help me?" Jennifer is with Ned, who has just pulled out the sutured drain from his abdomen. Ned was an "open and close" case, his abdomen full of cancer that was inoperable. The Jackson Pratt drain was draining foul, white milky fluid that smelled and indicated to other patients in the room, and even people entering the room that something was rotting. "Ned", Jennifer muttered to another colleague as she walked towards the awaiting "team" members, "is delirious, probably from all that Dilaudid that he's received in the last 48 hrs."

Dr. Capers began the discussion prior to entering Stanley's room. Dr. Capers explained that he received a call from the nurses on the night shift, regarding Stanley's uncontrolled pain. Dr. Capers looked to Jennifer for her report on Stanley's pain this morning. "Even with the Dilaudid dose being titrated up, and the increased frequency of breakthrough medication, his pain is still not under control," Jennifer reports. Dr. Capers entered the room and immediately noted that Stanley's wife was very anxious about Stanley's uncontrolled pain. Stanley was reddened in the face and pleaded that he receive something. Dr. Capers guided Stanley's wife into the chair and stepped back to survey the situation. Immediately, he ordered Stanley to receive Dilaudid 17mg. subcutaneously. He remarked that "this should work quickly, within a few minutes." As the team listened to Stanley's report of pain, they waited and watched to see a remarkable change, that quickly occurred after the injection. Stanley's wife changed as well. The true assessment and rationale for Stanley's pain being "out of control," was not understood until later.

Sensing that there was more to this story than Stanley's physical pain, Dr. Capers took Stanley's wife to the quiet room where they talked. She was very tearful, related to her fear of "coping at home." Seeing Stanley in so much pain heightened her own anxiety to the point that she felt she could not take Stanley home. "I do not know how I would cope if Stanley were to have this much pain at home." The fear of Stanley dying at home left her terrified that she would no longer be able to live in the same house. In a lengthy discussion regarding the options of palliative care, Stanley's wife made her wish known that she would prefer Stanley to remain in hospital until he died. However Dr. Capers explained that because Stanley's death was not immanent (within days or even the next weeks), remaining in hospital to die was not an option.

Dr. Capers, along with Stanley's wife, discussed the situation with Stanley. Stanley wept openly at the thought of dying in a strange environment. If he could not go home, he preferred to stay in hospital. Yet that same day, Stanley's name was put on the waiting list for transfer to a palliative care unit in a long-term care facility. Jennifer later spoke with Stanley's wife who expressed a lot of guilt for not wanting to take Stanley home. She felt bad that she could not take him home, as "it was his home, too." Stanley understood that his wife could not care for him at home. What he could not understand is why he could not spend his last days in a place where he felt comfortable, surrounded by those who had cared for him for weeks. Why in his last months of living should he have to become accustomed to yet another environment?

The nurses on this unit also struggled with moving Stanley to another facility against his wishes and the wishes of his family. Nurses understand that the cost of palliative care in acute care is expensive, and that resources in the community, such as hospice, remain inadequate for the increasing numbers of dying individuals needing their services. "Why can more money not be devoted to palliative care in acute care to benefit many dying individuals who require the service?" nurses ask! The consultation team provides an excellent service for dying individuals and their families, but even they have little control in ensuring that dying individuals die in a place of their choice.

There have been many changes and challenges in the way in which palliative services are delivered. Until the last five to seven years, the majority of dying individuals were cared for in hospitals. Few alternative care settings existed, and home care programs often did not have the resources to provide extensive support. Discharge of the dying individual from acute care was not a priority concern. Currently, however, there is recognition that dying individuals require and access a variety of care options in their last months of life in order to meet the different needs that arise from the nature of their disease process, social situation, and lifestyle.

Given this, a priority for palliative care services to be planned in a co-ordinated and integrated manner has prompted a shift in emphasis from acute care to community based care options. Quality care can be provided in the home, giving the patient further options for care and potentially increasing autonomy and quality of life. However, a shifting of care from hospital to home presupposes that care providers will be available in the home. The availability of professional caregivers will depend on setting for example; urban vs. rural and program, and there are regional differences in the availability of home support and or hospice care . Regional Health Authorities have attempted to meet these demands, with the development of alternative care environments such as free-standing hospice, speciality home care programs, and specialized units in acute care centres. The role of acute care hospitals within the region is now focused on assessment and treatment of acute pain and symptom management with a goal of discharging the patient to the most appropriate care setting. Although in theory many of the Canadian palliative care programs advocate for care in the home setting, the nurses on this study unit hear from dying individuals and their families that many concerns exist. This finding suggests the need to re-evaluate the delivery of service within the region.

The trend of more individuals choosing to die at home requires a shift in expectations and socialization of both professionals and society as a whole. *Nurse Nancy* said:

> Unless the government recognizes the worth of dying at home and fully covers the cost of services like they are in the acute care setting, health care professionals (in particular nurses) are not going to feel ethical about sending a dying individual home to die. In addition many of our patients are elderly, and you have an elderly individual caring for their dying spouse. There is a chance that they are not going to be able to see the care through to the end. It is also not unrealistic to expect that over the course of the illness a change in thinking as to the most appropriate place to die may occur for the family. You can only imagine the guilt that they are experiencing, when their loved one is not able to die at home.

Nurses on this study unit are living the reality of care becoming fragmented. Sometimes the actual care provided does not conform to the philosophy of palliative care relationship or to the expectations that these nurses see as foundational to palliative care.

Health care professionals, from all levels of the system, are under great pressures to contain costs and to consider the clinical implications of all decisions that are made. It became clear very quickly how the nurses, who had worked an average of 12 years on this unit, were struggling with the issues that exist for dying individuals and their families. Although many of the nurses supported the proposed changes occurring in the community for palliative care, they were living the day to day challenges of journeying with dying individuals within a larger system which they deem at times to be inadequate and fragmented. Current care is not in concert with their professional and personal values of caring for dying individuals.

Loretta. I shadowed *Nurse Barbara* who was caring for Loretta, a 52 year old lady who had lived for many years with lung cancer. At present Loretta is in the final stages of her illness, and was expected to die several weeks ago. Loretta was holding on to life "by the tip of her fingers." Loretta, now in a coma, was in the care of her family and the health care team to make the "best" decisions for her. The health care team has expected Loretta to die immanently. They are now caught in the dilemma: should they stop all life support and let her die? or should they continue with present treatment and transfer her to a long-term care facility?

Barbara positioned Loretta in high fowlers with oxygen @ 4 litres/minute. Loretta had a peripheral IV for hydration and antibiotics for pneumonia. She had a pick line for pain medication, a G Tube for enteral nutrition, and several heart medications. Loretta had been experiencing air hunger, with laboured breathing, and apneic spells lasting 15-20 seconds. Her colour was grey and she did not respond to verbal stimuli. There were long periods where Barbara and I stood simply to watch her respirations. I wondered how long her respirations would last. Barbara did not take the rate of her respirations or do an oxygen saturation level. Instead we just watched.

Barbara commented on Loretta's tube feed, and the need to add "another can of energy". Looking at it this way as "energy" helped her to deal with her feelings of "futility". I wondered why this was being continued at this time? Is hydration/nourishment a false sense of security? Did this process boost the family's image that "something was being done?" The issue of stopping hydration presents an ethical dilemma for everyone. Barbara discussed feeling caught between her beliefs and the beliefs of others. She showed me the infection at the G tube site. Could this be a rejection of Loretta's own body to the foreign G tube? Perhaps this is a sign it is time to stop. Continuing several medications at this time made little sense to me. I asked Barbara the reason for continuing all their treatments at this time. Barbara explained that Loretta's physician was not a palliative care doctor and "did not see the need to consult the palliative care consultation team." As Loretta had rallied several times, the physician and the family were reluctant to stop active treatment. Thus a decision was made to continue treatment and transfer Loretta to long term care where she would be cared for. Barbara was faced with watching Loretta 'hang on' to life, and prayed that she was not suffering. "It seems to me that with adding more long term care beds in the city, that we keep patients alive longer than we should. In years past on this unit we would have allowed Loretta to die without all this treatment, and we would have cared for her to the end on the unit. The journey would not have been interrupted. We would have been able to see her through without her being moved elsewhere to die."

It was evident to me that there exists on the unit a tension for nurses between being a patient advocate and looking out for the economic realities of the health care system. The nurses repeatedly spoke of their frustration with the ways in which palliative care patients were discharged from acute care. They sensed that patients and families were often confused with the move to other facilities as many felt that the hospital was the best place to be for them to die. Nurses like *Nurse Darlene* found it challenging to direct them towards other options because of the pressure for beds in an acute care facility.

> In today's health care system, patients who stay in hospital for a long period of time are a huge cost. They are not welcome to stay anymore.

> There's a push to move any dying individual to a community hospice or home. Sometimes, people do not want to go and I think that should be respected. Sometimes I think people are sent home without all the help that they need in place. They are rushed home! We end up seeing them back here. It's like a revolving door.

Nurse Beverly explained that dying individuals (like Jane) are a prime example of this. Jane will be sent home where her family will care for her. Jane's chemotherapy has been stopped so her type of rapidly growing cancer will end her life quickly. Jane will require IV home therapy to keep her nausea under control. A home care nurse will visit her daily, but the rest of her care will be up to Jane's husband and elderly mother. Jane will probably be back in hospital as her husband's limited medical plan will not cover the full cost of the expensive anti nausea drugs she requires. Nurses on the unit are concerned that Jane will not receive adequate support at home. They are concerned she will suffer in her dying.

The Changing Context of Care

The changing culture of palliative care has affected this unit greatly. The relationship that nurses value when journeying with dying individuals and their families are being compromised. Nurses expressed, and I witnessed, many situations where dying individuals, if given the choice, would wish to remain in acute care. Nurses acting as advocates for patient's wishes are often not supported because of cost management. Many of the nurses expressed their feelings of loss of close relationships to dying individuals that has changed the culture of the unit. *Nurse Barbara* voiced this perspective:

> It takes time to get to know patients and their families. Important issues don't come up right away. I miss the close commitment we were once able to give patients. We had a much more intense relationship. The relationship made it personally gratifying, the feeling that we were able to make a difference. We've had cases where we have been an advocate for the patient and pleaded that they were really not in any shape to leave. This particular person stayed, but we really received flak for this.

It was evident that pressure to discharge patients was strongly enforced from many levels of the system. Nurses stated that philosophically they knew that they had the support from their supervisor. In reality, they experienced the pressure from other levels of the health care system. *Nurse Ruth* eloquently articulated the changing role of nurses on this palliative care unit.

> The nurse's role has changed to stabilizing the patient's pain and symptoms and doing discharge planning, to get them out of acute care, either to a hospice or home to die. In fact, even the family's role has changed. Families now play 'health care police', an intermediary or barrier between the nurse and the patient. It's really the family's role to make sure that the patient's needs are being met now, as the nurse plans the patient's discharge. The nurse doesn't have time to develop a relationship with the patient because she's too busy meeting the family's needs on behalf of the patient.

Overall, these nurses' feelings about discharge do not stem from concern about the quality of care that is given by clinicians in community services such as home care and hospice. Rather, they are concerned that the health care system does not have the adequate resources to provide quality end of life care in hospital, hospice, and community. *Nurse Muriel* expressed her concerns:

> You can send a patient home to die and supposedly if they cannot manage at home they can go to hospice. In reality, however, the waiting list for hospice beds is so long that they usually die at home anyway. The death at home is neither peaceful or a good memory for the family. Furthermore, the patient's autonomy is not being upheld. The patient's choice to die in an environment that they feel will best meet their needs is being taken away.

Nurse Eileen discussed how a recent patient experience in the changing palliative care context impacted her feelings of letting the patient down about contributing to a lack of dignity of dying individuals.

> I'll never forget this one case where a lady had cervical cancer that was not picked up until it was too late. Her tumour was growing so rapidly and she was not in good pain control. She was a single mom with two girls who decided they couldn't handle seeing their mom like this so they moved away. I don't know what the push was to get her home. She was alone, and not in good pain control. She didn't have supports, and emotionally she was a wreck. She went home, and then went to another hospital to die. She didn't come back to us. Obviously we didn't do our

part. It really hurts to see this happen. Nurses suffer when things like this happen.

Facing Death

Nurses on this palliative care unit often help dying individuals face the transition from cure to comfort. However, there is no hard distinction between active treatment and palliative care. The philosophy of palliative care service espouses that the relationship is 'blurred,' with some patients receiving a combination of anti-cancer treatments and palliative therapies. Palliative care is also of benefit to many dying individuals months prior to their death versus just in their last weeks of life. Dying individuals like Rosza, Jane, Bill, and Helen have experienced this. Nurses in palliative care are see them through the transition from life to death.

The transition from cure to palliative in the journey is often not an easy one. For dying individuals, families, and their caregivers, there is a frequent oscillation between hope for cure and acceptance of decline and death. The transition from active treatment (aimed at cure or life– prolonging goals) to palliative treatment (aimed at comfort and support) is often experienced as a gradual, confusing, ambivalent process for anyone involved. It is my impression that the health care system does not support this ambiguous transition. On the contrary, the system often requires dichotomous thinking and forced black and white choices when it comes to making this transition. It is often the nurse who supports the dying individual and family in this transition of facing death. The following exemplar describes an elderly gentleman's experience of facing a transition from acute care to long term care. Although this individual acknowledged that he was dying, the transition was made more difficult and confusing because of the forced move to another facility. The reasons for this forced transition made by the institution remained ambiguous to the patient. The following observation posits the *Nurse Ruth's* role to be one of fostering hope for the dying individual.

Discharge rounds informed the nurse that her elderly gentleman patient (Jack), would be transferred to a long-term care facility to die. Ruth knew that she would be obligated to broach the subject with Jack. This position was one that was never easy for Ruth. Her approach was usually to be as positive as possible, even in situations filled with uncertainty. Jack did not appear surprised that Ruth wanted to discuss the placement in long term care. Jack acknowledged his recent loss of independence He came to the realization that he needed full time care and could not manage on his own. He spoke of his weakness and loss of appetite. More than once during the conversation he mentioned his "readiness to die." What was unclear to him was why he had to move yet one more time. "Are they just considering cost he asked? Are they considering my needs at all? Is it really necessary to move me one more time at this stage in my life"? Jack, although he was not in agreement with the decision, interpreted it as a "decision made and done." Ruth listened attentively to Jacks questions and acknowledged his concerns. "I can't imagine how this must be for you Jack. I agree that it doesn't seem fair to move you one more time. I wonder though, if the environment will in time seem more homelike, and allow you to be more comfortable when you die. Do you think this is possible Jack? Maybe you will be able to spend more quality time with your family, and help them to be more at peace."

The decision to move Jack to long term care was not helpful to him in making this transition to death. Nurses on the unit expressed that helping dying individuals make this transition is becoming a greater part of their role as nurses. As Ruth says, "We are having to change our thinking of how we can help patients to move on. We know that this is an important responsibility and yet we still feel the loss of not being with them to the end" Ruth was attempting to preserve hope for Jack. She later discussed the importance of preparing Jack to see long term care in a positive light. Her goal, she said, "was to help him to achieve whatever goals were meaningful to him, and to be closer to his relationship with his family." To help Jack find meaning in this move is important. Hope, Ruth told me, becomes "the accomplishment of the goals before death comes." In this process, Ruth also developed a personal meaning towards death that sustains her in her professional work. The reciprocity of meaning provides satisfaction and may be an important factor in the development of expertise and commitment in Ruth's work.

Time as Essence in Palliative Care

Time, as essence in palliative care, has become increasingly important and challenging for these nurses. The changing culture of palliative care on this unit has shortened the time these nurses spend with dying individuals as they move to other facilities to die. Time takes on a whole new meaning. For those who do complete their dying journey on the unit, families often ask nurses the question "How long will it be? or, " How much time do you think we have?" The nurses told me that, although they asked these questions regularly, they remained the most difficult questions to answer. Nurses are asked these questions because they are present during each hour of the day. Patients and families struggle with the reality that their time together is limited. Nurses struggled in witnessing the family suffer with this reality. I observed *Nurse Barbara* answer this question of Willy's son.

I could sense that this was uncomfortable for her by her hesitant response and intense facial expression. She responded by saying "I have to be honest and say I cannot answer that. Although many physical signs lead us to believe that death is near, I would never put a time frame on the experience." The interconnectedness of the suffering experienced by Barbara and the son, who was mentally and emotionally preparing for the nurse's answer, was evident. The anguish and fear of uncertainty was etched on Willy's son's face. Barbara was silent, and then spoke in a soft voice, "I wish I knew."

Being present at the time of death is important to the nurses as well. One nurse referred to this time as "standing in a privileged moment". This transition reveals its deepest meaning, knowing that time is of the essence. All the nurses in this study spoke of their commitment to ensure patients do not die alone. They encouraged family members to stay with the patient and to be there at the time of death. Their goal is to include the family in caring practices that promote their connection with the patient. It is often healing for the patient, family, and nurse. *Nurse Eileen* expresses her views of dying in the company of others.

> No one should be alone to die. Dying individuals need people to be around them. They are much more at peace if they know someone is there. Sometimes we have to encourage family members to risk moving closer to and holding the hand of their loved one. After, families express their gratitude for the loved one's dignified life and peaceful death. This helps them to move on. When family is present at the moment of death, it is healing. There is a sense of peace and relief. We always make sure someone is there, even if time is tight. It's just a priority.

Time pressures, within the context of the nurse's work on this unit were evident in many ways. Holistic palliative care that includes dying individuals and their families takes time. There were several instances where nurses conveyed an awareness of the difference between the care that they value and have been taught to provide, and the care that they are able to give. When time is inadequate, the result can be moral distress for nurses and a related negative impact on dying individuals who receive care that is not holistic. The experiences of only having time to do basic care, and not being fully present (because their thoughts are occupied with doing and not being) are distressing. Several nurses described staying overtime until someone could be with patients who were dying alone. Many nurses voiced that the system was forcing them (because of lack of time and staff) to give care that undermines their own values. Nurses suffer from feeling that they have not adequately done their job. *Nurse Muriel* relates her feeling of pressured care with little time:

> The environment doesn't allow us to care the way we need to. Sometimes I've been so caught up in everything around me that I'm really not aware of where I'm coming from. I do things but I'm more like a robot, I'm not a nurse. I had to leave a dying patient who was alone once because another patient down the hall was irate that I wasn't changing his IV bag. There was no one nearby to help and I couldn't stand the irate screaming from down the hall. We couldn't satisfy the needs of the dying individual, because there were not enough bodies to go around. That haunts me. It's as bad as having someone in poor pain control that you can't do something fast enough.

Nurses talked about having time as "really being able to listen... To actually stand there and focus on your patient's voice without being interrupted from a million other sources." *Nurse Darlene* talked about finding herself "wishing that dying individuals would just hurry their conversation, so that she could move on to the next task at hand." She realized that she was compromising the care of her patients, just so that she could be viewed as being efficient. The following story revealed by *Darlene* portrays her plight with time.

> Mary had amyotrophic lateral sclerosis (ALS). She had lived with her disease for several years, and was very clear on how she wanted her care to be given. She would often try to communicate these needs to us, but she could not speak clearly enough for us to understand. Out of frustration, she would break into uncontrollable crying, trying to explain how she wanted to be positioned, or to have her curtain opened more, or whatever. It took so long for her to explain what she wanted, and I just couldn't wait. Something so simple as this and I didn't have the time to figure it out. What kind of care is this?

Nurses on the unit cope with these issues by talking to one another. They feel they have a voice through discussion with each other and through their nursing unit manager. They have learned through experience how to identify situations, in which they are forced to distribute their time in unethical ways. Together, they reflect on these situations and discuss the kind of nursing practice that they want to be involved in. They describe their culture as one that is important for them, to challenge standards or practices that they see as unethical.

The "rush" of time as well as the "robbing" of time is not only an issue of loss for these nurses but also one that jeparadizes the quality of the dying journey for the individual. The development of a trusting, caring nurse/patient relationship takes time. All of the nurses stated that this luxury of time to "see your patient through the journey of dying no longer exists." Many feel that the healing developed through the relationship of getting to know the patients and their families just is not there like it used to be. In fact, some wonder if more harm is done as the journey is not only interrupted (when the patient is discharged to another facility), but added burdens are placed on the family in such a way that invites concern and trepidation regarding the remainder of the journey. The quality of the nurses' work suffers, as well as their fulfilment as nurses, losing the rewarding reason they became palliative care nurses, the intimacy of the nurse-patient relationship. *Nurse Ruth* shares her perspective:

> I find that my role as a palliative care nurse has changed a lot. I feel like most of my time is spent preparing the patient for discharge. There is so little time for getting to know them deeply. It's just that superficial data needed to make sure that their discharge is at least smooth. I think that changes in acute care with the push to discharge patients, creates a lot of suffering for nurses. They suffer because it's not the patient's agenda, so were dealing with something that we are imposing on them, and expect them to make decisions at a time when they already have so many decisions to make.

Nurses on this unit recognize the importance that time plays for families to find strength and or meaning in they're loved ones dying journey. Nurses support feelings of fear, separation, and anxiety of family members with attentiveness, specifics, with genuineness, with relation. As the dying individual's time is often shorter on the unit, nurses sense that their role with families in helping them find strength and meaning is even more important than before. Nurses want to feel confident that families are prepared to go home with or find comfort as their loved one moves to another facility.

Rosza. As I observed *Nurse Nancy* care for Rosza, I watched her acknowledge, anticipate, interpret and nurture Rosza's family. Rosza was a fifty-eight year old lady with cancer of the lung. Rosza had been receiving active radiation therapy to slow and or eliminate the tumour. During her last visit to the cancer clinic, Rosza was told that the treatment was not working and therefore would be stopped. Nancy was aware from previous contact with Rosza's family, especially Rosza's son, that the oncologist had explained to them that he was very optimistic that the treatment would slow the growth of the tumour significantly. Nancy knew that Rosza's son would be particularly upset about his mom's condition so she asked Rosza when she thought her son was planning to be around. In the meantime Nancy phoned the radiation oncologist to glean more information about Rosza's physical status and why the treatment was stopped.

Nancy met John, Rosza's son, later that day. Nancy explained to me that John has experienced illness firsthand, as he was a paraplegic from a bike accident as a child. John, through his illness, had worked through many uncertain periods threatening his sense of being and intactness as a person. Through his experience John has grown considerably as a whole person. He lives independently and views illness as something that can be conquered. Knowing this, Nancy sensed that he might think about his mom's illness in the same way.

Nancy met John in the hallway as he wheeled towards his mom's room. She greeted him asking him how he was doing. John did not talk about himself but voiced how worried he was about his mom. "I am really shocked and bewildered about the fact that they stopped my mom's radiation therapy." Nancy listened and asked him what he was told, and what he perceived was his mom's progress and plan for the future. John did not feel that the oncologist gave his mother a fair chance with treatment and thus wants the treatment continued. John had already made an appointment to see the oncologist. John asked Nancy if she knew why the treatment might have been stopped. Nancy commented that she did not know the exact reason for his mother but she provided general information as to why treatment may not be continued. Nancy gently offered John the palliative care services of the consultation team, if he felt they would be helpful. John was not at the point of seeing his mother as palliative. Nancy reached out to John providing any information that he thought might be helpful. Nancy made sure that John knew that they were there if he needed him.

Working in the Middle

Nurses, more than any other health care professional, are aware of the need for co-operative interaction, and are likely in the best position to foster it, because they often work "in the middle." Everyday, nurses advocate for the patient's wellbeing by co-ordinating the physician's plan, the institution's policies, and patient's views of what is good. Working in the middle is a privileged position of fostering co-operative moral decisions made by all. In palliative care, moral decisions are made by teams, which include the family. Nurses, because of their close relationship with the patient and family, are often in the best position to be involved in and make moral decisions. Nurses are accustomed to considering each person's beliefs and values, and have learned how to think from the position of "other." Nurses use this ability in orchestrating "smooth" everyday care. *Nurse Ruth* voices her frustrations of working in the middle in today's health care environment.

> Other disciplines have a specific area of interest. They focus on the problem at hand, whereas, I think the nurse tries to see the patient, and the family, everything as a whole. You're trying to look at the big picture, be the person who is communicating with the other disciplines and advocating on behalf of the patient. It's almost like you're trying to protect the patients from the system so they don't get sucked into the system and fall through the cracks. My God, I hardly have time to see the patient, I'm too busy organizing everything else!

Working in the middle, although advantageous, can also be troublesome to nurses. Occasionally nurses have to challenge the desires of other team members to ensure that the well being of the patient is the ultimate goal. There are times when significant situational constraints interrupt this goal. From this, nurses often suffer moral distress with remnant feelings of guilt, anger, frustration, and powerlessness. *Nurse Barbara* shares her frustrations of working in the middle.

> Some times, as nurses, you feel really helpless and powerless, when no one listens. I've talked to doctors on call that just didn't understand how much pain the patient was really in. Finally I had to say, "do you have any idea what it's like to watch somebody in pain?" Like I had to get real personal! You feel like everyone is coming at you, the patient, the family,

> and there is nothing you can do. It's better now but there are still times when you feel like no one cares. You know that you are not meeting anybody's needs including your own professional ideals.

There are also times when nurses are caught between their obligations to patients and families, physicians and other health care professionals These multiple obligations can conflict and may leave nurses in situations where they cannot implement the moral choices that we wish to make. Nurses, in this study have learned through experience, to voice their frustrations to others. *Nurse Barbara* discusses the commitment she makes to herself:

> There are times when patients make decisions about their life that you don't agree with. The first few times I didn't do anything, I just did what they wanted and I suffered inside myself. Now I ask, and as a caregiver, I think I have the right to ask. I ask them why or how, so that I can understand and they are usually willing to talk. I have seen things happen requested by the family and doctors and I'm in the middle, but I ask why. Sometimes I can't fulfil the request and the doctor will come in and do the care. I respect them (doctors) for that even more than you can imagine.

Barbara through this reflection of self has become consciously aware of her own values as well as the values of the dying individual and the physician. In identifying the differences between these values she is able to seek understanding and establish a common ground. Based on her values Barbara is able to make a moral commitment to herself, and in this way the caring relationship is maintained.

Gary. Observing *Nurse Muriel* care for Gary, allowed me to witness how "working in the middle" places nurses in the important position of engaging in the body of the other, the disease entity, and the treatment choices which confront the nurse. In illness and suffering, bodies are not forgettable, they are always present in the memories and conscious of the nurse. In this experience Muriel embodies Gary's pain and with courage and compassion seeks to fulfil her moral obligation.

Gary, a young man of 48 was in the final stages of bowel cancer that now had metastesized. Prior to being re-admitted to the hospital, Gary lived at home with his wife and young children. Four weeks ago, Gary was admitted with severe back pain, which had been determined to be metastases to the sacral plexus, resulting in *neuropathic* pain involving the sciatic nerve. Throughout the four-week period Gary was in hospital, several pain medication regimes had been tried to control Gary's pain, leaving Gary with serious side effects such as dizziness, nausea and vomiting, extra pyramidal effects such as muscle twitching and visual hallucinations. This period of time left Gary bedridden and incapacitated. During the last two months Gary has only been able to tolerate limited amounts of solid foods, quickly becoming cachectic, weighing less than 140 pounds. Gary, who is close to 6 feet, has lost over a hundred pounds.

Over the past week Gary has refused to take pain medication of any kind. Muriel has been one of his primary nurses from admission and has watched his body decay and his hopes and spirit fade. We are present in the room now to bathe and turn Gary. For the last couple of days he has been refusing any nursing care. Today is no different.

I watch Muriel as she approaches Gary lying rigid in bed, eyes closed and teeth clenched. Muriel touches Gary's shoulder, and he painfully flinches in bed. Muriel softly asks Gary for his permission to wash and turn him over. Gary flatly refuses. Muriel pulls back the cover to reveal Gary's cachectic body. A look of horror comes over Muriel's face. Muriel, who has been off for the past week finds that a large area the size of a twoonie, that has now broken down revealing a weeping open area deep enough to insert many inches of strip guaze. In a trembling voice Muriel voices her concern and frustration, "Gary, I have watched your skin break down from a small red area, to now where the skin is weeping and open. I'm really worried about the rapidly deteriorating condition of your skin. We need to turn you on to your side or before long I will be able to place my fist in the open area. My gosh, this has happened so quickly."

In obvious despair, Muriel leaves the room. In shock she stops at the desk to report her findings to the unit manager. The unit manager is obviously aware, as she nods her head in disappointment. In the clean utility room, where Muriel gathers her equipment, I ask how she plans to approach Gary's situation. "I have watched Gary's body deteriorate and I feel obligated to do my best in helping his body to heal, whatever that means. I cannot just stand back and watch him deteriorate further without an honest attempt to make the best of his remaining life. I have to try and help him to gain our trust in being able to alleviate his pain, and to become more physically active and in control of his body."

Moving back into the room, Muriel explains to Gary that she is going to wash him and move him on to his side. Gary is silent, but does not resist Muriel as she begins to wash him. When she attempts to move Gary on to his side, he becomes rigid, and refuses to move. "You're in pain Gary, won't you take something so you can at least move easier? I know that you have experienced some awful side effects from the medication, but you were on so many drugs. If I were to give you just a small amount, perhaps you would at least be able to tolerate moving on to your side." Gary refuses any medication. Muriel, feeling like she has little choice, calls for the help of two other nurses. Together they move him onto his side. Screaming with agony, Gary is positioned on his side with pillows. Beads of sweat are present on Muriel's forehead, she feels the pain that Gary has experienced, but consciously knows that her overall goal of preventing further bodily deterioration is most important. Helping the physical body to heal is a beginning step that Muriel views as her moral obligation to Gary's well being. "I know that other nurses would not move Gary because of the agony he experiences, but to me, that's giving up on a valuable human life, a life that deserves respect. Turning away would only deny him the value that he deserves." Muriel brushed Gary's brow with her hand, and placed a cold cloth on his head. I watched her grab for Gary's hand, I could see that they both squeezed tight. Muriel swallowed and closed her eyes tightly fighting back the tears. Her embodied awareness of her suffering, reached Gary's. They suffered together.

The very nature of the health care system today, the changing context of palliative care on this unit, and the importance of time in the dying individual's journey, makes working in the middle even more of a challenge. Ethics, for nurses, calls us to make the best decisions we can. However dilemmas are addressed, the nature of ethics is sometimes grey and "in between." All decisions are made under the spectre of wonder, uncertainty, and other possibilities.

Summary

The nurse's practice on this palliative care unit has been changing. Nurses are faced with pressures of time that is rushed, impacting the quality of care they give to their patients. Time has also been robbed from them as pressures to discharge quickly from acute care, does not allow for the intimate nurse patient relationship they value. Nurses suffer with the loss of this relationship, as they believe that the dying individual's journey is interrupted and healing may not occur, as they move from place to place.

In palliative care, working in the middle can be viewed as an advantageous position for the nurse to be in, as the nurse is in the best position for co-ordinating a safe and peaceful dying journey for the dying individual. In the middle however, the nurse is obligated to many individuals, some of whom may not share similar values and beliefs about how the dying journey might look. Nurses are faced with tough choices and moral decisions embodied in suffering. Living with the consequences places nurses in a vulnerable position, a position that at times makes it difficult for them to uphold the standards of palliative care practice that they desire.

Chapter Seven

Creating a Moral Space for Suffering

> *I feel a deep, personal bond and extreme closeness to her as I care for her body. On the other hand I think she is the closest person to me. I constantly learn from her about myself and my work. And I never feel I am doing the giving. It is as though she is always the one that is giving to me.*
>
> *(Nurse Barbara)*

> *The healer has to keep striving for the space ..in which healer and patient can reach out to each other as travellers sharing the same broken human condition.*
>
> *(Nouwen, 1986, p. 93)*

A "good death' is a death that is timely, openly accepted, and one that is experienced peacefully without pain and suffering. In pursuing a good death, nurses are knowledgeable, present and empowering. The previous chapter informed the reader about how issues of the health care system, such as financial constraints, lack of quality time to give care, inadequate resources, and the difficulties arising within teams, challenged the work of nurses. The inability to meet their professional/moral responsibilities in caring for the dying, often resulted in nurse's suffering.

In this chapter, I will explore the struggle of nurses as they balance the demands of professional obligation (moral agency) and personal meaning. Nurses hold a moral imperative to understand, comfort and alleviate suffering. Thus pursuing a 'good death' is not always reachable. It is this struggle that I believe contributes to 'nurses suffering'. Being "called into relationship", nurses embody the experience of suffering, pain and joy, an identity that seems to be a part of the culture of nurses who work in palliative care.

The chapter begins by exploring the theoretical concept of embodiment, a precursor for mutual healing in suffering. Writings will uncover experiences of suffering in the embodied relationship and the struggles experienced during prolonged periods of suffering. In the embodied relationship, where nurses create a moral space for suffering, compassion and courage are present. These moral qualities foster the healing process, and allow possibilities of strengthening spirituality and finding meaning in suffering. The ability to continue to live in the daily realities of suffering will be explored as it exists in the web of giving and receiving that is ingrained in the culture of these palliative care nurses.

The Experience of Suffering

Nurses are called to relationship with dying individuals, whose journey often includes the experience of suffering. In palliative care, living with death and suffering, as they care for dying individuals, is a part of the nurse's reality. Nurses, as well as patients and families, bring histories of death and loss into the caring relationship. In this study, I learned about the intricacies of suffering in the nurse-patient relationship. The relationship, although complex and emotionally exhausting, in many ways portrayed the gratifying 'call to relationship' for these nurses. Being called to the 'face of suffering', nurses share pain and suffering, a moral commitment which they embrace. *Nurse Barbara* expressed the relationship in this way:

> I believe in palliative care, it's not one person who suffers, it's multiple persons. It's a family suffering, or it's a partnership in suffering. Nurses and dying individuals help one another. I mean some days you cry with the patients when they get their diagnosis, or when they are having a bad day. Or sometimes you cry because it's just where you are in your life. We are all very vulnerable in these intense experiences, but we are all in it to help each other.

In this way, the nursing relationship is an intersubjective experience. Intersubjectivity subsumes the notion of embodiment. Embodiment is the giving of one's entire self, the ways in which meanings, expectations, and values are expressed and experienced in the body. Human knowledge is multidimensional. Sensing and feeling are as human as thinking. The human self includes perceptions, feelings, emotions, dispositions, attitudes as well as thinking. Nurses are concerned with things like feelings, emotions, and the body. Aspects of the human condition which make people uncomfortable, are often of central concern to Nursing.

Embodied nurses are fully present to others and their experiences, and are also aware of their own bodies in relation to the experience. They have a moral obligation to the individuals' bodies, as living flesh, where humility and compassion sharpen our senses to act cautiously, reflectively, and with understandings stemming from experience. Since human persons are susceptible to pain and suffering, embodiment, (in an ethical sense) is a lived, bodily relation to the other.

The nurse in an embodied relationship experiences feelings, as a part of being and becoming in the relationship. In the nurse to patient relationship there is reciprocal sharing, an accepted norm of mutuality where each person helps one another. Suffering with, in *compassion* for the other, the nurse creates a space for suffering. Etymologically, the word compassion is derived from *passion*, which is the suffering of pain; being acted upon; a powerful affection of the mind; and *com*, which means in combination or in union together (Hoad, 1986). Compassion means to suffer pain together. The embodied nurse facing one who is suffering creates an open space where she listens to the pain, sees the pain, touches and feels the pain. Of course, the intensity of the experience of the nurse is different from the patient. Intense immediate emotions may be felt by the nurse, however, they serve to generate a moral process, necessary in attempt to comfort and/or alleviate the individual's suffering. This moral process or choice is compassion. *Nurse Jennifer* talks about her beliefs about suffering with a dying individual:

> Suffering connects us with our humanity, of who we really are as individuals. When a nurse witnesses suffering, she sees a person suffering. This person brings forth the compassion within us. This last summer we cared for a women who was only thirty-two years old. She had two children. I'll never forget the four- year old outside of her hospital door crying "Mommy, Mommy, Mommy." You (the nurse) feel so helpless, your heart just stops, you feel so empty. Often, there is the immediacy of crying with them, the sadness is overwhelming. It's like a transference imagining for yourself, how devastating that would be. Then your next reaction is to help them. How can I make this experience so that they feel loved, dignified, and worthwhile? How can I lessen their burden of grief? We try and meet them where they are. It's never easy and never routine. Physical pain is much more strategic; a plan of care usually comes to your mind. Not with suffering, it happens in the moment.

The moral quality of compassion involves a union in another person's suffering, not merely an identification of the suffering but identification with it. To *suffer* is to undergo, to endure, to tolerate, and to allow (Hoad, 1986). Nurse Jennifer, voiced how being in compassionate relationships with patients allows one to be in a unique position to ensure that sufferer is not alienated, that the experience is acknowledged, and that the path taken to alleviate suffering is open. When we create a space for suffering, we suffer together. In relationship with our patients, we unite, to create an acknowledgement and perhaps an understanding of suffering. *Nurse Eileen* talked about the union of suffering, the changes in relationship that occurred for both herself and the patient when suffering was acknowledged.

> I remember the feeling of caring for a patient who finally after several days of being together, revealed to me that he was scared of dying alone. He told me how betrayed he felt by his physical body, how diseased and distasteful he felt he was to others, but that I could look beyond his diseased body and capture his spirit. In this experience he felt whole. He told me that our relationship made him feel valued and worthwhile. When he told me this, I remember starting to cry, and he held my hand. I sat there not knowing what to say for what seemed like a very long time. I will never forget this experience, and the strength he gave to me as his nurse.

Enduring Suffering

Through embodiment and compassion nurses suffer with others. Nurses openly engage with dying individuals where they meet, to experience an energetic absorption of individuals' pain, suffering, and fear and, commiserate with their frustration and anger. This sense of suffering, is recognized by nurses as a call to relationship, a call to be known, to be heard, and validated, and an opportunity to recognise one's own vulnerabilities and humanness as nurses.

Nurses on the unit have recognised the merit of pondering their own personal experiences of suffering before they are able to truly understand their patients. Nurse Jennifer said:

> Our effectiveness of caring for suffering individuals is wrapped up in what we have learned in our own struggles to find meaning in suffering. Knowing ourselves helps us begin the journey of understanding the patient. Suffering does change us and usually for the better. Frequently we experience a deepened compassion, a more tender heart, or become less judgemental. We are morally committed to doing good.

Nurses remain focused on doing good through appreciating what the intensity of dying means for their patients and their families. When patients and families are suffering, nurses want to know what it is like for them, and through their relationships with patients nurses endure personal suffering. This commitment from nurses increases their vulnerability to dying individuals suffering and to loss. *Nurse Barbara* explains:

> I know I've done my job well if people are peaceful and they slip away quietly and it doesn't cause any grief for the family. But when people are screaming in pain and you can't settle them, you know that the family are suffering too. It's very hard. It's unsettling. It's my job to make sure that they are comfortable. I know that when death comes they will be comfortable, but it's getting to that point, holding on, keeping our strength that is difficult. Suffering lingers, it just doesn't disappear. The need to nurture, to care, is always a part of our being you just can't leave a person if they are uncomfortable.

As I observed and listened to the nurses, I often wondered if nurses in their vulnerability were helpful to dying individuals in suffering? Should they convey their suffering to dying individuals? What would this accomplish? I observed nurses in their vulnerability, where nurses, in their words and gestures, convey the anguish, fear, and bewilderment that they are experiencing. From the nurse's vulnerability emerges an intensity of empathic regard, and a corresponding refinement of physical ministration in which the smallest gesture or the least touch is capable of easing the dying individual's suffering. Thus in embodiment, vulnerability of nurses suffering is enabling. Sharing of one's vulnerability was authentic, a moral response, an acknowledgement, and embracing of another's suffering. That sharing of vulnerability represents a rich synthesis of nurses and dying individuals, of embodiment, union, and transcendence, and allows for understanding all dimensions of suffering in persons. Observing nurses revealed their vulnerability uniquely embodied in each experience of suffering.

I was reminded however, by *Nurse Darlene*, that although a nurses vulnerability can be enabling, there are experiences where "patients do not let you into their suffering. Nurses in their vulnerability, are not able to always break the barrier of suffering." Even with several encounters with suffering, we are not united in suffering. Nurses endure the vulnerability they experience because of the commitment to improve the human condition, to produce positive changes, to encourage growth, to enable others to live life to the fullest, and to alleviate suffering.

Nurses on the unit discussed their philosophy as based on the intrinsic worth of each individual for whom they cared. Understanding of the persons' suffering necessitates gaining knowledge of the ideas held by suffering individuals regarding their identities, their lives of the past, present, and future, their relationships to others and their environment, their aims, and their anticipated actions. Knowledge of persons is partly knowledge of how persons live, as well as what they live for. For these nurses, protecting patients' inherent worth is a central moral feature of nursing practice that calls them into relationship with others.

Protecting the worth of silent individuals who cannot speak or choose not to speak about their experiences, values, and beliefs presents a challenge to even the most experienced palliative care nurses. Nurses naturally feel most comfortable with individuals who share their feelings openly. Respecting the dying individual's wish to not share suffering is troublesome. Nurses voice feeling 'helpless' because they sense the loneliness and alienation of their patients. Nurses leave the dying journey feeling like they have walked away from suffering and that the patient has died alone. *Nurse Helen* relates this experience:

> I remember caring for Beatrice who would willingly accept my physical comforts of positioning her body into supported positions, and taking ice chips so that her lips were not parched. But she would literally lie there with tears streaming down her cheeks, making no eye contact. I held her hand, and she did not resist, but I could not feel a connection. Nurses openly accept that you cannot connect with every individual, but Beatrice was connecting with no one. After she died we all prayed that our suffering somehow reached hers, and that she knew that we were reaching out to her.

I remember after hearing Helen's story, thinking about *Nurse Muriel*. I recall observing Muriel as she cared for Gary (description in Chapter 6 p. 186-188) and reflect on the suffering that Muriel experienced. Muriel spoke about feeling "helpless." Her suffering and vulnerability took hold. She reached out to Gary's bodily deterioration and acted out of a moral obligation to help Gary's body to heal. I remember also feeling helpless, wondering if Muriel should insist that Gary be turned as it caused so much pain. When I listened to Muriel speak, I realized that her actions were out of compassion and courage. Muriel did not turn away from Gary's suffering to ease her own. Instead she valued protecting the integrity of Gary's body, hoping to prevent further deterioration. Muriel's vulnerability, embodied Gary's suffering. In compassion they suffered together.

In the dying journey, there are occasionally patients who choose to die alone, wishing no one to be present in the room with them. Respecting their wish to be alone is morally distressing to nurses. Not being physically present with individuals' makes nurses feel like they are not being responsible, and in a sense that they are not able to "see the face of the other." In relationship, nurses expect an oscillating rhythm of giving and receiving. The union of giving something of oneself for the purpose of being important to another person, and the experience of doing what is good, is fulfilling. *Nurse Jennifer* voiced her feelings of moral unrest, of having to walk away.

> When patients want to be left alone to die, it's a very different kind of caring and attention you have to give. I mean it's not your conventional nursing care... that you feel proud of. You are not able to visually see that you have done a 'good' job. I remember entering a patient's room to do my initial rounds and let him know that I would be his nurse, and he said,

> "Thank you, now please leave me alone, I just need to be alone." I had a lot of difficulty physically leaving him alone. I just did not feel that I was exactly meeting the standards of being a good nurse in my opinion. That was his choice and you had to respect it, but you still feel responsible for him and it's not easy to walk away.

It took courage for this nurse to 'walk away' from this relationship. Yet the responsibility and responsiveness of this nurse was kept alive in her desire to honour, acknowledge and keep open a space for sharing suffering. As I watched the suffering of the nurse wanting to go in the room to make sure the patient was alright, she allowed me to understand that the space she created for suffering was ever present. Her courage to endure and accept the others suffering from a distance was admirable.

Embodied nurses who are fully present to their patient's suffering are also attuned to their own bodies. Knowing ones self (discussed earlier in this dissertation) is imperative for excellent care for those who are suffering. *Nurse Barbara* talked about knowing her body in this way:

> When I have suffered in my relationships with patients, I'm very weary. It's a combination of physical and mental fatigue. I start to say to myself, "I wish I would do this or that". I become so exhausted I stop eating full meals, healthy meals, I don't walk to the store, I ride. I can barely walk down the stairs to put the laundry in. I know I'm lacking because I start to use the "I wish line". My husband says my hair changes, and my skin colour changes. There is just an appearance about me when he says "You look awful". My whole body feels it.

All of the nurses in the study talked about introspection and experience as ways by which they developed this self-awareness. *Nurse Eileen* described her experience:

> When I have a day where patients and their families are suffering, my body knows it. I find talking to others relieves the despair that I feel. I'm not looking for answers, just the ability to 'sound off'. Sometimes I walk home from work, it's about a twenty minute walk. It gives me a chance to look over the shift and kind of well...I did this, I wish I'd done that, and by the time I get home I've worked through what I need to. During the winter I exercise, I workout on those mindless machines, and my mind just wanders. Sometimes I think about only pleasant things. Keeping fit revives my spirit. I feel refreshed and ready to be with those who need me.

Creating a Space for Suffering that is Prolonged

When an individual's suffering and dying is prolonged, the nurses experience great distress. Nurses spoke of many experiences where suffering was prolonged. We had repeated discussions of the uneasiness nurses felt regarding the use or abuse of technology with dying individuals in order to prolong their lives. They described experiences where the prolonged suffering of individuals occurred as a consequence of "heroic measures." It was not unusual for nurses to be left with orders that they believed made little sense. *Nurse Ruth* explains:

> I'll never forget this 82 years old gentleman who had a "radical neck dissection " for cancer of the larynx. He opted for the surgery so "that he could have more time with his family". Postoperatively he received the standard tracheostomy and feeding tube. After weeks of nausea and

> vomiting from not tolerating the tube feeding, his weight dropped dramatically and he began to literally fade away. The look of terror in his eyes when he attempted on several occasions to remove his tracheostomy, was too much for me to watch. I kept asking myself, what was he telling us? Why do we keep re-inserting this trach upon the wish of his family? Were we only prolonging the anguish, fear, and suffering of this individual? What kind of death are we creating for this individual? I remember stopping in the middle of inserting the trach, saying to the daughter who was holding his hands down, I cannot do this anymore. But someone else did!

The unveiling of suffering in this individual's face, his need and vulnerability, shaped the moral response of Ruth. To be touched by the individual's suffering helped Ruth to understand that care cannot be strictly equated with treatment given. The suffering that Ruth experienced represents a sense of transformed responsibility through her embodied relationship with him. Ruth recognized that the impersonal and de-humanizing act of continually re-inserting the tracheostomy was only intensifying his suffering, and that this treatment was prolonging and intensifying death. It is these experiences, where nurses claim that medical treatment is serving it's own needs and not the needs of the dying individual. It was Ruth's embodied compassion that gave direction to her actions and commitment.

Nurses, in creating a space for suffering, respond and listen to the bodies and personal needs of dying individuals whose greatest fear has become further suffering. Nurses act in ways that comfort, that convey respect, so not to increase the vulnerability which individuals are experiencing. The acts of protecting or preventing further suffering have the potential to transform suffering. Through embodiment, listening and responding to the body, nurses see their goal as comforting and or alleviating suffering. I observed *Nurse Barbara* in this experience. She listened, responded, and acted in a manner that considered the dignity and worth of the dying individual and her family.

I was present with Barbara as we repositioned Geraldine to ease her breathing. At this time, a respiratory therapist and a student entered the room to 'assess' Geraldine's breathing status. The therapist and the student performed a full assessment, auscultating breath sounds and checking oxygen saturation levels. The therapist suggested that a 'high flow' oxygen mask might improve Geraldine's oxygenation level, and her breathing. I observed Barbara throughout this assessment. She was silent and listened to the therapist's suggestions, until the mention of an oxygen mask. Barbara acted professionally, thanking the therapist for his assessment, but politely reminding him that Geraldine was dying and needed to be 'comforted and not treated aggressively'. Barbara humanized the experience, connecting the families needs, voicing how they might feel seeing Geraldine for the last time with an oxygen mask on. Barbara promised that she would provide comfort measures to reduce suffering and alleviate Geraldine's laboured respirations. Barbara told me she felt the mask would only serve the purpose of 'medicalizing' Geraldine's death.

Nurses feel the discomfort and pain of dying individuals. I witnessed nurses on the unit in embodied experiences where they unconsciously mimicked other's discomfort, such as: the fidgeting of restlessness, the twitching of sharp stabbing pain, or the grimacing of unrelenting chronic pain. An understanding discussed in interviews by the nurses, was that alleviation, comfort, and nurturance of pain and suffering are imperative. Pain that is excruciating and is continuous conflicts with the nurses' self-understanding as one who assures comfort and nurturance of pain and suffering. The nurses spoke of how watching dying individuals suffer in pain for prolonged periods, made them feel exhausted. The situation can become unbearable to watch. *Nurse Muriel* expressed her suffering in the following story.

> I'll never forget this lady we had. She was so wonderful. She was a nurse too. She had cancer and it spread to her spine. She was admitted in absolutely excruciating pain. She was not processing the drugs anymore because her liver had shut down, I guess. All I remember was her screaming. The horrifying, piercing sound that continued, and did not let up, even stayed with you after you left the unit. I remember her begging, and pleading for pain control. How do you think it made me feel? I remember feeling motionless in the room, because we had tried everything physically possible that we knew, and it did not work. She needed a block and she didn't get it. We tried everything but we didn't meet her needs. She lived for about a week screaming in pain. We never did get her pain under control. Nursing these patients, you feel like you've been run dry, a wet noodle that's gone flat.

In suffering with this patient, Muriel allowed, endured, and connected to the expressions of suffering that this person experienced. I asked Muriel how she responded in this situation: What moral action did you take? "Besides giving her all the pain medication I could, providing all the physical comfort measures I thought might work, I tried to make sure she had the most peaceful environment possible. She didn't need any added stimulus so we moved her to a private room." And how did you care for yourself, I asked her? "At this point, I couldn't just sit there and be with her. The only way I kept sane was to do things. Nurses do things, to keep their mind off there own suffering! I guess I wasn't very compassionate." Muriel humanised the experience of suffering to the best of her knowledge and expertise. Her comment of "keeping sane" was her way of enduring suffering, and continuing to keep a space for suffering. In keeping a space for suffering, Muriel was able to concentrate on how she could best care for this individual. In all of her actions Muriel was sensitive to the dignity and worth of this individual.

Compassionate care is not always easy. Compassion is not simply about responding to the feelings of those who are suffering, but rather it is a deep sense of commitment, and solidarity with them. It is this sense of solidarity, one's willingness to enter into the problems of suffering, the questioning of one's values, and the accepting of another's, that is the core of compassionate care. Compassionate care then is not simplistically taking away another person's pain or suffering, but it is entering into that person's experience so as to share their burden in solidarity, and hence enable them to retain their respect and dignity. *Nurse Helen* told me this story:

> Sometimes you watch patients suffer but you have to respect their choice to suffer. We had a patient who refused to take pain medication to almost the end. You couldn't turn him over, you couldn't do any of his care. Nobody needs to die like that but it's sometimes out of our control. In the meantime we suffer. By the time he decided to take medication he was so terrified of dying that we all cried. His wife then begged me to keep

> giving him something, anything and not everyone was willing to do that. We all endured suffering until it was over. I swore I would never put myself in that type of position again, but you always do. It's just a part of why we are there.

Commitment, remaining focused and poised to act, and enduring vulnerability, as portrayed in the above situation is the nature of true compassion. The courage to suffer with dying individuals (in a way that they choose) is not always easy. In this instance the dying individual chose to suffer in pain, and would not allow Helen to help by giving medication. Helen, in this experience, endured the vulnerability of feeling isolated from her patient's suffering. In honouring and recognizing his needs she endured vulnerability and created a space for suffering.

Strengthening Spirituality in Suffering: The Nurses Presence

My soul is very sorrowful, even to death: remain here, and watch with me.
(Matthew 26:38)

Spirituality is an inherent and integrating, and often an extremely valued, dimension of the dying journey of individuals and their families. Spiritual distress or "soul pain" is a common experience in those who are dying and often an experience that is not addressed or understood. Nurses discussed that prolonged suffering threatens the intactness of persons. The experiences are complex, varied, and individual, and if left un-addressed, may stifle the opportunity for growth, heighten the loss of a sense of meaning and purpose, and lend to poorly controlled symptoms. The compassionate nurse, in an embodied relationship of suffering with others, creates a moral space where she/he considers the dying individuals expression of spirituality. She embraces the loneliness, the anxiety, the need to incorporate a transcendent dimension in one's life (faith or religion), the need for relatedness, and or the need to search for meaning in suffering. For me, spirituality is an inner strength, related to a belief in and a sense of interconnectedness with a greater being. The embodied nurse values the dying individual's inner strength and enables them to trust the messages from their inner voice. *Nurse Beverly* voiced her role in helping dying individuals who are "lingering" in their suffering experience.

> There have been many dying individuals we cared for who have lingered in their suffering experience. It is our role to help them find their spiritual selves. I often have a conversation about what they believe about their suffering, what their inner self is telling them. Often it's discussing things like, what they need to accomplish, what is left not done, what they feel is holding them back. Sometimes they need to resolve some conflict within, or they are just not ready for death. Sometimes someone needs to come to them. These are spiritual issues that nurses help dying individuals acknowledge.

Spirituality delves into the nature of humanity, the deep mysteries of life. Spirituality, as related to nurses in an embodied relationship, encompasses: values, meaning, and purpose; turning inward to the human traits of honesty, love, caring, wisdom, and compassion; helping others to search for a higher authority, guiding spirit, or transcendence that is mystical; and helps to create healing of body, mind, and spirit that may or may not involve organized religion. Nurses in their practice, allow for an open interpretation of what the individual considers to be divine or a transcendent Other, and in helping others find their expression of spirituality, turn to their own deeply rooted values and beliefs. Thus, it is important for nurses, to explore the dying individual's beliefs about suffering and illness, and where they turn for comfort, security, direction, and answers. The following exemplar portrays *Nurse Ruth's* commitment to understanding a dying individual's beliefs about suffering and her illness. Prior to the shadowing visit, Ruth informed me that Esther seemed 'not herself' when she cared for her yesterday. She was feeling like there was "something on Esther's mind that she wanted to talk about".

During the observation I sensed the compassion of Ruth in trying to understand Esther's experience. She was not forceful but gave Esther the impression that she was "present" for her. Ruth's body language and her presence conveyed that she was interested in knowing how Esther was that morning, as she did not rush out of the room after her morning care. After filling out her dietary menu, Esther made the comment "I wonder what the rest of my life will be like, nurse"? Ruth sat close to her and focused her attention on Esther. Ruth asked how she was feeling and if she was experiencing any feelings that were frightening to her. Esther asked Ruth how her pain would be controlled? Would it get worse, would she be able to communicate to the nurse how she was feeling? Ruth, sensing that Esther was fearful of prolonged suffering, asked her if she had particular beliefs about suffering and if so, had these beliefs changed over the course of her illness? Esther did not have any particular beliefs about why she was suffering. She told Ruth that upon acceptance of her illness and facing her feelings about death and dying, that her suffering had changed. She was feeling 'OK' now but that the uncertainty of how the end would come was frightening to her. Ruth asked," Is there anyone that you have felt close to during this suffering experience? When you are closer to your death whom might you want to be present?" Esther talked about her daughter being present, but also mentioned that she was "worried about her daughter's ability to cope with her death". Ruth assured Esther that the health care team support and comfort would be given to her daughter during and after her death.

It is evident that Ruth felt competent and comfortable with addressing Esther's spirituality and her death. She tried to provide a dimension of hope, assurance and comfort in acknowledging Esther's spirituality and a commitment of presence in her dying journey. Nurses, on this unit, discussed that their encounters with facing mortality on a frequent basis encouraged them to look for signs that their patients were expressing their spiritual selves. *Nurse Nancy* told her story about how she knew her patient was needing to express his spiritual distress:

> You can usually tell when your patients have spiritual concerns or questions. Often times they will talk about their life experiences at various stages in their lives; such as past relationships, past deaths of individuals that they have been close to, things like that. You just get the sense that their reminiscing in the past is now bringing them to the present where they are now questioning their personal experience of dying. These are the kinds of clues that I usually take to mean that they are questioning their beliefs and sometimes expressing their faith to you. I always try to just drop what ever I'm doing and listen. Missing these kinds of openings, would only convey a lack of respect, that they and their spiritual needs are not important.

The way individuals cope with suffering is unique. For those individuals seeking help, the sense of relating to another, voicing their suffering is therapeutic. The choice to suffer alone may be sought as a path to individual growth or the suffering may become all consuming, making relations with others not possible. The following exemplar portrays *Nurse Helen's* commitment to be present for a patient (Bert), to ensure that his spiritual needs were acknowledged. In addressing these needs Helen helped him to express his feelings of loss, as a way of working through abandonment and spiritual emptiness.

Bert. Bert, you seem so sad today. Is something troubling you that I can help you with? Bert did not reply, but Helen waited in silence. Bert stared straight ahead, but the nurse remained seated, and placed her hand on his. Bert spoke to reveal that he was feeling lost. "With each day I realize that I am not able to do for myself what I used to be able to do. My wife, being blind is really not able to provide for me the care that I need. My sons do not want me to come home, as they cannot be there enough to provide adequate support. I feel alone and abandoned. Why is God wanting me to suffer this way? Where will I go from here?" Helen sensed that Bert was feeling very lonely in his suffering. Although she recognized that he wouldn't be going back home, Helen worked to connect him with his wife and sons who were important to him. With Bert's permission she phoned his wife and arranged for her to visit. She sensed that Bert would find comfort with loved one's being present in his suffering. Helen also arranged a visit with a clergy member whom Bert had spent time with before. Helen focused her attention to what Bert was expressing. She recognized that her presence was important so that Bert could be accompanied in his suffering.

In all of the exemplars provided thus far, nurses presence has made the difference in helping these individuals express their spiritual needs. Being present on a consistent basis through the process of dying is primary spiritual care and addresses a most fundamental spiritual need, the need for transcendence.

Transcendence is a quality of faith or spirituality that takes one beyond self and suffering. Transcendence is more than an acceptance in the process of dying. At its basic level, transcendence is the means by which one finds meaning, it is where all one's spiritual needs are met. The embodied nurse in meeting the "face of the sufferer" ***watches*** with the dying individual, without judgement, and creates a space for meaning to emmerge and for the devine Other to be revealed. In this, the nurse does not require understanding, answers, acceptance, or conquering; all that is required is to ***watch*** and be present. *Nurse Jennifer* explains:

> Some nurses have difficulty with silence. They feel comfortable only if they say something. You really don't have to say anything. Dying individuals don't expect you to. What you need to do is listen. They are the ones that need to share, and they will. And if its dark, subdued lighting helps, so they can see you, it's just comforting to know you are there.

The ability of Jennifer to feel comfort in silence is a gift of the human spirit and creates a moral space for suffering. Being silent and fully present is the ability to convey the personal fears, and transcend role obligations and acknowledge the vulnerable humanness of suffering. It provides confirmation, nurturing and compassion and is an essential transcendent act. In my fieldnotes I noted:

> I watched as the nurse sat by the patient's side, silently, quietly, as if no one else was there. The patient's eyes were closed, but the nurse was stroking the patient's forehead slowly and methodically. Once and a while the nurse too would close her eyes as if she was concentrating, reflecting and reaching out to the space where they would meet. The nurse was not hurried or bothered by the noises outside of the room, she was fully present, in body, mind, and spirit.

Searching for Meaning in Suffering

A life threatening illness can provide an opportunity to view things differently, to alter priorities, to generate new ways of living, and to assign new meaning to the experience. One does not find meaning in a vacuum; it has everything to do with relationships, spirituality, and is intertwined with the beliefs that one holds about their suffering. Nurses are part of the dying individual's and their family's journey; they help them to review their life, integrate their experiences, and perhaps make sense of what is happening in their suffering. Nurses, themselves, search for meaning in this experience.

While the process of finding meaning depends greatly on an inward journey, it also relies on the 'telling of' that suffering that is being endured, and the effects of this suffering. The telling may reveal itself in language or be conveyed by the eyes, through the hands, or just in the way the body is held. The telling is the connectedness in the shared journey of finding meaning in suffering. *Nurse Jennifer* tells her story of finding meaning in suffering in her embodied connection.

> I remember this patient, my very first time with him, I walked in and it was like there were these piercing blue eyes that looked at you and there I

> was with my clip board and I felt really uncomfortable with his eyes. He had a trach with humidity and his breathing was laboured. He was so air hungry, and had been this way for a week now. Everything had been tried, and nothing was easing his breathing. I put down my clip board and he grabbed my hand, and I sensed that he was frightened. It seemed like he didn't want me to leave the room. Knowing that he had no family I asked if there was anyone I could call like a priest. His eyes closed and I sensed that he was comfortable with this. I didn't leave the room, instead we prayed together that peace would come and that his suffering would end. The priest came and he didn't let go of my hand. Not just any hand would do. I stayed until he died.

Jennifer in her embodied connection shared in an unspoken search for meaning in this gentleman's last hours of life. Her spirituality was the key to transcending this loss, and finding ways of maintaining this connection in the face of suffering.
In her presence, Jennifer served to affirm herself as a participant in this search for meaning.

It is important to note however that not all individuals will find meaning in suffering. Meanings are contingent because of our humanity. The very enterprise of making meaning is conditional, never assured. Individuals who have struggled through their life to find meaning, may not, in the last days of life find meaning. Nurses discussed how individuals whose physical symptoms are unmanaged without remission, also may not be able to address meaning and other spiritual issues, as they are more likely to focus only on physical needs.

There are many however who grow from their search. Most individuals in their search for meaning, cross over barriers of physical, emotional, and spiritual to embrace loved ones, to connect to their past, to the future, or to their God. Families cross over to truly understand their dying relatives, to advocate for them, to mend relationships, and stay at their side Nurses, in their embodied relationship with patients cross over emotional and spiritual boundaries to be with patients in their search for meaning. Their presence helps dying individuals to find their "whys."

All of the nurses in the study discussed the suffering they experienced helping dying individuals and their families search for meaning to the questions, Why me? Why him/her? These questions are not ones for nurses or others to answer. Rather it is a response to stay with the patient in her or his time of questioning and doubt. Many times providing an answer only stifles the patient's exploration of the suffering and its meaning. The urgency and the despair under which such questions are often asked makes the search that much more challenging. *Nurse Barbara* said: "It is so unfair, so painful for patients to suffer and search for meaning, as they bring forth painful memories and regrets. How much more difficult can it get?" It is these experiences in which nurses reach across and hold on to those who are vulnerable in their search for meaning. The following exemplar told by *Nurse Barbara* reveals the nurses' call to relationship', in searching for meaning in suffering.

> I'll never forget the experience of a young man we had who was dying of cancer. The experience of loss was insurmountable to all involved. Our patient was young, and in his short life suffered much physical pain and indignity because of his illness. His physical pain was unrelenting and not

> controlled before he died. The emotional loss of losing his wife and daughter and feeling they're suffering was tragic. It had not been a long time since he had been diagnosed, the progress of the disease was rapid, and because of his uncontrolled physical pain, quality time was not available to focus on the meaning of his illness or suffering. His death was not peaceful and the outward emotion of letting go for the daughter was very hard. The intense emotions had a congregation of nurses in the room at the time of death to support each other. A few hours after the death the family left for home, and almost immediately upon exiting the hospital the wife and daughter were killed in a car accident, a senseless accident that we will never forget. The death was so overwhelmingly shocking that many of the nurses present needed to visit the emergency room to be with extended family in their grief. The enormity of intense suffering of so many individuals, will never be forgotten. Many of the nurses gathered together later to pray that the family was now together and that suffering was over.

In the face of suffering and death these nurses through prayer, compassionate listening and presence opened a door for the search for meaning to occur. Even though not all of the nurses expressed faith in God or a higher power, their spirituality helped them to reflect on their own relatedness, love for each other and privilege of caring for those individuals. In varying ways, faith was a key support for each of them, to whatever degree they have developed this resource. Faith is a factor that both nurse and patient must not impose or question, but acknowledge and respect. Facing one's own mortality brings us closer to humanity and our faith.

The nurses' embodied relationship helps those who are searching for meaning to review their life, integrate their experiences, and perhaps make sense of what is happening in suffering. Nurses in their own search for meaning, enhance the care of the dying individuals and their families, and the potential for healing in suffering to occur.

The Connection of Colleagues

As patients move closer to death the potential for healing is often reflected upon by the nurse and the patient. The compassionate nurse in an embodied relationship awakens the healer within 'self', her vulnerability, is the vehicle for connectedness to others.

Throughout the dissertation discussions have revealed the importance of nurses creating a moral space for suffering. Joint transcendence, the mutuality of a healing relationship between nurse and patient and the release of compassion can promote self-healing and harmony in both. But what happens to the nurse when suffering of her patient continues, is prolonged and not dignified? Who supports and cares for the nurse when the patient dies, or many patients die within a short time of one another? Who helps the nurse when she has not been able to help the patient die a 'good death', when pain and symptoms are not controlled? Who does the nurse reach out to in her own vulnerability?

Nurses on this unit in times of need turn to each other (their colleagues). I asked these nurses to describe their colleagues. What are the qualities of these nurses who are able to support each other time and time again in the face of death and suffering? *Nurse*

Muriel shared her beliefs about her colleagues, and the mutual reciprocity that they shared:

> Palliative care nurses are the most wonderful caring people that I know. They are authentic in their support, The falseness of our behaviour vanishes when we are a part of death and suffering. Emotions are authentic, undisguised. I feel comfortable in sharing my own emotions, to reveal them to these wonderful human beings. They make me feel special.

Caring for dying individuals can be stressful work that requires a supportive nursing environment if nurses are to endure it. Colleagues and caring leaders who trust, accept, protect, and value a philosophy of palliative care are most important. Colleagues must share their humanness with one another, be familiar of each other's philosophy with life and death, and accepting of each other's strengths and weaknesses. Together they must work as a team drawing strength from each other's resources. They share responsibilities, ventilate, validate feelings and thoughts; they cry, laugh, discuss, inspire, and confirm each other. *Nurse Barbara* said:

> The nurses are wonderful, so supportive. We get together a lot, even last night, we were all together and we shared what ever we needed to. It helps us get rid of anxiety, stress when other people can talk about what they have gone through with the same person, or what they've gone through in another situation. It really helps. So you have a few laughs, or we have a few tears, sometimes and we go on. We do have lots of tears every so often, there no place to hide. But there's always somebody that puts their

> arms around you and says you're doing a good job, or you've done OK, or can they help you? They're wonderful, they're wonderful.

Through rough times, the nurses sensed that they were becoming more secure as a group. They felt that there was always someone in whom they could confide, and from whom they could gain strength, inspiration, and confirmation. An abundance of humour, joking and laughter helped to relieve tension in tragic experiences. The nurse in a difficult situation can count on her colleagues to "step in if she needs to step out". *Nurse Jennifer* comments:

> My colleagues will come in and pitch in if you have a hard time. They'll come in with you, or they'll deal with procedures, events, or whatever you need. It's that support again. Nobody ever, ever condemns you for your beliefs or how you do things on the floor. They always pat you on the back for doing a good job.

These nurses have grown together as many have been friends for fifteen to twenty years. They share in the lives of each other and their families, they are much more than just co-workers. The nurses in this study learned most about themselves from others, colleagues and patients. Through their interactions with others they have recognized and put to practice their own limitations, learned that no one, including themselves, is perfect, and that interdependence leads to every chance of succeeding. The unit environment that they have created is pleasant, peaceful, and nurturing. The nurses felt that the leadership, sensitivity and understanding of the care they had to give is acknowledged and respected. Most nurses, they said, are dedicated and committed to giving and following a palliative care philosophy. Of course there are others, because of a lack of experience or perhaps limited self- awareness, who are fearful of a suffering individual. They distance themselves from those individuals, making it difficult for others. Nurses on the unit understand. They do their best to guide and teach less experienced nurses. *Nurse Beverly* explains:

> Nurses on the unit know what it is like to be fearful of pain, suffering and your responsibilities as a nurse. We have had nurses who are scared to give too much analgesic, they don't want to be responsible for making someone too drowsy. It's scary to think that you have that much power. But you learn that it only lasts for a short period and in the end, the patient is much more comfortable. We support one another in these circumstances for the good of our patient's well being.

Summary

Most of the nurses see their role as being in a human to human relationship. Their professional knowledge and skills are a part of who they are as individuals. Being visible as a person, giving of the self, and exposing one's self to one's vulnerability are part of who they are as individuals. Being competent, enduring the suffering, and portraying a professional image provide both personal and professional satisfaction. The nurses perceive that they are improving their caring abilities, self- understanding, and their way of being. Although the context in which they work is changing where dying individuals are not remaining in hospital to die, nurses continue to allow space for others. In creating a space for suffering with others, nurses allow the possibilities for strengthening spirituality, and finding meaning in suffering. Nurses have voiced the connection and healing that is created together. It was born out of a relationship to suffer together, to commit, endure, tolerate and allow-together. They look to the future with hope. These nurses are motivated by their work and draw satisfaction from it, especially from the warm recognition they receive from patients and families. They are privileged and proud to be palliative care nurses.

Chapter Eight

The Continuing Conversation of Nurses Caring for the Dying

Pain and suffering belong to our pact with life. They are unavoidable if ominous companions and they cannot be written out of the script of life. Disasters are constituted by suffering, but not all suffering is a disaster. My suffering, the suffering of the I is something for me to work through, to get beyond.

(Caputo, 1993, p. 29)

Suffering is not bad, it is an expression of our humanity that calls to another. If the other responds in love and authenticity we can find wholeness and peace in our suffering. Left untouched, suffering can destroy our body, mind, and spirit

(Nurse Nancy)

In a sense, this research study has been a journey that is akin to rock climbing, difficult and exhilarating. Both activities force you into uncharted territory. Both share common qualities of uncertainty, anxiety, exposure, and loneliness. Both allow you to take responsibility and cultivate each step, even though you are roped to a wonderful team.

In this chapter, I discuss how interviews and observation visits with nurses, within their culture of caring for dying individuals, have led me to refine, foster, and develop a new view of what it is like for nurses to care for individuals in the dying journey. As I reflect on these changes, I am aware that my assumptions about palliative care nurses and the nurse-patient relationship have been affirmed and strengthened by this study. The importance of the nurse-patient relationship for healing and wholeness is profound. I have also learned a great deal about my views on suffering. I continue to believe that nurses' suffering is a moral response to the suffering of another. My beliefs about 'alleviating' suffering and the way in which nurses have come to understand suffering have changed and I will discuss how my thinking has evolved.

Descriptive knowledge from a study such as this is not easily presented in terms of conclusions and generalizations. Thus, I will attempt to capture the essence of this research journey by summarizing a few of the most influential factors that made a difference along the way, and propose what is needed from here in relation to education, practice, and research. The following three questions will serve as an organizing framework for this chapter: How has this ethnographic inquiry and proposed conceptual framework fostered understanding of this topic? As nurses in an embodied relationship of caring for dying individuals who are suffering, what should our moral actions be in helping to achieve self-healing and harmony for both nurse and dying individual in the journey? Finally, how has my understanding of caring for dying individuals, and suffering been transformed by this work?

Ethnography as a Way to Understand

An ethnographic inquiry is complementary to the philosophical foundations of palliative care. In beginning of the journey, this work asked the question, "What is it like for nurses to care for dying individuals? " Palliative care is 'whole' person care not only in the sense that the 'whole' person of the dying individual (body, mind, spirit) is the object of care, but also that the 'whole' person of the nurse is involved. The process of interview (conversation), and participant observation fostered an understanding of 'whole' person care. A palliative care philosophy also gives voice to dying individuals and their families, and the caregivers involved in the dying journey. The immersion into the culture of nurses, and the recognition of multiple viewpoints (nurses, dying individuals, and their families) is upheld by this inquiry.

The nurse's work in palliative care is always evolving as is the written text. The weaving together of nurse's stories, and interpretation from field notes (observation from shadow visits and quotations from related literature) began the process of writing an ethnographic text. The writing and rewriting continued following a second level analysis where data are arranged in themes. The ongoing rewriting developed into an ethnographic text that conveyed the context and humanness of the nurses' experiences in caring for the dying. The next level of analysis is left to the reader to form his/her own insights about nurses in the palliative care culture. The ethnographic text continues to evolve as the context shapes and is shaped by each unique experience of dying.

Overall, ethnographic inquiry has allowed me to bear witness to day to day experiences of nurses caring for dying individuals, and discover a deeper understanding of the ways of being, knowing, and doing that are inherent in a culture of palliative care nurses. I was able to observe, as well as understand from interviews, their commitment to embodied relationship as they journeyed with dying individuals.

The Theoretical Framework

In coming to the question: What is it like for a nurse to care for a dying individual? I proposed a theoretical framework to understand suffering in the context of the nurse/patient relationship. Conceptual underpinnings included embodiment and relationship. The following were stated as assumptions/purposes of the framework: 1) embodied relationships are inherent in the moral world of palliative care nurses to reach, acknowledge, and understand suffering, 2) nurses share their vulnerability of suffering as a way to reach the bodily suffering of others, 3) studying suffering in this way will allow for a more holistic/harmonious understanding of the body and self of suffering.

The assumptions of the framework were certainly supported by the findings of the study. The framework enhanced the potential of understanding suffering for palliative care nurses and nursing as a discipline. The data suggest that nursing is an art and a science, and that diverse patterns of knowing are necessary as nurses care for dying individuals. Nurses assimilate knowledge beyond empirical (scientific, factual) knowledge including ethical, personal, and aesthetic knowing. These ways of knowing are required for moral, humane, and personalized nursing (Stein, Corte, Colling & Whall, 1998), and the potential for harmonious/holistic understanding of suffering. The data also suggest that nurses ask ontological questions related to their ways of being in intending to understand suffering.

Ethical knowing, which constitutes the ethics of nursing, was revealed by nurses in an embodied relationship where the moral obligations of nurses to reach, acknowledge, and or intend to understand suffering was an imperative. Nurses, intending to understand suffering, create a space where nurses and dying individuals connect, where the potential for healing and or a transcendent coming together is possible. Nurses in conversation with dying individuals, explore values and beliefs that are important in the moment of suffering. It is in this space of understanding suffering, where nurses ask, Who ought I to be morally and how should I act?

The pattern of personal knowing, the quality, and authenticity, of the nurse patient relationship is revealed through personal/relational knowledge. The intention to understand suffering happens in a "call to relationship," where nurses question their own suffering, in relation to caring for the dying individual. This pattern is concerned with the knowing, encountering, and actualizing of the authentic self (Carper, 1978). It is clear that self-awareness is a precursor for reaching/acknowledging, alleviating, and or intending to understand suffering. Personal knowing is not only knowing one's self, but rather knowing how to be authentic with others. Being authentic means revealing one's needs and goals to relieve suffering. The findings suggested, however, that suffering is uniquely personal, and thus reaching and or alleviating another's suffering may not always be a realistic goal of the nurse, as working through suffering remains internal to the dying individual.

Asethetic knowing reveals the nurses' perception of what is significant in the moment of suffering. The pattern is focused on particulars rather than universals (Carper, 1978). Palliative care nurses pay particular attention to their "artful" practice, in an ontological sense. Nurses consider what their perceptual sensibilities reveal to them about the environment, their feelings of comfort/discomfort, and their connection to the dying individuals' suffering. In embodied relationships, nurses creatively and knowingly engage with dying individuals to envision possibilities of pursuing a 'good death." The importance of aesthetic meanings (shared vulnerability) in the dying journey is enacted in the nurses presence, as they attempt to relieve difficult symptoms, support finding meaning, and strengthen spirituality in suffering.

Carper (1978) and Chinn and Kramer (1999) point out that each pattern of knowing is an essential component of the integrated knowledge necessary for professional practice. This study has uncovered the importance of an epistemology that allows for not only empirics, but for an advancement of asethetics, ethical values, intuition and discovery, and a way of being in an embodied relationship with dying individuals. In creating a space where this knowledge and ways of being is enacted, the potential for and synthesis of understanding, the whole experience of suffering, is possible.

If one were to operationalize this framework in practice, the following questions need to be considered: 1) How will this framework change the day to day acts of nurses, 2) are the goals of nurses to reach, alleviate, and or understand suffering favourable to dying individuals, 3) would all palliative care nurses embrace this type of framework as a guide for their practice? The following themes suggest the potential benefits and challenges of the framework for these palliative care nurses, to capture the knowing and being of suffering.

Themes from the Ethnographic Inquiry

Nurses are 'called' to relationship. The nurses in this study frequently described caring for dying individuals as being a "vocation" or "calling," reflecting a moral and or spiritual essence to their care. The term vocation which is derived from the Latin word *vocare*, "to call," is broadly understood as defining an individuals' felt "call" to a particular ministry or work (Olson & Clark, 2000). In theological terminology the word vocation generally refers to a Divine call to undertake a particular activity or embrace a particular "stage of life" on behalf of God or the community (Olson & Clark, 2000).

Being "called" to relationship is an appropriate description of evoking a way of "being". Being called to care is a willingness to Be in significant relation, to be responsive to others, to be in spirit together (Chinn, 1994). Nurses as persons, described their "call" as a "giving," to be responsive to others, "to keep us in touch with life as it really is ", *Nurse Barbara* claims. The experience of suffering and evil turn on a "hermeneia," a certain reading of the human condition, and on a certain responsiveness and sensitivity (Caputo, 1993). Nurses in this study acknowledged that the imminence of death breaks through the facades behind which one can tend to hide. Stepping out into the open is refreshing but it is scary. By developing authentic care, nurses find that the rewards are immeasurable. A "call" to relationship is revealed to the nurse by looking into the face of the other. Olthuis (1997) invites us to see the face as "an epiphany of the nakedness of the other, a visitation, a coming, a saying which comes in the passivity of the face, not threatening, but obligating. I encounter a face, my world is ruptured, my contentment interrupted; I am already obligated" (p.136). In looking into the face of the other, nurses see and feel the pain but also see the spirit that people discover within themselves. Nurses care for the whole person (body, mind, and spirit). Being with people on the journey is a special kind of work that offers fulfilment of being in relationship with others.

The nurses are persons. Nurses learn and experience the art of building and sustaining relationships, and of bringing an authentic self to the relationship. As a person and as a nurse, the nurse has a desire to commit her/his self to the patient, to consider all their needs, physical, emotional, and spiritual. Regarding the patient as a 'whole' appears to require nothing less than the nurse acting as a 'whole' person. Therefore the nurse who withholds a part of her/himself is unlikely to allow the dying individual to emerge as a whole, or to comprehend that wholeness if it does occur. Nurses profess that they are not afraid to be involved; palliative care nurses need to be involved in order to make a difference. It is this sense of responsibility that helps sustain the call. Responsibility is responsiveness. To be responsible in an ethical way, one needs to understand the other person as well as the self. Self-understanding begins with understanding, one's own values and beliefs, having a sense of self. In understanding self, one can begin to understand the other (Vander Zalm & Bergum, 2000).

The relationship is a moral commitment. Nurses accept the pain and suffering as a part of their presence with dying individuals in their journey. Nurses' presence is a paradox; it is both simple yet difficult. It is simple because of the desire to help others; it is difficult because closeness that is mutually beneficial in a relationship increases the risk of vulnerability for nurses as well as patients. Gadow's (1999) discussion of sharing one's vulnerability provides us with valuable insight. She suggests that it is through embodied relations' where nurses reach out to others who are suffering. By joining another in vulnerability, nurses become vulnerable. Sometimes, the suffering of another may be so difficult to connect with that it may silence the expression of nurses. For dying individuals' emotional complexity to be understood and supported, the emotional dimension of nurses' being cannot be excluded, but must be consciously and directly engaged. Moreover, just as with the emotional, so too must the aesthetic, intuitive, spiritual, and physical dimensions of nurses be brought in relation to others'. Nurses in this study discussed that nurses who witnesses suffering, see a person suffering. It is our personhood that brings us to share in the suffering. Nurses risk hurt to keep the hope of wholeness and peace alive. Gadow (1999) discussed how nurses who do not let go of their vulnerability are able to reach across and hold on to patients in their vulnerability. Vulnerability is a "pre-reflective consciousness of the self" (Gadow, 1980, p. 94). This moral process or choice is compassion.

Compassion includes the intensity of self. A compassionate nurse feels the intensity of suffering. This compassion however allows them to reflect on or act in an attempt to comfort or alleviate the suffering of another. The vulnerability of others becomes the vehicle for authenticity. The intensity of suffering serves as a reflective process necessary for nurses to help dying individuals whom are suffering. Nurses concentrate on how they can best help dying individuals. This concentration or reflection is helpful to nurses in remembering why they are there. It gives nurses strength. Nurses experience suffering in the moment; there is no set plan or regimen to 'treat' suffering. The nurse's presence is supportive and empowering to patients and families as they travel an uncertain journey. Nurses in an embodied relationship ensure that the sufferer is not alienated, that the experience has been acknowledged, and that the possibilities for healing occur in listening and in dialogue between nurses and patients.

The " local moral world" for these nurses is changing. Experiencing the "local moral world" of these nurses has deepened the understanding of palliative care nurses and of human suffering, by reframing the experience of caring for dying individuals as an interpersonal process in a moral context (Kleinman, 1992). As a researcher, experiencing the "local moral world" gives primacy not only to the subjective reality of individual nurses, but to the social reality of this particular group of nurses. There are many cultural, political, economic, institutional, and relational sources and consequences that have affected their collective world.

The way of life for these nurses is a moral process of interpretation and collective experience, composed of many voices that foster social action between people (Kleinman, 1992). The values and beliefs that guide their individual and collective thoughts, actions, and decisions have not changed, yet their world surrounding them has. Within the healthcare system, decisions of economics in this world now drive the place of death. No longer is the autonomous choice of patients to die in hospital respected and upheld. The move to dying at home, in the community, is the environment that is viewed as economically feasible, and that allows for increasing autonomy and quality of life for dying individuals. At present, the dilemma that exists is that adequate resources for dying at home are not always present, resulting in fragmented care for all involved in the dying journey.

The "local moral world" of these nurses, in particular their roles and relationships with dying individuals, has been affected in many ways. The health care system acknowledges only the importance of "organizing dying individuals pain and symptoms, and preparing them for discharge to home." Valuing the intimate nurse –patient relationship is no longer a priority. Nurses' time is rushed resulting in "pressured care," little time for "presence," that makes a difference for nurses and patients in the dying journey.

Nurses' expressions of discouragement and suffering disrupt the "local moral world" and challenge their perceptions of who they are as palliative care nurses. Through this process, nurses gain new wisdom, but this does not replace the embodied relationships with dying individuals they once felt privileged to share with all their patients. The beliefs and behaviours of nurses in their "local moral world," striving to embrace the vulnerability of suffering, becomes a challenge. In many instances nurses struggle with the loss of the intimate nurse-patient relationship, finding it difficult to enact a moral process that intends to understand and heal suffering.

Actions for Self Healing and Harmony of Nurse and Patient

Ethical reflection of 'self.' Reflection is first and foremost if moral actions are to help achieve self-healing and harmony of both nurses and dying individuals. Reflection of self leads to exceptional quality care that is in spirit with our humanness and results from the beliefs and values that underlie nurses actions. Wiedenbach (1964) noted that the nurse's philosophy regarding the significance of life and the worth of each individual determines the quality of nursing care given. Nurses are usually aware of what they believe about nursing (our role as nurses), and about dying individuals (persons deserving of respect, dignity, and worth), but nurses also must turn inward to face their own existential questions. Personal knowing or knowledge of themselves allows nurses to engage with others as persons. The expressive dimension is the self as authentic (privately known) and disclosed (revealed to others) (White, 1995). "Personal knowledge is expressed as ourselves through the self"(Jacobs-Kramer & Chinn, 1988, p. 135). Nurses must believe that who they are as carers is the cornerstone of the healing process. Having an awareness of themselves as persons is the containing space for the other who suffers.

It is discomforting to be reminded of one's own mortality. Nurses however cannot offer 'whole' person care without opening themselves to those reminders. Nurses need to reflect on and explore their spiritual and ethical values, and their philosophical beliefs about illness, suffering, and death. Nurses maintain their personal integrity by providing the kind of care that is consistent with their values. The nurses in this study expressed that understanding their own suffering enhanced the possibility that they would be competent, and be trustworthy, and that they would give of themselves, listen attentively, encourage hope, and be open and honest. It is their own experience of suffering that enables them to be compassionate and share in the plight of another (Gregory, 1994). Personal suffering has a hollowing effect; it allows them the internal space to be able to contain the suffering of others.

A moral space. Nurses create a space that engages the other in the unique moments of suffering. *Nurse Beverly* said, "There is no plan to treat suffering like pain is treated; it happens in the moment." "The moral call is thoroughly personal, the command is not universalizable" (Bauman, 1993, p. 51). In their presence, listening, enduring, and touching, nurses create moral space. When nurses allow space for another they suffer together. Nurses do this in union or relationship with dying individuals. In creating a moral space, nurses are sensitive to the timing of their actions and are listening to the context of the situation. Their focus is on the moment, on the person's suffering. It is in this moment where the nurses intend to understand the experience of suffering. Bergum (1994) discussed the need for inherent knowledge that is constructed in the moment, knowledge that is constructed through understanding of the person. Suffering is understood within the individual's framework of meaning, rather than acknowledged from without by the nurse. Inherence, from this perspective places the condition (disease) within the individual's framework of meaning. The experience of the 'disease' is lived by that person, and the data come from within, rather than analyzed from without by the nurse. Knowledge for ethical care then is found in that particular experience at that particular time. It is a part of the nurse/dying individual's relationship that involves mutual respect, engagement, mutual thinking, embodiment, vulnerability, and freedom (Bergum & Dossetor, 2002). It is in this relationship that a moral space is created. It is within this space that nurses understand, give support, and foster hope for a peaceful death.

Suffering may not be relieved. Nurses should not assume that their moral actions always alleviate suffering. Alleviating suffering has always been the cornerstone of the mission of nurses. Lindholm and Eriksson (1993) suggested that compassion always alleviates suffering. I questioned whether this mandate has led us down a confusing path, as nurses do not have the ability to always alleviate suffering. The findings in this study support that nurses are committed to alleviating the suffering of dying individuals for whom they care. Nurses suffer with dying individuals so that suffering is shared and acknowledged. Nurses act out of compassion to help dying individuals strive for peace and wholeness, but nurses do not always alleviate suffering. The locus of suffering rests with dying individuals (Gregory, 1994). It is only patients who can ease their burden of suffering, as suffering is ultimately a personal matter (Cassell, 1982). Nurses' embodied relationships and their compassion may serve to help dying individuals search for meaning, strengthen spirituality, and re-establish a sense of connectedness. Nurses' compassion will allow dying individuals to work through suffering, but the suffering itself may not be alleviated, or eliminated. Nurses in this study were comforting to dying individuals. Knowing that another person shared in their suffering was a human connection that validated their suffering. The nurse's presence and compassion became the balm and hope for its relief. It is important for nurses not to undermine the importance of their embodied presence. In their compassion they need to be cognisant that 'being there' will not always make suffering go away or ensure that the meaning will be found in the suffering of dying individuals.

Suffering cannot be controlled. Nurses must reshape their vision of suffering as one that is a part of humanity, one that is not to be controlled. Suffering is the substance of life and root of personality, for only suffering makes us persons. At the root of suffering is endurance or bearing under (Gregory & Russell, 1999). "Persons who suffer are caught in something that at the time, seems without escape, without end" (p.177). In suffering, a part of our self risks being threatened or destroyed. Gregory (1994) discussed the merit of working through or transcending suffering as allowing individuals to endure suffering. Although nurses in this study did not want their patients to suffer, they did see the value that suffering brought forth for both the nurse and the dying individual. Nurses need to realize that suffering allows both nurses and dying individuals an opportunity to reflect on their values and beliefs about suffering and death. For dying individuals, suffering provides an opportunity to review their lives, and possibly strengthen relationships with family and friends.

As nurses, we need to consider the benefits that our suffering may have for dying individuals. Nurses need to recognize that their goal of achieving a "good death" is not always reachable, and honour their ability to endure suffering as a strength that allows them to help dying individuals in their suffering. In their vulnerability, nurses reach out to hold onto the dying individual's vulnerability. The nurse's vulnerability shows the intention of understanding the dying individual's suffering, and enables individuals to endure suffering, as they know that they are not alone in their suffering. This act of compassion begins the process of understanding the suffering of self and other. This does not mean that nurses should stop their efforts in pursuing a good death, or that they should change their vision of what a good death means (suffering was not present, that the individuals are able to experience peace, serenity, and wholeness as death draws near). Rather, nurses need to be cognizant of their attempts to control patient's suffering, by giving medication or abandoning dying individuals. *Nurse Muriel* said "we need to have courage to admit that suffering exists, and we need to try and reach it."

One way to try and reach suffering may be through fostering hope for a peaceful death. Travelbee (1971) viewed hope as receiving assistance from others, believing that positive change will occur in the future, perceiving that choices are available, and being able to experience trust, perseverance, and courage. Travelbee suggested that a nurse could not give hope to another individual, but could assist those who are suffering to maintain hope and avoid hopelessness. The nurse may assist in this process by being available and willing to help. Through their caring relationship, they may foster the development of hope.

Jevne (1991) discussed the importance of offering 'hope suggestions' by our actions and use of language. She states, "words can convey possibility, or can imply that there are no alternatives" (p. 21). Words to describe or explain suffering are not always possible, as suffering for some individuals may be unspeakable. The intention to listen, to be present, and to understand may be the key to maintaining hope or avoiding hopelessness. Several observations of nurses with dying individuals, revealed the importance of nurses bringing forth in conversation, dying individuals stories of suffering. These stories are where suffering looms, and nurses are able to reach the dying individuals suffering.

Changed Understanding

Can we truly understand Suffering? Prior to this study I believed, and the literature suggested, that nurses did not really understand suffering when caring for dying individuals. My thinking has been refined and changed by this study in many ways. I have begun to question the notion of 'understanding' suffering. I wonder whether one can truly understand another's suffering. Understanding presupposes the notion of certainty. In the dying journey, the path is bumpy, it is uncertain. This study has fostered my belief that each individual's suffering on the journey is unique and 'happens in the moment.' The intention to understand an individual's suffering is what matters to nurses. *Intention* in the Oxford Companion to Philosophy (1995) states that the notion of *intention* is directed towards action that is conceptualized in relation to others. During conversation with nurses and observation visits, I witnessed the intense desire to be in relationship, with the intention of understanding the dying individuals' expressions of suffering. Perhaps it is the 'intention' to understand suffering that is more realistic than the notion of 'understanding' suffering, as the certainty of 'understanding' suffering does not exist. This act of intention is compassion. This intention to understand, I believe has gleaned a different conception of understanding suffering. 'Understanding' in this sense, is not the spoken words of what suffering means, but rather an 'intention' to embody and commit to another's suffering. Through this commitment, one is oriented to interpreting the moment of suffering individuals' experience, often unspoken. Such a relation uses forms of knowledge that are not abstract but rather immediate, local, intuitive, emotive, informed, and embodied (Bergum, 1992).

This study revealed the importance of relational (inherent) knowledge in understanding the experience of suffering. The text (writings) uncovered suffering in an embodied relationship, the mutual sharing of vulnerability, trust, and connectedness that bring nurses and dying individuals closer to suffering and to humanity. Inherent knowledge of suffering is constructed through understanding the person, not as an objective body (a thing, heart, or breast), but "a living person where the body and self are one" (Bergum, 1994, p. 73). Nurses must link their abstract knowledge of suffering (pain, loss) to their inherent constructed knowledge of this person as 'a living person'. Of importance for these nurses was the ability to focus on the suffering that was expressed in the 'moment' and that which occurred in relationship, rather than the suffering analyzed from a chart or even from another colleague. This knowledge is "irreplaceable and unique to relationships, patients, and nurses," and is the knowledge of intending to understand suffering. Understanding suffering in the 'moment' took suffering to a deeper level where the intertwining of the physical and metaphysical closeness fostered the unity of body and soul (Kitson, 1987). Through attentive listening, touch, eye contact, and a sharing of one's vulnerability, nurses come to know the experience of suffering.

The importance of this relational (inherent) knowledge was also revealed when nurses discussed their dissatisfaction with the health care environment that threatened the possibilities of developing and sustaining embodied relationships. Without these relationships, knowledge of suffering is disengaged, felt to be more 'objective' and 'superficial'. Nurses without these relationships, suffered in silence. In a system where time to develop relationships and quality of care is lacking, the sharing of ones' vulnerability (suffering) is not possible. *Nurse Helen* said the luxury of "seeing your patients through the journey of dying no longer exists ". The intention to understand suffering, as well as these nurses fulfilment as nurses suffers as a result. In summary, I believe that an embodied relationship is necessary if inherent knowledge is to be constructed. Inherent knowledge is imperative for ethical action (compassion) to occur. Understanding suffering without inherent knowledge is shallow and inauthentic, and distorts nurses' reason for being 'called to relationship' in palliative care nursing.

Summation and Recommendations

The purpose of this study was to capture the experience of what it is like for nurses to care for dying individuals. Immersion into the culture of nurses through interview and observation uncovered the everyday work of palliative care nurses, the rewards and costs of commitment to palliative care. I have attempted to uncover the culture of palliative care nurses. The context of this palliative care culture brought out the richness of nursing practice and human spirit. The day by day journey of palliative care nurses is uncertain, but aims to comfort and alleviate symptoms, pain and suffering. Intention to understand and be fully present in the dying journey, requires that nurses must first, however, be aware of their own mortality, their beliefs about suffering and dying, and their moral agency that commit them to this work of pursuing a 'good death.'

Ethnographies such as this one, always remain an attempt. Our observations of nurses caring for dying individuals are ever changing. On the basis of this study, I pose the following statements and recommendations for education, practice, and future research:

Nursing Education

Reviewing the literature has identified that training programs have historically been deficient in directly addressing the need for palliative care education (Wilson, Anderson & Fainsinger, 1998). It goes without saying that nursing curricula should include palliative care as a compulsory area of study in both theory and clinical courses, and that educators should value the philosophy of palliative care as appropriate for many other areas of nursing practice. To value the philosophy of palliative care, however, one must recognize both personally and professionally, the importance that healing has in health care, as much as 'fixing' or 'curing.' By *healing* I mean the process of caring for or attending to the whole person. Healing is an integration or balance of the physical, mental, emotional and spiritual dimensions of ones self that leads towards personal growth and development (Olson, 2000). It is not something that can be "given to" or "done to", healing must come from within, others' can only facilitate healing. Most literature on *healing* emphasizes the importance of self-healing or self-care.

Nursing education needs to acknowledge the experiences that dying individuals can give to our student's learning and growth as individuals. The most important teachers here are the dying individuals themselves, and nurse educators must begin to become creative in finding these experiences for students. Students at different levels in their education would participate in different types of experiences. For example, connection with an individual with a chronic illness throughout their training may be helpful. Another possibility for a more senior student might be to spend time in a dying individual's home, participating in their care, attending in the continuum of care, as the patient moves through the transition of the dying journey.

Having received class theory and understanding the philosophy of palliative care, it would be helpful for students to attend some training sessions, similar to those of volunteers who choose to give support and be with dying individuals. I have chosen a relationship with a dying individual who is suffering, as an example. These sessions might be beneficial in allowing the students to reflect on what a healing encounter with a dying individual might be like in a controlled and safe environment, and to explore relational practices that are therapeutic in responding to dying individual's verbal and non-verbal expressions of suffering.

Understanding a Suffering Experience. The following suggested by Kearney (1996), explores how a session might unfold. The session might begin with the words of Cicley Saunders (1967) " I only want what is in your mind and in your heart" (p. 194). These words uncover the value of the students bringing themselves to the dying individual's experience. The facilitator then introduces the experience of 'total pain' exploring the many layers that are a part of it. In essence many of these layers respond to intervention however many do not. Some aspects of total pain do not respond and require a different understanding and approach. This approach requires more than our knowledge and skills, it demands something of us as persons.

The facilitator then explores suffering as a metaphor for those aspects of the patient's experience that do not always respond to intervention, and helps the students to understand that healing of suffering comes from within the person. This understanding invites the students to see that our relationship with an individual who is suffering is very different than an individual who is in pain. 'Helping' a person in suffering means finding ways of enabling a person to endure and live with their experience. To allow this we must stay with the person in their suffering. This is never easy as it brings us into suffering. Helping our patients in suffering has a lot to do with who we are as carers.

The facilitator then invites the students to reflect on an experience when they have been with a person who was suffering and no matter how hard they, or anyone else, tried, that person's suffering would not go away. Then, remembering the person and details of the situation, reflect on how they were feeling and how they reacted. By reflecting and writing what they remembered, the students are then asked to share their stories and identify with other students, common feelings or reactions.

The facilitator then asks students to consider how the person in suffering may have been feeling. This may uncover that many of the emotions are the same and thus shared. It is also important to help the students recognize the difference between response and reaction, where *reaction* is an unconscious action and *response* describes a conscious choice to act in a particular way. It is important to emphasize that there is not a right or a wrong way to respond, but this exercise gives us a way to recognize our patterns of reacting in the presence of suffering. In essence exercises such as this one, allow the students to discover the importance of bringing one's self to the experience of suffering, and a space for the person in suffering to enter. It is a beginning to help students see the potential for healing to occur in this relationship.

Nursing Practice

In this study I have come to understand and respect that nursing, as a discipline, blends varying forms of knowledge uniquely in practice: empirical, relational, and personal knowledge. First and foremost, the nurses in this study have affirmed the respectfulness of the other's knowledge that comes from living with the experience of dying and suffering. They have helped me to understand the importance of reciprocity of relationships in practice. Suffering is reciprocal and is experienced through embodied relationships, nurtured and supported in the space that is created between the nurse and the patient. In this space the nurses see, feel, and touch the dying individual's suffering.

Suffering has the potential to disconnect and alienate the dying individual from the deepest and most fundamental aspects of her/himself. Dying individuals who are experiencing difficult pain and symptoms, experience what Kearney (1996) calls "soul pain." Nurses assume responsibility to assist and alleviate these (physical, emotional and social) symptoms, using informed, up to date knowledge and skill.

It is compassion that helps us to act and respond to the suffering of another. Compassion is concerned with the whole person, and practices with consideration and sensitivity to the sufferer. Compassion or "suffering with" in an embodied relationship, invites several qualities of a nurse, necessary to act in a mutual and collaborative way. These qualities are: patience, honesty, humility, courage and commitment. Exploring these qualities here will elucidate nursing interventions with potential to attend to and or alleviate suffering.

Firstly nurses in an embodied relationship must have patience. *Patience* is a kind of perceptive participation with the other in which there is a sense of the other's own time and space. The nurse waits for the individual to "take in," and "to work through" their experience of suffering. With patience, nurses focus on moving away from their own needs, worries and tensions, to focus on the others. Nurses in this study discussed that with time pressures and heavy workload, patience was not always easy. There are times when significant situational constraints interrupt this goal. Situational constraints are "aspects of structural and interpersonal work environments that impede our standards of practice and thus jeopardise the quality of patient care" (Rodney & Starzomski. 1993, p.24). One nurse found that sharing her frustrations with the dying individual was therapeutic, as this sharing was often what helped to move her forward. In patience, the nurse remains in this experience of suffering, she "suffers with," and does not abandon the sufferer.

The nurse in this suffering relationship enacts *honesty*. In this experience she is open to herself and to the other. She continually questions her responses of suffering to the other and reflects on her emotions and feelings in the experience. She is conscious of her own body and that of the sufferer. She is authentic in her feelings with the sufferer and does not deliberately deceive or hide her feelings.

Humility is present in the embodied relationship of suffering in several ways. In each suffering experience the nurse fosters the uniqueness of each personal experience of suffering. Although the nurse brings her/his past experiences of suffering as part of knowing, she/he embraces each experience as one that will allow growth personally and professionally. The nurse pays attention to the sufferer as an individual, without imposing her/his own agenda. The nurse acknowledges the dying individual's suffering, invites the sufferer to share what they are feeling, and most importantly listens to the narratives of suffering that may be shared. It is these interventions which create space for another to enter freely, feeling trust and comfort.

Courage in suffering implies a withdrawing into oneself in order to create space for another to be her/himself. It involves challenging our own constraining and facilitating beliefs (Wright, 1999) about suffering, and concentrating on the stirrings of our own soul. Through sharing our pains with dying individuals, "we become aware that we do not have to escape our pains, but that we can mobilize them into a common search for life, those very pains are transformed from expressions of despair into signs of hope" (Nouwen, 1972, p. 93).

All of these qualities require *commitment.* The nurse who is committed accepts full responsibility for her/his actions and is willing to risk suffering with others, to be a witness to suffering. Those who refuse commitment by becoming detached, callused, and cynical in suffering are 'spectators' to life rather than 'witnesses' (Taylor, 1991). Creating an open space for suffering to occur can be achieved only at the cost of suffering oneself. Commitment is a moral expression of responsibility, responsibility that occurs from a call to relationship with others.

Nursing Research

Several questions from this study uncovered the need for further research in the experience of dying and suffering. In doing this study there were many experiences of suffering that were explored and many more that were left untouched. I wonder if these moments of suffering are ones that are unspeakable, or belong to the unknowable nature of suffering? Frank (2001) alluded to these questions when he asked; Can suffering be researched? Can research contribute to further suffering?

It is evident from this study that suffering has been uncovered in many ways, taught me a great deal, and allowed me the opportunity to reflect and grow from these experiences. These experiences compel nurses to offer healing practices that relieve suffering, and conduct research, to further our knowledge about what nursing practices actually do diminish or relieve suffering. Researching nursing interventions to attend to and or alleviate suffering is important in our discipline, particularly now when much research has been done to describe or define suffering (Morse & Carter, 1996; Morse & Penrod, 1999). While all these efforts have been helpful, I continue to believe that the best way to understand suffering is to explore conversations and experiences of nurses caring for those who suffer.

From this study there are many beliefs and meanings of suffering which need to be further explored. The belief that dying is in essence a spiritual experience was revealed in many conversations and observations with nurses. Wright (1999) suggests that suffering lead us into the spiritual domain as we are faced with asking the 'big' questions of life. She believes that suffering and spirituality are intimately connected. Research is certainly needed to understand the nurse-patient relationship in connecting suffering and spirituality, as well as the interventions that foster the connection to allow for the strengthening spirituality in suffering.

The literature indicates that many nurses do not feel comfortable with the spiritual aspect of care (Emblen & Pesult, 2001; Hurley, 1999), however, there were several situations in this study where nurses invited and created a space for spiritual reflection. Perhaps nurses unconsciously address spiritual needs. Many nurses reported how personal experiences of pain and suffering helped them to become more open to their patients suffering. Nouwen (1972) speaks to this concept he calls the "wounded healer," where one's own wounds are a source of healing, a willingness to see one's own suffering to help others. In reaching dying individuals spiritual needs, nurses revealed the importance of being there, listening to the cues and cries of a spiritual being, offering a space for wounded memories, providing healing rituals, touching the heart, and being in privileged moments. All of these 'nursing moments' are interventions that foster and strengthen the dying individuals' spirituality in suffering. In order to expand nursing awareness and competence in the spiritual domain, further nursing research is needed.

How nurses live in the midst of suffering and spiritual distress is another area where research is necessary. This knowledge is important to support and foster nurses' spiritual health. Religion has been found to be a source of strength for nurses (Narayanasamy, 1993; Taylor, Amantea, & Highfield, 1995). Nurses in this study certainly spoke of their faith as comfort and strength in holding on to others in their vulnerability. In addition, a spiritual or religious philosophy centred around a commitment to serve others is an important belief that nurses hold in times of suffering (Vachon, 1987).

A sense of spirituality may be helpful to nurses as they struggle to find comfort and meaning in caring for the dying. Further research on nurses' spiritual comfort in suffering and the reciprocity of comfort in dying individuals would be valuable in understanding the reciprocity of relationships in practice. Further to this, it would also be important to extend the research of suffering within the nurse-patient relationship in palliative care settings, such as hospice and home.

Summary: Self -Transformation and Closure

As a researcher in this study I have been affected by this work in many ways. Coffey (1999) acknowledged that "ethnographers" rarely leave fieldwork totally unaffected by their research experience. I have experienced profound joy and respect for all of the nurses who allowed me to enter into their lives as palliative care nurses. This feeling has been overwhelming. Their generosity, trust, and willingness to share their knowledge and time made my work gratifying, and I believe allowed the richness and humanness of this context to be uncovered. It was not unusual for these nurses to comment that caring for dying individuals has improved their own quality of life. This has certainly been true for me, as I faced and learned more about the fragility of life, but also reaped the joy of feeling the intense care and love these nurses show to dying individuals and their families.

In this study, there have certainly been challenges. Being invited into the lives of these nurses and dying individuals, I felt responsible to learn and represent the culture of these nurses with accuracy and clarity. The many precious moments I shared, have helped me to think about caring for dying individuals and suffering from many perspectives. I have recognized the uniqueness and the ambiguity as suffering happens in the moment, and perhaps have learned to accept comfort with not knowing what suffering really means. Most importantly, I have learned that nurses' suffering is not a 'bad thing" as stated in the opening quotations of this chapter. In essence, suffering can be healing to both patients and nurses. Suffering lives within embodied nurses who care for dying individuals.

I know now that conversations about suffering must go on, and perhaps my role is keeping open these conversations about suffering with nurses and others who care for dying individuals. Keeping these conversations open can only enhance the intention to understand, and sustain the call to relationship with dying individuals.

References

Aamodt, A. (1989). Ethnography and epistemology: Generating nursing theory. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 29-40). Rockville, Maryland: Aspen.

Agar, M. (1980). *The professional stranger: An informal introduction to ethnography.* New York: Academic Press.

Alberta Association of Registered Nurses. (1992). *Position paper on palliative care.* Edmonton, AB: Author.

Alberta Health. (1993). *Palliative care: A policy framework.* Edmonton, AB: Author.

American Association of Colleges of Nursing. (1997, November). *A peaceful death.* Report from the Robert Wood Johnson end of life care roundtable. Washington DC: Author.

Anderson, H. (1989). After the diagnosis: An operational theology for the terminally ill. *Journal of Pastoral Care*, 43, 141-150.

Anderson, J. M. (1991). Reflexivity in fieldwork: Toward a feminist epistemology. *Image*, 23(2), 115-118.

Asplund, K. (1991). *The experience of meaning in the care of patients in the terminal stage of dementia: Interpretation of nonverbal communication and ethical demands.* Unpublished doctoral dissertation, Umea University, Sweden.

Barnard, D., Towers, A., Boston, P., & Lambrinidou, Y. (2000). *Crossing over: Narratives of palliative care.* New York: Oxford University Press.

Bauman, Z. (1993). *Postmodern ethics.* Oxford, England: Blackwell Publishers.

Bean, C., & Holcombe, J. (1993). Personality types of oncology nurses. *Cancer Nursing*, 16, 479-485.

Beck-Friis, B., Strang, P., & Sjoden, P. (1993). Caring for severely ill cancer patients: A comparison of working conditions in hospital based home care and in hospital. *Supportive Care in Cancer*, 1, 145-151.

Benoliel, J. (1983). Nursing research on death and dying and terminal illness: Development, present state and prospects. *Annual Review of Nursing Research*, 1, 101-130.

Bergum, V. (1989). Being a phenomenological researcher. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 43-57). Rockville, Maryland: Aspen.

Bergum, V. (1992). Beyond rights: The ethical challenge. *Phenomenology and Pedagogy*, 10, 75-84.

Bergum, V. (1994). Knowledge for ethical care. *Nursing Ethics*, 1, 71-79.

Bergum, V., & Dossetor, J. (In press, 2002). *Relational ethics: The full meaning of respect.* Hagerstown, MD: University Publishing Group.

Bishop, A., & Scudder, J. (1990). *The practical, moral, and personal sense of nursing: A phenomenological philosophy of practice.* Albany, New York: State University of New York Press.

Bishop, A., & Scudder, J. (1996). *Nursing ethics: Therapeutic caring presence.* Boston MA: Jones and Bartlett Publishers.

Billings, J. (1998). What is palliative care? *Journal Of Palliative Medicine*, 1(1), 73-81.

Borgmann, A. (1992). *Crossing the postmodern divide*. Chicago: University of Chicago Press.

Boyle, J. S. (1994). Styles of ethnography. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 159-185). Thousand Oaks, California: Sage.

Bram, P., & Katz, L. (1989). Study of burnout in nurses working hospice and hospital oncology settings. *Oncology Nursing Forum*, 16, 555-560.

Bruyn, S. (1966). *The human perspective in sociology.* Englewood Cliffs, NT: Prentice Hall.

Burnard, P. (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461-466.

Byrne, C., Woodside, H., Landeen, J., Kirkpatrick, H., Bernardo, A., & Pawlick, J. (1994). The importance of relationships in fostering hope. *Journal of Psychosocial Nursing*, 32(9), 31-34.

Callahan, D. (1993). *The troubled dream of life: In search of a peaceful death.* New York: Simon & Schuster.

Canadian Palliative Care Association. (1998). *Canadian palliative care training manual*. Ottawa: Author.

Canadian Palliative Care Association. (1999, September). Board of directors *AVISO*, 27(2), 1.

Caputo, J. D. (1993). *Against ethics.* Bloomington: Indiana University Press.

Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1(1), 13-23.

Carson, V., Soeken, K., Shanty, J., & Terry, L. (1990). Hope and spiritual well being: Essentials for living with AIDS. *Perspectives of Psychiatric Care, 26(2), 28-34.*

Cassell, E. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306, 639-645.

Cassell, E. (1991). Recognizing suffering. *Hastings Center Report*, 5, 24-31.

Chenitz, W., & Swanson, J. (1986). *From practice to grounded theory: Qualitative research in nursing.* Menlo Park, CA: Addison Wesley.

Chinn, P. (1994). *Being called to care.* Albany N.Y.: State University of New York Press.

Chinn, P., & Kramer, M. (1999). *Theory and nursing: Integrated knowledge and development.* (5th ed). St. Louis, MA: Mosby.

Coffey, A. (1999). *The ethnographic self.* London: Sage.

Conrad, N. (1985). Spiritual support for the dying. *Nursing Clinics of North America*, 20 (2), 415-425.

Cooper, C., & Mitchell, S, (1990). Nursing the critically ill and dying. *Human Relations*, 43, 297-311.

Copp, L. (1974). The spectrum of suffering. *American Journal of Nursing*, 74, 491-495.

Copp, G. (1994). Palliative care nursing education: A review of research findings. *Journal of Advanced Nursing*, 19(3), 552-557.

Coyle, N. (1997). Focus on the nurse: Ethical dilemmas with highly symptomatic patients dying at home. *Hospice Journal*, 12(2), 33-41.

Curtin, L. (1985). Developing a professional ethic. *AARN Newsletter*, 4(10), 3-7.

Davitz, L., & Davitz, J. (1975). How nurses view patients suffering. *RN*, 10, 69-74.

Dubree, M., Vogelpohl, R. (1980). When hope dies-so might the patient. *American Journal of Nursing,* 80, 2046-204.

Dudgeon, D.,& Kristjanson, L. (1995). Home versus hospital death: Assessment of preferences and clinical challenges. *CMAJ,* 152(3), 337-340.

Dufault, K., & Martocchio, B. (1985). Hope: It's spheres and dimensions. *Nursing Clinics of North America,* 20, 379-391.

Duffy, M. (1992). A theoretical and empirical review of the concept of suffering. In P. Starck, & J. McGovern (Eds.), *The hidden dimension of illness: Human suffering* (pp. 291-303). New York: National League for Nursing.

Eisler, E. (1981). On the differences between scientific and artistic approaches to qualitative research. *Educational Researcher,* 10(4), 5-9.

Ellis, C., & Bochner, P. (1996). *Composing ethnography: Alternative forms of qualitative writing.* Walnut Creek CA: Alta Mira Press.

Ellis, C., & Flaherty, M. (1992). *Investigating subjectivity: Research on lived experience.* Newbury Park, CA: Sage.

Emerson, R. (1982). *Contemporary field research.* Boston: Little Brown & Co.

Emblen, J., & Pesut, B. (2001). Strengthening transcendent meaning: A model for the spiritual nursing care of patients experiencing suffering. *Journal of Holistic Nursing,* 19 (1), 42-56.

Emblen, J. (1992). Religion and spirituality defined according to current use in nursing literature. *Journal of Professional Nursing,* 8, 41-47.

Engel, G. (1968). A life setting conducive to illness: The giving up-giving in complex. *Annals of Internal Medicine*, 69, 293-300.

Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplant for Leukemia. *Oncology Nursing Forum,* 19, 883-889.

Ersek, M. (2001). The meaning of hope in the dying. In B. Ferrell, & N. Coyle (Eds.), *Textbook of palliative care nursing* (pp. 339-351). New York: Oxford University Press.

Everhart, R. (1977). Between stranger and friend: Some consequences of long term field work in schools. *American Educational Research Journal,* 14(1), 1-15.

Fagin, C., & Diers, D. (1983). Nursing as metaphor: Occasional notes. *New England Journal of Medicine*, 309, 116-120.

Farran, C., Herth, K., & Popovich, J. (1995). *Hope and hopelessness: Critical clinical constructs.* Thousand Oaks CA: Sage.

Farrell, M. (1998). National palliative care education and needs analysis. *Contemporary Nurse,* 7(2), 60-67.

Fehring, R., Miller, J., & Shaw, C. (1997). Spiritual well being, religiosity, hope, depression, and other mood states in elderly people coping with cancer. *Oncology Nursing Forum,* 24, 663-671.

Ferrell, B., Grant, M., & Ritchey, K. (1993). The pain nurse resource training program: A unique approach to pain management. *Journal of Pain and Symptom Management*, 8, 549-556.

Fetterman, D. M. (1983). *Ethnography: Step by step.* Newbury Park, CA: Sage.

Field, M., & Cassel, C. (1997). Approaching death: Improving care at the end of life. In M. Field & C. Cassel (Eds.), *Report of the Institute of Medicine task force on end of life care.* Washington DC: National Academy of Sciences.

Francis, M. (1986). Concerns of terminally ill adult Hindu cancer patients. *Cancer Nursing,* 9, 164-171.

Frank, A. (1991). *At the will of the body.* New York: Houghten Mifflen.

Frank, A. (2001). Can we research suffering? *Qualitative Health Research*, 11(3), 353-362.

Fromm, E. (1968). *The revolution of hope.* New York Bantam Books

Fryback, P. (1993). Health for people with a terminal diagnosis. *Nursing Science Quarterly,* 6, 147-159.

Fulton, R., & Langton, P. (1964). Attitudes towards death: An emerging mental health problem. *Nursing Forum*, 1, 105-112.

Gadow, S. (1980). Existential advocacy: Philosophical foundation of Nursing. In S. Spricker & S. Gadow, (Eds.), *Nursing images and ideals: Opening dialogue with the humanities* (pp. 79-101). New York: Springer Publishing Co.

Gadow, S. (1988). Covenant without cure: Letting go and holding on in chronic illness. In J. Watson, & M. Ray (Eds.), *The ethics of care and the ethics of cure: Synthesis in chronicity (pp. 5-14).* New York: National League for Nursing.

Gadow, S. (1989). Clinical subjectivity: Advocacy with silent patients. *Nursing Clinics of North America*, 24(2), 535-541.

Gadow, S. (1991). Suffering and interpersonal meaning. *The Journal of Clinical Ethics*, 2(2), 103-107.

Gadow, S. (1999). Relational narrative: The postmodern turn in nursing ethics. *Scholarly Inquiry for Nursing Practice: An International Journal*, 13(1), 57-70.

Geertz, C. (1973). *The interpretation of cultures.* New York: Basic Books.

Germain, C. (1986). Ethnography: The method. In P. Munhall & C. J. Oiler (Eds.), *Nursing research a qualitative perspective* (pp. 147-162). New York: Appleton Century Crofts.

Germain, C. (1993). Ethnography: The method. In P. Munhall & C. Oiler Boyd (Eds.), *Nursing research a qualitative perspective* (pp. 237-268). New York: National League for Nursing Press.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. (Eds.),(1993).*Through the patients eyes: Understanding and promoting patient centered care.* SanFrancisco: Jossey Bass.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Glaser, B., & Strauss, A. (1965). *Awareness of dying.* Chicago: Aldine.

Glaser, B., & Strauss, A. (1968). *Time for dying.* Chicago: Aldine.

Glaser, B., & Strauss, A. (1971). *Status passage.* London: Routledge & Kegan Paul.

Goetz, J. D., & Le Compte, M. D. (1984). *Ethnography and qualitative design in educational research.* Orlando: Academic Press.

Gregory, D. (1994). *Narratives of suffering in the cancer experience.* Unpublished doctoral dissertation, University of Arizona, Tuscon, Arizona.

Gregory, D., & Longman, A. (1992). Mother's suffering: Sons who died of AIDS. *Qualitative Health Research*,2, 334-357.

Gregory, D., & Russell, C. (1999). *Cancer stories on life and suffering.* Montreal, Quebec: McGills-Queen's University Press.

Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157(8), 1101-1105.

Haase, J., Britt, T., Coward, D., Leidy, N., & Penn, P. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance and self transcendence. *Image: The Journal of Nursing Scholarship*, 24, 141-147.

Hall, B. (1990). The struggle of the diagnosed terminally ill person to maintain hope. *Nursing Science Quarterly*, 3, 177-184.

Hall, B. (1994). Ways of maintaining hope in HIV disease. *Research in Nursing and Health*, 17, 283-293.

Hall, B. (1997). Spirituality in terminal illness: An alternative view of theory. *Journal of Holistic Nursing*, 15, 82-96.

Hammersley, M., & Atkinson, P. (1983). *Ethnography: Principles in practice*. London: Tavistok.

Hart, G., Yates, P., Clinton, M., & Windsor, C. (1998). Mediating conflict and control: Practice challenges for nurses working in palliative care. *International Journal of Nursing Studies*, 35, 252-258.

Herth, K. (1990). Relationship of hope, coping styles, concurrent losses, and setting to grief resolution in the elderly widow(er). *Research in Nursing and in Health*, 13, 109-117.

Herth, K. (1995). Engendering hope in the chronically and terminally ill: Nursing interventions. *American Journal of Hospice and Palliative Care*, 12(5), 31-39.

Henderson, V. (1961). *Basic principles of nursing care*. London: International Council of Nurses.

Heyland, D., Lavery, J., Tranmer, J., Shortt, S., & Taylor, S. (2000). Dying in Canada: Is it an institutionalized, technologically supported experience. *Journal of Palliative Care*, 16(1), 10-16.

Hickey, J.(1986). Enabling hope. *Cancer Nursing*, 9, 133-137.

Hinton, J. (1968). *Dying*. Harmondsworth: Penguin Books.

Hoad, T. (Ed.). (1986). *Oxford concise dictionary of English etymology*. Oxford, UK: Oxford University Press.

Hughes, C. (1992). Ethnography: What's in a word process product promise? *Qualitative Health Research,* 2 , 439-450.

Hurley, J. (1999). Breaking the spiritual care barrier. *Journal of Christian Nursing,* 16(3), 8-13.

International Council of Nurses.(1997). *Basic principles of nursing care.* Washington DC: American Nurses Publishing.

Jacobs-Kramer, M., & Chinn, P. (1988). Perspectives on knowing : A model of nursing knowledge. *Scholarly Inquiry for Nursing Practice: An International Journal,* 2, 129-139.

James, C., & MacLeod, R. (1993). The problematic nature of education in palliative care. *Journal of Palliative Care,* 9(4), 5-10.

Jevne, R. (1991). *It all begins with hope: Patients, caregivers, and the bereaved speak out.* San Diego CA: Luna Media.

Jourard, S. (1971). *The transparent self.* New York: Van Nostrand Reinhold.

Junker, B. (1960). *Fieldwork: An introduction to the social sciences.* Chicago: University of Chicago Press.

Kahn, D., & Steeves, R., & Benoliel, J. (1994). Nurses views of the coping of patients. *Social Science and Medicine,* 38, 1423-1430.

Kahn, D., & Steeves, R. (1986). The experience of suffering. Conceptual clairification and theoretical definition. *Journal of Advanced Nursing,* 11, 623-631.

Kahn, D., & Steeves, R. (1994). Witness to suffering: Nursing knowledge, voice and vision. *Nursing Outlook,* 42(6), 260-264.

Kahn, D., & Steeves, R. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing,* 11(1), 9-16.

Kaufman, K. S. (1994). The insider-outsider dilemma: Field experience of a white researcher "getting in" a poor black community. *Nursing Research,* 43(3), 170-183.

Kearney, M. (1996). *Mortally wounded: Stories of soul pain, death, and healing.* New York: Scribner.

Kemp, C. (1999). *Terminal illness: A guide to nursing care.* Philadelphia: Lippincott, Williams and Wilkins.

Kitson, A. (1987). Raising standards of clinical practice: The fundamental issue of reflective nursing practice. *Journal of Advanced Nursing,* 12, 321-329.

Kleinman, A. (1992). Local worlds of suffering: An interpersonal focus for ethnographies of illness experience. *Qualitative Health Research,* 2(2), 127-134.

Klugg, L. (1992, March). Some essential ingredients in a recipe for suffering. *Trends in Boethics Newsletter,* 1-2.

Kristjanson, L., & Balneaves, L. (1995). Directions for palliative care nursing in Canada: Report of a national survey. *Journal of Palliative Care,* 11, 5-8.

Kubler-Ross, E. (1969). *On death and dying.* New York: Macmillan Publishing Co.

Kuuppelomaki, M., & Lauri, S. (1998). Ethical dilemmas in the care of patients with incurable cancer. *Nursing Ethics,* 5, 283-293.

Lancey, L. (1969). Hope as a healer. *Nursing Outlook,* 17(1), 45-46.

Latimer, E. (1995). Caring for the dying in Canada. *Canadian Family Physician,* 4, 362-365.

LeCompt, M. & Preissle, J. (1993). *Ethnography and qualitative design in educational research* (2nd ed.). San Diego CA: Academic Press.

Lepp, I. (1968). *Death and its' mysteries.* New York: The Macmillan Publishing Co.

Limandri, B., & Boyle, D. (1978). Instilling hope. *American Journal of Nursing,* 78, 79-80.

Lindholm, L., & Eriksson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing,* 18, 1354-1361.

Lipson, J. G. (1991). The use of self in ethnographic research. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 73-89). Newbury Park, CA: Sage.

Lofland, J., & Lofland, L. (1995). *Analyzing social settings: A guide to qualitative observation and analysis* (3rd ed.). Belmont CA: Wadsworth.

Maeve, M. (1994). The carrier bag theory of nursing practice. *Advances in Nursing Science,* 16(4), 9-22.

Maeve, M. (1998). Weaving a fabric of moral meaning: How nurses live with suffering and death. *Journal of Advanced Nursing,* 27, 1136-1142.

Manias, E., Kristjanson, L., & Bush, T. (1997). Palliative care nursing education: Australian and Canadian challenges. *Contemporary Nurse, 6*, 96-97.

Marx, W. (1992). *Toward a phenomenological ethics: Ethos and the life world.* Albany New York: State University of New York Press.

Mayeroff, M. (1971). *On caring*. New York: Harper and Sons.

McWilliams, C., Burdock, J., & Wamsley, J. (1993). The challenging experience of palliative care support team nursing. *Oncology Nursing Forum*, 20, 770-785.

Melzak, R., & Wall, P. (1968). The gate control theory of pain. In A. Soulairac, J. Cahn, & J. Carpentier (Eds.), *Proceedings of the international symposium on pain.* London: Academic Press.

Morse, J. (1991). Strategies for sampling. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 127-145). London: Sage.

Morse, J., & Carter, B. (1996). Strategies of enduring and the suffering of loss: Modes of comfort used by a resilient survivor. *Holistic Nursing Practice*, 9(3), 33-58.

Morse, J., & Doberneck, B. (1995). Delineating the concept of hope. *Image: Journal of Nursing Scholarship*, 27, 277-285.

Morse, J., & Field, P. (1995). *Qualitative research methods for health professionals.* Thousand Oaks, California: Sage.

Morse, J., & Penrod, J. (1999). Linking concepts of enduring, uncertainty, suffering and hope. *Image: Journal of Nursing Scholarship*, 31, 145-150.

Moules, N. (1999). Suffering together: Whose words were they? *Journal of Family Nursing,* 5(3), 251-258.

Moules, N. (2000). Funerals, families and family nursing: Lessons of love and practice. *Journal of Family Nursing,* 6(1), 3-8.

Muecke, M. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research* (pp. 187-209). Thousand Oaks, California: Sage.

Mulder, J., & Gregory, D. (2000). Transforming experience into wisdom: Healing amidst suffering. *Journal of Palliative Care,* 16(2), 25-29.

Munley, A. (1985). Sources of hospice staff stress and how to cope with it. *Nursing Clinics of North America*, 20, 345-355.

Narayanasamy, A. (1993). Nurses awareness and educational preparation in meeting their patients spiritual needs. *Nurse Educator Today*, 13, 196-201.

Nouwen, H. (1972). *The wounded healer.* Garden City New York: Doubleday.

Nouwen, H. (1975). *Caring and the aged.* Chicago, ILL: Thomas Metton Press.

Nouwen, H. (1986). *Reaching out.* New York: Doubleday.

Nova Scotia Department of Health and Fitness. (1988). *Guidelines for the establishment of palliative care services.* Nova Scotia: Author.

O'Brien, M. (1999). *Spirituality in Nursing: Standing on holy ground.* Boston: Jones and Bartlett,

Oldnall, A. (1996). A critical analysis of nursing: Meeting the spiritual needs of patients. *Journal of Advanced Nursing*, 23, 138-144.

Olson, J. (2000). Health, healing, wholeness and health promotion. In M. Clark & J. Olson (Eds.), *Nursing within a faith community: Promoting health in times of transition* (pp. 31-41). Thousand Oaks, CA: Sage.

Olson, J., & Clark, M. (2000). Characteristics of health promoting faith community nurses. In M. Clark & J. Olson (Eds.), *Nursing within a faith community: Promoting health in times of transition* (pp. 226-236). Thousand Oaks: Sage.

Olthuis, J. (1997). Face to face: Ethical asymmetry or the symmetry of mutuality? In J. Olthuis (Ed.), *Philosophy at the threshold of spirituality* (pp. 131-158). New York: Fordham University Press.

Omery, A. (1988). Ethnography. In B. Sarter (Ed.), *Paths to knowledge: Innovative research methods for nursing* (pp. 17-31). New York: National League for Nursing.

Oxford companion to philosophy (1995). New York: Oxford University Press.

Paterson, J., & Zderad, L. (1988). *Humanistic nursing.* New York: National League for Nursing.

Pellegrino, E. (1993). Compassion. In E. Pellegrino, & D. Thomasma (Eds.), *The virtues in medical practice* (pp. 79-83). New York: Oxford University Press.

Perry, B. (1998). *Moments in time: Images of exemplary nursing care.* Ottawa ON: Canadian Nurses Association.

Punch, M. (1985). *The politics and ethics of field work.* Beverly Hills: Sage.

Quill, T., & Billings, J. (1998). Palliative care textbooks come of age. *Annals of Internal Medicine*, 120(7), 590-594.

Quint, J. (1967). *The nurse and the dying patient.* New York: The Macmillan Company.

Ramsey, P. (1970). *The patient as person.* New Haven: Yale University Press.

Rasmussen, B., Norberg, A., & Sandman, P. (1995). Stories about becoming a hospice nurse: Reasons, expectations, hopes and concerns. *Cancer Nursing*, 18, 344-354.

Rasmussen, B., Sandman, P., & Norberg, A. (1997). Stories of becoming a hospice nurse: A journey towards finding one's footing. *Cancer Nursing*, 20(5), 330-341.

Reed, P. (1987). Spirituality and well being in terminally ill hospitalized adults. *Research in Nursing and in Health,* 10, 335-344.

Reed, P. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing and in Health,* 15, 349-357.

Reich, W. (1989). Speaking of Suffering: A moral account of compassion. *Soundings*, 72, 83-108.

Rittman, M., Rivera, J., & Godown, I. (1997). Phenomenological study of nurses caring for dying patients. *Cancer Nursing*, 20(2), 115-119.

Rodney, P., & Starzomski, R. (1993). Constraints on the moral agency of nurses. *Canadian Nurse,* 10, 23-26.

Ross, L. (1996). Teaching spiritual care to nurses. *Nurse Educator Today*, 16, 38-43.

Rushton, C. (1992). Caregiver suffering in critical care nursing. Heart Lung, 21(2), 303-306.

Samaroo, B. (1996). Assessing palliative care educational needs of physicians and nurses: Results of a survey. *Journal of Palliative Care,* 12(2), 20-22.

Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. *Image: Journal of Nursing Scholarship,* 23(3), 161-166.

Sandelowski, M. (1994). The proof is in the pottery: Toward a poetic for qualitative inquiry. In J. Morse (Ed.), *Critical issues in qualitative methods* (pp. 46-63). Thousand Oaks, CA: Sage.

Saskatchewan Health. (1994). *Guidelines for developing an integrated palliative care service.* Saskatchewan: Author.

Saunders, C. (1967). *The management of terminal illness.* London: Hospital Medicine Publication Ltd.

Saunders, J., & Valente, S. (1994). Nurses grief. *Cancer Nursing,* 17, 318-325.

Scanlon, C. (1989). Creating a vision of hope: The challenge of palliative care. *Oncology Nursing Forum,* 16, 491-496.

Schroeder, C. (1992). The process of inflicting pain in nursing: Caring relationship or torture. In D, Gaut (Ed.), *The presence of caring in nursing* (pp. 211-220). New York: National League for Nursing.

Scott, J. (1992). Palliative care education in Canada: Attacking fear and promoting health. *Journal of Palliative Care,* 8(1), 47-53.

Sellick, S., Charles, K., Dagsvik, J., & Kelley, M. (1996). Palliative care providers perspectives on service and education needs. *Journal of Palliative Care,* 12(2), 34-38.

Senate of Canada. (1995). *Of life and death: Report of the special senate committee on euthanasia and assisted suicide.* Ottawa: Author.

Singer, P., Martin, D., & Kelner, M. (1999). Quality end-of-life care: Patients' experience. *JAMA,* 281(2), 163-168.

Smith, R. (1996). Theological perspectives. In B. Ferrell (Ed.), *Suffering* (pp. 159-171). Boston: Jones and Bartlett Publishers.

Speck, P. (1993). Spiritual issues in palliative care. In D. Doyle, G. Hanks, & N. McDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 517-525). Oxford: Oxford University Press.

Spradley, J. P. (1979). *The ethnographic interview.* Janovich, Fort Worth: Harcourt Brace.

Spradley, J. P. (1980). *Participant observation.* Janovich, Fort Worth: Harcourt Brace.

Spross, J. (1993). Pain, suffering and spiritual well being: Assessment and interventions. *Quality of Life,* 2, 71-79.

Starck, P., & McGovern, J. (1992). The meaning of suffering. In P. Starck, & J. McGovern (Eds.), *The hidden dimension of illness: Human suffering* (pp. 25-42). New York: National League for Nursing.

Steeves, R., & Kahn, D. (1987). Experience of meaning in suffering. *Image: Journal of Nursing Scholarship,* 19, 114-116.

Stein, K., Corte, C., Colling, K., & Whall, A. (1998). A theoretical analysis of Carper's ways of knowing using a model of social cognition. *Scholarly Inquiry for Nursing Practice*, 12, 298-303.

Taylor, C. (1991). *The ethics of authenticity.* Cambridge MA: Harvard University Press.

Taylor, E., Amenta, M., & Highfield, M. (1995). Spiritual care practices of oncology nurses. *Oncology Nursing Forum*, 22, 31-39.

Tesch, R. (1991). Computer programs that assist in the analysis of qualitative data: An overview. *Qualitative Health Research,* 1 (3), 309-325.

Thomasma, D. (1994). Beyond the ethics of rightness: The role of compassion in moral responsibility. In S. Philips & P. Benner (Eds.), *The crisis of care* (pp. 123-143). Washington DC: Georgetown University Press.

Travelbee, J. (1971). *Interpersonal aspects of nursing,* (2nd ed.), Philadelphia: F.A. Davis Co.

Van derZalm, J., & Bergum, V. (2000). Hermeneutic phenomenology: Providing living knowledge for nursing practice. *Journal of Advanced Nursing,* 31(1), 211-218.

Vachon, M. (1987). *Occupational stress in the care of the critically ill, dying, and the bereaved.* New York: Hemisphere.

Vachon, M. (1995). Staff stress in hospice/palliative care: A review. *Palliative Medicine,* 9, 91-122.

Vachon, M. (1996). What makes a team? *Palliative Care Today*, 5, 34-35.

Vachon, M. (2001). The nurses role: The world of palliative care. In B. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 647-662). New York: Oxford University Press.

Vaillot, M. (1962). *Commitment to nursing: A philosophic investigation*. Philadelphia: Lippincott.

Vaillot, M. (1970). Hope: The restoration of being. *American Journal of Nursing,* 70, 268-273.

Watson, J. (1979). *Nursing: The philosophy and science of caring.* Boston: Little Brown and Company.

Watson, J. (1985). *Nursing human science and human care: A theory of nursing.* Connecticut: Appleton Century Crofts.

Watson, J. (1988). *Nursing: Human science and human care.* New York: National League for Nursing

White, J. (1995). Patterns of knowing: Review, critique and update. *Advances in Nursing Science,* 17(4), 73-86.

Wiedenbach, E. (1964). *Clinical Nursing: A helping art.* New York: Springer

Wilson, D., Anderson, M., & Fainsinger, R. (1998). *Social and health trends influencing palliative care and the location of death in the twentieth century* Canada. Final Report to Health Canada National Health and Research Development Program.

Wolcott, H. (1992). Posturing in qualitative inquiry. In M. Le Compte, W. L. Millroy, & J. Preissle (Eds.), *Handbook of qualitative research in education* (pp. 121-152). San Diego, California: Academic Press.

World Health Organization (1986). *Cancer pain relief.* Geneva: Author.

World Health Organization. (1990). *Cancer pain relief and palliative care* Technical Report Series No. 804. Geneva: Author.

Wright, L. (1999). Spirituality, suffering and beliefs: The soul of healing with families. In F. Walsh (Ed.), *Spiritual resources in family therapy (*pp. 61-75). New: York: Guilford Press.

Appendix A

CRHA
Calgary Regional Health Authority

Recruitment Letter

Title of Research Project:
The Experience of Nurses Caring for Dying Individuals

**Investigator: Shelley Raffin , PhD (c) (Nursing)
Faculty of Nursing, University of Alberta
Phone: (403) 289-9231 or 220-6258**

**Supervisor: Dr. Vangie Bergum, Professor
Faculty of Nursing, University of Alberta
Phone: (403) 492-6676**

Are You A Registered Nurse Who Cares for Dying Individuals?

Have you Ever Suffered in This Experience?

Are You Interested In Volunteering In A Research Study About Nurses Caring For Dying Individuals?

I am a nurse who has cared for dying individuals. I am doing a research study to learn more about nurses and their experiences in caring for the dying. This study is part of my doctoral program.

I am also interested in learning about "nurses' suffering" in caring for the dying.

Nurses who are interested will be asked to talk about their experiences. It will be like an informal conversation. I will also spend some time with you in your daily work of caring for dying individuals.

An initial conversation will occur at a time and place convenient for you, about one to one and a half, hours in length.

Over a period of four months, I will occasionally spend time with you, as you care for dying individuals.

If you would like to hear more about the study, please call me (the investigator), at the above number.

Appendix B

Biographical Data of Nurses
Project Title: The Experience of Nurses Caring for Dying Individuals.

Date: ____________________

Code #____________________

Age: _____ **Occupation:** ____________ **Sex:** __

Number of Years Practicing Nursing: ________

What is the highest level of education you have obtained?

School of Nursing: _________________

College Diploma: ___________

University: _______

How many years: ______

Highest Degree: _______

Appendix C

Information Letter for Nurse Participants

Title of Project: The Experience of Nurses Caring for Dying Individuals

Investigator:	Shelley Raffin, RN, MN	Advisor: Dr. Vangie Bergum
	Graduate Student	Professor
	Faculty of Nursing	Faculty of Nursing
	University of Alberta	University of Alberta
	Phone: 289-9231	Phone: 492-6676

This information letter should give you a basic idea of what the research study is about and what your participation will involve. If you need more detail as you read, or information not included here, you should feel free to ask. Please read this carefully.

Purpose of the Investigation The purpose of the study is to understand what it is like for nurses to care for those who are dying. The data being collected is for the researchers doctoral thesis.

Procedure: The researcher will gather data during interviews and observations of nurses caring for the dying. The number and the timing of the interviews with each nurse will vary. It will depend on the nurse's schedule and opportunity to care for dying individuals. A maximum of five interviews /observations will be conducted with each nurse. It is the intent of the researcher to conduct an initial interview (1-1 1/2 hrs) in length. A time and place away from the unit will be arranged that is most convenient for you. Other conversations will occur with you every 2 or 3 weeks over a four-month period. Your time commitment would not be more than 10 hours.

Included in this time, will be periods where you will be observed while giving care to dying patients. These observation times will be arranged with you allowing convenience for you and your patients. The researcher will respect nurse and patient privacy at all times. In this study, the researcher will assume the role of "observer and participant". My role will be known at the onset to both nurse and patient. While I may participate in the care if necessary, under your direction. My primary role will be focused on observation. Please understand that the researcher is not evaluating your nursing care. Rather, is trying to understand what it ~~is~~ like for you to care for dying individuals.

Voluntary Participation: You do not have to participate in this study if you do not wish to. If you do choose to take part, you do not have to answer any questions or discuss any topics that you do not want to. You can drop out of the study at any time by contacting the researcher. Taking part or dropping out will not affect your nursing work in any way at the hospital.

Appendix C

Risks/Benefits: There will be no harm to you if you participate in this study. Taking part in this study will be of no direct benefit to you. Some participants may find it beneficial to have the opportunity to speak about their experiences. The results of this study may assist in the improvement of care which nurses provide to individuals who are dying. It is hoped that a better understanding of what it is like to care for dying individuals will occur.

Confidentiality: Confidentiality will be respected at all times. Your name will not appear anywhere in the study. Only a code number will appear on forms or data sheets. The tapes of the interviews belong to the researcher. The researcher will erase your name on anything leading to your identity. A typist will make written copies of the tapes. All records will be kept in a locked file cabinet. The tapes will be destroyed seven years after the project is completed. Consent forms will be destroyed as soon as the project is completed. The typed interviews and notes will be kept in a separate locked file cabinet indefinitely. This information may be used for educational or research purposes if the researcher obtains the proper ethical clearance. The typed notes will only be shared with the researcher's committee from the University of Alberta. Members of this committee will keep the information confidential.

If any changes occur that could alter your decision to continue in the study, the researcher will notify you immediately

Anonymity: Other nurses who you work with may be aware that the researcher is accompanying you. They may also hear things that you share with the researcher on the unit.

If you have any questions or concerns regarding this study, you can contact Shelley Raffin, her advisor, or the patient concerns office of the Calgary Regional Health Authority (CRHA). Questions must be answered to your satisfaction.

Appendix D

Interview Guide

The overall form of the interview is conversational. Generally the method is dialectical in nature, where encouragement from the interviewer promotes the participant to clarify and explain their statements as complete and specific as possible. Nurses will be asked to tell a story(s)of their experiences. The interviewer's task is to interpret for the participant what she/he thinks is being said.

The first interview will be to collect data about the nurse's background(both as a person and as a nurse) and obtain her/his sense of what it is like to care for dying individuals. The interview guide is as follows.

1. Welcome
2. Introduction /purpose of the research
3. Participants questions about the research
4. Background Data collection
5. Consent
6. Introductory questions:
    a) What can you tell me about you as a person and how you perceive suffering that will help me to understand your experiences of caring for dying individuals.
    b) Can you tell me what it has been like for you to care for dying individuals?
    c) Tell me about some of the experiences that have stood out for you?
    d) Have you ever suffered, yourself, when caring for a dying individual? If so, what was that experience(s) like for you? If not, can you imagine a situation where nurses might suffer?
7. If you have suffered, how would you have explained or described this suffering experience to a colleague?
8. What do you think caused the suffering?
9. What was the outcome for you? For your patient?
10 Who supported you in your suffering?

The next interviews/conversations will begin by recapping the last interview, asking the nurse to describe in her/his own words what she/he perceives as a suffering experience, and why it may occur in caring for dying individuals. Further to this, the interview will explore:

1) How nurses come to understand suffering both in themselves and their patients?
2) What their moral commitments are in alleviating suffering?
3) How have, or do they cope with their own suffering?

Further to these interviews the purpose of shadowing the nurse while providing care to dying individuals will be explained. The purposes of this experience will not be predetermined, except to state that it is the researchers intention to observe a general sense of the "culture" of nurses when caring for dying individuals. The participants will be encouraged to share their feelings of these experiences, either verbally or in writing with the researcher. These field-notes will be a part of the researcher's "ethnographic notebook".

Appendix E

University of Alberta
Edmonton

Canada T6G 2G4

Faculty of Rehabilitation Medicine
Rehabilitation Research Centre

3-48 Corbett Hall
Director (403) 492-7856 Telephone (403) 492-2903
Fax (403) 492-1626

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,
CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date: July 1998

Name(s) of Principal Investigator(s): Ms. Shelley Raffin

Organization(s): University of Alberta

Department: Graduate Studies; Faculty of Nursing

Project Title: The Experience of Nurses Caring for Dying Individuals.

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the patient information material and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-090798-NSG

Appendix E

CRHA
Calgary Regional Health Authority

May 21, 1998

Shelly Raffin
Faculty of Nursing
University of Calgary
2500 University Drive N.W.
Calgary, AB T2N 1N4

Dear Shelly,

I have reviewed your research proposal regarding palliative care nurses and their experience of suffering.

I offer my consent to the involvement of Unit 73 and would be happy to facilitate the enlistment of nursing staff in your endeavor.

Sincerely,

Clare Byrne
Patient Care Manager
Nursing Unit 73
Rockyview General Hospital

CB

Calgary Regional Health Authority

Appendix F

Consent Form for Nurse Participants

Research Project Title: The Experience of Nurses Caring for Dying Individuals.
Investigator(s): Shelley Raffin (Graduate Student The University of Alberta)
Sponsor: Maureen Best (Administrative Leader CRHA)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Research. The purpose of the study is to understand what it is like for nurses to care for those who are dying. The data being collected are for the researcher's doctoral thesis.

Procedure: The researcher will gather data during interviews and observations of nurses caring for the dying. The number and the timing of the interviews with each nurse will vary. It will depend on the nurse's schedule and opportunity to care for dying individuals. A maximum of five interviews /observations will be conducted with each nurse. It is the intent of the researcher to conduct an initial interview (1-1 1/2 hrs) in length, and perhaps a follow up interview if needed. These interviews will be tape-recorded. A time and place away from the unit will be arranged that is most convenient for you. Other conversations/observations will occur with you every 2 or 3 weeks over a four-month period. Your time commitment in total would not be more than 10 hours. At the time of the initial interview, you will be reimbursed for any child care and or travel expenses that you incur.

Included in this time, will be periods where you will be observed while giving care to dying patients. These observation times will be arranged with you allowing convenience for you and your patients. The researcher will respect nurse and patient privacy at all times. In this study, the researcher will assume the role of "observer and participant". The researcher's role will be known at the onset to both nurse and patient. While the researcher may participate in the care if necessary, under (the nurse's) direction, the primary role of the researcher will be focused on observation. Please understand that the researcher is not evaluating your nursing care. Rather, she is trying to understand what it is like for you to care for dying individuals.

Risks/Benefits: There will be no harm to you if you participate in this study. The only risks to you are self-disclosure and investment in a relationship with the researcher. Some questions asked in the interview may cause discomfort or stress when you are asked to recall feelings and or emotion laden events. These incidents cannot be anticipated, but if you express to the researcher that your participation in the study has caused you distress, then counseling services may be arranged. Also the occasional presence of the researcher may be experienced as bothersome during the nurse's "caring routine" and the researcher will respect the nurse's/patient's request to leave if desired. Overall the well being of the participants will be placed above the purpose of the research or the goals of the researcher.

Taking part in this study will be of no direct benefit to you. Some participants may find it beneficial to have the opportunity to speak about their experiences. The results of this study may assist in the improvement of care which nurses provide to individuals who are dying. It is hoped that a better understanding of what it is like to care for dying individuals will occur.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided for you by the CRHA, University of Calgary, or the researcher.

Confidentiality: Confidentiality will be respected at all times. Your name will not appear anywhere in the study. Only a code number will appear on forms or data sheets. The tapes of the interviews belong to the researcher. The researcher will erase your name on anything leading to your identity. A typist will make written copies of the tapes. All records will be kept in a locked file cabinet. The tapes and consent forms will be destroyed five years after the project is completed. The typed interviews and notes will be kept in a separate locked file cabinet indefinitely. Portions of the transcriptions may be used for educational, or research purposes if the researcher obtains the proper ethical clearance. The typed notes will only be shared with the researcher's committee from the University of Alberta. Members of this committee will keep the information confidential.

If during the study, any information about abuse of someone is disclosed by you, the researcher is obligated to report the incident (as mandated by the Alberta Protections for Persons in Care Act).

If any changes occur that the researcher thinks could alter your decision to continue in the study, the researcher will notify you immediately.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your nursing work in any way at the hospital. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact: Shelley Raffin at 289-9231, or her advisor Dr. Vangie Bergum at 403-492-6676 (the researcher will reimburse you for the expenses of this call). If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 220-7990.

____________________________ ________________________
Participant's Signature Date

____________________________ ________________________
Investigator and /or Delegate's Signature Date

____________________________ ________________________
Witness' Signature Date

A copy of this consent form has been given to you to keep for your records and reference.

Calgary Regional Health Authority

Appendix G

Consent Form for Observation Participants.

Research Project Title: The Experience of Nurses Caring for Dying Individuals.
Investigator(s): Shelley Raffin (Graduate Student The University of Alberta)
Sponsor: Maureen Best (Administrative Leader CRHA)
This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Research. The purpose of the study is to understand what it is like for nurses to care for those who are dying. The data being collected is for the researchers doctoral thesis.

Procedure If you agree to participate in this study, you will be asked to allow the researcher to observe and participate in your care under the direction of your assigned nurse. During these observations, the researcher will make notes and these notes will become a part of the data. The researcher is a registered nurse with years of nursing practice and teaching experience. If you are willing to participate your nurse and the researcher will obtain your written consent. These observation times will be arranged with you and your assigned nurse at an appropriate time for you. There will not be more than three observations sessions for a total time commitment time of five hours. The researcher will respect patient and nurse privacy at all times. You can ask the researcher to leave at any time if you wish.

Risks/ Benefits: There will be no harm to you if you participate in this study. The only risk to you may be a tiring/bothersome presence of the researcher, as your assigned nurse cares for you. The researcher will respect the nurse's/patient's request to leave if desired. Overall the wellbeing of the participants will be placed above the purpose of the research or the goals of the researcher.

Taking part in this study will be of no direct benefit to you. The results of this study may assist in the improvement of care which nurses provide to individuals who are dying. It is hoped that a better understanding of what it is like to care for dying individuals will occur.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided for you by the CRHA, The University of Calgary, or the researcher.

Confidentiality: Confidentiality will be respected at all times. Your name will not be present in the study. Only a code number will appear. The notes of the observation are the researchers. The researcher will erase your name on any thing leading to your identity. All records will be kept in a locked file cabinet. The notes and consent forms will be destroyed in five years after the project is completed. The typed notes will be kept in a separate locked file cabinet indefinitely. Portions of the transcriptions may be used for educational, or research purposes providing the researcher obtains the proper ethical clearance. The typed notes will only be shared with the researcher's committee from the University of Alberta. Members of this committee will keep the information confidential.

If during the study any information about abuse of someone is disclosed by you, the researcher is obligated to report the incident (as mandated by the Alberta Protections for Persons in Care Act).

If any changes occur that the researcher thinks could alter your decision to continue in the study, the researcher will notify you immediately.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your nursing work in any way at the hospital. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact: Shelley Raffin at 289-9231, or her advisor Dr. Vangie Bergum at 403-492-6676.

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 220-7990.

Participant's Signature	Date
Investigator and /or Delegate's Signature	Date
Witness' Signature	Date

A copy of this consent form has been given to you to keep for your records and reference.

Appendix H

Key Participants

Name	Formal Interviews	Informal Interviews/ Shadow Observations
1. Jennifer	2	4
2. Barbara	2	4
3. Muriel	2	4
4. Darlene	2	3
5. Ruth	1	2
6. Eileen	1	2
7. Nancy	2	3
8. Helen	1	2
9. Beverly	2	1

Appendix I

Examples Of Data Coding

Raw Data	Codes	Category
I always find it very emotional to watch family with their dying relative. I was there at the top of his head and I had to move away. The family rushed in and out. They started to cry; they couldn't handle it I started to cry too. She had this huge tumor, she couldn't sit, she couldn't lie on her back, and she was in so much pain. Every time we turned her, she was frightened and she would scream. She grabbed my arm and wouldn't let go. She cried, "No more".	Feel for patient Emotionally intense Feeling the patients pain	Suffering
I know that I've done my job well if people die peaceful and calm. But when they slip away, screaming in pain, and the family is grieving at the same time it's very hard, it's unsettling. I want them to be comfortable. Even if they are uncomfortable in death they seem to smile, they seem to relax. There is a comfort after, but getting right up to there, that stresses me as a human being trying to help them, it's awful.	A difficult death Striving for a good death	Compassion
You just have to look at their face, they just have to hold onto your hand. It's that well, that gut feeling. I don't know, it's just something that you can feel, that you see. We don't have to ask them, we have to touch. When you're present, you just know what to do, there is a lot of non-verbal cueing.	Silent suffering Presence	Esthetic knowing