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.

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

UMI[®]

**EXPLORING SPIRITUAL AND PSYCHOLOGICAL ISSUES
AT
THE END OF LIFE**

by

DAVID R. KUHL

**B.R.E. Providence College, 1974
B.A. University of Winnipeg, 1977
M.H.Sc. University of Toronto, 1981
M.D. McMaster University, 1985**

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY**

in

**THE FACULTY OF GRADUATE STUDIES
(Interdisciplinary Studies)
(Counselling Psychology, Medicine, Ethics, Medical Anthropology, Theology)**

THE UNIVERSITY OF BRITISH COLUMBIA

July, 1999

© David Richard Kuhl, 1999

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.

0-612-46369-9

Canada

ABSTRACT

The purpose of this study was to explore spiritual and psychological issues as experienced by persons who know they have a terminal illness. An existential-phenomenological method was chosen to understand and articulate the structure and meaning underlying the experience of living with the knowledge that one has a terminal illness. The study had its genesis at the bedside(s) of people who were dying, yet living or living, yet dying. The experience of knowing one has a terminal illness serves to bring life and consciousness to those who may have otherwise continued to live unconsciously, to exist in a potentially weary and dormant state, oblivious to the fact that life was passing them by.

The evidence of experience of knowing what it means to have a terminal illness exists in the words and expressions of the twenty-one people who graciously participated in this study as co-researchers. They have given testimony of their own experience to those of us who seek to understand that experience, to understand what it means to have a terminal illness, to confront one's end to life as it is known, to embrace life or to prepare to die. For some it was a single in-depth interview, for others there were numerous in-depth interviews over the course of two to eleven months. Eight of the twenty-one co-researcher narratives were presented in this study. Each interview was recorded by audio and video tape, the former being used for transcription. Subsequently, transcriptions were reviewed for accuracy. As a measure of trustworthiness, themes were identified by the principal investigator and presented in the context of the narrative to the co-researchers who confirmed the data and validated the themes.

Implications based on the themes identified in this study are presented under theory development, professional practice and future research. One of the strongest implications pertains to clinical practice in that the results could serve as the framework for a palliative care program which models palliative care as defined by the World Health Organization. The co-researchers were eager to tell their stories and to speak their truth with the hope that the care of persons with terminal illness would some day include care of people as whole persons—physical, psychological and spiritual.

TABLE OF CONTENTS

ABSTRACT.....	ii
TABLE OF CONTENTS.....	iv
TABLE OF FIGURES.....	vii
ACKNOWLEDGMENTS.....	viii
CHAPTER ONE: INTRODUCTION.....	1
A. World Health Organization.....	1
B. Sociobehavioural Cancer Research Network.....	5
C. Project on Death in America.....	6
D. St. Paul's Hospital, Vancouver, British Columbia.....	7
CHAPTER TWO: REVIEW OF THE LITERATURE.....	12
A. Introduction.....	12
B. Definition of Spiritual and Psychological Dimensions of Personhood.....	14
C. Review of the Literature.....	15
D. Goals for Future Research.....	23
CHAPTER THREE: METHODOLOGY.....	26
A. Qualitative versus Quantitative Methods of Inquiry.....	26
A.1. Introduction.....	26
A.2. Discussion of the Conceptual Framework of Qualitative and Quantitative Methods.....	28
A.2.i. Positivism.....	28
A.2.ii. Constructivism.....	31
B. Historical Context of Phenomenology.....	35
C. Phenomenology Defined.....	40
D. Translating Philosophy into Research Methodology.....	43
D.1. Turning to the Nature of Lived Experience.....	44
D.2. Investigating Experience as We Live It.....	48

D.3. Phenomenological Reflection.....	50
D.4. Describing the Phenomenon.....	53
D.5. Remembering the Question.....	56
D.6. The Phenomenon of Dying.....	59
E. The Design.....	62
E.1. The Question.....	62
E.2. Inclusion Criteria.....	63
E.3. The Participants.....	64
E.4. Interviewing and Analysis.....	65
F. Ethics Review.....	69
 CHAPTER FOUR: FINDINGS/THEMES.....	 75
A. The Co-researchers; The Themes.....	76
A.1. The Co-researchers.....	76
A.2. The Themes.....	77
A.2.i. Communication.....	77
A.2.ii. Iatrogenic Suffering.....	77
A.2.iii. Pain.....	78
A.2.iv. Touch.....	78
A.2.v. Time.....	79
A.2.vi. Longing to Belong.....	79
A.2.vii. Life Review.....	79
A.2.viii. Truth.....	80
A.2.ix. Who am I?.....	80
A.2.x. Transcendence.....	81
B. Communication between the Health Care	
Professional and the Patient.....	81
B.1. Context.....	81
B.2. The Initial Visit.....	83
B.3. Receiving the Message of a Terminal Illness.....	86
B.4. Communication/Relationship with Health	
Care Professionals during Hospital Stay.....	99
C. Maslow's Hierarchy of Needs: The Theory.....	110
C.1. Introduction.....	110
C.2. Physiological Needs.....	110
C.3. Safety Needs.....	112
C.4. Belongingness and Love Needs.....	113
C.5. Esteem Needs.....	114
C.6. Self-Actualization Need.....	115

D. The Psychological Themes: Maslow's Theory Applied.....	120
D.1. Introduction.....	120
D.2. The Experience of Pain; a Physiological Need.....	122
D.3. Safety Needs.....	131
D.4. Belongingness and Love Needs.....	136
D.5. Esteem Needs.....	143
D.6. Self-Actualization Need.....	153
E. The Spiritual Themes: The Transcendent Self.....	164
CHAPTER FIVE: DISCUSSION.....	185
A. Limitations.....	186
B. Theory.....	188
B.1. Erikson's Eight Stages.....	189
B.1.i. Basis Trust vs. Basic Mistrust.....	189
B.1.ii. Autonomy vs. Shame.....	190
B.1.iii. Initiative vs. Guilt.....	190
B.1.iv. Industry vs. Inferiority.....	191
B.1.v. Identity vs. Identity Diffusion.....	191
B.1.vi. Intimacy vs. Isolation.....	192
B.1.vii. Generativity vs. Stagnation.....	193
B.1.viii. Integrity vs. Despair.....	193
B.2. Discussion.....	194
C. Professional Practice.....	199
D. Future Research.....	203
E. Conclusion.....	206
REFERENCES.....	209
APPENDIX A.....	222
APPENDIX B.....	224
APPENDIX C.....	227

TABLE OF FIGURES

FIGURE 1 Ladder of Materialistic Inquiry.....	30
FIGURE 2 Circle of Constructivist Inquiry.....	33
FIGURE 3 Vase and Faces.....	38
FIGURE 4 Maslow's Hierarchy.....	111
FIGURE 5 Maslow's Hierarchy as a Program Framework.....	201

ACKNOWLEDGMENTS

I begin by thanking my family for the incredible support they have given me in the course of the past years—especially to Jean who shares my journey like no one else, and to Jennifer and Sarah who are full of life and laughter, thereby instilling others with hope.

I want to thank my research supervisor, Dr. Marv Westwood for the ‘truth, touch and time’ he has shared over the past years, for teaching me to listen, for being a mentor and a role model, for guiding me through a strong program, and for showing me what healing is really all about. I also thank the other members of my supervisory committee, Dr. Carol Herbert for supporting my application to the Project on Death in America, and then for caring about the impact of a doctoral program on me and my family; Dr. Bill McKellin for demonstrating another perspective to health and illness; and Dr. Terry Anderson for the guidance and direction regarding the dissertation. I thank Dr. Joan Anderson for the hours of consultation, for teaching me what it means to do qualitative research, and for challenging me to trust my sense of truth as I witnessed the experience of the people in the study.

I thank Mr. George Soros. Without his vision and commitment to changing the culture of death and dying, this project would not have happened. I will be forever grateful to him for his gift to me through the Soros Faculty Scholar Program, Project on Death in America. I thank fellow Canadian Faculty Scholars, Dr. Geri Frager for introducing me to the Faculty Scholar Program and for hours of encouragement and Dr. Harvey Chochinov for strongly recommending that I pursue a doctoral degree. Thank you to Dr. Balfour Mount, who as a mentor through the Project on Death in America,

along with my supervisor and Dr. Patricia Wilensky, ushered me through the darkest part of this project. Also to Dr. Robin Cohen who provided valuable insights to the design and work of this project. Then, I thank Drs. Susan Block and Kathy Foley as leaders of the Faculty Scholar Program and of the Project on Death in America, for supporting the idea of this research as part of a doctoral program in the context of being a Faculty Scholar. I also thank Ms. Mary Calloway for the encouragement and enthusiastic support.

I thank the administrators of St. Paul's Hospital for 'hosting' this project and for contributing to the time and space necessary to complete a project such as this. Within that context I thank my colleagues: Dr. Jacqueline Fraser for listening to me talk about this project for years and believing in me long before it was started; Drs. Millie Cumming, Daphne Lobb, and Fraser Black for taking my clinical work load and call so I could do the research. Thank you also for referring the patients to the research project. Thank you to Ms. Pamela Miller, Ms. Mary Ellen deGrace, and Mr. Jack da Silva for support and encouragement.

I thank St. Jude Resources and the people in the office, Mr. Mike Terrell who is one of the most generous people I know. For the gifts of time and space, thank you. Also thank you to Ms. Mary Jane Hamula for her assistance especially with computer and collating concerns, and to Mr. Larry Brock for answering questions, and for the good humor. I thank the librarians at the Library of the College of Physicians and Surgeons who consistently and with a pleasant manner provided a great deal of reading material for this project, and the administrative secretaries at Delta Hospital who ensured that I receive the material in a timely fashion.

I thank other colleagues, Dr. Betty Calam for the encouragement, and Dr. Jim Thorsteinson for creating the space in my position at St. Paul's Hospital to make this project possible. A special expression of gratitude to Ms. Jean Kozoway for the hours and hours of typing, for the tangible daily support, for the many cups of coffee and for the conversations that focused on the issues that arose through the course of the research. Also, thank you to Ms. Adrian Westwood for doing some of the typing.

The most significant gratitude is expressed to TM, who wanted his story told, and to the 21 people who participated in this study as co-researchers. It has been an honour to know you. I dedicate this work to you. I only hope I can do justice to the information you have shared, to the truth you have spoken, to the message that you want to give to others as they seek to embrace life.

I acknowledge that I am aware of the lives of some of the philosophers who developed the concept of phenomenology, philosophically and psychologically. While their work in this domain merits acknowledgment, their affiliation with the events in Germany through World War II must never gain respect.

. . . .

CHAPTER I

INTRODUCTION

When the Lord saw that he turned aside to look, God called to him from the midst of the bush, and said, Moses, Moses!" And he said, "Here I am." Then he said, "Do not come near here; remove your sandals from your feet, for the place on which you are standing is holy ground. Exodus 3:4-5

New American Standard Bible

Dying is more than a biological occurrence. It is a human, social and spiritual event (Corless 1990, p. 75). The focus of this research project is to explore the psychological and spiritual components of pain and suffering as experienced by persons with terminal illness. The project is based on the orientation position of the World Health Organization (WHO), previous research and work completed by health care providers working with people at the end of life, purpose of the Project on Death in America, and clinical observations in the palliative care unit of a tertiary care hospital.

A. World Health Organization

The World Health Organization (1990) defines palliative care as *the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. By way of explanation, palliative care:*

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;

- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and their own bereavement (WHO, 1990)

Much is known about pain in persons with cancer (Portenoy, 1989; Payne, 1990; Foley, 1985) and AIDS (Schofferman, 1990; Penfield, 1992; Ferris, 1995). The International Association for the Study of Pain (IASP) defines pain as *an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage...It is unquestionably a sensation in a part or parts of the body, but is also always unpleasant and therefore also an emotional experience...Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons* (IASP Subcommittee on Taxonomy, 1986). Efforts in providing palliative care for terminally ill persons have been primarily medical. Pain control has been greatly improved as has the management of other symptoms. Much slower progress has been made in understanding or alleviating psychological or spiritual distress (Lair 1996, p. 1).

It is known that persons with terminal illness experience stressors (e.g. anger, depression, fear) during the course of their illness (Breitbart, 1990; Expert Working Group, 1989; Vachon, 1995; Kuhl, 1994). These are commonly described as psychological features of pain and suffering. The foundation of this knowledge was initially described by people such as Kubler-Ross (1969). Her work describes the

experience of dying as observed by care providers rather than by the person who is dying. In order to understand the people who know they have a terminal illness, it is imperative to hear them speak about their experience especially as it pertains to pain and suffering.

Most individuals know what it means to suffer, in some capacity, but few are able to define it conceptually. Dr. Eric Cassell defines it as the *distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person* (Cassell 1991, p. 24). More recently it has been suggested that *suffering is a complex negative affective and cognitive state characterized by perceived threat to the integrity of the self, perceived helplessness in the face of that threat, and exhaustion of psychosocial and personal resources for coping. Biological, psychological, and social stressors can all cause suffering, but in the cancer patient a constellation of all three factors commonly occurs* (Chapman 1993, p. 11).

Callahan describes two levels of suffering. On one level he names the psychological penumbra of illness i.e. the fear, uncertainty, dread, or anguish of the sick person in coping with the illness and its meaning for the continuation of life and intact personhood. On a second level, he states that *the problem touches on the meaning of suffering for the meaning of life itself...The questions here no longer are just psychological but encompass fundamental philosophical and religious questions* (Callahan 1993, p. 100). Hence, it is important and perhaps imperative to look beyond the physical and psychosocial dimensions to the essence of spirituality characteristic of persons at the end of life (Doyle, 1992; Woodward, 1990).

The phenomenological analysis...indicates that the prevailing biomedical model of disease (which tends to focus exclusively on the dysfunction of the biological organism

and pathophysiology of the disease state) is an incomplete model for medical care. It will be suggested that an adequate account of illness must include not only a construal of illness in terms of clinically definable disease states but also an understanding of illness-as-lived. In this regard it will be noted that illness may be understood as a particular way of being in the world—a way of being that exhibits certain typical characteristics. Such characteristics must be recognized if one is to grasp what illness means to patients (Toombs 1992, p. xvi).

Kleinman et al (1978) explain that the process of illness begins with an awareness within the individual that there is a change in body feeling which results in the labeling of that individual by self or family as being “ill”. While most illness is managed outside the perimeters of the formal health care system, once within the system there is an increasing discordance between the delivery of care by the health care professional and the expectations of the lay population. In fact, the health care professional, namely the modern physician, diagnoses and treats the disease, that is an abnormality in the structure or function of some component of the body, and the patient suffers an illness, that is, a change in state of being, social function, or the experience of sickness.

The biomedical view of clinical reality...assumes that biologic concerns are more basic, “real”, clinically significant, and interesting than psychologic and sociocultural issues. Disease, not illness, is the chief concern; curing, not healing, is the chief objective. Treatment oriented within this view emphasizes a technical “fix” rather than psychosocial management. It is less concerned with “meaning” than other forms of clinical care (Kleinman 1978, p. 255). One must question how the health care professional and more specifically the physician then responds to the patient with disease,

or the person with illness, when the disease is not curable. Certainly at that point the experience of illness features more prominently, and the psychological and spiritual issues and concerns are equal or of greater significance than the physical manifestations of disease. It behooves one to examine what the psychological and spiritual issues/concerns might be for the person with an incurable disease, one that is almost certain to result in death.

B. Sociobehavioural Cancer Research Network

In 1995-96 the Sociobehavioural Cancer Research Network (SCRN) of the National Cancer Institute of Canada (NCIC) commissioned a review and analysis of the research literature pertaining to the psychological and spiritual issues as experienced by the individual with a terminal illness. The results of this effort were submitted to the SCRN in a paper entitled "Dying Healthy—Palliative care: A research Agenda from the Patient's Perspective" (Cohen, 1997). This paper, one of five papers written to establish SCRN priorities, composed of ten sections included my contribution, namely, the section on psychosocial and spiritual care. The literature review pertaining to spiritual and psychological issues conducted for that commissioned work, served as the basis for this research project and, along with a critique of the work of Kubler Ross, is presented in the section on the review of the literature. The need for qualitative studies in respect to the identified issues is summarized in the following quotation:

For many persons the experience of a terminal illness includes a process of healing and resolution, while for some it is a time of unrelieved suffering. The literature contains many narratives regarding spiritual and psychological issues written by professional caregivers based on their clinical experience. Less literature exists

which describes the experience from the perspective of the one who is dying. There is evidence that patient spiritual and psychological needs are inadequately addressed. Only in hearing the stories of those individuals experiencing a terminal illness will our understanding and knowledge of human suffering be enhanced. In this way we will also learn of that which is helpful in the struggle to find meaning and hope in the process of dying. Qualitative research is needed to understand not only the essence of suffering, its expression and interpretations, but also to learn which approaches best relieve suffering in the psychological and spiritual domains of the people who have advanced cancer (Cohen 1996, p. 14).

The richness of the patients' responses suggests how much we may still be missing with regard to many other diseases, where no careful listener has yet come along to hear the stories of the sufferers (Brody 1987, p. 96).

C. Project on Death in America

In 1994, Mr. George Soros gave an address for the Alexander Ming Fisher Lecture Series at Columbia Presbyterian Medical Center, entitled "Reflections on Death in America". In that address he reflected on his own experience of being with the dying, namely his parents. Of his father he stated, *I was there when he died, yet I let him die alone. I could see him, but I wasn't at his bedside;* and of his mother, *she had this experience...of walking up to the gates of heaven, and I was accompanying her...Her dying was really a very positive experience for all of us because of the way she handled herself and the way the family, not just me but particularly my children, could participate in it (Soros 1998, p. 4).* That was a portion of the speech which served as the inaugural address of the Project on Death in America, which supports initiatives in research, scholarship, the humanities and the arts, as well as innovations in the provision of care, public education, professional education, and public policy. Its purpose is *to promote a*

better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death (Soros 1998, p. 5). Understanding the experience of dying includes physical, emotional, spiritual and existential components. The role of the health care professional is seen by Mr. Soros, through the Project on Death in America, to extend beyond conquering disease and prolonging life to providing support in that inevitable phase of life—death. The funding for the Project on Death in America has funded a wide variety of projects and has served to underline the significance of research, education and training in addressing the needs of persons with a terminal illness. Through the education, program development and research supported by this funding, the issues pertaining to the end of life have been given a higher profile, a greater legitimacy, and a new credibility in universities, health care institutions and service organizations, and hopefully amongst the public. Dying and death is, after all, an experience which will complete ‘the journey’ for each of us. The major portion of this study was funded by the Project on Death in America.

D. St. Paul’s Hospital

The Palliative Care Program at St. Paul’s Hospital, situated on the tenth floor of a tertiary care hospital in Vancouver, British Columbia was started in 1989. Through this program, palliative care has been provided for more than 3000 persons with a terminal illness, primarily cancer and/or AIDS. Service by members of an interdisciplinary team is provided on a 15 bed unit in one, two, three, and four bed rooms, which for the most part face the mountains on the north side of the facility. Family members and friends are encouraged to participate in the lives and the care of the persons on the program. There

are no restrictions with regard to visiting hours. People may choose to bring in a favourite meal and share it with the patient using the kitchen to prepare the food, to watch a movie in the lounge, to sit outside on the north west balcony with a view of the Pacific Ocean, to assist in the bathing of their loved one in the special Arjo tub, or to spend the night in a cot next to the patient or in the family room which contains some comfortable lounge chairs, a hide-a-bed, and a private washroom. The walls of the unit display the art that has been donated by previous patients, family members and friends. One sitting area contains an aquarium, and a volunteer is often seen providing refreshments for the patients and their loved ones. While the unit has many features of a typical hospital ward, the ambience is different. As much as is possible in a tertiary care hospital, team members strive to give decision making authority, and control to the patient. This means that the team members must respect the varied cultural backgrounds which characterizes the patients on the unit.

In this environment, I along with my team members have witnessed the extent of suffering and pain as experienced by individuals with a terminal illness. For many, the experience is a process of healing and resolution, while for some it is a time of unrelieved suffering, marked by an occasional plea to end the ordeal. Through the experience of working in providing health care to those who are terminally ill, it becomes apparent that pain is a very complex experience. As per the definition of pain by the IASP, there is always a subjective component. For those who work with others who know they have a terminal illness, it is important to note that when physical pain and other symptoms are well managed, the individual may continue to experience psychological and/or spiritual pain. This aspect of pain needs to be more completely understood.

Clinical observations are important sources of information and have contributed to the genesis of this study:

Mabel, a 71 year old woman was admitted to the palliative care unit because the pain she experienced from the tumor in her lung was intolerable. While her home was in Saskatchewan, she was visiting her sister in West Vancouver at the time that the pain occurred. She was a very pleasant prairie type of person who saw good in all things, and who was somewhat stoic with regard to her pain. She did not want to be a bother for anyone and thought that the pain was hers to endure. Mabel's son, Tony aged 37, had assumed responsibilities on the family farm; her daughter, Kathy aged 34, served as a Canadian diplomat in Africa. Her husband died of a lung cancer when she was 56, after 22 years of marriage. She had a new companion who travelled between Vancouver and Saskatchewan to visit Mabel and to maintain his own farm.

The chest pain was controlled within a few days. As Mabel weakened, her daughter was invited to return from Africa in the hope that the two of them would be able to have some meaningful conversations before Mabel died.

One Saturday, on regular morning rounds, I went in to see Mabel. Her daughter had arrived from Africa the day before and was sitting at the foot of the bed. We spoke of Mabel's pain. She was pleased to be free of the discomfort. As she was talking about being free of pain, tears (a usual indicator of pain or joy) welled up in her eyes. I was surprised and for a second, feared asking about the tears. Would she say something to which I would not be able to respond appropriately? Would I be qualified to address the issues which were about to be raised? Would she be dissatisfied with the care she had been given? Would this require a great deal of time and therefore slow me down with regard to the other patients I still needed to see?

An appropriate question would have been, 'if those tears could speak what might they say'? Instead I said, I see those tears, is there something you would like to say? She said yes I want to say that I have not been a very good mother. Silence. Who speaks first? The doctor or the daughter? What is the appropriate response? I suggested that she direct that statement to her daughter, which she did. Her daughter who also had tears streaming down her cheeks by this point, stated that her mother was wrong as far as she was concerned. However, it was important to explore in greater detail the reason for the tears and the sense that Mabel had not been a good mother.

Mabel looked at Kathy and said, You know when you were 5 years old, you begged to take ballet lessons. We couldn't afford those lessons – it would have meant a long drive into town which would have

taken me away from the work on the farm, and we just didn't have the money to be able to let you take those lessons. All our neighbours who had little girls made the effort and provided that for their daughters. I have great regrets about not making that happen for you and feel like I was not a good mother, a burden she had carried for 29 years. Kathy looked at her mother and without missing a beat stated, I don't know how to dance as a ballerina, but how many of my childhood friends or adult colleagues know how to lasso a calf? The tears changed to a smile and then a chuckle. I stepped out of the room. They continued to speak for several hours. Shortly after this intimate mother/daughter interaction Mabel invited Tony to come from Saskatchewan so he too could benefit from such a conversation with his mother.

What is it like to know that one will die within hours, days, weeks, or months? What is important once one has been informed of having a terminal illness? Does anything change within oneself, in one's relationship to others, or in one's sense of God, the transcendent, or the spiritual? Is it possible to find value and meaning at the end of one's life? And does that differ from one's existence prior to receiving a diagnosis? How might I respond differently as a physician if I truly understand the phenomenon of dying? Are questions such as these even pertinent? Who might provide the answers to questions, insights to the experience and descriptions of one's inner being? Is death, as a societal taboo, a topic that even those who are confronted with having a terminal illness would avoid? These are some of the questions which this study attempts to address.

Presently, the reality of persons who suffer in the context of terminal illness is relatively unexamined. The goal in this investigation is to understand the lived experience of people with a terminal illness. In order to adequately address the research question of this project a qualitative methodology was selected as the most appropriate method to answer the research question. Only in hearing the stories of those individuals experiencing a terminal illness will our understanding and knowledge of human suffering

be enhanced. The participants in the study primarily represented a frame of reference which typifies a North American, Western ideology. A phenomenological approach has been implemented to establish a baseline of information on human suffering and to elevate this aspect of life to a new level of understanding and appreciation (Duffy, 1992).

More precisely, the method selected for this study is the existential-phenomenological approach which is a specific method designed to understand and articulate the essential structure underlying the experience of the particular phenomenon under investigation, in this case, terminal illness. The emphasis is on extracting the meaning of the experience. The method seeks to understand phenomena, not to explain, predict or control (Valle, 1978). Description through disciplined reflection is the main goal of the researcher following the analytic methods described by van Manen (1990).

This document will include a review of the literature, a description of the methodology employed in this study, a review of the themes which have been identified, and a presentation of the implications of the results.

CHAPTER II

REVIEW OF THE LITERATURE

A. Introduction

Only people with cancer can possibly know what it is like to have cancer. Once an individual is diagnosed with cancer, the meaning of that person's entire life is altered (Ferrell, 1993, p. 1472). This is true of any terminal illness. Only people who have a terminal illness can possibly know what it is like to live with that knowledge, only they can impart to others a true description of that lived experience. The end of life is an event of a physical, psychological and spiritual nature. The medical model focuses on physical well-being. Psychological and spiritual well-being are more difficult to conceptualize whether for purposes of discussion, description, intervention or research.

This chapter will present pertinent definitions, examine the literature regarding opinion, consensus and data based information, and address goals for future research. While these concepts may in part be distinct, they are interrelated and for that reason will be regarded as such for the purposes of this chapter. The research agenda proposed at the end of this chapter may assist in clarifying the distinctiveness of each. At this point it is important to note that in phenomenological studies analyses are generally inductive rather than deductive. For that reason, the definition of concepts such as spirituality, personhood and psychological well-being are somewhat incongruous with the selected methodology of this study. The definitions enable one to conduct a literature review to identify if and how spiritual and psychological issues for the terminally ill might have been explored in other studies.

The Cancer Control Framework of the National Institute of Canada was employed to assess the state of research pertaining to the spiritual and psychosocial components of palliative care for the adult population with terminal cancer (Cohen, 1997). In an effort to follow that framework and to be comprehensive, the initial literature review explored psychological and spiritual issues at the end of life using the following literature and key words:

- Medline (1991 to November 1995): spiritual, suffering, exp death, thanatology, terminal care, attitude to death, palliative treatment, pastoral care, exp pain, death anxiety, pain
- Bioethics (1973 to November 1995): end of life, PSTG, suffering, euthanasia, right to die, physicians, pain, suicide-assisted, terminal care, advance directives, decision-making, euthanasia-passive, living wills
- Psychology Abstracts (1967 to December 1995): suffering, spirituality, palliative care, hospice, death education, death and dying, death anxiety, death attitudes, terminal cancer, terminally ill patients, end of life
- Psycholit (January 1990 to June 1995): palliative care, terminal cancer, suffering, psychological, pain, spiritual, emotional distress.

Both review articles and individual studies were considered. They were categorized as descriptive surveys, qualitative studies, correlational, quasi-experimental, experimental studies, and scientific reviews and meta-analyses. Each category had criteria by which to

determine the quality of the study (See Appendix A). Only studies which were deemed to be very good or excellent by those categories were highlighted.

B. Definition of Spiritual and Psychological Dimensions of Personhood

The spiritual dimension of persons can be uniquely defined as the human capacity to transcend self (McKee and Chappel, 1992). It manifests itself as a state of “connectedness” to God, to one’s neighbor, to one’s inner self and to one’s environment in the broadest sense. All persons experience spiritual needs, whether or not they are part of a formal religious organization. Spirituality has been described as the “unfinished revolution in palliative care” (Corless, 1990; Highfield, 1983; Ley & Corless, 1988; Cassell, 1982, 1991).

Spiritually healthy persons are those who have satisfactorily met their spiritual needs for self-acceptance, relationships, meaning and/or hope, and spiritually distressed persons are those who have not. Perhaps one might define religion as the individual and community values, beliefs, and practices through which persons attempt to fulfill spiritual needs (Highfield 1983, p. 2).

Psychological well-being consists of attributes of worthwhileness, value, or satisfactoriness of life; usefulness, body image, or adjustment; emotions and anxiety; internal locus of control, recreation and fun; happiness; and developing learning, and fulfillment (Padilla 1990, p. 109).

The present question of the interpretation of the meaning of spirituality in the care of terminally ill persons reflects a concern that hospice providers have been less vigorous in their pursuit of relief of spiritual pain than they have of physical or psychological pain

(Ley and Corless, 1988; Charlton, 1992; Doyle, 1992; Mermann, 1992). According to the literature, health care providers are adept at physical diagnosis and treatment, and to a lesser extent, psychosocial intervention(s). However, they often ignore the spiritual component of illness, with regard to assessment as well as intervention (McKee and Chappel, 1992; Millison and Dudley, 1992; Widerquist and Davidhizar, 1994; Cassell, 1982, 1991).

C. Review of the Literature

Hopwood (1991) conducted two excellent studies pertaining to psychiatric morbidity in patients with advanced cancer. In the first study he determined how well two questionnaires, namely the Hospital Anxiety and Depression Scale (HADS) and the Rotterdam Symptom Checklist (RSCL) identify patients suffering from an anxiety state or depressive illness, compared with an independent interview by a psychiatrist who used the Clinical Interview Schedule. In this study of 81 women, he found that both were suitable for use as screening instruments and that both proved feasible in a busy clinical setting. He determined that these tools were superior to the detection rate of doctors and nurses involved in cancer care. Hopwood suggests that careful preparation is advisable in using either questionnaire as a screening instrument. More specifically, sensitivity, specificity and cut-off values should be checked, and the predictive value should be calculated according to the known prevalence of affective disorder in the population of patients to be screened. Used in this way, these two instruments could provide a valuable clinical tool in the detection of psychological morbidity. Of note is the need to know the

prevalence of affective disorder in a particular population. While this may be known for cancer in general, it may not be known for specific populations.

Subsequently, Hopwood used the HADS and the RSCL to assess the prevalence of affective disorders in a large outpatient sample of women with advanced breast cancer and to determine whether there was a change in psychological morbidity with time. He learned that the questionnaires detected different 'cases', that affective disorders may occur in up to one in four patients with advanced cancer of the breast and persist in one third of the cases, and that simple self-assessment questionnaires are a practical way of identifying and monitoring the psychological status of patients. He recommended that patients who were identified as such would best be assessed by a nurse trained in psychological assessment skills, so that intervention could be appropriately targeted. He recognized that the questionnaires are unable to give precise prevalence rates, recommending that further work is required to improve their performance in this area.

In another study, Coward (1991) demonstrated that women (Caucasian) with advanced breast cancer experience a sense of positive well-being and satisfaction with life that is related to reaching beyond their illness concerns to be involved with others, to share their wisdom and experience with others, to accept help when needed, and to find meaning in spiritual beliefs and in past experiences, regardless of age.

The results of a study of 26 Chinese women conducted by Wu (1990) suggests that there are different emotional patterns for the young and the old. The young (age 35 to 58) experience emotional states of bargaining and complaints, and less depression and acceptance than the older group (over 58). The awareness of dying was not significantly different across the two age groups. Dying was viewed as less tragic for the older group.

In this study, effects of family support on one's emotions were found to be significant. The group with immediate family support had a significantly lower score in depression and higher score in fears than did the group without. The latter challenges the belief that family support only creates positive effects. Furthermore, the dying patients with support from immediate family did not necessarily have more hope or see the situation as more pleasant and easier to accept than those with no such support.

Wu found a significant correlation between emotional states - awareness of dying was positively correlated with bargaining, depression, and fears. This provides important implications for the different patterns of emotions that dying persons might experience.

As much as Wu's study challenged the belief that family support only creates positive effects, so Padilla (1990) demonstrated that pain, a 'negative' feature of terminal illness, may result in a positive outcome, i.e. a richer, more loving family interaction. It was her intent to determine the content domain of quality-of-life attributes for patients with cancer. The responses of the patients in this study generated three very broad categories of attributes of quality of life, namely, physical, psychological, and interpersonal well-being. Psychological well-being was defined by four categories:

1. Affective/cognitive domain: enjoying or not enjoying life, happiness, spiritual support, inner peace/turmoil, ability to concentrate, communication, and self-esteem.
2. Coping ability: feeling of security/insecurity that includes financial security as well as a general feeling of security, type of mental attitude and expressions of adaptation and adjustment to life's events. New information revealed in

these data speaks to the relevance of goals, dreams, and hopes in defining quality of life and mitigating desire for death or suicide.

3. Meaning of pain and cancer: pain contributed to a richer, more loving family interaction. Pain and fear of disease contribute to the quality of life.
4. Accomplishments: feeling successful and satisfied.

Kagawa-Singer (1993) studied American-born Japanese and Anglo-Americans in an effort to broaden the concept of health to help provide a legitimate place in society of individuals with chronic, life-threatening illnesses. She proposed a theoretical framework to explain how patients could see themselves as healthy despite their disease. Their individual perceptions of being healthy were “based upon their ability to maintain a sense of integrity as productive, able, and valued individuals within their social sphere, despite their physical condition” (Kagawa-Singer 1993, p. 296).

A study by Reed (1991) could be categorized as fundamental research as well as research pertaining to program delivery, in that the results could be employed to influence program development. The purpose of the study was to determine terminally ill and non-terminally ill hospitalized patients’ preferences for spiritually related nursing interventions and to identify differences between the two groups. The participants identified several interventions for spiritual needs that fall within the domain of nursing practice, e.g. providing a facilitative environment, talking with the patient, or arranging for time for personal prayer, meditation or reading.

A comprehensive investigation was conducted in 1988 by the Canadian Cancer Society’s National Patient Services Committee, which included a series of in-depth studies of people with cancer living in Manitoba, Ontario, Quebec or Prince Edward

Island. Nearly 2000 people with cancer took part in the study. The sample represented persons who were experiencing the entire spectrum of disease progression. These people were asked very detailed questions pertaining to the type and stage of their illness, their personal situations, and their needs. Amongst the groups which reported the greatest “unmet” need was the group with “advanced” or “palliative” stages of cancer, describing the need for emotional support as a major theme in their lives (Vachon, 1991).

Other studies have demonstrated that persons with cancer experience increased anxiety and depressive feelings in association with pain (Strang and Qvarner, 1990; Strang, 1992; Massie, 1992). In one survey, 79% of the descriptions of people attaining a “healthy” death had references to the dying person’s need for some form of religious-spiritual dialogue (Smith, 1993). Of greater significance was the fact that more than 50% of those who would describe themselves as “not involved in organized religion” also had a need to talk about religious-spiritual matters.

Highfield (1992) considered the level of spiritual health as reported by oncology patients. In a study of 50 persons with lung cancer, employing the Spiritual Health Inventory, she found that the patients reported moderately high levels of spiritual health. She states that this is in contrast to the emphasis of current literature on the existential crisis precipitated by cancer. She also found, as did Heaven and Maguire, (1996) that nurse respondents did not accurately assess the spiritual health of their patients.

Mickley (1992) explored the relationship between spiritual health and religion, between spiritual health and psychological health, and the role of spiritual health in the coping responses of patients with devastating physical illness. Her cross sectional study of 175 women with breast cancer Stages 0 to 4 contributes to the understanding of

spiritual health. She demonstrates that women with a poorer prognosis are not necessarily less spiritually or psychologically well. Medical variables were not significantly related to spiritual well-being, religiousness or hope. Information such as this may be of value in addressing issues of suffering for this population. Only in clarifying issues of spiritual and psychological health will the needs of persons with terminal illness be appropriately addressed.

In an excellent and well known study, Spiegel (1981) tested the prediction that women with metastatic breast cancer who are involved in cancer support groups would benefit psychologically from the experience. These women were expected to experience less anxiety, depression, fearfulness and helplessness; to use less denial about their illness; and to be more vigorous with a higher self-esteem and a higher positive outlook on life.

In a controlled study of 68 women (34 with treatment, 24 as controls) psychological support groups were designed to focus on content. This included discussions of death and dying, related family problems, difficulties in obtaining treatment, issues of communication with physicians, and living as richly as possible in the face of terminal illness.

The data indicate that cancer support groups for women with terminal carcinoma of the breast prevent psychological deterioration and improve their capacity to master their predicament. Briefly, the findings were such that:

- significant differences were found for total mood disturbance as well as for tension-anxiety, vigor, fatigue, and confusion.

- changes were not found for denial, self-esteem, or sense of control.
- the group diminished the sense of helplessness the patients experienced in the face of problems.
- the group served as an antidote to the isolation that so often accompanies the process of dying.
- the group served to detoxify dying.

In summary, the evidence from this study confirms the clinical observation of recent years that direct group discussion of terminal illness, doctor/patient relationships, the process of dying, and related family problems provides comfort and psychological support to patients and is not psychologically demoralizing or destructive. Objective as well as phenomenological measures demonstrated that patients given the opportunity of working together in facing common problems become less anxious, confused, fatigued, and fearful (Spiegel 1981, pp. 532-533).

As a point of interest, at the 10 year follow-up of the Spiegel study, it was found that *patients with metastatic breast cancer randomized to weekly group therapy for a year lived significantly longer than did controls, by an average of nearly 18 months. This difference was statistically and clinically significant (Spiegel 1989, p.890).*

The most well known account of the experience of dying is based on the work and presentation by Elisabeth Kubler-Ross (1969) in her book entitled *On Death and Dying*. She provides an account of five emotional reactions (stages) which mark the psychological response to dying: denial, anger, bargaining, depression, and acceptance. While these reactions have not been empirically tested, they have been widely embraced

and incorporated into programs directed at providing care for persons with terminal illness. Many practitioners have accepted these without criticism or evaluation and have freely applied them to persons with terminal illness and also to their loved ones (Fulton 1995, p. 312-313).

Kastenbaum (1991) has identified the shortcomings in the Kubler-Ross Stage Theory. He states that the existence of the stages has not been established—there is nothing to demonstrate that these stages occur as designated, nor that the experience of dying is limited to these stages or responses to dying. While the theory won wide acceptance, there is no evidence that people with a terminal illness pass through these stages in the order in which they are presented. This acceptance may have reflected society's need at that time to fill a void of ignorance about the dying process. The methodology which was used in this study is narrow and limited. The interviews were conducted and analyzed by one person, a psychiatrist. One must question how patients respond to questions from a psychiatrist. Would they differ from answers given to a researcher, another health care professional, or a family member? In part, it is unfortunate that the stage framework has become a prescription for the experience of dying. This might prohibit a caregiver from recognizing the totality of the individual, the uniqueness of each person experiencing a terminal illness. Kastenbaum (1991) goes on to say that environmental dynamics may influence patient's behaviour. This is neglected in the stage process. For example, denial may be the result of medicine's orientation to cure rather than being a component of a set of stages that people with a terminal illness experience.

Corr (1993) acknowledges the tremendous contribution to information about death and dying made by Kubler Ross: *Although we all benefited from the work of Kubler-Ross, we cannot simply lean upon her work for the rest of time. Instead, we must continually strive to find additional good and further riches within ourselves. In particular, we must look within ourselves to go beyond the inadequacies of the stage-based model for coping with dying that Kubler-Ross set forth so many years ago* (Corr 1993, p. 81). Corr emphasized some of the same concerns raised by Kastenbaum, namely that there may be more than five ways of coping with death and dying, stages may not be interlinked, and that the five stages are not obligatory and ought not to be 'prescribed' by those who are providing care for the dying. He emphasizes the value of Kubler-Ross's work, as it teaches people that those who have a terminal illness are still alive. They may have unfinished work to address, they may benefit from the ability of caregivers to listen actively in identifying their needs, and they are able to teach others how to know themselves better. Kubler-Ross made a tremendous contribution to the understanding of the experience of dying. It is imperative that her work of curiosity and inquiry of persons with a terminal illness be continued.

D. Goals for Future Research

To date, most studies which have addressed the spiritual and psychological issues at the end of life are descriptive in nature. None of them test interventions which affect the spiritual or psychological well being of the individual. Those which have been completed, even with regard to their being primarily descriptive, are limited in number especially as pertaining to multi-site studies.

Research methods which combine cross-sectional with longitudinal strategies would provide more valid evidence of the significant changes theorized to occur as a person moves across the dying trajectory. The findings to date may be useful in planning more costly but more powerful designs for studying spirituality as a developmentally based resource of dying individuals (Reed 1987, p. 342).

Spirituality is a necessary component of modern medical practice. It is definitely an issue worth studying (Aldridge, 1993). Continued research in this area may ultimately provide the empirical knowledge base needed for purposeful integration of spiritual dimensions in care of terminally ill individuals (Reed, 1991).

In order to adequately address the research questions inherent in the psychological and spiritual needs of dying persons, a qualitative methodology would best be selected over the more traditional quantitative approaches. Through clinical practice it has been witnessed, that for many persons with a terminal illness the experience includes a process of healing and resolution, while for others it is a time of unrelieved suffering. Much has been written in the medical literature by observation of the patient; less literature exists which describes the experience from the perspective of the one who is dying. Some of the literature suggests that care may be incomplete (McKee and Chappel, 1992, Mermann, 1992, Heaven and Maguire, 1996). Only in hearing the stories of those individuals experiencing a terminal illness will our understanding and knowledge of human suffering be enhanced. In this way we will also learn of that which is helpful in the struggle to find meaning and hope in the process of dying. Qualitative research based on grounded theory methods is needed to understand not only the essence of suffering, its

expressions and interpretations, but also to learn about relief of that suffering viz. a viz. the psychological and spiritual domains of the people who have cancer.

In reviewing the World Health Organization's objectives for palliative care (WHO, 1990), Johnston (1995) has stated that *the validity of quantitative measures needs to be convincingly demonstrated in relation to patients' own descriptions of their experience. In-depth interviews with a phenomenological focus could provide a useful indicator of the comprehensiveness and validity of such quantitative measures (e.g. comparing results of a study employing grounded theory technique with the results of a Quality of Life survey). Discrepancies between qualitative and quantitative reports could indicate variation in individual needs and experiences, which cannot be assessed in instruments assuming common dimensions. It is possible that the deterioration of patients near to death may be partially addressed by longitudinal studies that adapt methodological procedures as the patient's condition dictates. [It is also possible that], a combination of quantitative and in-depth qualitative methodology might allow more patients to be included in research in the final stages of terminal care* (Johnston 1995).

To understand the lived experience of knowing one has a terminal illness one must hear from those who hold that knowledge. The initial method of inquiry appropriate to the question is an in-depth qualitative design. To begin the process of understanding this experience employing quantitative measures increases the possibility of introducing observer/researcher bias with the risk that the true experience will be diminished and not optimally understood. The results of subsequent quantitative studies would best be validated by comparing them to the results of qualitative measures.

CHAPTER III

METHODOLOGY

A. Qualitative Versus Quantitative Methods of Inquiry

A. 1. Introduction

The purpose of this chapter is to define and discuss qualitative and quantitative methods of inquiry. Quantitative methods are more commonly used in medical research while qualitative methods are generally employed by social scientists. The audience to which the results of this study are directed includes people who work in each domain. It is for that reason and because this work is based in an Interdisciplinary Doctoral Program, that the author believes that a presentation of the two paradigms with an explanation as to why the qualitative approach was selected is appropriate and of value.

The method of investigation for this study is the existential-phenomenological approach. Its intent is to extract the meaning of the experience of dying once the individual is known to have a terminal illness. This is a qualitative method intended to guide the researcher through the process of inquiry while suspending judgment and coming to an understanding of the experience. Through this process the researcher does not seek to explain, predict or control. In context, phenomenology as a qualitative research method has a long history in the social sciences, but has not been an essential component of research in health care.

The author of this document has been working as a physician for the past fourteen years. It is with that foundation of knowledge and experience that this study is conducted. One must consider the discipline of medicine in terms of clinical practice as

well as research. Sackett (1985) has stated that three challenges face every clinician every day. These pertain to making the correct diagnosis, selecting the management which does more good than harm, and keeping up to date with useful advances in medicine (Sackett 1985, p. x). This certainly comprises the efforts of those involved in curative medicine. Does the same hold true for situations in which a disease is not curable, (e.g. AIDS, some types of cancer, amyotrophic lateral sclerosis, etc) and/or where the probability of the natural history of the disease means the patient will die as a result of the disease. In these cases, a correct diagnosis is of importance, management must still be selected on the basis of doing more good than harm, of seeking to reduce or eliminate pain and suffering such that an optimal quality of life is attained (if possible), and keeping up to date is also of value and importance. Research questions must be directed at those features of illness and experience which contribute to pain, suffering and decreased quality of life.

In considering a research question one looks to quantitative and/or qualitative methodologies. It is important to understand the context of the methodologies with regard to the practice of medicine, whether its focus is directed at curing disease or addressing the needs of the person with a terminal illness. Quantitative methodologies are generally developed from the scientific paradigms of positivism and/or postpositivism, while qualitative methodologies might be considered as belonging to the paradigms of critical theory or constructivism. For the purpose of discussion, with regard to the two methodologies, only the paradigms of positivism (quantitative) and constructivism (qualitative) will be considered. Paradigms are defined by a patterned set

of assumptions regarding their ontological, epistemological and methodological premises (Denzin 1994, p. 13).

A. 2. Discussion of the Conceptual Framework of Qualitative and Quantitative Methods

A. 2. i. Positivism

Positivism is based on the belief that objective accounts of the world can be given (Denzin 1994, p. 15). It has dominated the formal discourse in the physical and social sciences for approximately 400 years. Ontologically one asks what kind of being is the human being, what is the nature of reality? The purpose or aim of inquiry in the positivist paradigm is to explain the phenomena with the ultimate intent of prediction and control of the phenomena. It is believed that research can, in principle, converge on the “true” state of affairs, that is, one can really know (realism). One might argue that the basic positions of this paradigm results in reductionism and determinism (Guba 1994, p.109). Epistemologically one must ask about the nature of relationship between the one who knows or would know and what can be known, that is the knowledge of that reality. In the positivist paradigm these are independent entities where the investigator must be capable of studying the object without influencing it or being influenced by it. *Inquiry takes place as through a one-way mirror* (Guba 1994, p. 110). Its methodology, meaning the way in which one knows the world or gains knowledge of it, is categorized as being experimental in seeking to verify hypotheses, *most usefully stated as mathematical prepositions or propositions that can be easily converted into precise mathematical (quantitative) formulas expressing functional relationships. Formulaic precision has*

enormous utility when the aim of science is the prediction and control of natural phenomena (Guba 1994, p. 106). Confounding variables must be controlled or manipulated so as to prevent improper influence over outcomes. In summary, criteria for evaluating this research includes internal and external validity, its theoretical framework is logical-deductive and its results are recorded by scientific report.

Quantitative methods of research are epitomized in the randomized double blind controlled trial with a focus on hypothesis testing through experiment controlled by means of randomization (Pope, 1995). *Because the randomized trial, and especially the systematic review of several randomized trials, is so much more likely to inform us and so much less likely to mislead us, it has become the "gold standard"* (Sackett 1996, p. 72). These studies are intended to provide evidence for the clinician such that the individual patient benefits from prior experience (both as individual clinicians and collectively) with groups of similar patients. They are comprised of *investigations in which identical groups of individuals, generated through random allocation, are and are not exposed to the putative causal factor, and are followed for the occurrence of the outcome of interest. This is the best evidence we will ever have* and is ranked above cohort studies, case-control studies and case series (Sackett 1985, p. 297). Evidence such as this is especially significant to accuracy in diagnosis and in selecting management which will maximize good and minimize harm. It is referred to by some as materialistic inquiry. *The materialist inquirer values progress, stresses the primacy of method, seeks an ultimate truth—a natural law—of reality...If one wants to understand the molecular genetics of hyperlipidemia or to develop a new drug, then this is the paradigm of choice. The*

materialist inquirer climbs a linear ladder to an ultimate objective truth (Figure 1)
(Crabtree 1992, p. 9-10).

Figure 1. Ladder of Materialistic Inquiry

Crabtree, Benjamin and Miller, William L. Doing Qualitative Research, Sage Publications, California, 1992, p. 9

A. 2. ii. Constructivism

Constructivism has similar notions to the interpretive, naturalistic and hermeneutical paradigms. *The aim of inquiry is understanding and reconstruction of the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations as information and sophistication improve* (Guba 1994, p. 113). The term constructivism is used as human constructions are being studied and constructions are being created by the researcher. Through this process of inquiry awareness of content and meaning of different constructions is increased. It is based on knowledge which enables one to understand his/her cultural life, symbolic communication and meaning (Crabtree 1992, p. 10). The ontology of constructivism is relativist, that is, constructions are more or less informed and/or sophisticated rather than being more or less “true” in any absolute sense. The constructions are dependent for their form and content on the individuals who hold them. They are socially and experientially based and are specific in nature although elements may be shared among individuals and even across cultures. It is this feature which distinguishes this paradigm from other paradigms. The epistemology of this paradigm is transactional and subjectivist in that the investigator and the object of investigation are interactively linked such that the “findings” are created as the investigation proceeds. This is a feature which distinguishes this paradigm from the positivist/post positivist paradigms (Guba 1994, p. 110-111). This difference lies in the concept of ‘knowing how we know’.

The methodology of constructivism is hermeneutical and dialectical: *the variable and personal nature of social constructions suggests that individual constructions can be elicited and refined only through interaction between and among investigator and*

respondents (Guba 1994, p. 111). There is an ongoing exchange between the investigator and the respondents such that the construction is more informed and sophisticated than those which preceded it.

The criteria which are appropriate for judging the goodness or quality of a constructivist inquiry are:

1. trustworthiness which includes credibility (paralleling internal validity), transferability (paralleling external validity), dependability (paralleling reliability) and confirmability (paralleling objectivity). Crabtree and Miller state that both the quantitative and qualitative methods seek the goal of trustworthiness of research findings. The constructivist does so as mentioned above, while the positivist seeks *trustworthiness through such means as control and randomizations, probabilistic sampling, replication, and objective instrumentation. In this way both...are equally "scientific" and "rigorous" but via different routes* (Crabtree 1992, p. 176).
2. authenticity which includes fairness and that feature which results in enlarging personal constructions, improving the understanding of constructions of others, stimulating action, and empowering action (Guba 1994, p. 114).

Constructions are attempts to make sense of or to interpret experience, the nature of which depends on the information available to the constructor and the ability of that person to process that information (Schwandt 1994, p. 129). The inquirer enters an interpretive circle and must be faithful to the subject (co-researcher), must be apart and a part of the process of inquiry, and must remain rooted to the context. In this paradigm

there is no ultimate truth; all constructions within their context contribute to whole truth, to the universe of stories. Hence this type of inquiry is best for storytelling with the inquirer performing an “iterative dance of discovery and interpretation” (Figure 2) (Crabtree 1992, p. 10-11).

Figure 2. Circle of Constructivist Inquiry

Crabtree, Benjamin and Miller, William L. *Doing Qualitative Research*, Sage Publications, California, 1992, p. 10

This paradigm is appropriate to understanding the patient's experience of pain or being informed that the patient has a terminal illness.

Qualitative research, then, does not generally seek to enumerate but seeks or attempts to assist us in understanding social phenomena in natural (rather than experimental) settings, giving regard to the meanings, experiences and views of all the participants. For this reason qualitative research is often seen as the antithesis of the quantitative method, the two approaches being presented as adversaries in a methodological battle (Pope, 1995).

Qualitative research employs many methods in its focus. It involves an interpretive, naturalistic approach to its subject matter. Those persons conducting qualitative studies do so in the natural setting attempting to *make sense of, or interpret, phenomena in terms of the meanings people bring to them* (Denzin 1994, p. 2). Some examples of materials used to conduct these studies include life story, interview, case study, personal experience to describe events, moments and meanings in people's lives. Qualitative researchers draw upon and utilize methods and techniques of approaches such as ethnomethodology, phenomenology, feminism, psychoanalysis and cultural studies to name a few (Denzin 1994, p. 3).

It is important to note that, while qualitative and quantitative methodologies are often regarded as adversaries, the methods complement and inform one another of information important to increase understanding and knowledge. Kuzel *asserts that there is no problem with combining quantitative and qualitative methods within a single research project, as long as one is talking about methods and not models or paradigms* (1991, p. 141). It is at the level of epistemology (how you know that you know) that

tension exists between the paradigms, that is, at the level of basic assumptions, such as objective reality versus subjective reality or the need to understand meaning versus the need to describe cause-and-effect.

In either case, be it qualitative or quantitative, as a physician one is aware that optimal practice and care for patients must be evidence-based. *Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients...It involves tracking down the best external evidence with which to answer our clinical questions* (Sackett 1996, p. 71-72).

Specifically and pertaining to this study of exploring spiritual and psychological issues at the end of life, it is important to enhance our understanding of those issues before we develop scales to assess the issues, or programs to address or respond to the issues. Initially, the research question of understanding the phenomenon of living with a terminal illness is best explored through a qualitative methodology. Subsequently it may be imperative to employ a quantitative approach to evaluate interventions and therapies designed to address spiritual and psychological pain and suffering. The qualitative method chosen for this study is that of phenomenology.

B. Historical Context of Phenomenology

The word 'phenomenology' is derived from *phainomenon* (to appear) and *logos* (reason). That which appears, appears in concrete experiences. The aim of phenomenology is the study of experiences to bring out their 'essences' (Pivcevic 1970, p. 11). Broadly defined, phenomenology is *a study of the contents of experience or of the intrinsic structures of consciousness* (Smith 1982, p. 93). That is, it seeks to understand

the lived experience of individuals. It is based on the work of German philosopher, Edmund Husserl (1859-1938). He is quoted by Hardy as saying the following: *it is apparent that, as a consequence of the fact that I am striving after the presumptive goal of true science, I cannot as a beginner in philosophy make any judgment or accept one which I have not drawn from evidence, from 'experiences' in which the respective things and states of affairs are present to me as 'they themselves'* (Hardy 1987, p. 31). For him phenomenology meant the rigorous and unbiased study of things as they appear so that one might come to an essential understanding of human consciousness and experience (Valle 1989, p. 6).

Husserlian thought holds two different intellectual worlds: one which is characterized by a profound commitment to the concept of a rational, systematic and complete science seen as *the prism within which everything both social and natural is fused*, and the other a skepticism about the *apparently naïve conviction that the systematic possibilities of science and philosophy imply that our knowledge of the world can exhaust the meaning of the whole, of the forms in which life can have significance* (Patocka 1996, p. x-xi).

While Husserl's approach not only seeks to be a rigorous science, it also emphasizes rigor as the central most important and profound access to meaning thereby claiming a crucial significance for human existence. *Science ought to and can provide human lives with a "spiritual meaning," the content and aim of life we need in order to be truly at home, at one with ourselves, with our life, and with our world* (Patocka 1996, p. 1).

It was recognized by twentieth century existentialists that it was not possible, employing methods of positivistic thinkers, to adequately understand and assess basic human issues such as joy, despair, love, freedom and choice. Hence existential concerns and phenomenological methods were combined into a philosophical discipline *which seeks to understand the events of human existence in a way that is free of the presuppositions of our cultural heritage, especially philosophical dualism and technologism, as much as this is possible* (Valle 1989, p. 6). The first of the people to do so was another German philosopher, Martin Heidegger (1889-1976), a student of Husserl.

Existential phenomenology became known as existential-phenomenological psychology when applied to human psychological phenomena, seeking to explain the essence, structure or form of both human behaviour and human experience as revealed through descriptive techniques including disciplined reflection (Valle 1989, p. 6). The assumptions of this discipline, existential-phenomenological psychology, also known as phenomenological psychology will be presented as per Valle, King and Halling (1989). Its fundamental claim is to provide an approach which enables one to appreciate a deeper and fuller understanding of human existence with regard to self and others.

First, the most significant issue pertains to the concept of viewing people as more than just objects of nature. The individual and his/her world are seen as co-constituting one another—*the person is viewed as having no existence apart from the world and the world as having no existence apart from persons* (Valle 1989, p. 7). Valle et al use the popular “vase and faces” to explain this concept (Figure 3).

Figure 3. Vase and Faces (Valle 1989, p. 7)

One can treat the center as ground and the surrounding portion as figure meaning one sees two facial profiles facing one another or one treats the center as figure and the surrounding portion as ground, meaning one sees a vase. The vase and faces cannot exist without one another. If the ground or the figure is removed in either scenario, the notion of the other does not exist. So it is with people and their world—if one is discarded, the other becomes meaningless. Given the nature of this study perhaps one might ask whether the same is true of living and dying, that is, is the meaning of one related to the

other? The world and the person are totally dependent on the other for existence, the meaning of the person's existence comes forth through the world and gives meaning to the world. It is for this reason that in existential-phenomenological thought, *existence always implies that being is actually "being-in-the-world"* (Valle 1989, p. 7). This is emphasized in the writings of Martin Heidegger who uses the term Dasein for 'being-in-the-world' (1996).

Being in the world is contingent on dialogue between the person and the world. This means the individual is active in the world in a purposeful way or passive in the world, because the world presents a situation in which the person must act. Therefore one must always make choices. This leads to a second feature of existential-phenomenological psychology namely that of situated freedom. Because the world is acting on the person, the person does not have absolute free will, and because the person can exercise choice he/she is not determined or preordained by causes independent of one's will.

A third critical issue has to do with consciousness. Again with reference to the work of Husserl, attention was focused on the world of everyday experience, communicated to others in everyday language, and not on the world created and described by scientific fact and theory. One might describe this as naïve experience, not focused on the external environment but the *Lebenswelt*, the *life-world*, the world as lived by the person. This is the beginning. It is without assumption(s) as to what might be behind or cause the life-world. *One could say that Husserl's domain was the domain of phenomena—pure phenomena independent of and prior to any reflective interpretation, scientific or otherwise* (Valle 1989, p. 9). Paradoxically, this means that the *Lebenswelt*

is independent of knowledge derived from reflective thought processes and is at the same time the starting point for all knowledge, including scientific knowledge. In order for this to occur, one must bracket one's preconceptions and presuppositions, that is place them into abeyance or to suspend one's biases. This is done by making the preconceptions and presuppositions explicit. So consciousness becomes that which 'makes present', that forum in which phenomena are revealed. Every attempt is made to describe that which presents itself to one's awareness exactly as it presents itself, and not in terms of that which we know or presume to know about it (Eckartsberg 1998, p. 4). It presents with the intention of orienting toward a world of emergent meaning.

The researcher attempts, by asking the question, What?, to understand the phenomena and is not concerned with explaining, predicting, or controlling them. The question, Why? is not asked as it implies an underlying causal view of the world. The phenomena becomes known by seeing it with different reflections and in assorted appearances on numerous occasions. Valle uses the analogy of a crystal which appears to have a variety of sizes and shapes dependent on the intensity, angle and colour of the light which strikes its surface. The constant, unchanging crystalline structure becomes known to the observer only after seeing the different reflections and varied appearance on repeated occasions (Valle 1989, p. 13).

C. Phenomenology Defined

Phenomenological research begins in the Lebenswelt, the lifeworld, the world of the natural attitude of everyday life described by Husserl as the original pre-reflective, pre-theoretical attitude. It is the study of lived experience. The writings of Max van

Manen will serve as a basis for providing further definition to the process of research in the context of that lived experience (1990).

By asking the question, “What is this or that kind of experience like?” phenomenology aims to gain a deeper understanding of the nature or meaning of our everyday experiences. It does so by providing insightful descriptions of the world without developing a taxonomy or classification, without explaining or controlling the world. It seeks to enhance one’s understanding of the world in which he/she lives.

One’s access to the world is through consciousness, through awareness of some aspect of the world. It is important to note that one cannot reflect on lived experience in the moment of that experience. To reflect on lived experience in the moment is to change the experience. Consider any emotion. If one reflects on sadness or anger, the emotion during that moment of reflection is changed. One can only reflect in retrospect.

Phenomenology seeks to capture the essence of lived experience, to understand *that which makes a some-“thing” what it is—and without which it could not be what it is* (van Manen 1990, p. 10). It is a systematic approach to uncover and describe the internal meaning of the lived experience, to interpret these meanings to a degree of depth and richness. This does not include statistical relationships among variables, a control of confounding variables, an assessment of frequency of a particular behaviour or on the predominance of social opinions. Its entire focus is placed on our Lebenswelt, our lifeworld.

Consider phenomenology in the context of science. The term science is derived from the Latin, *scientia*, to know, and is defined as the *knowledge of general facts, laws and relationships that is obtained through systematic observations and experiment*,

especially as applied to the physical world and the phenomena associated with it; any branch of knowledge arranged in an orderly system and considered as an object of study (Gage Canadian Dictionary 1983, p. 1004).

Phenomenology is scientific in a broad sense. It is systematic in that it employs specially practised modes of asking questions, of reflection and of recording and reporting results. It is explicit in that it is articulate (by virtue of content and form) in identifying and presenting the structures of meaning in lived experience. It is self-critical in that it reviews its goals and methods in an attempt to realize its strengths and its shortcomings. It is a human science as it only focuses on structures of meaning in the human world. This is in contrast to a natural science, which studies objects void of experiences which are consciously and meaningfully lived by those objects.

The term human science is derived from a German word, *Geisteswissenschaften*, a word which can be divided into three components, namely Geist, wissen, schaffen. Consider each of those components. While *Geist* is often translated into English as “mind” or “spirit” it includes an aspect of humanness which pertains to inwardness or spiritual refinement. In German then, the word does not have the cognitive overtones and pragmatic connotations which it holds in English. Knowledge as understanding is referred to as *a matter of the soul, spirit, embodied knowing and being* (van Manen 1990, p. 13-14).

The objective part of the word *Geist*, in the context of human science means that the human being is seen and studied as a “person”, in the full sense of the word, giving and deriving meaning to and from the “things” of the world.

The next two components of the term *Geisteswissenschaften* are *wissen* meaning “knowing or knowledge” and *schaffen* meaning “creating, producing, working”. *Wissenschaft* is frequently translated as science although something is lost in the translation as the German context of the word *Wissenschaft* would be understood to include the arts and the humanities. That is not the case in the English understanding of the word science which pertains more specifically to natural, i.e. physical and behavioral, sciences.

One of the distinguishing features between human and natural sciences is how the notions of theory and research relate to the practice of living. In the natural sciences theory informs practice, it precedes practice while in the human sciences it enlightens practice, it enables understanding as a result of reflection. *Human life needs knowledge, reflection, and thought to make itself knowable to itself, including its complex and ultimately mysterious nature* (van Manen 1990, p. 17). Such is the basis of phenomenology. Thereby it appeals to everyday’s common experience in order to analyze in a structured fashion the most common, most self-evident, the most familiar actions, behaviors, intentions and experiences which are met in the *Lebenswelt*.

D. Translating Philosophy into Research Methodology

In explaining the phenomenological research method, Max van Manen (1990) outlines six activities:

1. turning to a phenomenon which seriously interests us and commits us to the world;

2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented relation to the phenomenon;
6. balancing the research context by considering parts and whole.

Each of the above will be discussed separately in the following text.

D. 1. Turning to the Nature of Lived Experience

The first 'task' of phenomenological research is to identify the phenomenon which is of interest to the researcher. *To think is to confine yourself to a single thought that one day stands still like a star in the world's sky* (Heidegger 1971, p. 4). Phenomenological inquiry is *always a project of someone: a real person, who, in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence* (van Manen 1990, p. 31). The starting point is identifying that which truly interests the researcher with regard to some experience that human beings live through. The question then becomes What is this experience really like? The basis of this study is: What is it really like to know that one has a terminal illness? What are the spiritual and psychological issues/concerns that arise once one is informed of having a terminal illness? Do these change over time, especially as death becomes imminent? Only in living the question, in becoming the question and returning to the source of the object which can respond to the question, will one begin to understand the essential nature of that object. *To truly question something is to*

interrogate something from the heart of our existence, from the center of our being (van Manen 1990, p. 43).

It is important to note the orientation of the researcher with regard to the research question/topic. van Manen approached his work from the position of a teacher; I approach the experience of interest from the orientation of a physician. Consider the context. What does it mean to be a physician? In the most simple definition it means that one provides care for individuals who are experiencing illness. That care may include working to cure a disease, to eliminating pain, and/ or to diminishing suffering. Working in palliative care raises the question of what the experience of having a terminal illness is really like. To rid people of physical pain has become the corner stone of palliative care. However, after providing care for several hundred people it became apparent that, while rid of physical pain, people continue to suffer, to experience psychological, spiritual or existential discomfort. This became especially apparent one day when in speaking with a patient, Mrs. B. I inquired about her physical pain. The usual questions of its location, duration, intensity, and response to analgesics was inadequate. My usual armamentarium of knowledge, experience and skill was not sufficient to provide a 'tonic' which would eliminate the pain. I asked Mrs. B. whether she had a pain in her heart. With tears in her eyes she acknowledged that her most severe pain was truly in her heart, in that her daughter was about to marry against what she believed was in her daughter's best interest. Because Mrs. B. had spoken her truth and the daughter had chosen to marry regardless of Mrs. B.'s opinion, Mrs. B. felt that her daughter was making a commitment which would 'not have a happy ending' and that she would also lose the relationship she had with her daughter. Knowing she had a terminal illness intensified her grief in that

she would not be alive to develop a new relationship with her daughter, nor would she be present to support her daughter should her fears about the marriage relationship come to fruition. That scenario impressed upon me the need to understand the experience of dying from a greater breadth and depth. It clearly focused my attention as a physician on addressing pain and suffering (experience of illness) as opposed to curing (experience of disease). It resulted in the question, What impact does this experience really have on one's spiritual or psychological well-being? How does it affect one's sense of self, relationship with other(s) and concept of the transcendent, of meaning, purpose or value, of God?

Others have asked the same question. Kubler Ross for example, who in 1965 responded to the questions of four theology students who were to write a paper on crises in human life. These students considered death as the biggest crisis people had to face and asked Dr. Kubler Ross for assistance in studying death and dying (Kubler Ross 1969, p. 21-22). The five of them worked to have an open mind toward the process of understanding death and dying—they did not read any papers or publications on the topic, they did not review the patient's charts and they recorded only that which they personally noted in the patients or themselves. They interviewed over 200 patients. Subsequently Dr. Kubler Ross wrote her well known book, *On Death and Dying*. From that she also developed her work based on the five stages of dying. She asked the question about the experience and based her stages theory on her impressions of the information they provided to her. *No attempt was made to control or systematize the interview process or to check the reliability of the observations. Given these limitations, her conclusions are perhaps best viewed as hypotheses rather than as guides for policy*

formation. More sophisticated investigations are necessary to adequately evaluate speculations such as these (Schulz 1978, p. 6).

Physical pain never occurs without a subjective component. What is the essence of knowing that one has a terminal illness? How might this question be answered in such a way as to provide an understanding that allows others to grasp the nature and significance of the experience in a way that is deeper? What does it mean to be a physician in the context of a deeper understanding of human suffering?

In order to answer the question it is important to bracket one's assumptions and pre-understandings. Because of the information I have read, I believe I already have an understanding of the human condition and of human suffering. This is true also of my education, my relationships with people as a physician working in palliative care, as a grandson who sits at the bedside of a dying grandparent, as a son-in-law who provides care for his father-in-law as he dies, and as a friend who struggles with a roommate, who has a terminal illness at age thirty, to come to an understanding of what a 'premature death' means. I have been led to believe that my medical education is adequate to address and alleviate pain and suffering. I have trusted my teachers, my mentors and my role models. Like Kubler Ross, I believe I understand the process of dying, the spiritual and psychological issues for those with a terminal illness, the essence of pain and suffering by virtue of observing hundreds of people in the experience of dying. I have made inquiry about that experience, but not as a formal phenomenological study. Because of a personal quest for meaning, I hear the words and observe the actions of those patients for whom I have provided care from a personal *Weltanschauung*, a world

view which integrates meaning, value, purpose and respect into relationship(s) with self, other and God.

D. 2. Investigating Experience as We Live It

It is interesting that the *Lebenswelt* is both the source and the object of phenomenological research (van Manen 1990, p. 53). One's own life experience may serve as a source of information as it is readily accessible. These experiences may be similar to those of others and if used as a description of a lived experience, it is best to focus on a particular situation or event without providing explanation as to causation or generalizations which are interpretive of the experience. Descriptions of these experiences serve as data, the extent to which the personal pertains to the general marks their significance to experiential meanings.

Words used to refer to a particular phenomenon may have lost some of their original meaning and therefore have less of an impact than the experience under question may actually merit. Paying attention to the etymological origins of words may at times put one in touch with times when the impact of those words was greater and seemed to more accurately describe the experience. It is equally important to be attentive to common expressions which are used in everyday language. This would be worthy of consideration when conducting phenomenological research in any health care setting. It would be important to listen carefully to the words used by the professionals as well as those employed by the patients. Consider as an example the definitions of patient and client. The former, from the Greek, *of pati*, means "to suffer", (Webster's 1981, p. 833) while the latter means "to engage [obtain] the services of another" (Webster's 1981,

p. 206). How one who suffers is seen in society is very different from that of one who obtains. Much of the language in hospital reflects military operation: 'battle disease', 'defenses are down' 'wipe out immune systems' 'can't give up fighting the disease' or 'he has given up the fight'.

Through phenomenological research one borrows *other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience* (van Manen 1990, p. 62). In so doing, the researcher becomes more experienced. The intent is not merely to hear their experience so as to be able to report on that experience from their point of view but to listen so as to understand the nature of the phenomenon as an essentially human experience. Data may be obtained from participants by way of interviews, written responses, biographies, diaries, journals, or by participant observations.

It is important to note that there exists a distinct difference between the gathering of experiential material and analyzing it. The conversational interview may simply serve as a method of gathering material (stories, anecdotes, recollections, etc.) about the lived-experience or serve as an opportunity to reflect with the participant. In the case of reflection, the interviewee becomes a collaborator and therefore is often known as the co-researcher. This study certainly included components of conversational interview as well as conversations which were based on reflection.

An interviewing technique employing open-ended questions was selected for this study. Its purposes were:

- to explore and gather narrative material which would serve as a resource for developing a richer and deeper understanding of the phenomenon of knowing one has a terminal illness; and
- to develop a conversational relationship with the co-researcher about the meaning of the experience of knowing one has a terminal illness.

All interviews were recorded by audio and video tape. These were transcribed, themes were identified and reviewed with the co-researcher(s). It was in reviewing the themes that the researcher and co-researcher frequently began to explore the meaning of the experience. Questions based on the work of life review by Birren and Deutchman (1991) were used as a beginning to the conversation. The questions were adapted from themes/concepts of branching points, family, previous experience with death and dying, and meaning, value, spirituality. By way of introduction each co-researcher was asked about receiving the news that he/she had a terminal illness. The purpose of each of the concepts was to enhance, deepen, and strengthen one's understanding of the experience of knowing one has a terminal illness, of one's inner life, of one's spiritual and psychological journey.

D. 3. Phenomenological Reflection

The essential meaning of something is grasped through phenomenological reflection. Meaning is never simple nor is it unidimensional. In order to appreciate the structure of meaning of a particular text, it is of benefit to approach the text in terms of themes, also known as meaning units or structures of meaning (van Manen 1990, p. 78).

The themes may be regarded as the structures of experience. *Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure—grasping and formulating a thematic understanding is not a rule-bound process but a free act of “seeing” meaning...[It] may be considered simply as a means to get at the notion we are addressing* (van Manen 1990, p. 79).

van Manen (1990) provides twelve points which answer the question, What is a theme?

1. *Theme is the experience of focus, of meaning, of point.*
2. *Theme formulation is at best a simplification.*
3. *Themes are not objects one encounters at certain points or moments in a text.*
4. *Theme is the form of capturing the phenomenon one tries to understand.*
5. *Theme is the needfulness or desire to make sense.*
6. *Theme is the sense we are able to make of something.*
7. *Theme is the openness to something.*
8. *Theme is the process of insightful invention, discovery, disclosure.*
9. *Theme is the means to get at the notion.*
10. *Theme gives shape to the shapeless.*
11. *Theme describes the content of the notion.*
12. *Theme is always a reduction of notion.*

Themes can be identified in three ways (van Manen 1990, p. 92-94). In the holistic approach one attends to the text as a whole asking which phrase best captures the fundamental meaning of that text. Identifying a theme is basically a judgment call and

may differ from reader to reader. In the second approach one highlights the statement or phrase which seems essential to the experience being described. In the third approach one considers every sentence or sentence cluster. As the lived-experience is examined and themes are identified, there are some which begin to emerge as common.

In this study it was the second approach which was implemented. Once the themes were recorded, the theme, as well as the highlighted section were separated from the portion of the text which was not highlighted. These themes became objects of reflection, and in follow-up interviews were reviewed with the co-researcher(s). The co-researcher confirmed that the theme as defined by the researcher accurately described the experience. In this way *the interview turns indeed into an interpretive conversation wherein both partners self-reflectively orient themselves to the interpersonal or collective ground that brings the significance of the phenomenological question into view* (van Manen 1990, p. 99).

The process which took place for this study began with a collaborative analysis. Following the first interview with the first of twenty-one co-researchers, themes were identified by the researcher. These were initially reviewed with a group familiar with the process of theme identification as per phenomenological research. The 'collaborative themes' were shared with the co-researcher as a method of further validation. Subsequently themes were identified only by the researcher and then modified and validated by the co-researcher and researcher, such that the themes really described the experience of knowing one has a terminal illness.

It is important to differentiate incidental themes from essential themes. The essential themes are those which describe aspects and qualities of phenomenon without

which the description would be incomplete. One asks questions such as *Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning* (van Manen 1990, p. 107)? One such idea would be to ask whether it is necessary to have a known diagnosis of a terminal illness to really experience what it is like to know that one is dying. That one will die is a known fact; is it part of one's experience of daily life? If the study truly conveys the meaning of the experience of knowing one is dying, then the reader ought to be able to determine on a personal level whether or not their living includes the real knowledge that they will die.

D. 4. Describing the Phenomenon

Language and thinking are difficult to separate. Van Manen describes phenomenology as the application of logos (language and thoughtfulness) to a phenomenon (an aspect of lived experience), *to what shows itself precisely as it shows itself* (van Manen 1992, p. 33). As Heidegger stated, *phenomenology means to let what shows itself be seen from itself, just as it shows itself from itself...[It] neither designates the object of its researchers nor is it a title that describes their content. The word only tells us something about the how of the demonstration and treatment of what this discipline considers* (Heidegger 1996, p. 30). The description of the experience of having a terminal illness is the "thing" which I attempt to describe. The description is only an example of the original experience. *If the description is phenomenologically powerful, then it acquires a certain transparency, so to speak; it permits us to "see" the deeper significance, or meaning structures, of the lived experience it describes* (van Manen

1992, p. 122). This transparency is achieved through the themes which have been identified and subsequently validated. Themes are based on that which is spoken, how it is said, that which is observed and that which is evoked in the listener/observer. Using 'examples' from different co-researchers serves to enhance the possibility of awakening that which, in the listener/observer, mirrors the lived experience of the co-researchers as it pertains to a particular phenomenon.

Silence speaks. There is a literal silence, that is essentially the absence of speech. Secondly, there is also an epistemological silence. The latter is the silence which confronts us when we face the unspeakable. Many co-researchers in this study stated through the course of our time together that they were able to speak that which until that moment in time had not been spoken. For some it appeared to be a silence occurring because of the absence of listener, for others it was a silence because the experience was felt to be such that it could not be described adequately and therefore remained unspoken. Another possibility for the silence would relate to the sense of embarrassment or shame on the part of the speaker if the truth were spoken or received with judgment on the part of the listener. The silence may also occur secondary to the person's linguistic competence, a sense that the description is not expressible in a particular context, or as a function of time, where the narrative may not be spoken at one point in time but very well described by the same person at another time. As examples, this occurred through the course of the study and included a wide range of experiences such as learning of their terminal illness, being told by a family member that the relationship between parent and child was over, and the description of having watched a woman being raped. And thirdly,

there is an ontological silence which is the silence of Being or of Life itself. This occurs at the moment of profound insight or at the moment of a meaningful experience.

Telling an anecdote as part of the narrative process may serve to make the phenomenon comprehensible. Anecdote is defined as *a usually short narrative of an interesting, amusing, or biographical incident* (Webster 1981, p. 43). This is an important feature of phenomenological research in that positivist/post positivist researchers criticize qualitative research as being 'merely anecdotal' and therefore less credible. The anecdote must be understood in terms of phenomenological research as *a methodological device in human science to make comprehensible some notion that easily eludes us* (van Manen 1992, p. 116).

The experience of knowing of one's impending death due to a particular disease may elude most people on a daily basis. Yet approximately 75% of the population will know well in advance what their likely cause of death will be. An anecdote describing the experience of someone who knows their diagnosis may have the effect of changing the abstract theoretical knowledge to an understanding of the reality of a lived experience. It forces one to appreciate the relation between living and thinking, between the situation for the individual who knows their diagnosis and the reflection of one who realizes he/she is mortal as a result of hearing of the experience of learning that one has a terminal illness. One's experience is based on the anecdote of another, resulting in a similar emotional response without necessarily receiving a diagnosis of a terminal illness.

The lived experience of an individual linked to classical figures by way of anecdotes may result in wisdom, sensitive insight and truth. What then is the value of the anecdote as part of the narrative in phenomenological research and writing? Stories catch

our attention. They invite us to a reflective search for meaning, wisdom and truth usually through one's connection from the story told to the story of one's own experience. Anecdotes teach and enable people to make sense of the world.

In writing, the researcher seeks to make the lived experience understandable—thoughts are fixed on paper, that which is internal becomes external, that which is known by one person becomes known by another. It fosters reflection, in a sense it objectifies the subjective, and focuses one's awareness on the moment and the experience, on the writer and the audience simultaneously. If successful, the text of phenomenological research enables the reader to see that which tends to hide itself. The message is communicated in and through the words. Therefore how one writes is essential to certain meaning more so than what one writes. Words, spoken and unspoken must be heard in order to catch the full meaning of experience.

D. 5. Remembering the Question

Exploring spiritual and psychological issues at the end of life—How does knowing that one has a terminal illness impact their sense of self or being (Dasein), their relationship with others, and their sense of purpose, meaning, God—that, for this study, is the question. It is asked of persons who know they have a terminal illness. What is that experience like? Is knowing that one has a diagnosis which will likely result in death different from not knowing that diagnosis? What difference might understanding the experience of those who know make for those who don't know? How many clinicians know what it is like to have a terminal illness? And how many of those can be absolutely

certain that they know the experience of the patient who does know that he/she has a terminal illness?

Four conditions ascertain that a strong and oriented relation is attained and maintained.

1. The text must be oriented. The purpose of a phenomenological study is to capture the essence of a lived experience, in this case that of knowing one has a terminal illness. The lived experience might be regarded as the text. The essence is a description such that the structure of that lived experience is explained and revealed in such a fashion so as to enable the reader to understand and appreciate the experience in its whole truth. It is *both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive* (van Manen 1992 p. 39). In terms of this study, the phenomenological concern does not focus on the nomological or factual aspects of the experience of knowing one has a terminal illness, but on the nature of the phenomenon as meaningfully experienced. My orientation to that experience is not one of mere curiosity, but as a physician who has spent more than 10 years in working with people who have that knowledge. The orientation is one of caring and healing as opposed to curing. It is one that seeks to focus on knowing the spiritual and psychological experience of those who know they have a terminal illness. I recognize that, in terms of being trained as a physician, one is not trained to understand or address the spiritual and psychological nature of personhood. In that context, in that orientation, I seek to work with the co-researchers to recall the experience in such a way that the meaning structures of this experience as they live(d) through them are brought to awareness in such a way that the reader can recognize and

appreciate this as a possible experience. I work to remain true to the object, the true nature of the experience.

2. The text must be strong. Strength is related to being perceptive, insightful and discerning with regard to the object, the subject of investigation, so as to show it, describe it, and interpret it for what it really is. This includes the entire process, whether interviewing and listening/observing through that interview, reflecting on the content and presentation of the interview/transcription or in bringing to speech or presentation one's reflective understanding of the experience. The researcher must concentrate on being focused as opposed to being disinterested or superficial and therefore at risk of being false. Like the adage, 'To know another is to walk a mile in his moccasins'. One must 'stay in those moccasins' asking what is the meaning, the experience of that effort. One cannot remove the moccasin, nor alter the path which the moccasin walks.

3. The text must be rich. A rich description explores a phenomenon in all its experiential ramifications. Remember that the aim of phenomenology is to *transform lived experience into a textual expression of its essence—in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience* (van Manen 1992 p. 36). In this study, the richness of the text determines how closely and truly the reader will experience the essence of living with the knowledge that one has a terminal illness. The text can never be exact, it is only capable, at best, of producing a replication. The specific point in time and space occupied by one person can never be fully known by another and can never be relived by that person.

Phenomenology seeks to relive that experience as fully as possible. Richness determines how closely the relived resembles the lived.

4. The text must be deep. Depth takes the lived experience beyond the superficial into the level of meaning. In order for that to occur *one must meet with it, go through it, encounter it, suffer it, consume it, and as well, be consumed by it* (van Manen 1992, p. 153). Depth moves one beyond the ordinary to the place of secret, that which may be hidden, veiled, or mysterious.

In producing research that is oriented, strong, rich and deep one invites dialogue with those who interact with it just as *cool water invites us to drink, the sandy beach invites the child to play, and an easy chair invites our tired body to sink in it* (van Manen 1992, p. 21).

D. 6. The Phenomenon of Dying

In order to understand the phenomenon in question one asks, what is it? What is the experience of knowing one has a terminal illness? In order to understand the experience one must consider individual themes as well as all the themes, the parts as well as the whole. One must work with those themes, with the knowledge of the experience which exists in the literature, as well as in one's own experience of working with the dying for the past decade. Through the course of the project it is essential to be open to techniques, process and sources which may not be known at the outset of the project.

It is important to note that in understanding the experience there may be an effect on:

- the institutions in which the research is conducted. Practices in caring for persons who have a terminal illness may be challenged and require change if results of the research are taken seriously. In this case it might have an impact on the hospital and the university which 'hosted' the study.

- the co-researchers involved in the study. This is discussed in the section on the design. The intense conversations which occurred in the interviews could lead to new levels of awareness and could have an impact on life-style and priorities in living. If the interviewer is not sensitive to those possibilities, the co-researcher might also feel anger, an increased sense of hopelessness and possible despair.

- the transcriber. In hearing the 'stories' of the co-researchers as one types, one might identify with some of the issues and concerns that are raised through the course of the conversation. As this is somewhat of a longitudinal study and the interviews are intimate, they might trigger an emotional response in the transcriber.

- the researcher/principal investigator. It is known that phenomenological research serves as a form of deep learning which might result in a heightened sense of awareness/consciousness, and perceptivity in the primary researcher. The 'success' of this type of research depends on working to have a deep and realistic understanding of the experience under study.

The object of study is the spiritual and psychological experience of the person who knows that he/she has a terminal illness, either cancer and/or AIDS. The tendency in medical practice is to assess by asking a myriad of questions followed by a tentative diagnosis, to order investigations to confirm or dispel that notion, and follow-up with a

plan of action regarding treatment of disease, controlling pain and/or managing symptoms. In order to understand the spiritual and psychological experience of knowing what it means to have a diagnosis of a terminal illness from a position of being without the knowledge of having that diagnosis, the researcher must be entirely open to listen, observe and sense through the narrative the experience as described by the co-researcher. For the most part, co-researchers were interviewed in their own homes, with the exception of a few which took place on the Palliative Care Unit at St. Paul's Hospital. The purpose of multiple interviews was to review themes, as well as to gain an understanding of the experience over time, a longitudinal approach. Clearly this could only be achieved by identifying people with cancer and/or AIDS who knew of their diagnosis with the understanding that it would likely be their cause of death. Those individuals had to be willing to participate in discussing a topic which could be emotionally upsetting and certainly regarded by some in society as a taboo. Pain, nausea, weakness, and lethargy contributed to difficulty in participating. For some it meant a second or subsequent follow-up interview was not possible. These served as examples of the lived experience of dying, of knowing that one has a terminal illness. The question that needed to be asked of those who were willing and able to participate was: What is the meaning and significance of the experience? That question underlies all other questions which were asked, the narratives that were spoken, and also serves as the mainstay of articulating themes.

van Manen states that *the research process itself is practically inseparable from the writing process* (1990, p. 167). He is aware that some qualitative studies produce lengthy reproductions and fragments of transcripts with the intent that data be allowed to

speak for themselves. He feels that studies that present data in an interesting fashion and combine that with insight, context and impact more closely achieve the purpose of phenomenological design, that is, to understand the lived experience. He includes several examples of organization of data and presentation, namely, thematic (each chapter or part elaborates on an essential aspect of the phenomenon thereby contributing to an understanding of the whole), analytical (to describe the phenomenon from a particular perspective such as that of etymology, or the social sciences), exemplification (to describe the phenomenon from different vantage points—the experience of having a terminal illness as a parent, a child, a senior, due to AIDS, due to cancer), exegetic (organize around writings of authors within the tradition of phenomenology) and existentially (organized against the existentials of temporality [lived time], spatiality [lived space], corporeality [lived body] and sociality [lived relationship to others]). This study will be organized primarily by themes but will incorporate features of most of the other approaches as well (van Manen 1990).

E. The Design

E. 1. The Question

The purpose of this study was to conduct a qualitative study to advance our understanding of the experience and process of dying as it pertains to the spiritual and psychological components of personhood. The objectives of the project are to:

- establish a phenomenological base of information on spiritual and psychological issues at the end of life.

- derive themes which represent the experience of spiritual and psychological issues at the end of life.
- identify implications (based on the themes) to advance the care of the dying.

The content of the study was obtained by interviewing persons who knew they had a terminal illness. This study was not an attempt to do a cross-cultural or cross-religious comparison. The conceptual framework reflects a western enlightenment worldview. This is manifest in the inclusion criteria, the theoretical basis in phenomenology and the use of Maslow's hierarchy of needs used to enhance understanding of the results.

E. 2. Inclusion Criteria

In the initial design of the study it was determined that five to twenty people would participate in the study. The goal was to seek depth of understanding (qualitative) more than breadth or distribution (quantitative). People included in the study were those persons who:

- were known to the physicians working in the Palliative Care Program at St. Paul's Hospital, Vancouver, British Columbia;
- had a terminal illness, either cancer or AIDS and were aware of their diagnosis and prognosis;
- were able to speak English fluently;
- had a life expectancy of 1 to 12 months;
- had unimpaired cognitive function with an ability to understand the nature of the study.

People who were considered for the study were initially contacted by one of the physicians working on the Palliative Care Unit at St. Pauli's Hospital. The study was described to the patient by the physician with an explanation that participation was entirely voluntary. Voluntariness meant that the choice to participate or not would not affect clinical care. If they chose not to participate, the principal investigator would not be informed of their identity or their appropriateness for the study. Those who chose to participate were told they could withdraw at any time, again without impact on their clinical care. These people were given a letter of invitation (See Appendix B). If they were interested they had opportunity to discuss the project with the principal investigator and subsequently signed the consent form (See Appendix C). The principal investigator was also part of the palliative care team. He was not permitted to conduct any interviews during the days or weeks he worked as a physician on the unit. If any of the co-researchers were patients on the unit during his shift, other physicians were asked to see those people. Only during times of being on-call was he directly involved in the care of co-researchers as patients. No interviews were conducted during that time.

E. 3. The Participants

Twenty-one people participated in the study. Of these 14 had cancer, 7 had AIDS. Ten people were interviewed once, while the other eleven were interviewed 2 to 12 times. The ages ranged from the mid twenties to late eighties. Of the persons with cancer there were 6 men and 8 women, and of the persons with AIDS there were 6 men and 1 woman. Those who had a single interview either left the hospital without a

forwarding address, did not respond to phone calls, or died before a second interview could take place.

For the purpose of this report a sample of co-researchers was selected. It included 3 men with AIDS and 4 women and 1 man with cancer. One of the co-researchers was only seen once, and therefore the themes were reviewed with one of the committee members who is overseeing this project. For those who were interviewed more than once, they validated the themes identified from their transcriptions.

E. 4. Interviewing and Analysis

Each of the interviews was recorded by audio and video tapes. The audio tape was transcribed by the principal investigator or by one of two transcribers. Tapes are kept in a locked office and will be stored in a locked cabinet. Only the principal investigator, the transcribers and members of the committee working with the principal investigator have access to the data. Themes were identified by the principal investigator and validated by the co-researchers. At best, this is only a partial representation of what the experience is actually like. The method has limitations.

Consider first the process of gathering the information, of hearing the narrative. In describing the role of the narrative, Mishler quotes from Gee, a linguist, stating *one of the primary ways—probably the primary way—human beings make sense of their experience is by casting in a narrative form...This is an ability that develops early and rapidly in children, without explicit training or instruction.* He also quotes Cohler, a psychoanalytically oriented psychologist who refers to personal narratives as *the most*

internally consistent interpretation of presently understood past, experienced present, and anticipated future (Mishler 1991, p. 67-68).

The narrative of the co-researcher, in some instances described as the respondent, begins in response to a question on the part of the principal investigator, also described as the researcher or interviewer.

In this study, questions were based and adapted from the work of Birren and Deutchman (1991). They included four areas of life review and served only as a guide to the interaction between researcher and co-researcher:

- **Branching Points:**
 - From your point of view, what were the major branching points in your life?
 - What were the events, experiences, interactions with people and places that had a major influence or impact on the way your life has flowed?
 - In your view how has your diagnosis served as a branching point in your life? How might your life be different if this had not occurred?
- **Family**
 - The history of your family includes your family of origin (grandparents, parents, siblings, uncles and aunts) and your family of adulthood (spouse, children, grandchildren). Some family members have been important in positive ways and some in negative ways in shaping your life.
 - Who is your family?
 - What family members have had a major impact in shaping your life? Why?
 - What would another person have to know about your family in order to help understand who you are and how you've come to be the person you are?
 - How has the knowledge of your illness impacted your family relationships?
- **Death and Dying**
 - Prior to knowing about your terminal illness, how have your experiences with death affected you and your character?
 - In what ways have your reactions to death changed over the years?
 - How has your life been affected by knowing that you have a terminal illness?

- Meaning, Values and Purpose
 - Were there any religious traditions in your home as a child? Have you carried them on? Why or why not?
 - What are the principles that guide your life?
 - Can you tell me about how you come to know what was/is right or wrong or what it means to be moral?
 - Do you have a philosophy of life now? What is it?
 - What does your life mean? What does human life mean in general?
 - What are the main things you tried to accomplish in your life?
 - What, would you say, has been your purpose in life? Has that changed with the knowledge of having a terminal illness? If so, how?
 - Has it had an impact on your sense of meaning of life? If so, how?

At the outset the respondent was asked to state who they were, their diagnosis and a description of the experience of learning of their diagnosis of a terminal illness. That was the beginning of the conversation, of the narrative. Conversation is a joint process. All that is asked of the co-researcher is to respond to the question(s) of the researcher.

That first question could be seen as *part of a circular process through which its meaning and that of its answer are created in the discourse between the interviewer and respondent as they try to make continuing sense of what they are saying to each other* (Mishler 1986, pp. 54-55). The first question was much like that of a medical interview seeking factual information which in the course of a visit to a doctor's office would not require a great deal of time. The physician would expect that the answer be straightforward, concise and brief. In that way the patient and physician jointly construct the conversation which is 'normal' in a doctor's office. In a sense the physician is like a detective seeking to find the information which will enable him/her to identify the cause of the patient's 'problem'. This approach is reductionist in nature. In the case of this project, the conversation began with a similar question, asked, in this case, by a physician

as the researcher with the expectation that the co-researcher would have a different response. In this instance the researcher plays the part of the witness—one who by listening and observing learns what it means to have a terminal illness. While the diagnosis might be given by naming a disease, the experience of receiving that information required more than a single word or term. In order to witness, pauses, restating or rephrasing the question, accepting the answer without judgment, asking for clarification, and probing for more information were essential to the process of gathering the information necessary to understand the experience of the co-researchers. *Respondents learn from how interviewers respond to their answers what particular meanings are intended by questions and wanted in their answers in a particular interview context* (Mishler 1986, p. 54).

Secondly, consider the limitations of recording and transcriptions. *It must be borne in mind that the initial record—audio- or video-tape or running observation—is itself only a partial representation of what “actually” occurred* (Mishler 1986, p. 48). The study focuses on that which is being communicated by verbal and non verbal communication. The verbal or linguistic features were transcribed from the audio tapes or in one or two instances when the audio taping failed, from the video tapes copied to audio tapes. *Each transcript includes some and excludes other features of speech and rearranges the flow of speech into lines of text within the limits of a page. Some features of speech, such as rapid changes in pitch, stress, volume, and rate seem almost impossible to represent adequately while at the same time retaining the legibility of the text* (Mishler 1986, p. 48). The nonlinguistic features of speech, e.g. gestures, facial expressions, and body movements are ‘captured’ on the videotape if not on the audiotape,

but are difficult to describe. Accuracy is enhanced by re-viewing and re-listening to the tapes. It is the most reasonable facsimile available to the researcher who seeks to understand experience through the narrative.

Thirdly, there are limitations with regard to identifying themes. These lie in the ability of the co-researcher to describe and define the experience and to subsequently understand the themes chosen to represent that experience. The researcher also brings limitations with regard to his/her own personal history, professional bias, and ability to accurately understand and articulate by themes the experience of another. The researcher works to know the experience of the co-researcher. The entire experience, the complete truth can never be known.

F. Ethics Review

In the context of research, one must consider possible ethical problems, in general and specifically in palliative care. Historically, with regard to medical experimentation, some doctors regard for scientific progress and process superseded their respect for human liberty and dignity. They failed to differentiate between their fellow human beings and guinea pigs (Roy 1994, p. 48). Following World War II, the trials at Nuremberg, Germany included the trial of twenty doctors who carried out experiments on human beings which resulted in the death of those people. The Nuremberg Code was established as a result of these trials. It is comprised of ten principles which emphasize *respect for human beings and the protection of their health, lives, dignity, rights, needs, and interests in any conduct of medical research and experimentation...*[It includes the

concept that] *consent of patients and volunteers involved in medical research has to be competent, voluntary, informed, and comprehending* (Roy 1994 pp. 322-332).

Since the Second World War, research projects in medicine have increased in number, in size, scope, objectives, and in complexity of design. As a result, research ethics has emerged and continues to develop. Roy et al have summarized the ethical issues specific to research ethics: they *all demonstrate and express variations of three basic tensions or conflicts between:*

- *welfare of individuals and the common good of society as a whole;*
- *a doctor's responsibilities as an individual patient's physician and a doctor's responsibilities as a scientist and clinical investigator; and*
- *patients' demand for rapid access to promising new treatments and the need (scientific, clinical, and economic) to evaluate new treatments rigorously with regard to safety, efficacy, and the cost-benefit ratio* (Roy 1994, p. 49).

In order to ensure ethical practice with regard to research it is imperative that there be continuous feedback between specific judgment on specific projects and principles and norms for ethical conduct of research. This requires interdisciplinary collaboration between scientists, clinicians, methodologists, biostatisticians, ethicists, and representatives from other disciplines. This is especially true as research in both the quantitative and qualitative domains continues to flourish. It is important to note that the parameters of qualitative research may be less well known in the biomedical world and therefore research in this domain requires diligence and vigilance to make certain respect is equal to that demonstrated in quantitative research.

Randall and Downie (1996) have outlined 'ethical problems' in the area of palliative care. While they discuss the issues pertaining to competent as well as incompetent persons, only the former will be considered as the latter do not fulfill the inclusion criteria of this study. Co-researchers were assessed for competence by medical colleagues who also referred them to the study.

Randall and Downie acknowledge the condition of persons receiving palliative care by emphasizing the problem of pain or discomfort. They do not differentiate between physical and spiritual/psychological pain or discomfort. It is their sense that people in pain/discomfort might be regarded as being more vulnerable, than those who are pain free, and more dependent on their care providers. Beauchamp and Childress, two prominent American ethicists have said, *Many dying persons face inadequate counseling, emotional support, and pain control. To them their condition is intolerable, and no avenue of hope exists. They would rather kill themselves or be killed than face what they understand to be a bleak future without relief* (1994, p. 238). One must question whether these people are able to give a truly voluntary consent? None of the co-researchers in this study were experiencing intractable pain or other symptoms at the time they were invited to participate in this study. If any of them were in pain or in discomfort at the time of a scheduled interview, co-researchers were given the option to cancel or postpone the interview. On several occasions the interview was canceled either by phone or upon arrival at the home of the co-researcher. One might argue that for people in pain/discomfort there could be value in being involved in a research project which is attempting to address the intolerable features in their condition. It could serve as a source of hope for persons at the end of life. Consider one of the co-researchers in this study.

BZ was a sixty seven year old woman who was interviewed thirteen days before her death and again two days before her death. She was exceptional in that one of her daughters had conducted a qualitative study as part of her doctoral program. In speaking with her daughter about the study, BZ had gleaned a strong understanding of qualitative research and for that reason, in part, was interested in participating in this study. Another reason for agreeing to participate was based on her desire to contribute to an enhanced understanding of having a terminal illness; it provided meaning for her:

“Well, it meant a lot to share this.”

Those were the last recorded words she spoke to me. She died twenty eight hours later.

By nature of their situation, patients who know they have a terminal illness have a limited amount of time and energy available to them. As a basic measure of respect, perhaps they would best be left ‘in peace’ to spend time with friends and family members. This may be especially true when the research is based on interviews which could result in discussion of painful topics, e.g. a study which is directed at an evaluation of the care being received, such as the scrutiny of the relationship between the health care provider and the patient. In the present study, the concern raised, in the submission to the institutional review board, pertained to the awareness that the co-researcher might experience as a result of the content of the interviews. This awareness might contribute to emotional distress especially if the co-researcher felt the issue(s) would not be resolved prior to death. On the other hand, the awareness might lead to resolution and therefore could be regarded as a benefit. So for some it might seem to be a benefit with regard to resolving personal issues and concerns, while for others it might result in a heightened awareness of their emotions which could be considered to be ‘painful’. Some

participants might experience both the distress and the benefit. This description was acceptable to both review boards, one at St. Paul's Hospital and the other at the University of British Columbia. However, through the course of interviews which were conducted as preliminary to the study, it became apparent that spiritual or psychological pain might actually be experienced by the co-researcher(s). Consequently, arrangements were made for the co-researchers to be seen by a qualified counselling psychologist should he/she experience pain which resulted from one of the interviews and chose to see such a person. Of the twenty-one co-researchers two chose to be seen by the psychologist.

I refer again to the interviews with BZ. Nine days after her initial interview she asked for a second interview. Because of her knowledge of qualitative research she knew that, in terms of this study, validation of the themes would be the strongest if she confirmed their accuracy. Therefore, realizing she was getting weaker, she requested a second interview at day nine, knowing that I usually returned only after three to four weeks. As I entered her room I realized that she was considerably weaker and that she would likely die in a day or two. Due to the weakness she was experiencing, she was only able to whisper. I expressed my concern about spending time with her when I felt strongly that an hour of interaction, reviewing themes would further deplete her of energy and strength to speak with family and friends. I raised this as an 'ethical' concern. She stated that as this was one of her last requests, it would be unethical not to proceed. I asked her permission to invite her daughters to be present so that they too could benefit from the conversation. She was pleased to have them join us. Near the end of the interview she spoke of her 'cup of joy' as "a cup full plus reserve." One of her daughters

spoke of being present as a privilege. Again, BZ's last recorded words as a co-researcher were, "it meant a lot to share this".

CHAPTER IV

FINDINGS/THEMES

Talking about death is very difficult for a lot of us in the beginning.
Co-researcher QN

Through the course of this study, twenty-one people spoke of their experience of knowing they had a terminal illness. For most of them the experience included a component of discovery—learning about who they really were, what their relationships meant to them, and about meaning, purpose, a Higher Power. Many of them also spoke of the significance of health care providers—visits to their doctors, visits from their doctors as they learned about their terminal illness, and the care and conversations that were part of their experience during their stay in hospital. If one had to choose a single word to describe the study it would either be relationship(s) or Dasein (borrowed from Heidegger). These people courageously spoke of their real experience of ‘Being-in-the-world’ and of their relationships. The latter included relationship of self, with others, namely family, friends, and health care providers, and with a Higher Power which for some translated into Nature, meaning, purpose, God.

This chapter will be divided into five sections. The first will provide a brief description of the co-researchers and of the themes they identified through the course of this study, through knowing they had a terminal illness. The second will address the relationship between the co-researchers and the health care providers. The essence of those relationships is best described through the communication that occurred in the relationships. The third section will present a description of Maslow’s hierarchy which will serve as a theoretical framework for the fourth section which will focus on the

themes as they pertained to the co-researchers' sense of self and relationship to others. The fifth section presents the themes pertaining to the transcendent self, the spiritual component of personhood.

A. The Co-researchers; The Themes

A. 1. The Co-researchers

Who are the co-researchers? The common feature among them is their knowledge of having a terminal illness, either cancer or AIDS. All of them had been in at least one significant adult relationship with another—partnered, married, divorced, widowed, dating, separated; some were gay, some were straight; some were childless, some had their own children, some had adopted children, some had grandchildren. Their ages ranged from the mid twenties to the mid eighties. Examples of their careers included teaching, studying, carpentry, nursing, parenting, and public relations. Homes were located in the west end of Vancouver, in the downtown east side (one of the poorest areas in the city), in Burnaby overlooking a park, in Kitsilano, and in West Vancouver overlooking the ocean (one of the wealthiest areas). Most lived in one or two bedroom apartments, two co-researchers lived in single room apartments, and one in a house. In terms of income, co-researchers defined their socioeconomic status as being dependent on society via the welfare system, as being comfortable, and as being 'well off' having the means to do anything they would chose to do.

Co-researchers spoke of their roles as parents, as children, as employees, as friends. A few of them spoke of being lovers. They also talked about favourite past times—hooking rugs, baking, travelling, walking, learning to play the guitar, and

shopping; favourite places—a cottage on one of the islands, a ocean cruise, a park, the mountains; and fond memories—eating ice cream with their children, laughing with their grandchildren, conversations with a brother, sewing a dress for a family member, meeting a celebrity. One of them spoke of politics and the effect of government policies on his life. These people spoke of the changes in their bodies as the disease within them progressed—the ascities, the weakness, the bedsores, the shortness of breath, the weight loss, the change in physique.

A. 2. The Themes

A. 2. i. Communication

The interactions that health care providers have with patients are significant to the experience of knowing one has a terminal illness. The encounter may contribute to the positive or the negative nature of the experience. The content as well as the manner in which it is delivered, the verbal and the nonverbal components of communication contribute to the essence of the message—what is spoken and how it is spoken are important to the experience. This is especially true at the time of the initial visit, at the time that one is given the diagnosis of a terminal illness or told that the illness is one which will likely result in death, and during the course of any hospitalizations which occur as a result of the illness.

A. 2. ii. Iatrogenic Suffering

The co-researchers stated that the manner in which health care providers speak to persons with a terminal illness adds to the suffering they experience. For some this was

so severe that suicide became a viable option, for others it reduced self confidence, resulted in feelings of isolation, altered perceptions of health care providers as being persons with compassion, and eliminated any hope they might have had.

A. 2. iii. Pain

When pain is present, it becomes the focus of the experience of having a terminal illness. For some, pain had been a constant reality during some course of the illness, for others it was intermittent, and for most the possibility of experiencing pain contributed to a sense of fear and/or anxiety. When any of the co-researchers experienced pain of significance they were unable to participate in the study. Some reported that when they had a mild discomfort talking about their lives to an attentive listener decreased their discomfort and enhanced their sense of well-being.

A. 2. iv. Touch

Like communication, touch has the capacity to be experienced in a positive and a negative way. Through their experiences co-researchers felt that some health care providers saw them as objects, when, for example, they needed to be turned to prevent bed sores or investigated to determine a diagnosis or the impact of the disease. They longed to be touched in such a way as to diminish their sense of aloneness, to experience a sense of 'being connected to another', to enhance their sense of well-being. Touch was seen as a source of healing.

A. 2. v. Time

One day, like any another with regard to time—sixty seconds per minute, sixty minutes per hour, twenty-four hours per day—the co-researchers had an experience which distinguished that day as different from any other day. On that day they were informed that they had a terminal illness, a disease which would likely end their lives. For some it was predicted to occur in months, others it would be years. All experienced a sense of ambivalence after they had received that information, would the time remaining in their lives be used to embrace living or in preparing to die?

A. 2. vi. Longing to belong

All the co-researchers spoke of a desire to ‘belong to another in relationship’. All recognized the significance of the family of origin, longing to understand relationships with and connection to parents and siblings. Those with close relationships with children experienced a sense of hope in the legacy left in their children; those with ‘broken’ relationships with children longed for resolution before death. Love of another, especially that of family members, was seen as essential to a peaceful death. When relationship with family was severed or impaired, co-researchers developed intimate relationships with friends and neighbours. All longed for a sense of belonging with at least one other person.

A. 2. vii. Life Review

With the knowledge of a terminal illness, the co-researchers began a process of reviewing their past. This included their family history, their professional history, events

and interactions which had been believed to be forgotten, and for some, a realization that some features of one's life were not resolved. This process resulted in a recognition that people who are dying are still living.

A. 2. viii. Truth

This emerged as one of the most powerful themes. It included the truth of the co-researcher and often the truth of others, especially family members. Many felt a strong need to speak their truth to someone who would hear it . They also longed to hear the truth of their family members, not necessarily for the resolution of conflict or differences but 'simply' to hear the truth, with the hope of understanding themselves and their family members more fully.

A. 2. ix. Who am I?

Ultimately the co-researchers wanted to know and understand themselves. Many of them referred to the socialized self as losing significance and acknowledged the emergence and recognition of the true self. They spoke of their own values, their appreciation for who they were, their recognition of personal qualities and traits, their need to be seen by others for who they were and not for the person they might be expected to be. In the context of this theme one realizes a cultural limitation as members of some cultures would not understand the concept of an 'individual' self for the individual person is only known in the context of family and/or community.

A. 2. x. Transcendence

Through the experience of having a terminal illness, most of the co-researchers spoke of a 'power beyond themselves'. This was noted in nature, in relationships with others, in a recognition of a need for strength, love and integrity resulting in a wholeness which they had not previously recognized. For the most part, this power was spoken of as a Higher Power. In the context of a terminal illness and the experience of physical weakening due to disease progression, the essence of the spiritual dimension became ever greater. For some it served to eliminate all fear of death.

B. Communication between the Health Care Professional and the Patient

The reality of death and the perceptions of the participants—the dying person, the doctor, the family members—are separated by a wide gap. We need to bring the two into closer alignment. Doctors who are on a first-name basis with disease must re-acquaint themselves with the patient. They must recognize that, by focusing exclusively on conquering disease and prolonging life, they abandon the dying when, in their own words, there is nothing more to be done. They must come to terms with their own death in order to provide proper care for the dying.

George Soros, 1994

B. 1. Context

The purpose of this section is to review the content of a sample of the interviews in order to enhance the reader's understanding of the experience of being informed that one has a terminal illness. Its purpose is not to write the definitive article on doctor patient communication/relationship. This will include three components: first, the initial encounter with the physician which, for some, preceded the time at which they were given the diagnosis; second, the time at which they were actually given their diagnosis;

and third, their experience of interacting with health care professionals during their hospital stay.

Branching points are those events or experiences in one's life which significantly affect its direction or flow (Birren 1991, pp. 67-69). These points shape our lives in an important way. Based on the concept of branching points, as a starting point of conversation, I began each interview by asking the co-researcher to tell me how they learned about their diagnosis and how they were informed about the fact that they had a terminal illness, e.g. In your view has your diagnosis served as a branching point in your life? How might your life be different if this had not occurred? The responses, in general, were given over the course of thirty to sixty minutes and for many were remembered as the source of considerable pain. For some, the pain they experienced resulted more from the method in which the message was delivered than from the content of the message. One might actually regard this as 'iatrogenic suffering'. *When our intervention [communication] is directed solely at disease and symptom control, no matter how technically good it may be, we will not only fail to relieve suffering, but we may even be its cause (Johanson, 1991).* Others recognized the value of truthful communication delivered in a clear compassionate fashion which characterized their experience and served as the basis of hope. In either case conversations/relationships with physicians as well as other health care professionals held a significant place in the lives and memories of the co-researchers. Some experienced both the impact of the iatrogenic suffering resulting from the communication or relationship with one physician and the hope experienced in the relationship with another physician. One of them actually used the experience to challenge her physician to 'do it properly'.

B. 2. The Initial Visit

The opening question of the interview was directed to learn about and understand the experience of receiving the diagnoses of a disease which was known to be terminal, or to learn about the time that they were informed that the disease which they experienced would likely be the cause of death. Some of the co-researchers chose to speak of the experience of communicating with physicians even before the diagnoses of a terminal illness was made.

Communication begins as soon as one enters 'the presence' of another. It has a verbal and a non-verbal component. The conversation between the doctor and the patient is regarded as the 'backbone of the visit' (Crabtree 1992, p. 149). For a patient it begins with the visit to the physician, presenting the reason for making the visit. The doctor, in turn, listens, asks questions about the particular problem and the impact of that problem on the individual's life, and makes a diagnosis, which is confirmed by investigations and followed by a treatment plan.

Consider the following account of a man, MO, in his early twenties making his initial contact with a physician. He had a previous diagnosis of diabetes:

...at night you know I'm not able to sleep because of this [pain] so it got to the point where I was taking handfuls of Tylenol, where I was not sleeping at all, where I was you know grumpy and edgy at all times um I'd get up in the middle of the night, test my blood sugar, find that it was above 12 or something like that, be in extreme pain...its 2, 3 in the morning. And so I'm getting dressed going for jog, coming back, checking my pulse and making sure my heart rate was up, so that my blood sugars would drop so that the pain would go away...my school work is absolutely nose diving...I had to drop all my classes and I thought you know I'm just gonna concentrate on my health...at the same time I I was working...so I'm having to get up in the morning after a night of no sleep, do my morning preparations, go out to work...come back and you know have somewhat of a life after that uh,

it was just impossible, I couldn't do it...I didn't have a whole lot of confidence in the medical professional at that point in time...until eventually you know its its just got such a grip on me, such a hold on me that I can't do anything about it so I go to see a doctor...I was telling [him] about you know a weight loss and night sweats and problems of this nature and um he just sat me down and gave me a speech essentially that said well our bodies thermostats are are set that at certain level uh you're just a naturally slender guy and you know you're stressed out a little bit more and don't worry about it and sent me on my way...he wrote in in in the appointment, patient is obviously unhappy I could do nothing for him...you know I came in there complaining with a lot of symptoms and that just sort of perpetuated this uh problem that I had with the uh medical establishment and uh just drove a further wedge in between myself and it...

This young man felt an estrangement from the medical professional. He was unhappy and in retrospect resentful at not being taken seriously. Communication is more than listening or focusing on disease, it includes getting to know the patient as a person. When that occurs the patient will have a sense of self respect in the presence of the health care providers based on a feeling that they value him for who he is and for what he has done (Cassem 1988, pp. 733-734). This will be discussed further in the next section. Another co-researcher, CO in her mid sixties also felt she wasn't taken seriously. She felt that her interaction with the medical doctor decreased her trust in the system, eroded her personal confidence, and resulted in emotional pain and suffering. She felt that she was not heard and that the experience was one of humiliation:

I went to a doctor, ordinary medical doctor, and uh, he said well, (pause) he took x-rays, upper barium or something like that, and (pause) he told me it was the windpipe and the esophagus, I had problems with that and uh, (pause) and I was going to have that for the rest of my life. And I said well I feel there's something more, that it's down below (pause) and he said no (pause) didn't think so and he gave me a prescription, he said follow this for ten days, or whatever they write on the prescription, and then come back and see me (pause) but I felt so terrible after a few days I never did fill the prescription at all. I didn't feel he gave me the right (pause) diagnosis. It was just intuitively, I felt

that way. So I went back and I told him (pause), in I thought a rather nice way, but he got very annoyed with me (pause) extremely annoyed and he asked me who I thought I was. If I had had training in this field, and I said “no” and he said he took years of training and also the x-rays show things, and then he told me I was a hippie-kid, he thought from that generation and (pause) and he started hurting (pause) emotionally so, and he also wrote me another prescription (pause) and he sort of threw it at me and he said “take this and come back in another ten days”. But I went out and I was totally devastated (pause) and for a couple days I didn’t do anything but I felt worse and I phoned my son and told him and he said something’s wrong, you have to go to another doctor (pause). I said “I know I do but I’m losing faith because I did phone up Physicians and Surgeons and asked them if they had (pause) doctors that (pause) maybe dealt in some other way besides just the medical establishment” and they said “no, not really”.

In contrast, this woman made contact with a second physician. This doctor decreased her emotional pain and suffering:

I went to him and he was totally different. He just looked at me and he said “but why didn’t you go to a doctor?” and I said “I did” but (pause) I felt (pause) maybe due to my condition I wasn’t thinking straight and I felt (pause) disempowered so (pause) he asked me if I had time that day. I said “yes”. He said “I want you to go to the Hospital and I’m gonna put you in Emergency tests you know right away”. This was late afternoon (pause) and I went and he even came and saw me that night and it was wonderful because from then on I got (pause) understanding of what it was...and that’s (pause) how through Dr. Y on the North Shore that I (pause) can really say that he put me on the right path to uh being helped right away, (pause) you know and he was understanding, he didn’t berate me or anything so (pause)...He listened and he was compassionate. He realized that I did have pain, (pause) you know.

CO described the second physician as one who listened, who has compassion, built trust and respected who she was. Through that encounter her self esteem was enhanced. MO also went to see a second physician:

...this doctor this time was a different doctor um took my claims a little more seriously um immediately sent bells off in his mind when I starting talking about night sweats and not able to sleep and to have Tylenol that I was taking...And he looked at me and he said definitely

not your imagination. There is something going on in there...I was relieved you, it had been 2 years of going through this bullshit, now I was finally gonna get some, get some answers.

He experienced relief at being taken seriously, at being heard.

B. 3. Receiving the Message of a Terminal Illness

In a recently published review article on breaking bad news the authors raise the question about the definition of bad news. They report that it pertains to *situations where there is either a feeling of no hope, a threat to a person's mental or physical well-being, a risk of upsetting an established lifestyle, or where a message is given which convey to an individual fewer choices in his or her life* (Ptacek 1996, p. 496). The authors emphasize the fact that the news may vary in its subjective or objective severity. Each of these may be, and likely are experienced to different degrees by the giver of bad news and the recipient. It is important to note, as do the authors, that most of the articles used as the basis of the review are written specifically from the perspective of the physicians without a great deal of inclusion from the patients. Given the complexity of human emotion and cognition which is part of receiving bad news, one might conclude that it is somewhat presumptuous to know what helps or hinders a particular patient in receiving bad news unless inquiry of the recipient is made. As an example of introducing the possibility of bad news, one might say prior to ordering investigations, 'Given the results of these investigations are unknown to us at present and that there are several possibilities, some of which might be serious, how would you like to receive the results?', or 'If I needed to give you

some news which might be difficult to hear or accept, how would you like me to do that?' The second limitation of the review, also noted by the authors, pertains to the lack of theoretical justification and empirical validation. This is illustrated in the question, "Does how the news is delivered make a difference to the patient and/or to the patient's family and friends?" Validation for a question such as this can only be obtained from those who are having the experience of receiving the news of a terminal illness. Others are left to intuition and opinion which may or may not be accurate. It is in the validation that the information becomes 'evidence-based'.

There seems to be little argument that informing someone that they have a terminal illness would be regarded as anything except 'giving bad news'. It is difficult and uncomfortable to give bad news to anyone, whether in a personal or professional context. The idea that it is the responsibility of the physician to inform the patient that he/she has a terminal illness has changed in the course of the past decades. A survey conducted in 1961 indicated that 88 percent of physicians who participated in the survey preferred not to tell cancer patients of their diagnosis if it was a noncurable cancer (Oken, 1961). That study was repeated in 1979 indicating that ninety-eight percent of responding physicians believed it was preferable to inform patients of their diagnosis (Novack 1979). One questions how receiving this news might impact the patient. Consider the experience of several of the co-researchers.

I begin with MO:

I spent I guess about two and one half to three weeks at a Hospital and the entire time that I was there they sort of danced around the issue you know, well, what is it? It could be anything...all these doctors are running around doing all kinds of tests that I've never heard of, you...I waited and waited and they sent me down to pathology and I'm waiting and waiting some more and you know days are clicking by and this is very stressful not only for me, for my family...I got tired of waiting and I knew when the nurses would be on rounds and I went to the nurses station and pulled my chart from from the nurses file there, opened it up, looked under diagnoses, and it said metastatic carcinoma. And at that point of time that meant about as much to me as you know a foreign language so I wrote it down on a little piece of paper and quickly dragged my PCA back with me to my room and when the nurse came in to do the vitals I said, do you have a medical dictionary? She said yeah, why? And I, curious to look up a few terms. She brought the dictionary, I flipped it right through to carcinoma - cancer - so um I looked up the word metastatic- something that has spread - OK. So now I've, I've got an idea of whats, whats going on.

Through this portion of his admission to hospital MO felt that medical staff were avoiding the topic of his diagnosis and that physicians were cautious and ambivalent in speaking with him. He became apprehensive and fearful as communication was limited and indirect. He was eventually exasperated, and tired of waiting. He found the experience to be stressful especially as he was uninformed, feeling that he was kept "out of the loop". He took control by checking his chart for the diagnosis. Approximately three weeks after his admission, MO was transferred to the cancer institution.

And uh then it kinda dawned on me again you know you sort of like different bells that are going off, the first is that they actually wrote it down in my diagnoses but didn't tell me, the second is now that I'm being transferred over to the cancer clinic that didn't really hit me until I actually walked through those doors...I'm here so there's got to be something going on...and [I] wasn't liking it and I made this fact known and the admitting nurse turns to me and says well what do you expect this isn't the Westin Bayshore...I guess about an hour after that uh a doctor comes bounding in...she seemed to be in an awful hurry and came in and said oh wow you're actually sitting up and and talking.

The way they explained uh to me from UBC I figured that uh you'd have been lying down and barely conscious...that was all happened to me in about an hour so I've been introduced to the cancer clinic by virtue of walking through the doors, I've had this wonderful nurse point out the obvious that is not the Westin Bayshore to me and an oncologist comes in tells me, rattles off this big pathological name for for something that I've got inside of me and tells me that I'm gonna die in about two, two and half years...Every single little thing along the way you know added to the confusion and the, the anger...So there's little things that just added and added and added and the combination was the doctor who came in and, and in a span of about two minutes took away every dream, hope or anything I had in my life, you know...there's a resident on the...team who can give the same message that uh my chief oncologist can give me and yet after she'll tell me it, I'll feel hopeful, yet when my chief oncologist tells me it I feel like the Lion's Gate Bridge is a viable option...[With the resident] there's more of an understanding there, there's more of an empathy, and more of a compassionate eye.

While MO felt angry, confused and disregarded mentioning that the Lion's Gate Bridge was a viable option, he did not to my knowledge make any attempts to commit suicide.

That was not the case for one of the other co-researchers, KR.

I'd been placed in isolation because they didn't know what, what was wrong with me and I was un, unable to leave the room or anything else and so in came Dr. Z. with his flunkies, flunkies I call them cause they all follow these doctors around in the hospital, there's about five or six of them all behind him and he walked in the room and took one look at em and went "Aah" a wonderful example, a textbook case example, a perfect example, all of you look at this, it's , you're gonna see a lot more of this in the future, look at it, memorize it in you mind cause you're gonna see lot of this. And I said of what? He said oh, you're seroconverting, you're becoming HIV positive, but don't worry you've got five years left, patted me on the arm and uh (pause) walked outta the room (pause) and uh just left me there.

This person was left in his room for two hours before a nurse entered to inquire about his well being. He stated that apart from feeling like a specimen, an object, a textbook case he also experienced a sense of hopelessness, isolation, abandonment, fear, and despair. He generally found the experience to be dehumanizing. He acknowledged

that doctors hold power over patients in their communication with them, for when doctor's speak it becomes the patient's truth; when doctors give people a life expectancy, it is believed, it is taken seriously. KR believed that he would die within five years.

Here's this guy that I've never seen before in my life walking into my room saying I'm a textbook example of somebody sero-converting and dying...he is a very respected physician, but I think he has the bedside manner of a billygoat...He probably thought he was doing the right thing but uh (pause) but to do that and then to leave me alone for two hours is uh (pause) probably uh, you know, I would have to say that being left alone for the two hours after uhm (pause) really made my mind set that I didn't have to live for five years that I could take my life and just call it quits now.

KR felt that doctors must be aware of their patients emotional well being and seek to preserve that well being especially when giving bad news. Being alone after hearing of one's terminal illness results in feelings of abandonment, despair and suicidal ideation. He attempted to commit suicide for which he was admitted to the psychiatric ward.

Nobody in all this time (pause) challenged my, my, my thoughts or Dr. E's diagnosis that I was going to die in five years.

Following that episode he redeemed his life insurance, travelled to places he had previously only 'dreamt' of visiting, and spent the money on his friends.

I did exactly what the doctors told me because I felt that's what I had to do to die, uh or whatever right. Cause they were looking after me and uh, I got really confused so uhm, when they told me that I had to have a shunt put in for feed tube, tube-feeding and be catheterized and I said I never, I never second-guessed it, that's what I was supposed to do and uh, the I got so isolated, isolated and, and, and, and I'd have to say I was living in hell because I was listening to all the doctors.

It wasn't until ten years later that KR began to deteriorate. He remembered the day he was informed of seroconverting as though it had only occurred twenty-four hours earlier. He had strong feelings about receiving bad news and how it would best be given.

Memories of how a diagnosis was given stay with people for many years. Ten years after the diagnoses LS remembered the following:

I went into the hospital on daycare and he did a surgical biopsy. Now I can't remember, the surgical biopsy was also negative, so he said we'll just keep watching it, so we watched it and I guess it was three months seems to me that June through September finally it was growing so rapidly he said we'd best have it out anyway no matter what it is and I went in for surgery and uh he removed it. It was a node and it wasn't until then apparently that there was a diagnosis. I was still in the hospital. This part is, this is the first trauma. Up to then I don't remember any great emotion. I was up up in my room lying in my bed and uh still coming out of whatever anesthesia I'd had and uh the doctor appeared at the door of my room. I was by this time sitting on the side of my bed, I had tried getting up and walking cause I like to get up as soon as I can, but I was still a bit woozy. And he came to the door and said, We were wrong, it's cancer. No he didn't say cancer. He said it's uh non-Hodgkins lymphoma and normally I would know what that was but I was dazed and I said what's that mean? And he said, it means you have cancer. Don't worry, I'll make an appointment for you at the cancer clinic. And left. He never came in, stood at the door, left.

LS remembered feeling stunned, angry and indignant. I refer again to the review article by Ptacek and Eberhardt (1996) in which these authors make recommendations about breaking bad news. These are divided into two categories, those which pertain to the physical and social setting and those which pertain to the message.

Consider first the physical and social setting. Ptacek and Eberhardt include four features of this component of communication:

- (1) the news would be delivered in a space which is comfortable, quiet, large enough to accommodate staff and family members and such that privacy is ensured.
- (2) the physician delivering the news would do so at a time that is convenient for the patient. This serves as a strong message of respect for the patient. It means the patients would be most likely to feel safe in asking questions of clarifications and in expressing emotions about the experience.
- (3) the news would be given in person hopefully by a physician or health care provider who is known to the patient. The message is conveyed in at least two dimensions, the verbal which is heard, the nonverbal which is seen and felt. Those two modalities can contradict or undermine one another. The nonverbal, that is how the message is given, is likely to be the one of greater impact.
- (4) there may be value in identifying a patient's support network and having another person or persons present if the patient should want that to be the case. These features will be reviewed in the context of the experience of the co-researchers.

LS's response to being informed of cancer was one of anger and indignation. A decade after the event, she remembered how her physician informed her adult sons first and then informed her of the cancer from the doorway of her room:

Anyway, and then it, I realized without telling me or having me tell my children, he had phoned my children first. He didn't know whether either of my children was uh an idiot or somethin, he just phoned my two sons and spoke to them and said your mother has uh cancer. So that bothered me and I had to stay in overnight and in the morning the nurse uh during the night the nurse came in because I was weeping and uh she held my hand and I said, she said what is the matter, are you in

pain? And I said no, not in pain, I'd just uh am very upset about the way in which a. I was told that I had cancer and b. that he would tell my children and not let me and ask me would you like me to tell them or would you like to tell them? I think I should have been given the choice and she stayed with me awhile and I fell asleep and in the morning she came and said uh the doctor said you can go home now. I'm not a very assertive person. Uh but must have come a very very deep in me and I said no I'm not going to go home, I'm not going to get dressed, I'm not going to move until the doctor comes back. So you give a message to the doctor that he has to come back to see me this morning. I'll stay here until, I said I'm not even going to put my clothes on until he comes back. So he came to the door again and I said come in. He said, what's the matter? You can go home now. And I said nope. Um I have to tell you something. He said well what is it? And I said, it's the way you told me I have cancer. What? What did I do? I said you stood in the door. We have a relationship of more than three months where I felt that you felt I was a human being not just a cancer and then you tell me this, you stood in the door and told me and went away. Well he said, what what could I have, what should I have done? I said well you know you should have come in, you could have come in I said and just put your hand on me, put your hand on my shoulder, put your hand on my arm and say you've got cancer. It would have made a big difference to me, just touched me you know and say you've got cancer. You don't have to cry, you don't have to say poor thing, just you've got cancer, you know and we're going to take care of it. Well he said I have to tell so many women this he said, I can't, you know, that's that's the only way I can do it. And I could see you know that his emotions were involved as well, but I thought to myself, that's his profession.

In reviewing the themes LS felt that the way in which she was told about the cancer was absolutely more emotionally painful then the actual diagnosis. She felt it had complicated her life because one of her sons

came in in a terrible emotional state, threw himself on the floor beside the bed and crying you know and I had to lean over and say uh you know if you're going to behave like this you, I won't be able to see you because you'll make me feel as though I'm dying. I have to know that I'm going to be OK, you know, so you have to buck up and help me by not acting as though this is a death sentence. I'm going to be alright and have treatment. And uh he was near collapse, a nurse had to come in and take him out. I understand why.

She emphasized the need for compassion, for human contact, for recognition of a personal relationship. She felt that in touch one might convey a message of hope. And while she recognized that it might be painful and feel uncomfortable to inform people of their terminal illness, she felt strongly that inherent in the profession of medicine and a patient centred approach was the skill and ability to convey such a message with empathy,

empathy should be there, understanding that this person who is here with the cancer is not a cancer.

The doctor-patient relationship begins with a person to person relationship.

KR received the news about becoming HIV+ ten years before the initial interview. As he spoke, he described the event as though it had just happened. The memory was still vivid in his mind. He felt that bad news ought not to be given by a stranger.

Here's this guy that I've never seen before in my life walking into my room saying I'm a textbook example of somebody sero-converting and dying...then he's walking out on me and I never see him again. [For him, the] family physician would be quite good, yah, cause you, you have a , you would have stronger relationship with your family physician because you see that person more often right and you, you would respect them.

The majority of patients with a terminal illness receive care from family physicians (Foley, 1989; Latimer, 1995). Family physicians are in a unique position to know individuals and their families over time, to act as guides, interpreters, and advocates, to provide continuity of care throughout the illness experience (Latimer, 1995; Burge, 1995). Nuland says it well when he makes *an unspoken plea for the resurrection of the family doctor. Each one of us needs a guide who know us as well as he knows the pathways by which we can approach death. There are so many ways to travel through*

the same thickets of disease, so many choices to make, so many stations at which we may choose to rest, continue, or end the journey completely—until the last steps of that journey we need the company of those we love, and we need the wisdom to choose the way that is ours alone. The clinical objectivity that should enter into our decisions must come from a doctor familiar with our values and the lives we have led, and not just from the virtual stranger whose superspecialized biomedical skills we have called upon. At such times, it is not the kindness of strangers we need, but the understanding of a longtime medical friend. In whatever way our system of health care is reorganized, good judgment demands that this simple truth be appreciated (Nuland 1994).

KR believed that bad news would best be given by people with appropriate skills in the presence of loved ones while someone was holding the patient's hands. He made the following comments regarding the news about sero-conversion:

So that's where I think it should be a group of people like, after that happens, he knows what it is, he goes out, he tells the people on the Ward, uh KR is sero-converting, he's becoming HIV positive and that probably has about five years to live, you know, whatever and this group that whatever could be uh, uh, psychiatrists or a psychiatric nurse and a counsellor and whatever uh, would get together and phone someone that cares about you, bring them in, tell them first, and then come to the room, right, and say we have to have a talk, and uh, and that way uh (pause) bring up the fact that uh, I'm sero-converting or you know, or what or that you would have cancer or you whatever, that you would have someone you loved or cared about with you to hold your hand and whatever and cry with you.

Another co-researcher, HJ was informed of his diagnosis and prognosis in a busy emergency department, namely that he had AIDS and that he would likely die from the pneumonia he had at the time. After that he fell asleep only to be woken to sign a Do Not Resuscitate form.

It appears that the features of the physical and social setting as described by Ptacek and Eberthardt (1996) are in keeping with the wishes of the co-researchers in this study. The desire to have family and friends in the room at the time that bad news is given is expressed by several of the co-researchers. When a diagnosis of cancer was given at the doorway of LS's hospital room, the recipient of that news remembers the anger and indignation for many years. From her experience one can certainly appreciate that the giving of bad news may result in iatrogenic suffering. LS stated that in order to give bad news the right way, the doctor would be very effective in communicating with empathy by sitting next to the patient and touching that person, not by 'addressing the cancer' from the doorway.

Consider the experience of BZ, a 68 year old woman with breast and lung cancer,

Dr. P has at all times taken time to, not just talk to me, but to my whole family...with a lot of empathy and sort of touching me from time to time while he was talking to them. Now my youngest lost her cool and she got up and left the room (pause) which (pause) was what, but (pause) he finished talking to [names the family members] and then one of them went to find [names daughter who left]. He was in the lounge with her with his arm around her.

BZ was in a private room with her three daughters (her support network) at the time that Dr. P talked to her about the terminal nature of her illness. As she was admitted on the weekend, she was initially under the care of Dr. W who was covering for Dr. P. It was Dr. P, the physician who knew BZ well who gave her the bad news. They had quiet and privacy, BZ was comfortable, Dr. P took time to answer all their questions, and he touched BZ as well as the youngest daughter. In that context a safe and trust filled relationship is established with BZ and her family. Perhaps hope is born in the context of truth. That describes the setting, now the message.

Ptacek and Eberhardt state that the recommendations, regarding delivery of bad news based on the literature, focus on *balancing the need to ensure that the patient or family comprehends the news being conveyed while doing so in ways that do not exacerbate the discomfort associated with the news itself. An additional theme running through much of this advice is to break the news in ways that contribute positively to the coping of the receiver* (1996, p. 498). This was reinforced by the experience of one of the other co-researchers in the study. Other only because he is not one of the 8 included in those used to demonstrate most of the themes. Those persons will be regarded as 'other co-researchers' throughout this document. In any case, his recommendations about communication stated that physicians need to speak the truth, present alternatives and to give control back to the patient:

I think the main thing is to be honest and tell you that I can't restore you to the way you were (pause) face that fact, that's because that's the fact and you have to accept uh and then offer you alternatives. You know on how you can survive uhm (pause) and I think stressing the positive aspects of what you can do, not what you can't do.

He felt that it is important for physicians to learn to listen, to be clear in the process of care delivery and to explain the process and the problem often as is necessary for the patient to understand:

I think the simplest answer to that is to uh (pause) is to say here's the problem and we're gonna go step-by-step-by-step. (pause) So you'd lay out a road map, it doesn't have to be complicated, but I mean just say, well okay, uh, we'll have a briefing tomorrow and uh we'll uh review the situation the next day. Dr. H does that, he, he gets all the information (pause) and when he was satisfied he had all the information then he talked about where we were going and so I trust him, you know.

It has been documented in other studies that patients do not hear much of what is said after the initial portion of the bad news is given and do not recall the information given to them about the message (Eden, 1994).

Recall the instructions of LS:

I said well you know you should have come in, you could have come in I said and just put your hand on me, put your hand on my shoulder, put your hand on my arm and say you've got cancer. It would have made a big difference to me, just touched me you know and say you've got cancer. You don't have to cry, you don't have to say poor thing, just you've got cancer, you know and we're going to take care of it.

She asks for the message in simple terms. BZ would agree,

he knew us well enough by then, my daughters were there too and or, two of my daughters and he knew us well enough by then that he didn't fiddle around, he just said yes, it's cancer.

She generally felt very fortunate about the medical care she had received. She felt that physicians had taken time to answer her questions as well as those of her family such that choices could be made based on complete information and full knowledge.

I guess the first thing is I trust all my physicians and uh (pause) so, and they've been totally up front (pause) and uhm answered questions in detail plus which um (pause) I have a daughter who's very involved in the medical field and uh, she has sat in on all the important interviews and has asked questions that have clarified things in their minds too, so (pause) in my own case I couldn't have asked for it to be handled better because everybody had been so up front with me, told me what, what it might be, what it might not be, what uhm (pause) I mean they just couldn't have been more honest, so it didn't come as a, a sort of a shock, a bolt out of the blue at all, it was just one of the case scenarios they described that they hoped it wouldn't be.

Both BZ and LS knew that their diagnosis might be one of a terminal illness. One was distraught after receiving the message, certain that it would have been received with less pain had the physician made physical contact, spoken it in gentle, simple terms, and

provided some assurance that she would not be abandoned but receive ongoing care; the other was content in her sense of safety and trust that the physician was speaking truthfully and with compassion to her, as well as to her family. She felt confidence and hope that she would be well cared for, for the duration of her illness.

B. 4. Communication/Relationship with Health Care Professionals during Hospital Stay

While the communication surrounding the diagnosis of a terminal illness involved primarily the physician, the stay in hospital included other professionals as well. For some, communication added to the degree of suffering, for others it contributed to the sense of trust and safety.

It is important for health care providers to recognize that a patient's room and area around the bed are seen by the patient as being equivalent to their home, their personal and private space. This is the sense that was experienced by CO:

...as I was talking on the phone, she was working on my arm here and I just about turned around and slugged whatever it was (laughs) and then I realized it was her and uh, then she just left. She's never said what she wanted or if she did something, or you know, she never came back...Well I just would have liked to have known what, why she was looking at my [arm]...Well, (laughs) it's almost kinda silly to say, like, but yah, I almost feel violated, you know, cause you're in, because if you're in this condition...just like there's an intruder in the house...if they want me, you know, no matter what, just call me...I react properly to my name just like anybody else would if they're being called.

CO felt vulnerable and at the same time was shy to express that feeling. She found it difficult to say things which might jeopardize the caregiver in some way,

Oh, I don't want her to feel like I'm calling her up on the carpet or anything.

Co-researchers expressed a desire to be treated with respect, as people rather than as disease entities. CO stated:

Well, I, I guess you still want them to think of you as a real human being and that (pause) just because you might be gonna have your demise in, you know which nobody would know when, that they still treat you with respect and as much as they would their colleagues, or you know. We're all different temperamental, different temperaments and uh, when we work with people, we get to know sort of their temperament and I think if we're half-decent person we, we try and work in that, in those parameters where we don't overstep their bounds.

Respect includes privacy. According to CO,

It's just like (pause) going to the bathroom, you know, it's a, that's a very private matter for us and it's just hard you know, for us, I think...It's like sometimes there's not even just one doctor will come in, they uhm, (pause) they'll have a student or someone with them, you know who mightn't be as far, or thoughtful.

Respect includes information (risks and benefits) about procedures and interventions one is receiving. About her IV, she said:

I just wonder about this thing. This kind that's in your arm, and I've had it in for a long time. Can it grow in your arm, or can, can they, can they flush like the...I'm just wondering like if something is in there and then it's covered over with skin, so that it would be harder to take it out?

QN stated that,

you have to be able to deal with them as a person and be able to relate to them, at some level in order to provide the care that they need because you know, you're not just a name or a chart.

While MO had a positive experience in relationships with some nurses, others added to his suffering:

Some nurses were absolutely great, absolute dolls, others would uh get in there and if I'm telling them you know please don't use that vein, then they come back, "Well, I've been doing this for seventeen years and who do you think you're trying to tell" and then they'd do it and

and they'll be injecting morphine in there and I'm getting a reaction where it's turning red all the way up and you know they're having to come back with the Benadryl and stuff like that.

Through that experience MO felt confusion and anger. He is the co-researcher who was not informed of his illness by the physicians during his three weeks in hospital. Of his experience he said,

But you know I've since come to the realization that that's just you know baloney, nobody deserves to be treated like that, let alone a 21 year old male you know, it's just uh it's not right, and it's not, not fair to the patient or the patient's family.

HJ had a similar experience with his IV. He was in a different hospital.

...she told me nothing was wrong. Uh I told her on the fifth day, it hurt the whole time that IV was running. I had a daily IV that had to run its course. As I recall it took about two hours for that bottle...She knew it was bad, I told her it was bad. It hurt, it hurt again and again. She gave me a shot through the tube on the fifth day when I was complaining again and again and it turned rashy red. I, and I complained again, I said something's wrong here, you know, I'm in a lot of pain. So she changed the IV and she'd missed the vein. I was, the stuff was going into my arm and it was swelling up and she says well I'll come back in five minutes if it still hurts and I'm ready to rip the thing out (laughing) and climb out the door.

HJ found that sarcasm expressed by the nurse(s) was demeaning. He felt that he was not being heard, nor taken seriously. He felt abused and that a small number of care providers had a detrimental impact on the patient care, overall.

QN had very strong feelings about his experience with some of the health care providers. He felt that they have a choice and opportunity to use power and authority in a positive way or a negative way.

There's some nurses that are power hungry, that, that you know. There's one nurse that I remember mentioning to you the last time you were here, she was sure I was taking my mask off and she loved to point her finger at me, you're a bad boy, and she, she loved being in

control. It was a power trip to her because I couldn't fight back. And, I, I didn't understand why it was so important for her to be right. Maybe because she was weak at home, maybe her husband was abusive and she had no control at home. Maybe she was the one who didn't have the, the power...But she had power there, and she used it there. And you didn't, so you, you had to like go along with it. Well, what I found was that the moment, you don't need to take power away from someone by, by yelling and screaming. You kill them with kindness. You just, you just talk to them like a person. When I said to the one nurse it must be hard having a, such a heavy load, like in having six or seven people that, on this floor must be very, very difficult no wonder you're tired. I can do certain things for myself, if you just let me know, I won't you know, instead of Mr. I, Mr. I wake up, it's time to take your pills and they shove them down your throat. I mean I thought this is not the way I'm gonna be treated. Excuse me, I'm not, you know I'm not stupid, I have a brain and I deserve to be treated properly and just because you're a nurse with a little tag, don't mean nothing to me but how you treat me does. And I was just shocked at how once you, once you let them know you won't be treated that way, they treat everybody else in the room better. It's so awful to say that but there are nurses who love to be bullies.

He felt that nurses ought to be familiar with information about patients:

...to me it's empathizing with them and letting them know you understand they must be overworked, they must be tired, but you know, reading your chart is part of their duty and if they don't know enough about you, they should at least have the decency to ask and not to treat you like you're demented when you're not. Like a man had brain surgery but he was fully functional, he knew his phone number, his address but he was slow in speech and I was shocked at the way the nurses were treating him. I just thought I can't believe this. I can't watch.

When they don't read the chart and they make all these assumptions, it really does, you get really tired of repeating what exactly is going on.

People in hospital are more than their disease; they are individuals, human beings,

let them know you're a human being, you're an individual, you're, you're, not just a guy with AIDS or any patient, you're a person, there's a person underneath all of those mechanical things. And then if you're

lucky you touch something with them and you, you can form some sort of a connection that makes you human.

People with a terminal illness want to be treated as though they are normal/real, to be talked to person to person, and less as a professional to a person,

just treating me like I'm still a real person. And talking to me about uh, talking to me as an everyday person.

LS said:

I don't want to be treated as another patient in the next examining room uhm, I'd like to be a whole person with a life of my own and uhm and duties and family and the whole person and then my medical treatment uhm to be related to who I am not only to what I've got wrong with me. Is that clear enough? Yeah to be related to who I am as a person as well as to the cancer, the lump, the pain in my gut cause thats not who I am ...Why is this young man or woman going into the medical profession? Does he or she have a real empathy for uh the whole human condition?

Co-researchers stated that they want to be heard and to be seen as a person, not as a number or a disease entity. In speaking with the health care professionals, HJ said

I know I'm talking to a wall.

QN felt that he was seen as a burden by some,

they do have very strong feelings of what's right and wrong [pertaining to persons with AIDS] and you're just a real burden to the medical system, one of high cost.

He felt that attitudes towards patients are expressed by the way health care providers speak to them and by the way they treat them,

the way a person can turn someone tells you how they treat them. You know, like if they have to turn an old lady over on her side like, here sweet, I mean it's roll her over very roughly...that's what I mean, it's the way they treat you.

He felt that there was discrimination against persons with AIDS,

this is how we deal with an AIDS patient here. We just pull out the door put an extra Attends on the bottom, you know make sure that, you know he's a heavy case you know, so lets just leave him in the room, close the door and that's exactly what they do.

To be a patient with a terminal illness, is to feel vulnerable, very dependent and without control. Of his experience in the intensive care unit, HJ stated:

...it's like I was one of the machines in a lot of ways most of the time and there was a couple of girls making jokes about men and that one of them saw me with my eyes open and did a little [nudge] to the girl that was doing the talking and she turned around and looks at me and grins and I, I wanted to say something but no, these people were holding my life in their hands (laughs). So I had to be (pause) polite and just lay, just gave her a, I can pull out a steel stare, amazing how weak I was I could still give a steely stare..

...if I could've stood up, I would've walked outta' that hospital right then...talking about us as if we're dead or already gone or not there...I was just so angry (laughs). Just, you know, these people were making fun of me and all these other people, and I can't even lift my arms, I couldn't even lift my arms...it was just that coldness there...it was just about one quarter of the crew, and also they used that room as uh, during shift changes and gettin' all the doctors and interns, they all stand around up in, by the sun window and uh, sit there and discuss everything and all that.

At times this feeling of vulnerability is so great that the co-researcher felt that an advocate was necessary. For QN:

I was terrified. I was tired being told that I was pulling the oxygen mask off at night. No one in their right mind who needs oxygen is taking their mask off. It's falling off and you're you know. I'd wake up and I'd be gasping for air or, or they, you know, they'd come in and say, well you almost died and you gotta stop pulling the mask off. Well I'm not pulling it off. You're supposed to be coming in here to check that it's on...It was terrible. That, that's what, I will never forget that. They were blaming me...you know, they, their own failings they blame on you and you know, you're dying, so no one else is gonna, there is no advocate standing at your shoulders to protect you...And this is where I felt that very much that you're vulnerable and you needed someone there to help, you needed someone...And that you needed a protector, you know.

On a positive note, he found that some nurses knew what it meant to listen, to be compassionate and to understand him. He felt that in being understood by another, his understanding of himself was enhanced.

And what I found is that the nurses...did listen to you, very, very and they often heard things you didn't know you were saying (laughs) which, which is interesting...they often help you understand what you don't understand and it helps you develop that sense of self, and of, they help you understand that there's, that you may have been, that you may mean something that you don't realize.

All the people in this study had or have a terminal illness. That means all the health care providers working with these individuals are providing care for the terminally ill. Most of the conversations involved the co-researcher, physicians and nurses. Very little was said about any of the other persons on the health care teams. The absence of counsellors, spiritual leaders, social workers and volunteers is noteworthy.

George Lair (1996) has written extensively about sharing the journey with those who are dying. He emphasizes the importance of integrating psychological, social and spiritual care with medical care as a means of providing palliative care. Palliative or hospice care is a philosophy of care more than a place of care. If those working in palliative care focus primarily on the physical needs of the individual who is dying, they risk missing the 'crisis' of one's awareness of their own mortality, as an opportunity for his/her personal growth. This is true for any persons working in health care who are providing care for persons with a terminal illness. Many of those professionals will not see themselves as providing palliative care or may be complacent in the care that they provide accepting physical comfort as the primary goal of care. That is a significant compromise in provision of whole person or patient centred care.

Consider communication as the basis of an opportunity to facilitate personal growth at the end of life. I use Lair's model of communication as a method of enabling that growth to take place (Lair, 1996). Lair emphasizes the need to bring to the relationship *feelings of unconditional positive regard and empathic understanding for the client, [patient]* (Lair 1996, p. 157). If these feelings and attitudes can be communicated to the patient, the opportunity for personal growth will be optimal. That means whatever works to communicate unconditional positive regard and empathic understanding, i.e. acceptance, is appropriate. To communicate acceptance one must let the patient know one's understanding of what that person is feeling and expressing. This can be done by simply saying, "I see", "I understand", or by repeating the client's words and emotions. It will assure the patient that the health care provider is willing to listen and working to grasp the meaning of what is being said (Lair 1996, p. 158). One could also ask questions for clarification. One must be aware that the way in which questions are stated may simply result in clarifying a particular issue. They may also influence the direction of the conversation. Understanding and caring can be communicated by restating what the person has said and by reflecting the feelings in the communication.

It is important to note that people come into a terminal illness at different levels of spiritual and psychological consciousness. The level will determine the response with regard to communicating positive regard and understanding. If questions are raised at a level that is incongruent with that of the patient who has not developed abilities at that level, one is actually communicating a lack of understanding, and certainly not communicating empathy.

Lair goes on to say that, *as the freedom to explore the self becomes felt and the need to defend lessens, the natural direction will be toward increased self-exploration, increased perception of the self as subject, and increased awareness of feelings* (1996, p. 161-162). The freedom to explore the self can only occur in an environment of safety and trust. One must recall the events of the initial visit to the physician, learning of the diagnosis, and treatment in the institution. For many of the co-researchers, those events resulted in feelings of being emotionally unsafe. In order to explore the self and thereby come into greater consciousness, it is imperative that safety be restored. Only then will the individual be able to let go of the need to defend him/herself.

Communication is the basis of a relationship, and a significant part of empathy is knowing the relationship (Lair 1996, p. 162). Lair presents four aspects of communication/relationship that are appropriate to working with persons who are terminally ill (1996, pp. 164-168).

1. The nature of relationship is nondirective and patient-centred. The patient has the freedom to introduce those aspects of self which are of most concern. It is important to know that what the patient perceives as necessary to bring into consciousness, the possible struggle to bring it into awareness and the willingness/courage to share it is as significant as the content. To wait for that to occur and to understand its significance is likened to the process of a phenomenological study.
2. The effect of the relationship on the patient regardless of content or end result. To be understood by another is to enhance one's understanding of self. How patients perceive themselves in relationship to others contributes to their

conception of themselves. *Relationship is not a contact between two separate entities but a single event involving the two people as an integral whole* (Lair 1996, p. 165). Significant relationships may be disrupted, for a variety of reasons, through the course of illness and dying. This may alter the significance of relationships with health care providers.

3. It is important to know how the patients perceive those who provide counselling, their degree of trust in that person and their willingness to allow that person into their world of experience. Again, that is also characteristic of a phenomenological study.
4. How meaningful communication occurs and its consequences are significant to the patient being able to move into greater consciousness. One must continually work with the patient to understand the deep inner experience of dying. One's aim is to help the person bring feelings into congruence with cognition. *It is a process of approximating the feeling as closely as possible, measuring that against the total experience, and correcting the labeling of the feeling on the basis of the measuring. This continues until there is a felt sense that what the person has called the feeling is, in fact, an accurate description of the actual experience* (Lair 1996, p. 167).

Relationship at the end of life is certainly as important as it is at any other time during one's life. Meaningful relationships may contribute to decreasing despair and increasing integrity. It can only occur through communication, caring and understanding. In training people who provide care for persons with terminal illness it is important to acknowledge that the aim is to provide skills in such a way as to promote increased

personal awareness and insight. In fact, to understand the inner life of a patient can contribute to development and maturity of the health care providers which in turn impacts the growth of the patient. Features of growth such as that will be considered in the next sections of this chapter.

C. Maslow's Hierarchy of Needs: The Theory

C. 1. Introduction

The major portion of the themes will be discussed in the next section. In order to enhance one's understanding of the themes, they will be presented in the context of Maslow's Hierarchy of Need. This particular psychological framework was chosen for the purpose of helping in the interpretation and making sense of the experiences and themes reported by the study participants. It is meant to capture the essence of the experience and not meant to serve as a template to identify the themes. This section will include a discussion of Maslow's theory. Perspectives of Erikson, and Jung as discussed by Hollis, will also be incorporated into the document to accomplish the same objective.

Maslow's motivation theory is derived most directly from clinical experience, but conforms to observational and experimental facts as well.

C. 2. Physiological Needs

Maslow states that the starting point for motivation theory is two physiological drives, namely homeostasis, *the body's automatic efforts to maintain a constant, normal state of the blood stream* and appetite as *a fairly efficient indication of actual needs or lacks in the body* (1970, p. 35-36). *Undoubtedly these physiological needs are the most prepotent of all needs. What this means specifically is that in the human being who is missing everything in life in an extreme fashion, it is most likely that the major motivation would be the physiological needs rather than any others. A person who is lacking food, safety, love, and esteem would most probably hunger for food more strongly than for anything else* (1970, p. 36-37). If all needs are unsatisfied, then the physiological needs

dominate with the capacity to envelop one's entire sense of the present, as well as the future. This means that non-physiological needs would not be recognized at such a time, and higher motivations would be obscured. Conversely if the physiological needs are met other needs will emerge and will subsequently dominate the organism, the person. When these are met, a new and higher need will emerge. In that way basic human needs are organized into a hierarchy of relative prepotency (See Figure 4).

Figure 4. Maslow's Hierarchy

It is important to note that gratification is as significant in motivation theory as is deprivation. Gratification releases the organism from the domination of a particular physiological need, allowing other more social goals to emerge. When gratification occurs over long periods of time, physiological needs no longer exist to determine or organize behaviour. They lie dormant as potential determinants of behaviour emerging only if they are thwarted.

In writing about physiological needs Maslow uses hunger as the primary example, stating that for the individual who is hungry, all consciousness is preempted by that sensation. All efforts and capacities are directed at satisfying the hunger; the entire organism is defined and preoccupied to gratify the hunger. That which is not useful to address the need is disregarded, silent, pushed into the background until such time as the hunger is gratified. How is hunger experienced by the individual? It begins with one's sense of appetite and then moves to discomfort, possible pain, and lethargy. The experience of hunger might be regarded as similar to the possible pain and symptoms which can characterize a terminal illness. The experience of pain or nausea can, like hunger, preempt all consciousness. The organism is dominated by this experience, consumed to seek relief from those sensations, and limited in its ability to address higher needs. These needs will be presented.

C. 3. Safety Needs

If physiological needs, including pain and other symptoms which cause discomfort are gratified, a new set of needs emerge, namely the safety needs: *security, stability, dependency, protection, freedom from fear, from anxiety and chaos, need for*

structure, order, law, limits, strength in the protector, etc. (Maslow 1970, p. 39). Like the physiological needs, if unmet, the safety needs dominate the organism—receptors, effectors of the intellect, and all the other capacities are engaged as safety-seeking tools. And in a similar manner the present and future, with regard to outlook, philosophy, and values, are dominated by the need. When this need is strong, the potential power of the physiological needs is underestimated. Maslow uses illness in a child to demonstrate the resulting threat to the sense of safety in the child. Vomiting, colic or other pains are cited as causing the child to see the world in a different way, that which has been stable becomes unstable, requiring reassurance from the parent. Generally in our society this need for safety would only be seen in emergencies (e.g. war, disease, natural catastrophes, crime waves, etc.). Only under those circumstance would safety be seen as an active and dominant mobilizer of the organism's resources (Maslow 1970, p. 42). While Maslow regards disease as a threat to safety for an adult, it would seem that symptoms such as vomiting and pain resulting from disease would be a greater threat to the 'physiological self' than to the 'safety self', and will be regarded as such for the purposes of this study. In our society, healthy adults generally enjoy a peaceful, stable, well functioning environment safe from wild animals, extremes of temperature, criminal assault, chaos and tyranny. Therefore safety needs are no longer active motivators.

C. 4. Belongingness and Love Needs

The next level of need is that of love, affection and belongingness. At this level the individual will long for affectionate relations with people in general, i.e. for a place in his group or family, and will work hard to achieve that goal. If the goal is not attained,

the person will have strong feelings about the absence of friends, a spouse, or children, and *will feel sharply the pangs of loneliness, of ostracism, of rejection, of friendlessness, or rootlessness* (Maslow 1970, p. 43). Maslow states that this need stems from *our deeply animal tendency to herd, to flock, to join, to belong* (Maslow 1970, p. 44). He emphasizes that love and sex are not synonymous and that love needs involve giving and receiving love.

C. 5. Esteem Needs

Following the need for love is the need for esteem. *All people in our society have a need or desire for a stable, firmly based, usually high evaluation of themselves, for self-respect, or self-esteem, and for the esteem of others.* Maslow divides these into two ancillary sets: first, *the desire for strength, for achievement, for adequacy, for mastery and competence, for confidence in the face of the world, and for independence and freedom;* and second, *the desire for reputation or prestige, status, fame and glory, dominance, recognition, attention, importance, dignity, or appreciation* (Maslow 1970, p. 45).

When these needs are met, the individual will experience feelings of self-confidence, strength, worth, capability, adequacy, and of being useful and necessary in the world. If these needs are not met, the opposite will occur, i.e. feelings of inferiority, weakness and helplessness, resulting in discouragement. It is important to note that the health and strength of the self-esteem is proportionate to the degree that the respect of others is based on competence, real capacity and adequacy to the task. In that regard it is necessary to distinguish between achievement resulting from determination, will power

and responsibility and the achievement resulting from one's natural ability, that which stems from one's true inner nature, constitution, one's biological fate or destiny (Maslow 1970, p. 46).

C. 6. Self-Actualization Need

The fifth level of need is the need for self-actualization, the need to be who one really is, to do that which one is meant to do. This would be equal to the process of moving from the socialized self to the true self, the potential self to the actualized self. Jung speaks of this process as the *way of individuation*. *Individuation means becoming an "in-dividual", and, in so far as "individuality" embraces our innermost, last, and incomparable uniqueness, it also implies becoming one's own self. We could therefore translate individuation as "coming to selfhood" or "self-realization"* (Campbell 1971, p. 121-122). One must be true to his/her own nature in order to be at peace with him/herself. That means the artist must paint, the author must write, the healer must heal, the athlete must play his/her sport. Individual differences are greatest at this level.

People who are self-actualizing people:

- have less frequent experiences of hostility, hatred, violence, malice and destructive behaviour;
- change their anger and aggression to anger against injustice, to indignation, to resistance against exploitation, and to self-affirmation;
- have less fear of expressing their own angers and aggressions and do so more wholeheartedly when they do express them (Maslow 1970, p. 127).

How do people experience self-actualization? They are able to accept themselves at all levels (e.g. love, safety, belongingness, honor, self-respect) and see reality more clearly than those who are not at the level of self-actualization. They are spoken of by Maslow as healthy people. If they feel bad, it is generally about discrepancies between what is and what might be (Maslow 1970, pp. 156-157). By Maslow's description one might even regard those with a terminal illness as being capable of enjoying good health. The healthy or self-actualizing people are certainly described as being relatively spontaneous in behaviour, inner life, thoughts, and impulses. They enjoy solitude and privacy to a greater degree than others and are more objective; these people *make up their own minds, come to their own decisions, are self-starters, are responsible for themselves and their own destinies* (Maslow 1970, p. 161). They assume responsibility for their own development and growth, enjoying satisfaction in life from within their own being and are able to appreciate repeatedly the essential goods of their existence and that of people around them. Some of these people enjoy a mystic experience, *feelings of limitless horizons opening up to the vision, the feeling of being simultaneously more powerful and also more helpless than one ever was before, the feeling of great ecstasy and wonder and awe, the loss of placing in time and space with, finally, the conviction that something extremely important and valuable had happened, so that the subject is to some extent transformed and strengthened even in his daily life* (Maslow 1970, p. 164). Perhaps this might be regarded as the spiritual domain.

Persons who are self-actualizing have deeper interpersonal relationships with others, albeit with a relatively small number of friends. At the same time they are able to behave democratically, that is, they are friendly with others regardless of education, class,

race, color or political belief. They are strongly ethical, do right and do not do wrong, strive to do good and not to do evil. Without exception they are creative, original and inventive which characterizes every endeavour they undertake. In that context these people resist acculturation, maintaining a particular inner detachment from the culture in which they exist.

Self-actualizing people are not without imperfections. They too have wasteful habits. They are not free from vanity and pride and are able to be stubborn and irritating, at times ruthless. They are generally strong personalities, independent of the opinions of other people (Maslow 1970, pp. 174-176).

Maslow presents other characteristics of the basic needs (Maslow, 1970). These are essential to understanding the theoretical framework which this hierarchy provides for understanding human development. It is a feature which did not characterize the five stages of dying as described by Kubler Ross, resulting in misunderstanding of the process she outlined as well as misplaced expectations. Maslow acknowledges that, while the needs are presented as though the hierarchy is a fixed order, they are not experienced as rigidly as implied. He cites several exceptions. Examples of these people are those persons who are innately creative and experience the drive to creativity as the most important need, people who have experienced life at a very low level (e.g. chronic unemployment) whose level of aspiration is permanently lowered or deadened, and those people who have high ideals or social standards who become martyrs for those values.

Maslow clarified that most members of society are partially satisfied in all their basic needs and partially unsatisfied in all their needs. One need does not emerge as the 'previous' one is satisfied (Maslow 1970, p. 56). Most of the needs, for most of the time

are largely unconscious. They are neither exclusive, nor single determinants of certain kinds of behaviour. That which is conscious with regard to everyday desires may be regarded as a symptom, a surface indicator of a more basic need (Maslow 1970, p. 56).

Within the sphere of motivational determinants any behavior tends to be determined by several or all of the basic needs simultaneously rather than by only one of them (Maslow 1970, p. 55). There is some behaviour which is not determined by need or motivation, but may be altered by variables external to the self; some behaviour is simply expressive—a reflection of the personality.

What about those persons with unmet needs? Maslow regards such individuals as being sick or less than fully human...*Clearly, therefore, the basic needs stand in a special psychological and biological status. There is something different about them. They must be satisfied or else we get sick* (Maslow 1970, p. 92). Through the course of this study we learn about the levels of need, both those that are met and those that are not met, from the experience of people who know they have a terminal illness. One must ask how one might provide the opportunity for the persons who know they have a terminal illness to move to the point of self-actualization, of individuation. Unfortunately the system as it presently exists, actually impedes the process for some. The implications of the study will be discussed in the following chapter.

The levels of need have been described. The themes have been identified quite separate from any theory. For purposes of discussion and presentation, these themes will now be considered in the context of Maslow's levels of need. It is important to note that each of the levels will be discussed individually. One must be reminded that needs are not experienced in such a distinct way. As stated earlier, Maslow acknowledges that,

while the needs may be presented in a distinct and fixed order, they are not experienced as rigidly as that presentation may imply. This is certainly as true for persons who know they have a terminal illness, as it is for the examples he cites.

D. The Psychological Themes: Maslow's Theory Applied

D. 1. Introduction

The purpose of this section is to review the themes expressed by persons who know they have a terminal illness with the intent to enhance understanding of the lived experience of that knowledge. The themes are presented in the context of Maslow's hierarchy of basic needs with the awareness that the co-researchers may have experienced a loss and/or threat effect to those basic needs by virtue of their pain, illness or impending death.

Maslow does not write a great deal about pain, illness, or the imminence of death. He does allude to these features in his discussion of psychopathology. After presenting the hierarchy of basic needs, Maslow presents the concepts of frustration and conflict as they might contribute to 'psychopathology'. Both can be experienced without necessarily resulting in a diversion from psychological well-being. Consider then the concept of frustration. Usually frustration is defined as *not getting what one desires, of interference with a wish or with a gratification* (Maslow 1970, p. 105). Maslow states that it is important to distinguish between deprivation per se, and threat to personality as they pertain to frustration. Some deprivations are not important to the organism, i.e. substitutes are found with relatively few serious side effects, while other deprivations may be a threat to the personality, i.e. to the life goals of the individual, to his/her basic needs, especially self-esteem and self-actualization. It is in this context that Maslow considers pain, illness and death.

When considering the threat (pain, illness and imminent death) to the individual one must, first, look at the direct impact on the organism, the damage to or loss of

function whatever these might be (loss effect) and secondly, the reactions of the personality in responding to these threatening losses (threat effect). When one knows that death is a very likely outcome of a particular illness, one may lose self-confidence and therefore feel threatened. *When we can no longer handle the situation, when the world is too much for us, when we are not masters of our own fate, when we no longer have control over the world or over ourselves, certainly we may speak of feelings of threat. Other situations in which "there is nothing we can do about it" are also sometimes felt to be threatening. Perhaps severe pain should be added in this category. This is certainly something we can do nothing about* (Maslow 1970, p. 110). Pain might certainly present a threat to the individual who is experiencing the pain. Fortunately, much has changed since Maslow wrote this. A great deal can be done to alleviate pain; unfortunately, that happens too rarely. As pain is always a subjective experience it must be regarded as a threat to the intact person.

Maslow summarizes experiences which may be felt as threatening:

- *danger of thwarting or actual thwarting of the basic needs and metaneeds (including self-actualization) or the conditions upon which they rest,*
- *threat to life itself,*
- *threat to the general integrity of the organism,*
- *threat to the integration of the organism,*
- *threat to the organism's basic mastery of the world*
- *threat to the ultimate values* (Maslow 1970, p. 111).

Working in palliative care I have observed that each of the above threats seem to be experienced by persons with a terminal illness. However, the primary purpose of this study is to understand the experience of having a terminal illness. That is only possible if pre-existing impressions and judgments are suspended. Every effort has been made to do exactly that as the themes are presented.

D. 2. The Experience of Pain; a Physiological Need

I'm only afraid of pain. I'm not afraid of death, I'm not afraid of dying, I'm afraid of pain. I'm terrified of pain, bad pain, cause I've gone through so much of it, you know.
Co-researcher GI

When you're that sick you feel totally, totally terrified. I cannot tell you how terrifying that is...My body had given up. The only thing I had was my brain and even that I couldn't really rely on it.
Co-researcher QN

Most of the 3000 people who have been part of the Palliative Care Program at St. Paul's Hospital for the past decade have been well cared for with regard to food, shelter, and clothing. That is, their basic physiological needs have been met. However many of them experience pain. To be pain free might be regarded as a basic physiological need. Bonica reported that of 75 percent of patients with advanced cancer experience pain, more than 25 percent of these people experience severe pain and forty to fifty percent experience pain as moderate to severe (Bonica, 1990). Up to eighty percent of persons with AIDS have been reported to have had pain (Ferris, 1995; Penfield, 1992; and Schofferman, 1990) with many of them experiencing more than one type of pain. Pain generally increases with disease progression in persons with AIDS. One of the themes in this study pertains to pain: Physical pain is part of the experience of persons who have a

terminal illness, for some it is a constant reality, for others it is intermittent (i.e. it comes and goes) and for many, its reality is featured in their fear/anxiety of experiencing pain.

In their review of the literature, Field and Cassel found that other symptoms experienced by persons with cancer are shortness of breath (9 to 52 percent), nausea (3 to 71 percent), and vomiting (12 to 50 percent) (Field 1997, p. 128). Based on my own clinical experience, I would add symptoms of fatigue, lethargy, dry mouth (at times so severe it is difficult to speak), difficulty swallowing, insomnia, and drowsiness as those which contribute to discomfort such that one would have to conclude that basic physiological needs are not being met. QN acknowledged that pain is a part of life:

Well you know, that's part of life, it's part of life, pain is part of life. The, the only way you can feel absolute joy is to feel pain. You don't know what joy is until you've felt pain, and you can't feel happy for someone for being at peace unless you know how much they're suffering.

When asked if QN experienced greater physical pain because of his psychological pain, he replied:

Affect my physical pain, what an interesting question. To a point, it would because part of the pain I was feeling at the very beginning was fear of being alone and, and I was so scared. I remember being terrified and the one comforting thing was having my sister...there. [I was afraid of] not having done enough, not having made resol-, you know, had resolution to all this stuff that had been going on for years and not having real answers to any of these things and when, when I finally accepted the fact that maybe I really was gonna die and...I said a prayer and said "well, if you're gonna take it, take me, make it quick, and if you're not, please don't make me suffer too long.

One of the co-researchers, MO, defines the experience of pain:

...all I found myself doing was more of the same and not I'm not sleeping at all so it's getting to the point where in the middle of the night four or five o'clock in the morning rolls around I'm tossing and turning from the pain and from the discomfort. And I'm just so

exhausted, you know this has gone on for weeks on end and I fall asleep simply from sheer exhaustion not from actually being able to fall asleep or anything like that. I was falling asleep with the pain with whatever and I was just thankful if I got forty minutes, fifty minutes whatever the case might be.

He goes on to speak of the effect this had on him, his job, his relationship with his friends and his appetite:

...at the same time I I was working, had a job in customer service so I'm having to get up in the morning after a night of no sleep, do my morning preparations, go out to work, be pleasant to customers all day and uh perform my duties adequately at work, come back and you know have somewhat of a life after that uh, it was just impossible, I couldn't do it. I started uh snubbing friends so much that they stopped asking me out and stuff like that and I got so exhausted that I couldn't I literally couldn't take care of myself, you know, breakfast, dinner whatever, I just was so exhausted I wouldn't eat plain and simple. If I had to get up and actually make food for myself that uh it just wouldn't get done.

Recall MO was also presented in the section on communication. Through his experience of receiving bad news (threat to the organism's basic mastery of the world), of pain (threat to the general integrity of the organism) and of a terminal illness (threat to life itself) he had great reason to feel threatened. This is likely expressed when he said:

I was taking science at UBC, you know, I, I've believed very much in scientific uh process and everything was very much black or white to me there was none of this middle ground, you know, math problems had an answer, there was no 'no answer', and uhm, you know, those kinda people were the people to be respected, to be, their knowledge was, was vastly greater than that of my own and ya had to listen to what these people say and take what they said. But you know I've since come to the realization that that's just you know, baloney, nobody deserves to be treated like that, let alone a 21 year old male, you know, it's just uh it's not right, and it's not, not fair to the patient or the patient's family.

There were days in which it would not be possible for a co-researcher to participate in the study due to discomfort/pain. One co-researcher, GI, described her experience of pain:

I'm only afraid of pain. I'm not afraid of death, I'm not afraid of dying, I'm afraid of pain. I'm terrified of pain, bad pain, cause I've gone through so much of it you know. I've had a rough time, the last year, the last two years, a real rough time and I've gone through a lot of uhm excruciating pain.

It is at the physiological level that the medical model is focused and excels. In this model the aim is to maintain the functioning of the human organism at a physiological level intervening at any point in which there is real or presumed pathology. Fortunately for approximately ninety percent of the people linked to a palliative care service, their pain is well controlled. However, during the course of the pain and for some even once the pain is alleviated, the patient may stay at the physiological level of need and is at times, only seen as such by the people providing care. To focus on the physical dimension characterizes most of medical education and training, a focus which begins in medical school, resulting in years of intense training to develop expertise in order to respond to 'pathology'. As a health care professional one must appreciate that the technology intended to reverse disease process or to alleviate pain and suffering, may actually contribute to emotional suffering. This was the case for KR, as the medical technology served as a barrier between himself and his son:

I was hooked up to a tube feed, catheterized, whatever and he saw this, he ran. He usually does run when he, in a situation he can't deal with.

This was one factor which contributed to the severance of the relationship between a father and his son. That potential outcome of the technology was not likely considered in the decision to insert the feeding tube and the catheter.

Good, a medical anthropologist, addresses this issue as he records the experience of learning to become a physician, *You're not there to just talk with people and learn about their lives and nurture them. You're not there for that. You're a professional and you're trained in interpreting phenomenological descriptions of behavior into physiologic and pathophysiologic processes* (Good 1994, p. 78). The patient is presented as a disease process localized in an organ or in tissue of disordered physiology. The person who experiences the disease as illness, the discomfort as suffering, becomes a medical project, reduced to the organ or tissue of concern. The only important features are those which enable the physician to make a diagnosis and to begin intervention(s) (Good 1994, p. 80). The Lebenswelt of the patient is disregarded and essentially ignored. In relationship to the physician, the experience of the patient is one of 'iatrogenic suffering' in which the individual is filled with despair, loss of hope and suicidal ideation. This was discussed in the section on doctor patient communication.

In speaking of the experience of pain, emotional or physical, co-researchers spoke of the touch of another, as alleviating the pain. In fact, the importance of touch emerges as a theme, with regard to pain, both physical and emotional. LS had the same procedure done on different occasions:

[there was] nobody to be with me and hold my hand and tell jokes, or something whatever they do...It was the most horrifying experience, and I was angry, I was really angry..

Through this experience she felt absolutely alone, estranged from the physician performing the procedure, in pain and horrified. She realized that on subsequent procedures there might be value in inviting a friend or a member of her support group to join her:

I felt that if there was someone from my support group sitting beside me and holding my hand and talk, just talking, I didn't care what they were saying, just a voice going through me while I was doing it and uh the result was painless, absolutely two painless uh um biopsies.

During this procedure LS felt that in the touch of another there was healing and a sense of 'witness'. The voice of that person, although she could not remember what the person had been speaking about, contributed to a pain free experience. She also recommended that doctors touch patients when they give the patient the diagnosis of a terminal illness. She felt that touch was a necessity of life.

For me, touch is almost a necessity of life, yes it is a necessity of life. We need to be touched. (pause) When you attend one of the meetings of the group, in Callenish, [a retreat community] you know, prepare because there's just, there's a lot of touching going on there and I think it's magical, I really do feel that if it isn't physically healing, it certainly emotionally and psychologically a way of healing for those who need that.

KR made the same recommendation, that there be a family member in the room at the time the patient is given the diagnosis, "cause you know you've got someone there to hold your hand". The specific instruction to the family member is that they hold the patients hand. Human contact seems essential to one's sense of well being:

I was pretty screwed up in one way, in a couple of ways and I was shut out by my family so I was uhhhh, yet I was a little bit screwed up, I needed escape and of course it was the women first, the drugs came second. I needed that close human contact, it was the human contact I needed first...And unfortunately a drug, a drug addiction came along with it.

Physical contact—touching, stroking, holding, feeling another’s breath are ways of expressing love and affection (Schulz 1978 pp. 80-81). *The dismay of being sick comes in part from the loss of close human contact; touch is medicine’s real professional secret—Lewis Thomas* (Moyer 1993, p. 3). What is the significance of human contact, of touch? In an interview with Bill Moyers, Rachel Remen begins to answer that question (Moyer 1993, p. 355). She speaks of touching as a way of healing. She acknowledges that we don’t touch each other a lot in this culture, and then when we do it is often misunderstood or sexualized. Physicians are taught that they touch people only to make a diagnosis for if they are touched in any other way, even as a means of comforting them, it may be misunderstood. *Touch is deeply reassuring and nurturing. It’s the first way a mother and child connect with each other...what a mother is saying to her child with that touch is “Live” ... “Your life matters to me”* (Moyer 1993, p. 355). Remen also mentions the impression of people with cancer who have been touched. They describe the touch as though they are merely a piece of meat. She reports that one woman said *“Sometimes when I go for my chemotherapy, they touch me as if they don’t know anybody’s inside the body”* (Moyer 1993, p. 355).

At present, Remen works with adults who have cancer. Earlier in her career she was the associate director of pediatric clinics at the Stanford Medical School. During her time there, one of her colleagues, Marshall Klaus, the chief of the intensive care nursery conducted a study to explore the effect of touch on the infants, so small they could be held in one’s hand. Half of the infants were touched (gently rubbing the back with one’s smallest finger) for fifteen minutes every few hours. Those babies survived better than

the one's who were not touched. Remen surmises that isolation may weaken us and touching may strengthen the will to live (Moyer 1993, pp. 355-356).

Michael Lerner, also interviewed by Moyer speaks about touch, *to put your hands on another person with healing intent is tremendously comforting. It's a way of expressing and receiving caring* (Moyer 1993, p. 338). He makes reference to therapeutic touch, a technique of laying on of hands. The provider enters a state of meditation and holds the hands above the patient, not on the skin, and feels the healing energy come through her/him. Some studies suggest that there are physiological changes which occur in the blood chemistry through this process. One study, controlling for placebo effects, demonstrated that wounds in people who received therapeutic touch healed faster than those who did not receive it. While more studies are needed to improve our understanding of the benefit of this method of touch, there may be components or factors which we never understand as they may be beyond human rationality (Moyer 1993, p. 338). It is imperative that this method of touch be critically examined. A well studied and documented correlation between touch and a sense of well being could affect training, education and ultimately patient care.

This is well summarized by QN:

All I cared about was that someone was touching me and I knew that I wasn't alone, it's so important, it's so important.

Whatever else we are, we are bodies and that as bodies we need to touch and be touched by each other as much as we need to laugh and cry and play and talk and work with each other (Buechner 1991, p. 74-75).

While pain is a specific component of the illness experience, the experience itself may be such that the physiological needs dominate the experience. As lethargy, weakness and other symptoms increase, one's lifestyle may be altered, resulting in a tremendous sense of loss. Such was the case for GI:

I wanted to die for two years, very much, because I couldn't live a normal life, you know. I wasn't living normally. I was living but I couldn't go out, I couldn't travel, I couldn't uh, uh so many things I couldn't do that I enjoy doing...I can't go very many places. You know, I can't go out and stay with my daughter like I used to, and I can't go to Reno and I, there's so many places I ca-, I can't go because I'm sorta tied down here...I can't do what I want to do so uhm, I'd just as soon go on...the sooner the better.

I've had a uhm, uhm, replaced valves. So I have heart problems, I have a uh, lung problems, I have hearing problems, I wear glasses (laughs), I've got false teeth, I wear a wig, there's nothing real about me and this bothers me very much. I wish I could have gone on before all this had to happen but it happens to older people.

GI felt that in her experience of illness, there was a great sense of loss, a theme expressed by others as well. In her wish that she would die soon, she agreed that speaking of death ought to be a more open topic and that it is important for people to realize that for some death may be desirable. In that context, she stated clearly that it is important to respect people's wishes with regard to prolongation of life and treatment at the end of life. With regard to the disease progression that she was experiencing, she seemed to convey a message of helplessness. This was certainly a theme emphasized by BZ:

This is the first time I've felt mortal. Before it was surgery, which is, excuse the expression 'cut and dried'. Uh, the mastectomy (pause) I treated more as a challenge to overcome to, uh, cause I was just 40 and you know still had quite a life and uhm I really didn't (pause) that's a hard one because uhm, my husband couldn't handle it and we split up very shortly after that. So there was a lot going on in my life, I mean our obviously our marriage wasn't doing too well anyway, uhm and the (pause) next two episodes (pause) were routine chest x-rays that picked up tiny, tiny lesions so I considered myself very lucky, and again a challenge and get back, get on with life. So this is the first time (pause)

that I, I'm having to adjust to knowing that I'm not gonna get better. I'm finding that quite difficult, or not difficult but I'm not, I'm not used to a defeatist mindset and the spirituality is what's pulling me through.

BZ exemplifies Maslow's theory that most members of society are partially satisfied in all their basic needs and partially unsatisfied in all their needs (Maslow 1970, p. 56). BZ was very aware of her physical demise, her physiological need and equally aware of who she truly was, in body, but more importantly to her, in spirit.

Pain, either in reality or in anticipation resulting in anxiety and/or fear, is part of the experience of living with the knowledge of a terminal illness. If it is a reality, pain, like other unmet physiological needs, may dominate the person's existence, with the capacity to envelope one's entire sense of the present as well as the future. As individuals near the time of death, if they are pain free, the anxieties and fears regarding pain subside and higher motivation becomes part of the experience.

D. 3. Safety Needs

Well, I think a lot of people want time, they like (pause) that that their providers can give them a bit of time, like maybe talking or just holding them (pause).

Co-researcher CO

As a reminder, safety needs include *security, stability, dependency, protection, freedom from fear, from anxiety and chaos, need for structure, order, law, limits strength in the protector, etc.* (Maslow 1970, p. 39). Disease alters one's sense of stability, freedom from anxiety and reinforces the need for structure and order. Because the course of illness experience is unknown, people are left to their own imaginations as to what might occur. They seek information, by way of verbal and nonverbal communication, from physicians and other health care providers.

This was certainly the case for MO:

...then all things are starting to flow by me like, you know, being in the CT scan room and having the CT scan done and turning over and seeing six or seven physicians there pointing and uh looking at the computer screens and there and trying to read their faces and not one of them you know showing any bit of emotion whatsoever or coming in to calm me down or anything like that...Every single little thing along the way, you know, added to the confusion...

He experienced confusion and chaos and was seeking structure and order. The role of communication in the relationship between the health care providers and the patient were considered in the first section of this chapter. It seemed to be significant to several levels of need, those of safety, esteem and belonging.

If the patient is left to imagine what the illness experience will entail he/she may be left with an unrealistic sense of what is most likely to happen. This may include a fear of having one's personal wishes disregarded:

No, I'm not afraid to die and I'm not worried about going, I'm worried about being uh pain or being kept alive as a vegetable or as, where somebody has to do everything for you...if you can't go to the bathroom by yourself or even look after your, your body...

In saying that, GI felt that people are to be respected, especially as pertaining to treatment/intervention at the end of life. Illness has the capacity to change the structure in one's life:

I can't do anything. I can't get interested in anything, I can't travel, I can't go anywhere. Uhm, I used to enjoy movies and bingos and things. I've lost all enjoyment in them. So it's just a matter of living from day to day waiting to die and that's no good. It's just no good, it's making me sick and they, they can't tell me anything when I ask them, you know. How long they think it'll be, they have no idea. I know they can't tell to a certain point, but I mean between six months and two weeks is a difference...I have no idea whether I'm gonna live a year or I'm gonna live a month. That's very hard to take. Especially when uhm, I'm just living to live, that's what I'm doing. I live to take the puffers six times a day, to take the pills so many times a day, to fill the

pills up every four days, to, all I'm doing is working with pills and puffers and...It absolutely controls my life.

GI experienced anxiety about the life she was living, about the possibility of pain, and about being alone at night. She entertained the idea of ending her anxiety and state of uncertainty and that was depressing and anxiety provoking for her.

I'm depressed, yah, very much so because I can't live. I can't live and I can't die and that's uh depressing. I guess I could die, you know. I've certainly thought about it but I think you pay for it if you do. I'm not anxious to have that happen...I think something will happen to you just uhm, for doing that...Whatever you do will come back on you I think and if you do that, something's gonna come back on you that you're not gonna like.

GI's sense of safety was threatened by several features of her illness experience. She had known pain earlier in her illness and was anxious about it recurring, she felt paralyzed with regard to her 'normal' activity in that she did not have a sense about the length of time she would be alive, and she considered suicide but felt anxious about the consequences, in the spiritual sense. This became the focus of her thoughts and her conversations.

It is important to be aware that what is said and how it is said, contribute to the patient's sense of safety. When safety is not present the patient may experience anger, depression, anxiety, and it may increase their desire for death. It would seem that a decreased sense of safety has an effect on hope, as reported by MO who considered the Lion's Gate Bridge a viable option after hearing his diagnosis, KR who attempted suicide following his hospital stay in which he was informed of his illness, and LS who, despite being discharged, would not leave the hospital until the physician came back to speak to her in a respectful manner regarding her diagnosis.

In contrast, BZ felt that it was important to know that ‘caring’ is available when cure is not possible. She felt that knowledge was important to her sense of confidence. It decreased her anxiety:

I’m not frightened of death itself or any of that, I would prefer not to lose my dignity and I would like it to be tidy and I even feel confident about that especially with palliative care and I feel better about the sort of the management of the progression, however slow or fast it happens.

Of interest is the concept of “there is nothing we can do about it” as mentioned in the introduction to the section on themes. Based on clinical experience, it is not uncommon to hear from patients that the term has been spoken to them when physicians have reached the point where they know it is no longer possible to cure a disease. Maslow clearly indicates that it is threatening to hear a statement such as that. It may be the first statement a patient hears after receiving the diagnosis of a terminal illness. This was not the case for the co-researchers in this study.

The previous statements can be summarized in a theme of time and timing relevant to the experience of having a terminal illness. What is time? It is a question asked by many philosophers, Husserl being one of them. Augustine being another. To that question he answered: *If no one asks me, I know; if I want to explain it to a questioner, I do not know* (Eissler 1955, p. 265). By definition, it is *the measured or measurable period, during which an action, process, or condition exists or continues; a continuum which lacks spatial dimensions and in which events succeed one another from past through present to future* (Webster’s 1981, p. 1213); *duration, indefinitely continued existence, progress of this viewed as affecting person or things* (Sykes 1976, p.1212). Wilber speaks of physical time which just clicks along, sixty seconds per minute, sixty

minutes per hour, twenty-four hours per day, seven days per week, etc. and narrative time—the time that marks the history of one's own life story or self, the time that carries and recreates hopes and ideals, plans and ambitions, goals and visions; the subtle time that can speed up or slow down, expand or collapse, transcend or concentrate, according to its interest—the time which transcends physical time (Wilber 1983, pp. 77-78). The order of physical time is unchanged and continues. The theme pertains to the sense of narrative time which is altered by the knowledge that one has a terminal illness for it affects one's life story, hopes, plans and ambitions, goals and visions. *Time is constantly in us and around us; nevertheless, we cannot grasp it...The primary experience of time...is entirely bound to the course of inner processes* (Eissler 1955, p. 266). In the experience of having a terminal illness, the individual is reminded that the duration of those inner processes is limited. Narrative time ends. The combination of narrative time changing and eventually coming to an end can result in anxiety and chaos, thereby threatening one's sense of safety. For some, the simple knowledge of having a terminal illness will pose a threat; others find the uncertainty of the timing of the impending death as a greater component of chaos. Either may result in an internal confrontation of how one exists in the time of living that remains. Does one prepare to die or embrace life?

As an aside, those who work with terminally ill people witness physical time and narrative time, in that they observe that the narrative time ends for the patient, while the physical time continues for them, the caregiver. How does this effect the care they provide? Kastenbaum reports about a study conducted by Glaser and Straus concerning staff responses to the issue of certainty and time. He reports that staff interactions with

patients are closely related to the expectations they have about the time and certainty of death based on four types of expectations;

1. *certain death at a known time.*
2. *certain death at an unknown time.*
3. *uncertain death but a known time when certainty will be established*
4. *uncertain death and an unknown time when the question will be resolved*

(Kastenbaum 1977, p. 165).

Given the preceding section on communication, one must question whether staff understanding of the certainty and timing of death of patients affects the patients' sense of safety and, if so, is it in a manner which enhances or detracts from the existing degree of safety? Does it enable the process of embracing life or preparing to die to come to resolution?

D. 4. Belongingness and Love Needs

I put at the top of the list [of things that matter] your relationship with family, friends...I feel because I have two sons, one of whom is an alcoholic...I do have a feeling of aloneness, uhm, where family is concerned.

Co-researcher LS

Recall that this level of need includes love, affection and belongingness. It is at this level that the individual longs for affectionate relations with people in general, for a place in his/her group or family. To be otherwise is to experience the pain of being lonely, feeling ostracized, rejected, friendless and without roots. This was certainly expressed by the co-researchers.

The significant theme is that a sense of belonging is an essential ingredient of well-being for persons who know they have a terminal illness. First, people want that

sense of belonging to and from their family of origin and from their family of adulthood. When it is absent, there is a sense of being ostracized, and of grief; when it is present there is inner peace and comfort. Feeling ostracized seemed to characterize the experience of persons with AIDS more than the experience of persons with cancer. Some of the co-researchers chose to separate themselves from their families and continued to long for connection with them; others were ostracized by their families. In either case, it resulted in pain. Secondly, when the sense of belonging is compromised with regard to the family of origin, people seek or long for that sense from another community. Rejection from that chosen community aggravates the pain experienced by the rejection from the family of origin.

Consider first the sense of feeling ostracized. QN felt that the source of being ostracized by his family of origin stemmed from the shame they felt with regard to AIDS as well as to homosexuality:

...the whole truth of the matter is that they still think that this is my own fault because I was gay.

Because I think that the typical reaction by a family who is in denial, which is what I believe a lot of families go through, is that they, they at the very end they realize that you're dying but deep down inside they think it's for the best, and not for you but for them because this is like a big thing hanging over them, this big black cloud of shame.

...my family has a very, they're, I think they have a real problem with me being gay that they've never dealt with and I think they have a real problem with me having AIDS which they, they don't wanna deal with. I mean it's just something that they, they, they cannot understand how I survived first of all to them, they're gonna have to go through this again in their mind I'm sure and I don't think that they're prepared to do that so they've distanced themselves so far now that when the time comes, I probably won't have them around because they don't know me, they don't know who I've become, how different I am than what I was before and what my needs are.

KR felt ostracized by some of the members of his family of origin as well as his family of adulthood. With regard to his family of origin:

I, I love my younger brother very much. I wish I had him around me all the time. My older brother lives here, uh well, we, we tolerate each other. Uh, he's a Jehovah Witness, doesn't like the gay issue and I don't like the Jehovah Witness issue so we don't talk about things so, but uh uh he's there, but he isn't he can't give me the support that normal brother would be, let's put it that way.

And with regard to his family of adulthood:

...he [his son] came and saw me but to, to, make it short and I enjoyed my time with my son again. I made peace with him. Uhm, I took him to Las Vegas, uhm we were doing dinners whatever uhm, meeting for lunches and uh (pause) and then just before Christmas (pause) he came to me and everything in his life that was negative was my fault (pause). I had done nothing right and the only reason he ever came to the hospice was he felt sorry for me and he could play nice for a few months 'til I died. Well I haven't died yet so would I please fuck off and go do it, those were his exact words. So that's why plan B [suicide] came up, big and strong.

He was also estranged from his daughter. LS also felt estranged from her two children, her adult sons. Her sense of estrangement and aloneness left her longing for a daughter:

So, I put at the top of the list [of things that matter] your relationship with family, friends...I feel because I have two sons, one of whom is an alcoholic...I do have a feeling of aloneness, uhm, where family is concerned, uhm, I keep thinking, you know, all through my uhm, married life I said I was so glad that I'd had boys, you know, the old theory that it's harder to bring up girls sort of thing, but I was, was happy with my three boys, I was, after V. was born, after the second one was a boy I never thought about having a girl, and the third one was a boy. But at this time of my life, I don't know, it seems to me that I might have more closeness with a daughter then I'm able to have with my son... I have good relationships with my children, but I don't...they're emotionally constipated...I often say, "I haven't the vaguest idea how you feel about me" (Pause) And it's true, I don't.

LS felt that the intimacy in her relationship with her sons had ended twenty-seven to thirty years earlier in that they had a brother who died suddenly thirty years prior to these interviews; their father died three years after that. The tragedy and grief of those events was never discussed amongst the three of them. LS acknowledged that the death of a child might mean the death of a family.

There's a lot of guilt around the death of a child. A lotta guilt and I think I mentioned that I think that's what sometimes ends up driving a man and a wife apart when a child dies. A lotta guilt...I think to be absolutely honest, guilt for every time (Pause) I had been less than perfect (Pause) as a mother...(Pause) I don't think I've ever forgiven myself (Pause). I don't think so. You know it may be one of the reasons why I'm not afraid of dying.

In reviewing the themes with GI, she agreed to the following, when a parent is ill and dying, the presence of children is greatly appreciated. She acknowledged my spoken sense that the presence of children has a calming influence:

...she came for the last long weekend and uh she, she feels guilty that she can't be you know closer or with me. But I don't want them to feel like that, why should they, they've got their lives to lead, it's not gonna help me in any way for them to uh, to uh interfere with their work or anything. It's not gonna change a darn thing for me, so you know I'm trying to tell them forget about it, just, I have help, good help, I don't, I, I don't need them basically except I'd like to have, I'd like to see them but I did, but I would like to see them when I'm well.

This was also the experience of BZ, although it was demonstrated by her more than it was spoken by her. Recall the second interview with her, which occurred twenty eight hours prior to her death. Because of her weakened state, she asked for a second interview before the usual three to four week time interval. Subsequently I inquired whether her daughters might be present for the review of the themes—BZ stated that she would be very pleased to have them present, she found comfort in their presence.

HJ felt alienated from his mother, in that she was not interested in discussing his illness and/or death:

...we don't discuss it much. My Mom doesn't want to. She doesn't want to. She'd, she'd rather put it out of her mind, you know, and I can see that, you know I can see that just talking to her. I've talked to her all my life (laughing), I can see that it bothers her, and she, she'd rather think that I'm here okay and doing fine and everything, and she doesn't have to worry about me, and she doesn't want to think about it or talk about it, and that's understandable.

In the midst of his adversity, HJ found solace in his connection with his children, simply by being who they were and by seeing them develop. His illness served as the basis for a reunion with one of his three children:

I still have the contact and, even more so with one of my children now since this disease, the one that was kind of drifting apart, it's kind of brought us back together again, so there is, there is one upside...Where do I find, find comfort? (pause) Oh, that's going to be a tough one. Mostly when I visit my kids to see and see that they're, they appear to be turning out to be well responsible uh, (pause) citizens. Nah I'm pleased that, uh, uhm I'm pleased about the kids, they seem to be turning out okay, that's the one solace I have.

HJ did not allow his children to visit him in his apartment because of the location. He visited with them elsewhere. For that reason he felt disconnected at times. Of his children he said:

I'm proud of them but it hurts that I can't, it hurts, a lot of things hurt, it's, it's hard for me to come back down home when I'm out there in the real world (pause) and I am sitting there on the bus or that skytrain and I'm coming back here and ahh, I go into such a feeling (laughs) of depression, you know, I'm coming back downtown you know and (pause), I don't know I, I-I get conflicting feelings...But what keeps me on track with that is, you know, my family...you know that's the only thing that's really holding me because there's nothing for me to do...I think I'd probably be a bit more depressed (pause) no I'd definitely be more depressed. You know, it'd be like I had no one, I'd really be locked away by myself.

In situations where there was no sense of belonging between the co-researcher and his/her family it was developed through other relationships. For LS it was through relationships with a support group where she found a connection to others. It symbolized hope, life and healing for her:

I feel that (pause) it would be horrible to live without having some sort of [meaning], even you know, no matter how long you live, I feel you should, there should be some meaning to it. (pause) When I'm in a group (pause) and again this is, this is (pause) kind of mysterious uh (pause) had I not had cancer I wouldn't've met most of the people for whom I now seem to have some meaning (pause) and people who certainly have a lot of meaning in my life and these are the people I support and uhm (pause) and who support me in return. Whereas if I didn't have that meaning in my life, I wonder, you know, how, what, what meaning there would be now.

Well my life is deeply tied in now with the young people who are who are going through this. I hope to be, you know I can sit there in the group and when it's my turn to speak if there are any new people I just say uh 10 years and look at me. I don't look sick. I fought, I fought all the way and you can do it too. I hope anyway to be a symbol of the possible, the possible. Because some of them come in newly diagnosed, and really depressed. They think that they've had it you know and not necessarily so. Hmm. So this is my mission now and I'm deeply into Callanish [a retreat program to address spiritual and psychological concerns/issues for persons with cancer, in a way such that 'healing' may occur] of course. I'm hoping to be of some use there too.

QN spoke of his fear of abandonment and its origin in his childhood. He recognized that without a sense of belonging in childhood one might experience difficulty in trusting others as an adult:

I can remember a an incident that happened when I was two years old, that I will never forget that I think had a lot to do with my fear of abandonment which was, my mother uh had told us at a very young age we were adopted, very young, a far younger than I think a normal person should tell their adopted child, there, there was no home study. It was an adoption arranged, at the time, through a priest she worked with, in the Children's Aid Society. In those days it was done. She, uh, my

sisters, and I, were at the breakfast table, and my sisters and I were fighting over something and I said “you’re not my sisters anyway”, and I might have been four or five I guess, not two, and, and my mother said “what did you say” and I said “they’re not my sisters anyway”, and so she said “go to your room” and I did, and I packed up. She said “pack up an apple cart”, one of those round things with handles “of all your stuff”. And I put in all my toys, and my teddies and my pillow and my blanket and she dumped it on the bed and left me at the Sacred Heart Hospital, which I thought was the Children’s Aid Society, and left me there all day. And what she was saying then is that “don’t you ever, ever say that they’re not your sisters”, and “you, none of this is yours”, so I was always left, left to feel I was only there because they wanted me there, like they could take me back at any time, that I was used goods...and her dumping that, of seeing, like seeing her dumping out my apple cart, I remember sitting on it in the parking lot of this, this big building was there and I remember people coming and asking me “what am I doing”, and I said “I don’t know, I’m waiting for my Mom to pick me up”. My mother was parked oh, six, six blocks away or something, it wasn’t far...she left the stuff on the bed...at my house, but she took the basket and me and left me sitting in the parking lot, what, in front of what I thought was the Children’s Aid Society, cause I was like being returned but it was the Sacred Heart Hospital. I didn’t know that cause I was...was my punishment. So, when she picked me up, she says “are you ever gonna say that kinda thing again” and I said “no”, and she brought me home and I was so thankful. It was getting dark, I was hungry, I was scared, I didn’t know where I, I mean what was gonna happen, but from that moment on I was made aware that nothing in that house belonged to me.

QN felt that in order to be in relationship with another person, either family member or friend, both must work to understand the other. This was not his experience with regard to his mother during his childhood or his father in QN’s adult life:

I don’t want him [father] in my life because he’s caused me so much pain. But the pain that he causes me I can let go of because I know that he doesn’t understand and he will never understand...

...my father, I wish he could understand it when I say “Dad, you know I wanna talk to you about something that’s important to me, that you understand that (pause) if I die (pause) before you do, I’ve missed out on a whole life, you’ve had your life” and you know he doesn’t, he doesn’t want to understand or he can’t understand or he won’t understand, and I’m just tired of trying to figure out which one of those

three options it is. So, I, you make new friends with new, and a new family.

He felt that true friendship is of greatest importance. In it there is a strong life force, intimacy and a sharing of self. He felt that at the time of death the family of choice may be more significant than the family of origin:

I can honestly say I can count the number of friends I have on one hand...you have a lot of acquaintances and you have a lot of people in your life but people that you can really trust and, and, know that they'll be there for you are far and few.

I feel I've, I've developed a new family...so you set up a Power of Attorney and he knows who you want and A. knows all these people that I want around and who I don't want around but the physicians and the nurses are gonna, it's gonna be very difficult for them to, to get the family to understand that, you know, if you're not here for your brother, don't don't come, just don't come.

By speaking of their relationships with their parents, siblings, partners, children and friends, the co-researchers expressed their need for belonging. Some spoke of the pain they experienced in feeling rejected and ostracized, all valued the need for love, affection and belongingness, especially at the end of life. The significance of love was expressed as vital to the experience of knowing one has a terminal illness.

D. 5. Esteem Needs

I am discovering that I have mattered to some people, so that sense of no self-worth is kind of leaving. So that's my gift. Co-researcher BZ

As mentioned earlier, Maslow divides the esteem needs into two sets, one as a desire for achievement, independence and freedom and the other for prestige, status, fame and glory. This is reflected in the way co-researchers reviewed their lives, professionally

and personally. A review of their lives seemed to reinforce their sense of esteem. For QN it was freeing and resulted in the healing of a longstanding wound:

What does it do to me talking about it? It frees me...It's freeing to be able to actually express (pause) the truth about the, the reality of what my life is...it's actually closing the wound, a wound that, that's been open for years...

LS had a sense of worthiness and appreciation of her life, she felt value in her personal history:

I had had a good life, I was a school teacher, and I felt that I'd been a big success in my chosen field, it was obvious from the reactions, you can tell that uh I had been retired, I had travelled, I had had children, I had seen my children grow up and um maybe it was that's my theory is that it didn't frighten me, it didn't make me angry, I didn't have the uh acute emotional reactions that I have seen others and heard um and I think its because there's a difference between hearing that your life is threatened when you're in your twenties and thirties and hearing when you've already had a life span.

LS felt that it was important to "go on with life, to live, not sit down and wait" and to give of oneself:

I've knit over 600 pairs of slippers for cancer patients. They're all over the province. I'm still knitting by the, as long as my eyes hold on. You know I have little projects and I kept going.

Knowing one has cancer results in remembering, self reflection and life review. That is a recurring theme. The impact of such reflection and review varies. *Through it we hopefully tally a ledger that allows us to affirm an essential goodness in life and to bless our participation in that goodness. To the extent that our lives have been tragic or that we have participated in life in an evil or negative way, and these issues remain unresolved we will struggle. Also, if we are unable to view joy and tragedy as two poles on the continuum of life, we will struggle* (Derrickson 1996, pp. 14-15). For LS life review resulted in a sense of status and recognition. That was not the case for GI. She felt that in reviewing one's life it is difficult to forget the bad—the bad is more prominent than the good. Things one has tried to forget about or believed forgotten come to the fore

in life review. GI felt it would be of value to be freed from the guilt, from being ashamed and from the bad:

I do a lot more thinking of course now, uhm, about it, about my life was or is, and uh, and what I've done and things like that but it hasn't affected me in any way I don't think...Trouble is you, you reflect mostly on the bad which I find out so I'm trying to forget to do that, just forget about it because you do, you pick out the bad. You pick the bad things, not the good...I mean, I guess your, the guilt feeling of, of the, of the things you've done is much greater than any of the uh, uh good things that brought you happiness. It's the guilt feeling over it that makes that, that uh, that takes priority of the good that I might have done. I don't know, I just know most of the bad (laughs). That's what I seem to know. If most of the stuff I wish I uh, I wish I could forget about but now it's all coming up, which is very strange...I'm not proud of myself, in no way, shape or form.

GI felt she would experience a sense of peace if she could be forgiven for the things for which she felt guilty. She had a strong desire to be free of that guilt.

I've done too many things that I'm guilty, I feel guilty for, tha uh I wish I didn't have to think about, you know, I wish it'd never happened...it's not much fun (laughs) thinking, day-after-day...day-after-day when all of a sudden you think, oh God, I didn't do that or something, uh, and you , you're not free of it and yes I would like to be free of it. I don't think I will be 'til I die and then maybe not (laughs) who knows.

This need for self esteem is emphasized in a prominent theme that people who are dying are still living. BZ recognized the apparent paradox in that statement, "live, living, living by dying". She knew that in dying, in death there is life. KR realized the same:

I came to realize I had to forgive myself and go on with plan A, live my life...The only thing, the only person I can change or help is myself...Well, living 'til you die, take, doing things, uhm, I've, I've, see I only got this, figured that out after being in the hospice for eight months, figured out plan A, but I after I got outta the hospice...I started this plan A, I got myself a computer, I taught, learned how to take, you know I took some night courses, I learned about a computer, I didn't know how to turn one on but now I'm emailing and video-conferencing all over the world. Uhm, so I'm enjoying things...

He felt that living includes purpose, activity, pleasure and learning new things. He also felt that it must have a component of giving of self and if possible, leaving a legacy. This is in keeping with Maslow's description of achievement, mastery and competence, as well as a desire for reputation, recognition and appreciation:

...so I started doing things and uhm, I decided uh the new Cottage Hospice uh I, (pause) when I was s-sitting there, I went bang, that's where I wanna leave my name (pause). I wanna do something to leave my name in somewhere cause I, I have my funeral all set up and everything, there'll be an immediate disposition, ashes (poof) done, right. Uh, that's the organizational part of myself, it's all paid for, it's done. Uhm, but I said I'm gonna raise the money for the fireplaces at the new Cottage Hospice (pause). Uh, so I've been working on that since the day I asked for them, I've been raising the money, I've somewhere around twelve to thirteen thousand dollars of my fifteen thousand dollar goal, uh for these fireplaces. Uhm, and no I've decided that I would uh put a personal touch for them and I'm hooking a rug for in front of each one of the fireplaces, a hearth rug, I'm, I'm making them, I'm, I'm doing that. I found out uhm that the stained glass which was supposed to be in the conservatory they're not putting in right now because they don't have the money. I'm going to pay for that one way or another. I'm either going to pay for it before I die or after I die, it's gonna be in my Will to pay for it, so uhm, (pause) but I've got involved in things like that. And I, I, (pause) I have a real closeness to the, the fireplaces. Elizabeth Taylor gave me \$3,500.00 towards my fireplaces. They're, they're my fireplaces...that's what I, what I call living.

HJ had a sense of pride in being self sufficient and experienced a sense of loss at no longer being able to be productive as he had been in the past. He had a sense that he was not living life to the fullest which resulted in anger and frustration, i.e. feeling deprived of his ability to achieve his life's goals:

...I really have an uncomfortable time adjusting to living like a dole, living on assistance. I've always all my uh life paid my own way, I don't even go to them for anything extra like their uh handicapped bus passes or basic anything. I don't ask for anything other than what I take, what I get and I have a hard time dealing with that, the fact that I can't at my age, that I can't go out there and do something, you know. And I, part of its my own fault too, you know, I collapsed owing

Revenue Canada money, (laughing) and I collapsed just before the busy season, so I send them in my only pittance and here I was uh you know struck down with this disease, handicapped, and owing the government money which doesn't exactly (laughing) ease things at all. But I have a hard time, its the poverty, the fact that I ha- have to live down here...I'm still a normal person that's been stuck into a non-normal world and there is a very hard adjustment to that. Uh I can, I, I can easily understand why a lot of people who live down in this community of despair do turn to (laughing) drinking and drugs.

HJ longed for the independence and freedom he had known prior to his illness. He felt that words could not adequately describe the sense of loss through the experience of having a terminal illness. In fact, he felt that he had lost everything:

Yeah, you know, I've lost everything. You know, I went from uh having this beautiful, nice, spacious apartment full of uh furniture, plants and knick knacks, to uh, living in skid row, so that's quite a change.

He felt very alone, stigmatized by his dependence on governmental social assistance for housing and food, and determined in a sense to demonstrate that he was normal. In recognizing that he wanted to live he said:

[I want to] get some self-worth. Get, get outta here, get doing a few things. Get a little bit of life, even if it's only a part-time life...design and build a few things, get into a bit of, get into my crafts... You know, like I'm a cabinet maker, you know, I need to either rent a small space in a shop, just to get out and create and do things....I wanna live...now. I don't wanna live in the what if, what if, what if before or what if future.

Apart from feeling ostracized, the examples of KR and LS and their children were also examples of another one of the dominant themes throughout the study which was that of the significance of the parent/child relationship. This was significant to parents with regard to their children, as well as to children with regard to their parents. A few of the co-researchers spoke of their relationship to their parents as well as to their children.

One of the features of being a parent is to evaluate the quality of one's parenting skill(s); it is painful to feel that one has not been a good parent, and to question whether one did what was in the children's best interest. GI stated:

I just said I didn't think I was a good mother, I wasn't because I didn't know then what I know now. But uh, of course they're not gonna say, no you weren't (laughs). I mean I just told them that was my fault that I hadn't been a good mother to them. I uh, all this stuff come up later as I you know, as I grew older we learned a lot more about children and I think I was pretty tough on my kids. I expected them to be adults before, you know, I didn't give them a chance to be children. Uh, I wanted them to be smart, I wanted them to learn. They did, they did pretty good and I don't think they regretted it cause it sorta pushed them into uh, my daughter's a psychologist, my son's an accountant, the other daughter married and has child, uh four children.

One parent felt protective of her adult daughters, wanting to comfort them:

Um (pause) my initial reaction was oh my God these poor girls uhm (pause) sort of wanting to apologize for putting them through this, I still feel that way but (pause) uhm, that was my initial reaction.

As stated previously, people who are dying are still living. That theme, was as expressed by QN:

Despite having a terminal illness, one is alive.

After confronting death, everyday is a miracle.

In that sense and in the experience of dying, just as in living, they have a need for self respect and for the esteem of others. In the context of that experience, a powerful theme emerges: the truth of self and others, especially family members, must be spoken and must be heard, preferably by one another.

Consider the concept of truth. Webster's defines truth: *sincerity in action, character, and utterance; the state of being the case (fact); the body of real things, events, and facts (actuality); the property of (as of a statement) of being in accord with*

fact or reality (1981, p. 1246). Oxford states that that which is true is *in accordance with fact or reality, not false or erroneous...showing life as it really is* (Sykes 1976, p. 1246).

In regard to truth, HJ said:

You know there's duplicity with my parents involved and my mom's in retirement and she should have the time to rest and enjoy her retirement and not dwell on things that she could have caused or done that eventually led to me and my demise down here. You know, I just don't want any guilt feelings on anyone else or anybody sitting there stewing things over, so you know, what I found was, I never told you...So I've always held that inside...and I have to downplay it...I was having a hard time trying to live on this level...it was getting to me and I was winding up lying...it was a build-up of contact with a lotta family...trying to connect with family...mostly my kids...I'm facing it all and telling people the truth

I haven't talked about this to anyone...confession is supposed to be good for the soul...just sitting here, it came out because I didn't want to sit here and talk about my sanitized life to you and that would've been the duplicity so I figured I'd just, best give you the real facts.

I hated the duplicity...may state for a fact that when it comes to everything regarding my life, except for that damn fiasco, I'm fanatical about the truth uh. being honest with people and I want them to be honest with me.

While on his 'death bed' HJ had a strong sense that he was alive and wanted to escape the sense in his room that he was dying:

I had the feeling hey, I'm lucky to be alive but I'm dying, I'm handicapped, I'm going down the tubes. You know, I'm stuck in a room, everybody in this room's dying. (pause) Everybody that paraded through was on their last months. So (pause) not much to be optimistic about there when you're in a dying room.

When people believe they are dying and have been told that is the case they don't want to be left alone to stare at the walls—'to do so is hell':

I'm not gonna sit here and stare at the walls and people for my last day...like I'm in a prison cell, [I want] something to get my mind away from just sitting here dying and watching, just sitting here dying. I

wanted something, you know, I was imagining, I don't know how the hell I could do this, but I was imagining old John Wayne movies, and I was trying to run in my mind to entertain me to get me away from all this.

CO agreed that truth is very important. It is essential to intimacy; it deepens and strengthens relationships:

Well I think truth (pause), I think truth is very important cause sometimes (pause) you might have, say it's against a person, like have a grudge due to something, if you can (pause), if you can be honest enough and even admit that you don't like that feeling, and you don't know why you have that for this person, and if it, if it is, is reasonable or you might have their opinion, you know. And it's (pause) it's nice to be, it feels good to feel that uhm (pause) I guess close or honest with a person that you can divulge certain things (pause) without them saying "oh you're crazy, or that's stupid" cause right away you feel (pause) well, I woulda been better to have kept it in.

Truth spoken by those we love may be painful to hear and provide insight necessary to change one's life:

And I feel my children were very loving when they told me. Like I know one of my sons that's what he used to say Mom, he [Dad] will say jump, and you will say how high (pause) you know. So I mean stuff when they'd say that to me it hurt me a bit because I. I felt well how could I be so dumb, you know, that my child has to tell me... That, that was one of the reasons it hurt me a bit for them to tell me, but it opened my eyes.

Speaking the truth includes the topic of death, a subject openly discussed among the family members. BZ says:

...we don't dodge the word 'dying'...which is much healthier for all of us.

KR expressed his ideas about truth. He agreed that to speak truthfully to one another within the family of origin as well as the family of adulthood is necessary for inner peace.

I believe in the truth, that is the truth and uhm, cause I believe that truth only hurts once (pause) but a lie lasts forever and uh whatever and other

than my younger brother everybody seems to be playing games...if they were real, honest...If everybody was just acknowledge and put on the same playing field and we could talk and look at each other in the eye and, and speak, uh, that, that's okay right. You know you look at my family, what do I have, you know. I've got uh, a son and a daughter that don't speak to me, yah I have a grandson that uh (pause) most likely I'll never hear from (laughs) or see or whatever, when he, when I found out he was born I did [send] something to him but I never got an acknowledgment but uhn, I didn't expect it either. I have a brother that uh, Jehovah Witness in S. that has these rules and regulations. I have another brother that I haven't spoken to in twenty years. And all it comes down to the one person in my family that I could actually sit in a room and talk truthfully, openly and honestly is my younger brother.

KR felt that truth is paramount at the end of life, that the game playing must end:

A person that's terminally ill they, they don't have time, they, all they want is the truth, they want it from their doctor, they want it from their friends, they want it from their family. You know, let's solve the problems before I die. The only way you can do that is by telling the truth (pause) and if you don't tell the truth you play games and you're just wasting everybody's time...you don't have time to waste.

He emphasized that time is of the essence in terms of speaking the truth, ending the game playing and working toward resolution. He felt that to know and hear the truth is preferred to silence and to not hearing the truth, even if resolution means people part ways—they do so with more knowledge and possibly greater understanding:

You don't have time to play games, let's put everything on the table, tell the truth, okay and, and we can take whatever we want, we can still decide that I'm an asshole, or you're an asshole, I really don't wanna see you but at least we've tried and this is what I feel, you know and we've got the truth out there. You're not playing some game, well geez, I don't know or you know, I feel sort of, you know, just put it out there and then there's, then there's uhm (pause) what is the word I'm looking for, uhm (pause) resolution, resolved but it's final then, it, it's, when you're there it's complete, it's final, it's over, you know you go from that moment forward, either with the person or without the person, there's no more games.

Only in speaking truth to one another is it possible to gain an understanding of the other and to enhance one's understanding of the self. He realized that to bring family members together who are estranged from one another requires great skill:

...they'd have to be very strong and everything to be able to take my brother I haven't spoke to for twenty years and even bring him into the same room with me and for the two of us to sit down and say, okay, what were the questions, why haven't you phoned me or him saying, why haven't you phoned me you know, and it wouldn't be easy, it wouldn't be easy on anybody, it wouldn't be easy on anybody in the room so that's why the people would have to be very, very skillful in what they do.

To make an attempt at resolution prior to death is desirable. To know that every attempt has been made to work toward resolution with family members results in inner peace. In fact, the resolution or work toward resolution of issues between members of the immediate family is of greatest significance in preparing to die or embracing life.

...I would like to make peace, you can go all the way down the line and the only way you can do that like, like my brother, my other brother uh, cause I play games with my brother in S. you know, and my son, my daughter okay, let's go and even if we never see each other again, it's, it's poof? I'm gone and you know (pause) I would die more at peace knowing that it's been done, regardless, regardless of what it is cause it's final, it's over with, it's, it's the resolution has been done and this was the result...Peace (pause) uh, uh, peace, being able to final this pain and just resolve, you have peace within your body, within your soul, within, whatever you wish to call it...I'd have this peace within me that I could go and die and say okay I accomplished this with my son, I accomplished this with my daughter, I accomplished this with my brother, I accomplished this with my other brother and I'm at peace now for they know and my son knows I forgive him, and my daughter knows I forgive her (pause) and I can go in, (pause) I call it the death stance. I've seen it so many times in people that are you know, towards their ends and you can tell a person that is struggling because they haven't, they don't have that peace and in, I guess, for me, I don't wanna be that way, I, I'm trying, I'm organized, I don't want to have any negatives there.

Unfinished business in the 'psychological domain' results in pain. Because KR has spent time with others who had died of the same disease that he had, he knew the experience of dying as an intimate witness. This prepared him to confront some significant issues and relationships in his own life. Only in addressing the unfinished business, is one able to come to healing and peace, to wholeness.

I've been around other people that've died. I've seen how they've died when they have unfinished business. It's like you're, you're in-basket will always be full okay, but if you have the relationships defined, I guess that's the word I've been looking for—defined. It's not final, it's defined because they, they, they either continue or they end, they're defined and when you're reaching the final part of your life, you're at peace, you know what you wish and, and I would say you could, you could die with a smile on your face...a whole person...yah, you can sit there and die with a smile on your face.

QN felt that speaking the truth 'sets one free', that to do so is a demonstration of love, not to do so is to increase one's suffering. Speaking and knowing the truth is of great value, it is liberating and fills one with peace:

It is totally freeing, it is, it, like they say "the truth shall set you free" and when you are free then anything is possible, anything that, that's, that can be is then given opportunity to be. As long as you're bogged down in all this other crap, nothing can happen, nothing can...you're stuck, you're, you're not gonna move forward, you're not gonna move backward, you're just gonna stay right where you are. I can't imagine a worse death than one where you, I'd still be asking myself "do they love me"

I mean, I can't imagine a nicer death than to actually know the truth.

D. 6. Self-Actualization Need

The world sets in to making us into what the world would like us to be, and because we have to survive after all, we try to make ourselves into something that we hope the world will like better than it apparently did the selves we originally were. That

is the story of all of our lives, needless to say, and in the process of living out that story, the original, shimmering self gets buried so deep that most of us end up hardly living out of it at all. Instead we live out all the other selves which we are constantly putting on and taking off like coats and hats against the world's weather (Buechner 1991, p. 45).

...whatever reality may be, it will to some extent be shaped by the lens through which we see it. When we are born we are handed multiple lenses: genetic inheritance, gender, a specific culture and the variables of our family environment, all of which constitute our sense of reality. Looking back later we have to admit that we have perhaps lived less from our true nature than from the vision of reality ordained by the lenses we used (Hollis 1993, p. 7). Looking back one realizes that while each person has multiple lenses, he/she also makes choices to become the person they are.

The process of individuation begins when one asks the question, Who am I? Again, from Hollis, *individuation is the developmental imperative of each of us to become ourselves as fully as we are able, within the limits imposed on us by fate. Again, unless we consciously confront our fate, we are tied to it. We must separate who we are from what we have acquired, our de facto but false sense of self. "I am not what happened to me; I am what I choose to become" (1993, p. 97). It is the conscious realization of one's unique psychological reality, including both strengths and limitations (1998, p. 146).*

The process of individuation beckons each person at some point in their lives. As a process it is never complete and becomes more of a quest than a goal. One's image of self is in constant 'repair'. The answer to the question 'Who am I?' is always open for modification (Hall 1986, p. 47).

For purposes of discussion I present three of the co-researchers, each of whom asked the question of 'Who am I?' QN realized he needed to become his real self through the course of a near-death experience, HJ began to question who he was on awakening to the fact that he could no longer live a duplicitous life, and BZ admitted her addiction thereby 'looking in the mirror' to find who she really was. Longing to know and understand one's self, to answer the question, 'Who am I?' was certainly a theme that became prominent in this research.

For QN, the stimulus to individuation arose from his close encounter with death:

I'm really taking control of my life and that's because of coming so close to death, you realize that if you don't take control, no one will do it for you and you can't expect (pause) the doctor can't do everything, the nurse can't do everything, no one can do everything, but you can certainly make an effort yourself, at least for yourself and to, to try not to let the, the other stuff get in the way.

In 'looking inward' he re-experienced the pain of his childhood:

My childhood was a painful experience. It was not a pleasant one...It was one of humiliation...of course you know we're adopted children. You know you don't deserve. Uhm, we were treated very, very poorly by these two people, people that were good Catholics, we have to give these, these children a good home, we're doing our, our Catholic duty and I do believe that that's what they honestly felt and I felt that that was in their mind, they were doing the right thing and that's fine, but what they did do and I think they forget it, that they took the lives of three children and potentially ruined them.

I don't wanna play, live that game. I wanna, I wanted to live in the truth. And whether they want to deal with it or not is irrelevant...I was raised believing certain things and then to find out that none of those things were the truth. Well, right away I know there were lies, you know, born into a lie...so how can I believe anything that this person says.

QN believed that without resolution within himself he would exist in turmoil and that resolution lay in truth. To avoid that truth is to suffer and to live in hell, affecting one's death.

...dying bottled up would be horrible, I only imagine that being like going to hell. I can't imagine that being a pleasant death. I think that would be awful because you'd carry that around with you for eternity. It wouldn't just you know like a day, it would be for eternity. And if there is such a thing as reincarnation, you would come back with that with you.

...you would be forever in turmoil. It has to be resolved in that lifetime, I believe, and if the family, or friends, or whomever is there that can't or doesn't want to deal with these issues, then at least you know and you can close the jar, you know what I mean. Then, then you know that's okay, put that one away, it's over.

...everybody can pretend they're getting along. I don't wanna, that doesn't get you anywhere. Resolution is simply the truth, good, bad, or indifferent. It's the truth and that's all that seems to matter when you're at that point [of death] is that you know the truth, you know where you're going, that you feel good about where you're going, and you feel good about where you're going you just don't wanna bring this negative stuff along with yah.

In being confronted by death, QN realized who he was, that it was important to be real, to be himself, to be alive—being true to one's self requires less energy then to live pretentiously. In dying one is stripped of all that is important to society—money and image—one is left with honesty and truth.

...there's a new person, that, that part of me that died in that hospital, a part of me died, a part that was bitter, angry and resentful and, and hateful and spiteful died.

I belong to me and I choose to be this and that's, that's how I think I've survived.

This is who I am, like it or leave it...I don't try and put on airs, I used to think I was really important, you know, what jewellery you had and what clothes you wore and all these different things that used to matter

so much. They don't matter any more...he's a good guy, he's decent, he's a loving individual, that to me is important.

You're stripped of everything that's quote important to society, money, you know image, you know, you're right down to your bare bones, so all you have left is that honesty.

...it takes so much energy to pretend when you can use that energy for other things...Now if I was still so worried about what people thought about me, cause she was cleaning me (laughs) when she was telling me about this (pause) I think I wouldn't have remembered about her care because I would've been so concerned about this whole issue of, you know, being seen dirty and needing her to clean me but she did it with such dignity and, and made me feel like there was nothing wrong with what happened. And it wasn't just small talk, I wasn't just pretending to listen, I was listening.

In being true to himself, he was able to truly listen to others even in the midst of being cleaned after an episode of incontinence.

In dying one may realize a greater consciousness, come into one's true self by beginning to recognize the question of 'Who am I? and realize it's answer.

You do wake up, it, it is like uhm...it is like a revelation of some sort. All of a sudden all these things that were hidden are front and center, there is...no, no hiding them any more.

The socialized self dies; the individuated self is born, surfaces, and comes into reality;

And that's what I think makes us lucky people who do come close to death is that all that crap just flies off of you, it just sorta comes off you like layers of skin, you know, it just, all of a sudden you are just that, just like when you're born. All of that stuff is, is gone, you have none of that nay more and you're starting from scratch and I think that's what makes it different. All of this, all of those messages that you were taught, all of the negative stuff that you were taught are now replace with positive things, loving things, caring things, things that make you better, happier person. Funny how it affected me that way.

Through the experience of dying one is able to be one's self, know the self, and believe in one's self without fear.

I have faith and, and believe in myself now that I never had before...And being who I am, not afraid of being who I am.

In becoming true to one's self a new person emerges who may not be recognized by others for who he is.

...well you are a different person and they don't, they don't know this new person. So it does, it does cause that to happen.

In knowing one's self, pretentiousness ends and lies stop.

Not all but most people wear a mask of what they think people want them to be and you don't have that. And when you're lying in a hospital bed and you have your bum wiped by someone, you don't wear a mask any more, the mask is gone. So all of a sudden, you're freed of that, you know.

One can stop playing games and be honest and truthful with self and others. To die outside of truth is to die wounded, to understand one's truth and accept it is to die healed. not cured, but healed.

...don't lie to yourself, don't pretend because that only makes it more difficult to fight difficult to fight the physical disease, you know by, by healing, (pause) by telling yourself the truth you allow yourself to heal, you're not so busy trying to play all these games with yourself, your mind has more time to work on your body, it's really amazing how once you, you've forgiven yourself and freed yourself of all that other stuff, the body sort of works that way, the mind and body do work together and if the mind is so busy trying to uh, keep you from thinking of what the truth is, well your body is gonna be neglected, it's not gonna get that chance it needs to heal...It's so funny how people will just, will just deny it 'til they die. You must see that.

Next consider the experience of HJ. The following excerpt is taken from the sixth and final interview with HJ. I did not return to review themes, and therefore present his responses to the questions which followed after he initiated the conversation with, "I have

something to say to you today.” In asking the question, Who am I? he saw a new person, a person who chose to step from a life of duplicity to a life of truth.

There’s a new old HJ...I wanna live the now, I don’t wanna live in the what if, what if, what if before or what if future. I don’t wanna dwell on things but uh, I do feel like I’ve, I’ve learned from my experience and I’ve been down there, I’ve seen myself and I’ve seen what led to what...What events, what emotions, all the equations of events and emotions together to what happened.

I’m not a horrible, horrible character, you know. A lot of uh my guilt, shames and defences were built out of just simply being human...I made a few wrong directions when I was uh, in my teens and uh, but there was reasoning for that. You know that was my way of lashing out but then we, getting into my childhood which is (laughs) a little too deep and I got bad memories.

...there is pain there, me and my Dad fought like cats and dogs...we fought a lot and my Mom was moderating...I had low self-esteem, my whole life was mapped out to me from day-to-day even the sports activities I was allowed to enter into. My first job had to be McDonald’s because it would uh, the other job I wanted was construction was 40 hour work week day time, and that’s what I wanted, I wanted to get out there and do this. No, no we’re gonna have you work in a McDonald’s, a little swing shift so you can be in all these other goody things. Like I say, my whole life was dictated as a teenager...it eventually brewed to the point of where I, I said to hell with it and I left and I went on a wrong course. Well not really a wrong course, yeah I went on a wrong course, definitely a wrong course...I kinda got sucked deeper and deeper and deeper.

...my memory of my teen years, other than a lotta fighting with my father, there’s not too much, not too many clear memories in there...I’m not going to university. I couldn’t get into the Army cause they caught me at the border (laughs). So, I’m gonna go with a bunch of wacko bikers and uh, go hire out as mercenaries. And that wasn’t power and glory, that was nothing but shame and dishonour too, so that’s why the double, the double life, you know, James Bond, you know (laughs), whatever and that’s why this time, it just, that’s what took me, I think, that’s what took me over the edge. I dislike that double, the deceit...I don’t like duplicity, it’s uh, yeah, it’s just, I feel really uncomfortable. I don’t like, I was dragged into it. I didn’t do this to, show off, ah, ah, ah, it wasn’t that, it, I didn’t like it.

[This] came out because I didn't want to sit here and talk about my sanitized life to you and that would've been the duplicity so I figured I'd just, best give you the real facts.

...it's very easy with peer pressure to just, you know, keep going. You know it doesn't matter who your peers are, if it's only four or five peers, it doesn't matter you know, you're a unit, you're, you're a group.

...and in my case [to work against it would have been] suicidal and uh, threatening to my life...I could've taken a bullet if I would've tried to stop a rape. You have specific tasks to do if you're a non-participant and that's watching your buddies while they're off looting and raping. There, it's tough, I said it.

It is painful, but I put it away for so many years, so well, you know, it was just the past couple of months that all those, that whole year. Like I knew, I knew basically a couple of weeks ago, I says okay, you got little blanks here, you know it's time to actually sit down and work the chronology of those years or the events, the emotions, the breakdown that happened after that.

It hurt, it hurt, let me tell you it did hurt. Yeah, I haven't talked about this to anyone.

...nobody but me and God, like I say will know the actual events that happened.

...let's say I've con, made my confession to myself. Yeah, I've confronted my demons, yeah and I've mentioned that one, I said it a couple of times too, I've faced my demons...I didn't know, I blocked out the looting and the rape to an extent...I think it took about a year after, like I was actually back in country and I was travelling around and just drifting aimlessly and that's when I got involved with the drugs...I was pretty screwed up in one way, in a couple of ways and I was shut out by my family...I needed escape and of course it was the women first, the drugs came second. I needed that close human contact, it was the human contact I needed first. And unfortunately a drug, a drug addiction came along with it.

I'm glad I did talk to you today.

I've been giving out quite a few of my secrets. But, I'm, I'm feeling much better, you know, getting back where I'm on the straight, so to speak.

That's probably one of the reasons why it I just unconsciously had to tell you the whole truth is because I, I'm feeling a lot better going on the straight...

A theme expressed by these co-researchers is linked to the concept of being truthful: To know who we are as adults, we must understand who we were as children in the context of the family of origin, of family history in past generations. To understand the context of the family of origin is to begin to understand and appreciate 'who the world wanted us to be'. According to BZ:

...the girls are, I mean we've often talked about all that, and uh (pause) uh (pause) on both sides they've got fairly, I-I don't know how to put it, old families cause on my French Canadian side we're sort of settlers in Canada way back and on my father's side there's uhm their grandfather was a Lord and there's a lot of history there too and they're very proud of it and they don't capitalize on it or anything but so, family history has been very much a part of their upbringing and (pause) who I am because of it.

In looking more closely at who she was, consider what was spoken by BZ:

I'm in Alcoholics Anonymous and involved quite deeply and it's done a lot for me...and I think the (pause) big thing there is that (pause) I was an only child, uhm (pause) and (pause) I was a thing owned by my parents. I was dressed up and brought up to say "good evening" you know when cocktail hours sort of thing and uhm although I did not realize it at the time cause I didn't have anything in comparisons, it probably was a very lonely life. I know I loved boarding school, just loved it and uh (pause) because of that lack of connecting uhm (pause) and being brought up by nannies and governesses and stuff, I went the other way and I would not have a nanny and practically wouldn't get a baby-sitter but not quite and (pause) I guess that's more talking what I didn't want to do.

To acknowledge the alcoholism, attend Alcoholics Anonymous, to seek counselling, and to integrate the lessons therein meant BZ changed the course of her family history. She asked the soul searching question, Who am I? In the context of our families, what does the answer to that question entail. In part, it is given by the narratives of the co-

researchers. They spoke of their relationships with their mothers, their fathers and/or their children. For BZ:

And subsequently I became much closer to my father, my mother (pause) uhm, had some very good qualities, she was a very clever lady but she uh (pause) I mean Mom could look back and say she had an unhappy upbringing, and she was an alcoholic and uh everybody around her was an alcoholic.

She recognized that with regard to who she was in herself and in relationship to her father:

my sense of self was not to be found, uhm, because if I got honours why didn't I get a hundred percent? Uhm, I just couldn't satisfy them.

She had a sense of not being good enough, not regarded for her efforts. She recognized that the same attitude prevailed in her relationship with her husband:

...that prevailed, as it did with my husband. (pause) And it's uhm, he's very, very British (pause) and uh (pause) you know what it's like coming home and the kids are crying and everything "can't you shut it up?" sort of and he'd, they had had the same upbringing much as I had, so the kids were seen and not heard.

BZ spoke of her sense of self:

You know, I guess it has changed cause uhm, I think that I can face death liking myself now and I never, never would've been able to say that. I think that 's the big difference...again, it's shown me that I have got the inner strength. Uhm, I'd say that's the essence of it.

She spoke of the value of attending Alcoholics Anonymous seven years earlier where she began to take their program very seriously. She acknowledged the need to look at the 'whole picture' of who she was and only then could she truly begin to like herself more. She also realized that she:

mattered to some people, so that sense of no self-worth...is kind of leaving. So that's my gift...I am very grateful I can see it that way and

I'm hoping it comes through with those close to me and I think, I think it will.

In speaking of her family of origin as well as her family of adulthood, BZ was, in part addressing who she was. Knowing her family enables one to understand her more clearly. While her confrontation of self had started several years prior to her diagnosis of a terminal illness, the issues surfaced again as she reviewed her life. She seemed to appreciate that who she was, was comprised of her genetic composition (nature), the experience of being a 'product' of her family of origin (nurture), and her choice. *The wounds of the first generation hurt the second, who in turn wound the next, until someone suffers enough to come to consciousness and break the chain. Fate provides the initial wounding and the flawed parenting of each subsequent generation, and yet all are responsible for the lives they have chosen—as we too are responsible for our choices and their consequences. That one has made choices from a wounded vision, a flawed perspective, is usually clear only in retrospect, with the consciousness our suffering has brought* (Hollis 1995, p. 67).

The experience of knowing one has a terminal illness serves as a jettison of the self in that it propels the individual to search for the true self, the individuated self, the self-actualized person. It is the only way to live life to the fullest until one dies. One discards that which is token, or imitation and embraces that which is real. This is a continuous process which seems to move people from depression toward hope, through anxiety toward peace, and from despair toward integrity.

E. The Spiritual Themes: The Transcendent Self

Of the eight co-researchers whose transcriptions were selected to demonstrate the themes for this study, seven were interviewed more than once. All of those seven spoke of a spiritual component to their experience of living with the knowledge of having a terminal illness. It was described as Nature, God, a Higher Power, Jesus, Buddha, and for some as meaning, purpose or value. The purpose of this section is to present the themes and the content of the interviews which pertained to the spiritual dimension of the lived experience of knowing they had a terminal illness. In the previous section, the themes were presented and reviewed in the context of Maslow's hierarchy of need. In this section the themes will be presented as per each co-researcher.

I begin with the description of spirituality as given by BZ. This interview took place thirteen days before her death. The themes were confirmed in a second interview which took place twenty-eight hours before her death. The dominant theme especially as pertaining to the spiritual, for her and the other co-researchers as well, was that spirituality is the greatest resource and source of strength and comfort. It was something greater than herself, for herself, in the context of which she was able to accept herself, to laugh, to love and to enjoy life.

I was from the structured religious home, I was brought up a Roman Catholic and sent to Church, or uh, and then I converted to Anglican and the children were baptized Anglican and I just (pause) it was the thing to do. I have no deep beliefs. I knew there was something but I, and I didn't stop to take time to think of it. So it wasn't really until I got into AA and started to, first of all accept (pause) that I was an alcoholic and with that then I'd look around and see hundreds of people around me who enjoy life, (pause) laughing and joking how could they be, you know, uh and so it's evolved from that. (pause) I think this is where I really learnt spirituality.

Spirituality to me is a belief in a Higher Power, a Power greater than myself, spirituality. I happen to be fond of nature, I can get just by looking outside uhm (pause). Spirituality isn't any one thing (pause). It's it comes from inside for me and (pause) when I find I'm in a very bad space and discontent and everything, I know I have to go back to basics and think of spirituality and then I can ground myself again.

So this is the first time (pause) that I, I'm having to adjust to knowing that I'm not gonna get better. I'm finding that quite difficult, or not difficult but I'm not, I'm not used to a defeatist mindset and the spirituality is what's pulling me through. Uhm (pause) as I had mentioned to you, I'm in Alcoholics Anonymous and involved quite deeply and it's done a lot for me in (pause) uhm (pause), one of our things is 'let go and let God', (pause) I've used that. Uhm (pause) it's (pause) I guess again I, you have to use the same word is trust in turning myself over (pause) but uhm and praying for (pause) help for my children...I'm acknowledging my spirituality more then I ever have.

The term 'let go and let God' is a slogan which is part of Alcoholics Anonymous, a term which may seem incredibly simplistic or represent the core of one's spiritual being. It has been described as easy to say and difficult to follow: *Let go of the dark, which you wrap yourself in like a straitjacket, and let in the light. Stop trying to protect, to rescue, to judge, to manage the lives around you—your children's lives, the lives of your husband, your wife, your friends—because that is just what you are powerless to do. Remember that the lives of other people are not your business. They are their business. They are God's business because they all have God whether they use the word God or not. Even your own life is not your business. It also is God's business. Leave it to God.*

Go where your best prayers take you. Unclench the fists of your spirit and take it easy. Breathe deep of the glad air and live one day at a time. Know that you are precious...Know that you can trust God (Buechner 1991, p. 92). 'Let go and let God', a simple term, and for BZ a term which contributed to coming to know herself and to ultimately trust in a Higher Power for her own sense of fulfillment and for the well being

of her daughters. She expressed her awareness that as her physical well being was drained of its strength, her spiritual strength increased. Off the tape and near the end of her life, she said:

My cup of joy is filled to overflowing and that which overflows is also full.

When asked about the role of health care providers with regard to spirituality she said:

It's a very difficult one to answer because if somebody comes on to me (pause) and starts spouting, shall we say, spirituality, I back off. It's such a private concept so my answer would almost be that the patient has to call the shots on bringing it up. Because uhm (pause) well you ask me sort of my definition of spirituality and other people have different and that's fine it works for them. There's no wrong and a right but it's something I would not like to have (pause) forced on me or I wouldn't like to be confronted and uncomfortable. Such as I am very uncomfortable when chaplains visit in the hospital. Uhm (pause) again cause I can't get away from them.

As stated above, the second interview was conducted shortly before BZ's death. She was very weak at that time and only able to speak in a very soft voice. Two of her three daughters were present. When asked about the spiritual dimension she said:

BZ: It's different everyday

DK: Okay

BZ: More from day to day.

DK: So it's something that's dynamic, it's changing

BZ: Yup (pause) Cause a couple of times I thought did I say that? But yes.

DK: Okay

BZ: It, it shifts.

DK: Do you think it's different today than it was two weeks ago when we talked?

BZ: I think its stronger.

DK: The spirituality, in the, the sense of the Higher Power increases as time passes?

BZ: Yeah, it has for me.

DK: Can you say more about that?

BZ: Because I'm needing Him more.

DK: You need the spirituality. So as your need increases your sense of the Spirit, the Spirituality comes to you?

BZ: Yeah.

At that point BZ had transcended her physical limitations which were very apparent. While she was pain free, she was unable to care for her own physical needs as she was too weak. She was entirely content in the presence of her family acknowledging that her sense of well being resulted not from looking forward in sadness at what would be missed but looking back and celebrating what she had been given. Her boundaries of existence had changed from the defined world of the physical domain to the undefined world of the spiritual domain.

In combining the contents of the two interviews with regard to understanding spirituality as a feature of living with the knowledge of a terminal illness, AY validated the concept of spirituality as:

- not religion
- Higher Power
- power greater than one's self
- strength from within
- serves a purpose of grounding
- recognizes and accepts self
- allows one to laugh and to enjoy life
- private, to be raised by the patient
- involves choice
- sense of Higher Power increases over time as need increases

- different every day

She was the only co-researcher who specifically described the qualities of a 'spiritual physician'. Her description included features of kindness, empathy, speaking distinctly, touch, extending self to family, and speaking the truth.

A near-death experience had a profound effect on QN. It altered his sense of the spiritual:

I'm much more spiritual now than I ever was before because I do believe that (pause) I saw and, and, and, and did things that only someone who came within, I don't know, a fraction of a second of, of remaining on the other side...I remember being very content there and very happy there, even though I was very, very sick.

For QN, forgiving self and others were identified as key elements of spirituality as was addressing the issue of God:

Everything you've ever done in your life. Uhm, forgiveness (pause), regret, uhm forgiving those that you think have done something to you and forgiving yourself for things you think you've done, uhm dealing with spirituality, dealing with God for the first time in my life, I, I decided that I had to either I believed in God or I didn't and I, I prayed.

Spirituality is accepting others for who they are in a nonjudgmental way:

...no one ever said to me uhm "you need to ask for forgiveness for your sins". There was no judgment about lifestyle, there was no, there was nothing.

I believe in a Higher Power now like I've never believed before...I believe in God now. Not that I didn't believe in Him before (pause) but I believe (pause) that there is so much more out there than, than I'd ever thought. By praying and asking for forgiveness and, and giving forgiveness I got (pause) I think I made a deal. I'm, I would never take my own life now ever, I know it's a gift (pause) uhm, I, I can never be (pause), I'll never be the same, I mean I, I, no matter how bad my life may seem, I can always find something (pause) that makes me feel fortunate and I don't know if that's spirituality but what it's, I just have this belief, that things are meant to be. They will, they will work out

(pause) and that there's like, like it's no religion in particular but when you have, when you pray and, and your prayer is answered, you gotta believe that something, somehow happened here.

QN confirmed that for him spirituality pertained to a Higher Power, a belief in God, in requesting and granting forgiveness, and in prayer. In his experience, it is not associated with a particular religion. He also felt that it provided a connection to those who had died before him in that he acknowledged them in providing guidance for him:

Well, I'm sure that the people that I knew who had died had told me "get up there, you need to be there, get up there".

In his sense of the spiritual he realized that life is worth living and fun, that death is not an awful thing and that he had a sense of a spirit being with him, meaning he felt he was never alone.

I felt that somehow I'd been given a gift...maybe I was just learning that life was worth living and was fun. Even on oxygen (laughs) and unable to walk it was better than death, but (pause) that death was not a bad thing either. That's the other thing that I found out, that death was not such an awful thing...I'm never alone anymore.

The experience of the Spiritual included strength, love, acceptance and a response to requests:

...my Maker...was powerful, it was strong and it was full of love and it loved me unconditionally (pause) just, in spite of being a homosexual and having HIV and (pause) not having fulfilled "a life of uh Christian duty", it (pause) it loved me unconditionally and that all I had to was ask, Please help me and It did.

In that context he too found a resource of strength and a freedom from the fear of death:

I mean of all these things, where do I have the strength to go on? I believe that comes from within, from knowing now that I'm not alone, that there is, there is Someone there and whether we call Him Allah, Buddha, Jesus, whatever you want to call Him, there is Someone there (pause) and I think (pause) that I don't, I would not have ever known that...I'm no longer afraid of dying.

Acknowledging a Higher Power required courage on QN's part in that it resulted in his being ostracized by his peers:

...I tell you admitting to someone that you believe in a Higher Power in a gay community is not easy cause right away they think you're, you're strange. They don't wanna have anything to do with you.

In the context of the unconditional love experienced from the Higher Power QN was able to learn to love himself unconditionally. Like BZ, he also gave up control to the Higher Power and in so doing recognized that healing of the soul precedes healing of the body. Healing of the soul includes the wounds of childhood and adulthood, rids one of self hate and is the source of self love.

You can give up (pause) or you can put your faith into someone, into someone or something to help you along and that's what I did, I, I sort of let (pause) God...take control.

...along with the Higher Power loving you unconditionally, you have to love yourself unconditionally meaning warts and all you know, no one's perfect, so (pause) if if you are, if you want to use the Christian belief that you're created in God's image, well then (pause) you're, you're fine. If you want to use just ah, ah spiritualistic view of it and that we are all (pause) pure beings of some, you know, and this is just a vessel, then (pause) there's no reason in the world why I'm no more deserving than anyone else to be treated and to succeed and to, and to get healthier. We're, we're all deserving of love and we're all deserving (pause) to heal but you know, healing is something that has to happen in, in the soul first I think and then the body heals. It's funny how you have'ta heal all those old wounds as a child and as a young adult, and in my case having been a gay man, (pause) and a gay young man and a gay (pause) prepubescent boy, you grow up with all this self-hate. Once you accept all of that is just bull, (pause) you learn to love yourself as an individual, (pause) then you can start to heal. I don't think you could, you can heal until those issues happen and then (pause) once you love yourself for who you are

For QN, acknowledging the spiritual had to do with his personal history, his fears and self loathing—his sense that although he was seen as a mistake of nature by others, that is not the case.

...end of life issues, especially for gay men uh, uh that's that's what I'm speaking of has to do with God. They're afraid of hell, they're afraid of (pause) the brimstone and and and all of the the, the punishment for being bad so their fear of death is terrifying, it's it's like it's not gonna be good, it's gonna be awful, this is a punishment, that I'm I'm paying for my sins, I'm paying for what I've been, what I am, so you could help them by explaining that (pause) we're all equal, we're all loved, we're all okay (pause) and help them walk through that understanding that uh uh because there's often confusion and I like the, I like the idea of saying we're created in His image therefore if we're in His image, we're, we're we're okay. If we weren't we wouldn't be here, pure, pure and simple if He, if He didn't want us we wouldn't be here, and uh uh, the Christians hate that because it just, defeats their whole argument of us being (pause) you know mistakes of, mistakes of nature don't occur because (pause) we're here and animals that are born with two heads, they're still beautiful, (pause) they're not mistakes, it's the way they were meant to be and they should be accepted and loved for what they are.

In confronting death, one experiences the fullness of life. In part this is experienced in seeing nature and in providing care for others.

The simplest things of, of life are, are, are I 'm aware of them now. Like a plant growing, of you know a bird flying, you know you see them before but they mean nothing, you see them afterwards and they mean everything. And like, I'm taking care of my neighbour next door...I took on the role of caregiver because (pause) she needed someone and I could do that for her.

Truth is paramount, lying unacceptable:

Yeah, it's just plain, that's all, it's the truth, I can't lie. I'm not allowed to lie and I say I'm not allowed because the Creator, the Higher Power will not allow me to lie.

The sense of being cared for is a spiritual experience.

God takes care of those who take care of themselves...You, you, you just ask for, for it and he'll be there and he was there for me this time, so I'm thrilled.

In God/spirituality there is love without fear, forgiveness without guilt.

God loves everybody, and you know, no matter what you've done, he still loves you, you know. And you don't have to fear him and you don't, you don't have to ask for forgiveness, he's already forgiven you. All of this guilt just flies away, it just goes away.

The experience of dying viz. a viz. a near death experience it the ultimate wake up call spiritually and psychologically. Therein lies the opportunity to see one's self for who he/she really is. Through physical unconsciousness one may awaken to a greater consciousness.

It wasn't just wake up so you can speak to people but it was like wake up and this is, this is what it is, this is your life now...It was, it was, it was like being reborn. It was truly being given an opportunity to, to understand that we all control our destiny to some point by the way we behave in our present life. A lotta people go through life pretending they're something they're not.

To believe in a Higher Power contributes to being real. In truly knowing one's self and in believing in a Higher Power one finds resolution, completeness, wholeness and integrity.

...like all of a sudden all the pieces fit. There's you know, like people all go around searching for what'll make them happy, uh, drugs, cars, sex, whatever it is that their addictions are and they usually are addictions, they're looking for something. But once you find (pause) and, and put the pieces together of this puzzle, you no longer need these outside things to make you feel complete. You feel much better about being alive than, than ever before...understand that the wholeness that a person achieves when they start to believe in, in a Higher Power makes them a better person.

GI felt that spirituality is the higher part of the self (Higher Power) with whom one can communicate, a personal and private component of the self:

...it's (pause) the higher part of yourself, you know, it's you, but in, in your higher uhm (pause) we, I think we all have a higher and lower self, if we lived up our higher self we would be Jesus Christ but we can't so uhm, (pause) I think spirituality is, is part of what you are and it's uh, uh, (pause) it's just part of you...I feel I have a very uh close connection with my Higher Power. I talk and uh, I don't pray and things like that, or go around hooting or hollering. I never even bring up religion with anybody, I don't because I think that's private and should stay private, it should be your private uh, uhm (pause) your private time with God or you what, what you are with God.

...the spiritual value[s] are the, the decent things in life and integrity, honesty, truth, uh, all the, all the things that make for perfection in life.

In the discussion that followed the latter statement, GI agreed that when people are not existing in integrity, honesty and truth they have more despair in their lives than when they exercise their spiritual values.

The prayers of KR were directed at God through his mother who died twenty years earlier.

Uh and my form of prayer or uhm (pause) conversation with God, whatever it is, uh (pause) my mother, my mother God, it's actually my mother who died twenty years ago. I was very close to her and I know if she was alive today she'd be looking after me. Uh, and in one way she does because I talk to her all the time and uh, I don't pray to God, I pray to Mom and Mom looks after me (pause). So uhm, (pause) and my mother would help me when the time is right. Uh, at this point as I pray she, I, I'm amazed at the affirmations I get with, usually within 48 hours if I've decided to do something and then ask, ask for help uh, from, from my mother. I live alone so I can talk out loud or whatever and uh not bother anybody but uhm (pause), uhm, I get, I get replies, I get replies and it's, it's really, it's really strange and it's usually within 48 hours

LS experienced spirituality by virtue of the inner peace she found in the presence of nature.

...my spirituality is is tied to nature, so when I look for help instead of looking up you know, I look around. That was for me a confirmation in the fact that that's where my peace lies.

She had a longing for faith, for a belief in God.

I would love, I would love to believe, I would love to have faith...I'm not an atheist, I don't believe, but I do know I'm an agnostic. I know that uh it's not that I'm willing, it's just, I can't. I don't understand it.

Following the death of her son, she found healing in nature.

...one of the stops was at a um Buddhist temple. Just seemed so right when the guy in there, and you know you light your little incense which I did in V's name and when I sat down the priest was talking about the meaning of (whispers) death. (pause) beautiful. He talked about the tree and the leaf that falls in its given time and nourishes the earth from which the new leaves come and for some, for nobodies fault. I liked that. Nobody was guilty of anything. Sometimes a leaf will fall in May or June or July. And I went out of there kind of healed. This was the first sensible, and that what I began to see that I could find a religion, a spirituality in the things that I loved anyway. My mother could hold a leaf in her hand and be as adoring and wondering as a person holding crucifix or reading a verse in the Bible. In her old age I used to drive her down to that park around C. Lake (DK: Hm-m), stop the car, go out and take a leaf off a tree, a berry, a flower, you know, a log, or a piece of grass and bring it to her and oh nature is so beautiful. She would say only man is not so good but she'd say nature is kind and beautiful. And I think I'm like her. I see no, no deliberate cruelty in nature. I see the laws of nature taking place and sure there are bad things that happen. We see those all the time. But its not as though you're guilty of anything. It doesn't happen to you cause you were bad. And thats what I can begin to...I went to God. You know its like someone would go to church and pray...It gives me such a sense of of rightness, of power, of of um control that you know that I'm trust, and now I'm trusting my instincts. I'm going with my gut now.

LS found healing in nature and the experience of her illness resulted in a realization that meaning existed in relationships. Her definition of the spiritual was consistently in nature.

I'm not religious but I'm spiritual...I believe that there is a guiding force in life and in my life especially, which is related to world of nature, remember when I said when I needed um I needed to have some form of higher power because I wanted to put K. in the hands of a Higher Power, that it became a desperate thing for me, to find

something, and that without saying what it was that I wanted defined, without defining it or giving it a name or colour or anything since M. had said that it wasn't necessary you know for that. I um ended up, with, because after V. had died we had taken that trip across Canada, my eyes were drawn to the tops of the mountains thinking I would see him there. That I was again drawn to this uh vision of uh the force, the big bang which was not the creation described in the Bible um and I I had read from and knew from science that nothing that nothing that ever gets destroyed. Its there in some other form, so that the the strength and the and the uh power that had been there at that time was still with us and that I saw this as this wind at the top of the high mountain and I was able then to visualize the path that I took to lay V., not V., it was K. then, K. at the foot of this mountain and go away feeling peaceful just as other people go into church and lay their cares and woes in the Hands of God so that to me is spirituality.

Spirituality also included self acceptance, an acknowledgment that she was still searching and a recognition that she could not accept a punishing, judging component to the concept of spirituality.

Spirituality, for me, I don't know what it is for other people, has something to do with uhm, self-acceptance. I don't think that I ever knew I was spiritual until I reached a stage in my life very recently when uhm, I accepted who I was.

I was out reading Ecclesiasties yesterday. I'm still searching. But, uh, the whole idea of a, a punishing, a judging uhm is so foreign, you know, a tree give me unrequ-, unreasoning love, you know. I don't feel that I'm guilty of anything when I hug a tree, uh, or look at an animal or a bird.

Subsequently and through the course of her illness her sense of the spiritual changed— she looked for relief from her suffering acknowledging a Higher Power.

So this is where I'm at now and uhm (pause) looking for spiritual help because I know you'd like to hear about that (pause). I find my self (laughs) and uh, don't know whether it's hypocritical or what it is, but I find myself walking around saying (pause) uhm (pause) help...I use the word Lord and I use the word God (laughs) and the I think to myself uh (pause) you know you're, you're asking for it when you need but where are you when things are going well, yeah...what I'm doing now is transferring to my Higher Power, which I have been able to find as I

told you...[An answer to prayer] would look like a relief from (pause) at the moment, at this time, it would look like relief from this (pause) whatever the illness is.

At this point she defined spirituality in terms of the love she experienced in a group that was providing support for another woman with cancer. She also held to her initial sense of experiencing spirituality in nature.

Spirituality (pause) in essence for me is the feeling I get when (pause) I saw N. lying on the floor and (pause) no thought in my, no thought came to my mind about what I was going to do and I found myself (pause) on my knees beside her and my arms around her and holding her. And the feeling that I had as I held her in my arms and I whispered "I love you" (pause) that part of it uhm. Spirituality is listening to T.'s sister and (pause) feeling (pause) not pity, I felt pity too but feeling (pause) uhm (pause) loved, I'd never seen this person in my life before that. I felt and I could feel it in the whole room that was the most spiritual (pause) moment that I've had for a long , long time and it wasn't even in the forest or beside a lake, when without (pause) anybody saying anything. Somebody reached out in the circle and took the hand of the person beside them, then the other and it went right around and this is the way we send at the end of our circle, we have a circle and we hold hands and we send our love and energy around both ways and nobody, you know she was (pause) in extreme, you know she could hardly speak, just (pause) terrifying (?) and this happened (pause) that's spiritual.

Connected and, and you could just feel the love, you know it was, it's like touching something (pause) that's not palpable. It was so clear.

It's, spirituality is walking along the path in D. Park and seeing a fir tree, you know bigger round than my arms and reaching up into the sky and walking over and just, I wouldn't care who was looking, of putting my arms around that tree (laughs) and sucking in, you know going (deep breath) give me some of your strength, you know. Spirituality is hearing a, a stellar's jay and seeing him and (pause) such a beautiful, I don't know, you know.

HJ described himself as an atheist saying it was difficult for an atheist to embrace spirituality. It was easier for him to consider inner strength from a sense of morality for

with a moral purpose one has guidelines for living, one has a sense of integrity. In fact at times, all that one has is integrity.

A tough one to ask an atheist. (laughs). No, uh I do have my, I look at it more as a sense of morality. And the right, right moral direction. And I'm still on track with that to an extent but spirituality, that's a tough one...I get pride in the day. I am not down here, I have not succumbed to drinking or any of the other uh shenanigans goin on down here. Yeah and I haven't turned to a life of crime and even though I'm on poverty row, I will not, I will walk outta here a a proud man...a sense of integrity, yeah. Like I am not going to become a pitiful character. I'll walk out proud. (pause) And it's about the only thing I can do (laughs) you know, that's about the only thing I can really work at.

HJ did not see terminal illness as a reason to change himself or his previous beliefs. He held a belief in science and could acknowledge the place for religion in the lives of others, at times longing for components of religion to make his life easier, especially the belief in a life after death. He stated clearly that he was not able to talk himself into believing in an after life.

I'm an atheist. I tried (pause) when I was in the hospital and I'm dying and I, I says Jesus what a hypocrite. If he wants me, he'll expect me, he accept me for what I am, I'm not lying to him. So I'm not going to change all my beliefs and values just because I'm in dire, in a dire situation. (pause) Same thing as I couldn't become a, you know a card-carrying NDP member (laughs) just because I'm in the system now. You know I am what I am, and I'm either accepted for what I am or (pffffff) I'll go my own way. Uh, my beliefs in God? I believe in science, you know, the amino acids mixing with the uh, what is it, amino acids and uh enzymes (pause). You know in some lucky warm puddle somewhere, and that was (pause) I believe in evolution, I believe in science, you know. I just can't see somebody sitting there overseeing this whole big picture, it's just too much, I-I just can't envision it, and maybe there is but I can't envision it. And I'm one of those people that I can see how religion does bring relief, comfort, purpose to a lot of people, always had and I don't, I don't sit there and look at people and say 'you're dumb' or anything like that, you know, I mean they probably think I'm dumb. I wish I did have relig, religion in a lot of ways, it would make this a lot easier. A belief in life after

death eases the pain of suffering. Well, I'd still have that purpose you know, I'd say there is something after this, you know, despite the fact I'm down here in skid row with (pause) uh the people that live, that I'm, that I have to die with in my remaining time. Uh, there's something beyond, something to look forward to, that purpose, like I was saying a little bit earlier and that purpose would probably make this a lot easier (pause), other than me and my stubborn mule-headed (laughs) attitude in general.

While HJ denied being a very spiritual person, he recognized in himself a component of spirituality when it was defined as having purpose, meaning, value, and integrity. He summarized it by saying that for him spirituality was equal to doing good and that which was right. He learned to do right in the environment in which he grew up. For him the moral code of right behaviour was based on the ten commandments.

As much as HJ was taught about a moral code in his home, so CO was taught about God. She had inspirational teaching at home and was taught to pray before meals. That was how she began to acknowledge a Higher Power. She felt that the love of self is the foundation of love for family, siblings and ultimately God. She also felt that thankfulness, gratitude and awareness were essential to spirituality. She was especially grateful for being alive, for the opportunity to be on this world.

I feel, I do, I was given the opportunity to be on this world, I don't know where I came from, (pause) but (pause) yeah I feel that that was, that's just the way I think of it is, you know. I'll never have a bigger lotto.

She expressed her feeling of God as peaceful, happy, and blessed. She observed the presence of God in nature.

Well, it uh (pause) the feeling of God is, is such a peaceful, happy, blessed, you know, it's to do with everything, the smallest creature or even of things that we think of inanimate, like rocks, you know, nature's certainly is (pause) wonderful.

When above mentioned themes were reviewed with CO she added that in terms of spirituality love is the most important.

If one were to create a composite experience of spirituality for persons who know they have a terminal illness, one would generally address this Being as a Higher Power, a Being which has the capacity to love individuals unconditionally thereby in turn, enabling the individual to love themselves unconditionally as well. In the context of that love, the individual accepts him/herself with the awareness of the impact of wounds experienced throughout one's lifetime beginning in childhood. Hence, one is able to extend that acceptance to others as well. Because the Higher Power is able to forgive, and to love without judgment or imposition of punishment, the individual is also able to forgive self and others for all transgressions imposed on others or experienced personally. In the strength of this Higher Power, one experiences healing and is able to resolve personal and relationship issues some of which have resulted in self loathing, and great difficulty to forgive. One experiences a greater connectedness to others and finds deeper meaning in relationships.

The experience of the Higher Power is very personal and private. One no longer feels the boundaries and limits of self, for strength, love and integrity result in a wholeness not previously experienced. This is strongly felt in nature, from the smallest bird, through the eyes of a doe, embracing a tree, or looking to the mountains. There is a wholeness and a oneness with nature, which includes an extension of the self, beyond the self, to the Higher Power. In this context, one is filled with joy, purpose and loses all fear of death.

Chandler et al have described the nature of spirituality in the context of several psychological models including that of Maslow (1992, p. 168). They quote Maslow saying that he contended that *spiritual life (the contemplative, 'religious', philosophical, or value-life) is...part of the human essence...a defining characteristic of human nature.* It is certainly part of the human essence in the experience of knowing one has a terminal illness. Chandler et al identify the features which Maslow regarded to be characteristics of optimally functioning people, those he labelled to be at the top of the basic needs hierarchy, the “transcendent self-actualizers”:

- *a more holistic perspective about the world;*
- *a natural tendency toward synergy (cooperative action)—intrapsychic, interpersonal, intracultural, and international;*
- *much more consciously and deliberately metamotivated behavior (e.g. by truth, goodness, unity);*
- *more responsiveness to beauty;*
- *a greater appreciation for peak experiences;*
- *non-power-seeking attitude over others;*
- *the ability to speak naturally and easily—the language of “Being”;*
- *the ability not only to be aware of their self-identity but the capability of going beyond the ego self;*
- *attitudes that were more lovable and awe-inspiring;*
- *and more cognizance of the sacredness of every person and of every living thing (Chandler 1992, p. 168).*

The experience of the co-researchers is similar to the features described by Maslow. The terms differ and the purpose of the present study did not include a comparison to those who do not have a diagnosis of a terminal illness. Therefore it is difficult to incorporate all the features of the “transcendent self-actualizers”. A few examples of the features will be cited.

Some of the co-researchers demonstrated in their narrative a tendency toward cooperative action. Consider the words and attitude of CO:

I don't know if hopeful's the word but I'm very positive you know. I feel that man will progress...don't wanna be hurting each other just because our race or we think you have too much of that land, and that's what we want.

Truth and goodness characterized the co-researchers. The desire to know and speak the truth was discussed earlier and emphasized by QN:

Yah, it's just plain, that's all, it's the truth, I can't lie. I'm not allowed to lie and I say I'm not allowed because the Creator, the Higher Power will not allow me to lie.

For some, truth and goodness, included forgiveness, both as those who wanted to be forgiven as well as those who had a desire to forgive. In speaking of his concept of the Higher Power, QN stated:

I've given you the chance to forgive and I've given you the chance to forgive them and to go on.

...there is not healing without forgiveness. None. It, there's, there's a saying "you can tell someone you're sorry but there's the best thing to do is to ask them for their forgiveness." Um, you can say you're sorry for something, but its a lot more difficult to say "will you forgive me"?

So when my death was near me when I was in the hospital, all I could think of was finally, I, I can, I'll let go of all of that luggage, forgive my mother for abusing me, forgive my family for lying to me, forgive myself for hating myself, and ask the Lord to love me, for who I am, and and (pause) and by doing that I freed myself of so much that there's nothing my family can do to me now that hurts.

The co-researchers had a strong responsiveness to nature as well as a great appreciation for peak experiences. At times those were expressed simultaneously. Consider the experience of LS:

I bought a home on Pender Island which I am sure helped to stay alive through a lot. I was right in the middle of the forest, primeval with the ocean in front of me, walking miles, um beautiful, surrounded by beautiful garden, deer, you know into whose eyes. I told you about didn't I this lovely time when I went up to get my mail at the road and uh a little doe was standing there and she just turned her head. She didn't go. She was as far from me as that chair. She just turned her head and these huge darn eyes and we stood and communicated. We looked into each others hearts for the longest time and then she just turned her head quietly and walked away as if to say, I got it, thats fine. And the other wonderful experience, as I was coming home from the beach which was one of the beaches was about half a mile away. Walking home from the beach and uh through forest, the road went through forest on either side and it was just uh dusk and uh a stag, they're very small the Pender Island deer, a,a stag with his lovely antlers had just uh laid down to uh sleep I guess for the night or rest and he was not too far from the road and uh as I wal, as I started to walk by he uh raised his head like this. Looked, looked right at me as long as I stood there. Now these experiences are healing, thats what I call for me, healing or on the walks to see the the the broom in bloom all along the way or or the view of the sea and the mountains behind it or to see a little sail boat coming down through the pass or go down and sit on the beach and have um seals pop their heads up and look at you and once I was down there and I heard this floffling, hoffling noise and that there is a a point over to the right, the beach curves in like this theres quite a point her and I could hear this blowing and muffling and puffling and all of a sudden it came to me, the uh killer whales were coming, they come through there. I sat and I ran and looked and looked out and suddenly there they were you know. It was, it was the this is religious ecstasy. Now I know what you know an ecsta, ecstasy feels like. So I'm, I'm pleased with that, I'm I'm happy that from thinking that I was a a failed religious person to knowing that I have this spirituality which maybe is the reason that I can be as courageous as I have been with what I've been through for the last ten years. This was a development of this feeling that, by George, I'm not just a, a nothing.

I'm not religious but I'm spiritual...I believe that there is a guiding force in life and in my life especially, which is related to world of nature.

The same was true for CO, as was stated earlier:

...the feeling of God is, is such a peaceful, happy, bless, you know, it's to do with everything, the smallest creature or even of things that we

think of inanimate, like rocks, you know, nature's certainly is (pause) wonderful.

The sense of the transcendent in nature was also part of QN's experience. This was also stated earlier and is quoted here as it is part of the same response as the next quote pertaining to being lovable.

The simplest things of, of life are, are, are I'm aware of them now. Like a plant growing, of you know a bird flying, you know you see them before but they mean nothing. You see them afterwards and they mean everything.

In that context he also demonstrated an attitude of being more lovable:

And like, I'm taking care of my neighbour next door, (states name), she's not well, she's in the hospital, I'm the one who called the ambulance.

The term 'let go and let God' was discussed earlier. The essence of that statement is captured in the concept that the "transcendent self-actualizers" are more cognizant of the sacredness of every person. CO used that term to express the core of her spiritual being. In that statement she acknowledged that she was unable to change the lives of the people around her, whether family or friend. She knew that she was powerless in her ability to rescue, to judge or to manage the lives of others. She entrusted herself and them to a Higher Power.

The co-researchers certainly demonstrated a holistic perspective of the world with a tendency toward synergy, toward cooperative action and connection with family members for some and close friendships for others. Their behaviour was motivated by a desire to speak the truth, to forgive and be forgiven, and to accept self and others. Many of the co-researchers were inspired by the beauty of nature and scenery. The attitude of the spiritual experience is one of profound love and acceptance, not seeking power over

another, but seeking to live in truth and forgiveness, thereby living with a deep understanding of healing and wholeness.

CHAPTER V

DISCUSSION AND IMPLICATIONS

If we have been pleased with life then we should not be displeased with death, since it comes from the same master.

Michelangelo

The purpose of this study was to explore spiritual and psychological issues as experienced by persons who know they have a terminal illness. An existential-phenomenological method was chosen to understand and articulate the structure and meaning underlying the experience of living with the knowledge that one has a terminal illness. The study had its genesis at the bedside(s) of people who were dying, yet living or living, yet dying. The experience of knowing one has a terminal illness serves to bring life and consciousness to those who may have otherwise continued to live unconsciously, to exist in a potentially weary and dormant state, oblivious to the fact that life was passing them by.

The evidence of experience of knowing what it means to have a terminal illness exists in the words and expressions of the twenty-one people who graciously participated in this study as co-researchers. They have given testimony of their own experience to those of us who seek to understand that experience, to understand what it means to have a terminal illness, to confront one's end to life as it is known, to embrace life or to prepare to die. For some it was a single in-depth interview, for others there were numerous in-depth interviews over the course of two to eleven months. Eight of the twenty-one co-researcher narratives were presented in this study. Each interview was recorded by audio

and video tape, the former being used for transcription. Subsequently, transcriptions were reviewed for accuracy. As a measure of trustworthiness, themes were identified by the principal investigator and presented in the context of the narrative to the co-researchers who confirmed the data and validated the themes.

The purpose of this chapter is to present the limitations of the study and to explore the implications of the evidence resulting from the study. Implications will be considered in three categories, namely theory development, professional practice, and future research.

A. Limitations

The outstanding feature of a man's life in the modern world is his conviction that his life-world as a whole is neither fully understood by himself nor fully understandable to any of his fellow-men (Schutz 1970, p. 236). The limitations of this study consist of personal awareness and self understanding, language, and the choice of self disclosure made by the co-researchers.

The purpose of this study is to understand as fully as possible the experience of knowing that one has a terminal illness, that is, that one is dying. First, the description of the experience of dying is limited to the degree of awareness, understanding, or psychological and spiritual consciousness, of the co-researcher. Remember the stories of GI who acknowledged that she denied having a terminal illness for a year after the initial diagnosis and QN who only acknowledged the severity of his illness after a near-death experience. This limitation is minimized by virtue of inter and intra co-researcher

thematic saturation, meaning individual co-researchers experienced themes repeatedly and many co-researchers experienced and expressed the same theme(s).

Second the study is limited by language. How able is the individual to express accurately the experience of dying? And how are those words translated and understood by the interviewer? When physicians or nurses assess physical pain, they often use a visual analogue scale of 0 to 5 or 0 to 10. The score is accepted as the best measure, and at 'face value' regardless of the impression of the health care provider as to what the score ought to be, given the description of pain by the patient. Scores such as that have not been developed for loneliness, anger, grief or many of the other emotions experienced as part of knowing one has a terminal illness.

One must recognize that the message is more than words. It includes expression, tone, and silence—all the features of verbal and non-verbal communication. It is for this reason that validation is important, for the interpretation of the message by the interviewer was confirmed, altered or eliminated when the themes were reviewed with the co-researcher.

Third, the interviewer only hears that which the co-researcher chooses to speak. The choice to express his truth was made by HJ after many months of working together with the interviewer. For him, the video camera was a deterrent. It served as an impediment to his sense of safety and trust as to what might come of the information he provided. The safety and trust were only established after hours of interviewing which took place over an extended period of time.

Fourth, the themes which were identified are not comprehensive. Identification of themes is limited in part by the awareness and understanding of the interviewer.

Maslow's Hierarchy of Needs was employed as a means to enhance the readers understanding of the themes. It may in some regard also restrict ones understanding simply because of the limitations of the particular theory. Additional themes might be identified at another time of reading and reviewing the transcripts.

Fifth, medication might alter the perspective of the co-researcher. Most of the participants were not taking medication which altered their perception of reality. This is certainly a limitation of which one would need to be aware in making any psychological or spiritual assessment either for the purposes of research or in providing care for the terminally ill.

B. Theory

Erik Erikson's eighth stage of the life cycle is a particularly useful theoretical framework for organizing, integrating, and presenting major findings of this study (1980, 1982). In writing *Identity and the Life Cycle*, Erikson intended to present *the unity of the human cycle, and the specific dynamics of each of its stages, as prescribed by the laws of individual development and of social organization* (1980, p. 7). He borrowed from Marie Jahoda, defining a healthy personality as one which *actively masters his environment, shows a certain unity of personality, and is able to perceive the world and himself correctly* in order to ask the question, *How does a healthy personality grow or, as it were, accrue from the successive stages of increasing capacity to master life's outer and inner dangers—with some vital enthusiasm to spare* (1980, p. 53)? Erikson is known for his description of the eight stages one 'grows through' in the course of the life cycle. As one moves from one stage to the next, he/she experiences a potential crisis because of the

radical change in perspective. The most radical one occurs at birth when the individual changes from an intrauterine to an extrauterine existence. Through the course of development, the individual may experience rapid and radical changes enroute from birth to adulthood. Prior to drawing conclusions, a very brief summary of the eight stages will be presented (Erikson 1980, 1982).

B. 1. Erikson's Eight Stages

B. 1. i. Basic Trust versus Basic Mistrust (Infancy—I am what I am given)

Basic (i.e. not especially conscious) trust is an attitude toward oneself and the world which develops in response to the experiences of the first year of life. Trust refers to that which may be regarded as a reasonable trustfulness of others and a sense of trustworthiness of oneself.

When Erikson speaks of “a sense of”, he believes there are ways of conscious experience (accessible to introspection, where it develops), behaving (observable to others) and inner states (unconscious, determinable by test and analysis). Essentially he says that experiencing “a sense of” is a combination of the conscious and the unconscious which may be seen or witnessed by others. Adults who are impaired in their sense of basic trust will express a basic mistrust. They will essentially withdraw into themselves when they are at odds with themselves and/or with others. Erikson regarded basic trust to be the cornerstone of a healthy personality. Trust is linked to truth and hope in its definition: *assured reliance on the character, ability, strength, or truth of someone or something; a dependence on something future or contingent* (Webster's 1981, p. 1246). The psychosocial strength which emerges as a result of the struggles which

occur within the individual as he/she seeks to adapt, and resists adapting to the features of this stage of development, is hope.

B. 1. ii. Autonomy versus Shame and Doubt (Early Childhood—I am what I will)

The significance of this stage pertains to the development and maturation of the muscle system with the resulting ability to *coordinate a number of highly conflicting action patterns such as “holding on” and “letting go”*, of retention and elimination. This includes the development of the sphincters which must be controlled to experience, physically, the functions of retention and elimination. Hence, this stage becomes the stage of autonomy, the ability to retain and eliminate at will. So a child who develops a sense of self-control without loss of self-esteem will also have a sense of autonomy and pride, and without that, will integrate a sense of doubt and shame. The psychosocial strength of this stage is will.

B. 1. iii. Initiative versus Guilt (Play Age—I am what I can imagine I will be)

At this point the child sees him/herself as a person and seeks to discover what kind of person he will become. The significant features of this stage are one's ability to move around, the sense of language, and an expanded imagination. It is at this stage that the child also develops prerequisites for feminine and masculine initiatives. It is in the context of the imagination that the child may initially experience guilt because he/she may have “fantasies of terrifying proportions”. The conscience becomes firmly established in that the child feels shame, at being found out, and fear, at the mere idea of being found out.

This is the stage which may account for the experience of adults who link their worth to their achievements, that which they are doing or are going to do, as

opposed to who or what they are as individuals. The healthy individual will appreciate that people are of equal worth although they may be very different in kind, function, or age. Purpose characterizes the psychosocial strength of this stage.

B. 1. iv. Industry versus Inferiority (School Age—I am what I learn)

At this stage systematic instruction begins, the experience of doing what one is told balanced with doing what one likes to do. The child learns that productivity is not merely the result of play and fantasy but of “reality, practicality and logic”, features which characterize the adult world. He/she develops a sense of industry, that is, being able to make things, make them well, and to complete the task.

In contrast to the sense of industry lies the sense of inadequacy and inferiority. The sense of inferiority is a feeling that one will never be good enough. That is one of the dangers of this stage. A second danger pertains to the child’s identity being fixed on another in that he/she performs tasks for that individual rather than being all he/she could be for themselves. The third danger is that the child never acquires the joy of work and of pride of doing at least one thing well. At this stage, the psychosocial strength is competence.

B. 1. v. Identity versus Identity Diffusion (Adolescence)

Puberty and adolescence begin, the period of rapid body growth, genital maturity (a physiologic revolution) and an attempt to consolidate social roles. This is the time of transition from childhood to adulthood. At this time the inner conglomerate, that is, the alignment of previous basic drives, personal endowment and opportunities, culminates in the sense of ego identity. Self esteem grows to a conviction that *one is*

developing a defined personality within a social reality which one understands (Erikson 1980, p. 95).

The danger at this stage is that of identity diffusion and identity confusion, the latter being unavoidable at this time when the individual must contend with radical body changes, the flooding of body and imagination by genital maturity, the intrigue of intimacy with the opposite sex—all in the context of a variety of choice, chance and conviction. The psychosocial strength of this stage is fidelity.

B. 1. vi. Intimacy versus Isolation (Young Adult)

One's adult life begins as he/she works or studies toward a specific career, becomes increasingly sociable with the other sex, and in time marries and has children of his/her own. Once a reasonable sense of identity has been established, intimacy with the other sex can occur. Intimacy or attachment at this level would best be *devoted to an attempt at arriving at a definition of one's identity by talking things over endlessly , by confessing what one feels like and what the other seems like, and by discussing plans, wishes, and expectations* (Erikson 1980, p. 101). Where this does not occur, the individual is likely to isolate him/herself and become involved in stereotyped and formal interpersonal relationships which often result in failure. Too often people marry under such circumstances with the hope that they will find themselves in finding one another. Failing that that happens, people may believe they have the 'wrong' partner, rather than appreciating that the condition to become real, to become a true twosome is dependent on one's first becoming oneself.

The counterpart or danger point of intimacy is isolation. Erikson also refers to this as distantiation which he defines as *the readiness to repudiate, to isolate, and, if*

necessary, to destroy those forces and people whose essence seems dangerous to one's own (1980, p. 101). He goes on to present the concept of love and work (Lieben und arbeiten) as developed by Freud. It was Freud's response to the question of what he believed a normal person ought to do well. In love he meant that the individual would be able to express him/herself in generosity as well as in genital love. With the addition of 'and work' Freud meant a *general work productiveness which would not preoccupy the individual to the extent that his right or capacity to be a sexual and a loving being would be lost* (Erikson 1980, p. 102). From the resolution of the struggle between intimacy and isolation, one knows love.

B. 1. vii. Generativity versus Stagnation (Adulthood)

This stage includes the time of parenthood, the establishment of the next generations by combining genitativity (*potential capacity to develop orgasmic potency in relation to a loved partner of the opposite sex*) and genes (Erikson 1980, p. 102). This stage marks the growth of a healthy personality and when it fails one regresses to a need for pseudo intimacy resulting in a sense of stagnation and interpersonal impoverishment. One who knows the psychosocial strength of this stage knows care and caring of self, of others, and of ideas.

B. 1. viii. Integrity versus Despair and Disgust (Mature Age)

In integrity one experiences a sense of coherence and wholeness. This state of mind is marked by self acceptance, acceptance of others who are significant, acceptance that life is one's own responsibility, comradeship with men and women different from oneself, and the ability to defend the dignity of one's own lifestyle against physical and economic threats. This may be threatened by a loss of linkage of the

organizing processes within, namely, the Soma (the physical), the Psyche (the psychological), and the Ethos (the spiritual). Despair, and often a fear of death, emerges when ego integration does not exist. *Despair expresses the feeling that the time is short, too short for the attempt to start another life and to try out alternate roads to integrity* (Erikson 1980, p. 105). In understanding and resolving the tensions between potential despair and the reality of integrity one develops wisdom.

Based on the work of Erikson, Herman defines integrity as *the capacity to affirm the value of life in the face of death, to be reconciled with the finite limits of one's own life and the tragic limitations of the human condition, and to accept these realities without despair. Integrity is the foundation upon which trust in relationships is originally formed...The interlocking of integrity and trust in caretaking relationships completes the cycle of generations and regenerates the sense of human community* (1992, p. 154).

B. 2. Discussion

Through the course of this study it would appear that, regardless of age, the individual who knows he/she has a terminal illness longs for, and strives toward integrity, and in that process experiences despair. Despair may include components of anxiety and depression which are commonly identified as threats to one's sense of well being at the end of life. The components of anxiety and depression serve as an opportunity to work with the individual, to move from despair toward integrity. Fear, guilt, doubt, loneliness and grief are other features of life and certainly of the end of life experience, which would be expected to fill one with despair. However, if addressed effectively the very features

which usually result in despair can actually lead to self awareness and meaning. The experience of three of the co-researchers will be used to demonstrate such a process.

Consider the experience of BZ, who seven years prior to her physical death, experienced 'death' in the context of who she was as an addict. At that point she began the journey to move from the despair of alcoholism and all that entailed in her sense of self, relationship to others, and understanding of God to the integrity of who she was at the time of her physical death, stating that her cup of joy was full to overflowing, that her spiritual strength was ever increasing as her physical strength weakened. At that time she was free of pain, anxiety, depression and fear of death. Her experience of dying was characterized by the features spoken of by Erikson. It was the culmination of the fruit of the seven stages—she enjoyed integrity. She could celebrate her process of healing, despite not being cured, meaning her basic needs as defined by Maslow were met. She had self-actualized, she had individuated and could truly bask in the fullness of her spiritual being and thereby experience integrity as opposed to despair. She had hope in her daughters and grandchildren to carry forth her legacy of living 'truthfully' and in a Higher Power that she would be cared for through the process of dying and in whatever lay beyond that. I insert an anecdote. Because BZ granted permission for use of her tapes in education, I met with her three daughters a few months after BZ's death. They spoke of her favoured eight year old granddaughter who was asked by a non family member whether the death of her grandmother resulted in a great deal of sadness. The eight year old responded with, "Oh, no my grandmother told us that she was full of joy to overflowing." As a result the eight year old, who missed her grandmother, had a

confidence that the end of her grandmother's life was not a terrible event and that her grandmother would be all right.

One is left to ponder, what is the process that enabled BZ to die, full of love, full of hope, and ironically, full of life. For her, knowing that she had a terminal illness served as a confirmation that the courage of attending Alcoholics Anonymous and the conviction to follow through the program, brought her to a point of knowing who she was, in herself, in her family, amongst her friends and beyond herself to the transcendence of a Higher Power. That was her process, her journey to a point in time where the boundaries she needed earlier in her life to define herself were redefined to establish who she was in the context of her true self, to use Maslow's term, her actualized self, and in a sense her spiritual self, which in turn seemed to enable her to move through despair toward integrity.

Another co-researcher, QN indicated a similar process to BZ reinforcing Maslow's hierarchy of need moving toward self-actualization and Erikson's paradigm of integrity and self awareness. For QN, the experience of a terminal illness reached a pinnacle when he had a near death experience. Its essence was largely spiritual and was followed by a process of self actualization, of answering the question Who am I? So while the process of self actualization culminated in a spiritual existence for BZ, a peak spiritual experience culminated in a process of individuation for QN. One of the strengths of Maslow's model rests in his understanding that all people have part of each need met and all people have part of each need unmet. As an example, while BZ seemed to exist primarily in a self actualized state, she did experience some despair when she got

physically short of breath in the last twenty-four hours of her life, as reported by one of her daughters. The shortness of breath was ameliorated with medication.

The process of integrating the near death experience into who he was required months of self reflection for QN. He had to explore the meaning of growing up in the home in which he grew up. Only in courage could he question his relationship with his parents and siblings. As he processed who he was as a person who was male, gay, and who had AIDS, he also came to a point of integrating his sense of grief and loneliness into his being. He accepted that his family rejected him because of who he was, that his gay community rejected him because of his new spiritual self, and that the 'church' community like his family, rejected him for being gay. And yet, as he began to speak his truth, he was able to state who he was, the choices he would make with regard to that, to care for others, and to celebrate his confidence and hope in a Higher Power.

Remember the experience of HJ. It was during the last interview that he spoke of living a duplicitous life—a double standard that included his children, his mother, his ex-wife, his friends and acquaintances; a standard which was based on fear of rejection and retribution. For decades he was unable to speak his truth, to acknowledge his sense of guilt and fear, and as a result lived in loneliness and isolation. Jung observed that the work of the soul is comprised of three components, "insight, endurance and action" (Hollis 1996, p. 16). Once HJ had the insight into his duplicitous life, he courageously began to do what he knew he had to do. He moved from the despair in which he had existed for decades toward integrity by speaking the truth, by acknowledging the impact of his experience on his personhood, and by taking action in re-establishing honesty in the relationships with family and friends. He was willing to bear the consequences of his

actions. A week after the final interview, in a telephone conversation, HJ spoke of his new found freedom to be who he really is. He spoke of literally moving from his single room which characterized his isolation and solitude to a larger space in which he would be able to develop meaningful relationships with those who were important to him. He spoke also of seeking employment or some other opportunity in which he could exercise his talents in creating and building something as a carpenter. He acknowledged that his time was short and that he did not want to wait any longer to live truthfully. He was taking the steps toward integrity.

Consider the other co-researchers. Few of them spoke of physical pain. Being free of physical pain, enabled them to focus on other issues, therefore serving to inform us of the non-pain related issues which are significant to people who know they have a terminal illness. Those who had known physical pain, feared it and also respected the fact that they would in all likelihood be freed of that pain by medical or other intervention. The co-researchers were focused on their own experience of living, or remembering their lives, of seeking and longing to speak and hear the truth, to touch others as a means of being connected and contributing to a healing process, and to elicit from time, a quality of life that would bring them closer to understanding who they were, and who they might become.

Through the course of their journey, the co-researchers reported psychological suffering, in that relationships and events in their lives threatened who they were or who they believed they were. They were no longer able to ignore the psychological and spiritual pain they experienced resulting from the circumstances of their lives. What might that pain mean? How might those circumstances have contributed into making

them who they had become? Might there be some unfinished business—to grieve a child who had died decades earlier, to work to see one's self as a product of the Creator rather than a mistake of Nature, to seek reconciliation with a child who had left with the message that he would never return, to find hope in the time remaining when the physician had annihilated preexisting hope in one statement, to end the duplicity and to begin to speak the truth, to admit the remorse one felt about the sexual intimacy that had been lacking in a long term relationship.

Each person longed for resolution of their despair, including regrets, failed attempts, losses, guilt, and for continued integrity, for wholeness in knowing who they were.

C. Professional Practice

At the end of her last interview with me, LS asked whether a meeting could be arranged with herself, her two sons and a facilitator who might enable each of them to speak their truth. While that would have been possible, she subsequently got sick and chose not to proceed. She knew that for her, the process of moving from despair toward integrity included a truthful conversation between her and her two sons. Unfortunately she became too ill to follow through on her desire to converse honestly with her sons. Time was short and desire waned; that combination served to prevent the conversation from happening. This type of finding suggests that there is a potential role for the professional to provide counselling for persons at the end of life. Skilled counselling could facilitate the attainment of goals as well as of healing.

One of the strongest implications of this study challenges those providing care for people who know they have a terminal illness. The challenge is to be able and available to facilitate the process to self actualization, to experience with those who know they have a terminal illness the sense that the process of dying may actually be the time of optimal growth in one's lifetime. Being able to respond to the expressed needs of the patient in this way could only occur if the health care provider had the judgment, sensitivity and appropriate skills. Basic communication skills are essential to start the process of responding to the patient. Victor Frankl said of his experience in the concentration camps of the Second World War—*one could make a victory of those experiences turning life into an inner triumph, or one could ignore the challenge and simply vegetate, as did a majority of the prisoners* (Frankl 1959, p. 93). Knowing one has a terminal illness may result in that person believing that the real opportunities of life have passed. In another paradoxical sense, for some it may be an indication that life has just begun. How do care givers promote the latter?

In order to respond to the patient, the health care provider must begin by asking the same questions, Who am I? and Do I embrace living or do I prepare to die? *How we anticipate future events—and death—governs our "now" in substantive fashion and provides an important organizing principle in determining how we behave in life...a needed corrective to a widespread vogue of being mesmerized by the moment...Acceptance of personal mortality is one of the foremost entry ways to self-knowledge* (Feifel 1990, p. 541).

The results of this study provide a foundation for a palliative care program which would incorporate all the components of palliative care as defined by the World Health

Organization. Such a program would provide high quality, evidence based care in all domains—physical, spiritual and psychological. Maslow’s hierarchy of need provides the theoretical framework for such a program.

Figure 5. Maslow’s Hierarchy as a Program Framework

The physiological component of that hierarchy represents the pain, suffering and symptoms that people with a terminal illness might experience. The essentials of care as found in the biomedical model are necessary in order to address the physiological needs. At this level one would necessarily follow advances in psychoneuroimmunology, neurophysiology, and pharmacology. All components (the training of staff and/or the care delivered to patients whether addressing physical, psychological or spiritual needs) of the program as described on the diagram on the previous page would be evaluated. Studies researching the care delivered at this level would be primarily quantitative in nature. Hospital administrations would necessarily embrace the principles and practices of palliative care as complementing curative care, equally significant to the well being of the patients it serves. The clinical care would be well defined, evidence-based, compassionate care for persons of any terminal illness.

A program based on this model would require adequate resources such that staff members would receive support, education and training for providing comprehensive care (physical, psychological, and spiritual) for all patients at the end of life. Such a program would take into consideration the results of this study, with regard to the basic human needs of safety, belonging, self-esteem, self-actualization, and the transcendent self. Features of training would include skills to enhance communication, to understand the illness experience, to provide personal and family counselling, and to develop and integrate a myriad of interventions which would address the psychological and spiritual needs of the patients. Some examples of interventions include a process of life review as an individual or in the context of a group, therapeutic enactment (psychodrama), guided imagery, therapeutic touch and therapeutic healing, decision making processes,

meditation, etc. If provided, each of the interventions would be evaluated with regard to their impact on the patient, on the family, on close friends as well as on health care providers.

The team would be comprised of professionals who would be qualified to address the needs of the patient, and ideally resources would be such that the staff would have the time necessary to address the spiritual and psychological needs of the patient. The needs of the patients' families would also be addressed as they pertain to the time of dying, death and bereavement.

This program would incorporate a truly interdisciplinary approach to caring for persons at the end of life and would also serve as a teaching centre for each of the disciplines represented on the team. Ultimately, it would include a residency training program for physicians who choose to specialize in palliative care. For some, the training would integrate features of pain and symptom management inherent in a biomedical model with a graduate degree in counselling psychology. As well, an integrated program could also provide clinical training and career opportunities for people working in the area of counselling and clinical psychology.

D. Future Research

The findings identified in this study open a number of possible future studies. Those identified in this section do not exhaust the possibilities.

First, one might design some studies to further develop or deepen our understanding of the spiritual and psychological issues at the end of life. This could be done on a larger scale, especially if a multi-site study could be established. A method

such as this could combine life history/review with focused in-depth open ended interviews. Another methodology to obtain this information could be through focus groups, where the individual respondents have opportunity to express their opinions, and the synergy of the group adds to the depth and insight of the dialogue which occurs among members. These could be conducted with professional staff as well as with family members after their loved one has died.

Second, one might explore how spiritual and psychological issues or concerns affect physical pain. Health and Welfare Canada (1984) defined pain as a sensation and an emotional experience, always with its origins in a physical stimulus and always modified by the mind. It was described as always being subjective. *Pain is what the patient says it is and not what others think it ought to be* (Health and Welfare Canada 1984, p. 6). There is a need for more studies which compare pain managed only with analgesics to pain managed with analgesics as well as psychological and/or spiritual interventions. Is it possible that the spiritual or psychological pain might be experienced primarily as a physical entity? How might one develop a method of differentiating those issues? Perhaps a larger sample size could be considered.

Third, how does psychological or spiritual pain affect the patient's desire for death, including physician assisted suicide or euthanasia? And how does that pain as experienced by the patient, affect the health care provider? What are the effects of projection, transference and countertransference on the health care provider/patient relationship? How does the discomfort of the health care provider at the bedside of a dying patient affect the patient's sense of well-being? Is it possible that the discomfort of the health care provider at the bedside of a dying patient might, at a preconscious or

unconscious level, affect the health care provider's ability to provide care or to make accurate assessment with regard to the needs of the patient? Might the discomfort result in medication errors, leading to the patients increased discomfort or premature death?

Fourth, the themes could be separated and examined in a detailed qualitative manner. As an example, consider the themes of doctor/patient communication or health care provider/patient communication. One might explore what is said, what is heard and what is felt emotionally through the course of interaction in discussing a diagnosis, a particular symptom or an aspect of suffering.

The themes of truth, touch and time could also serve as the basis of further investigation. How does truth contribute to resolution of differences within a family? Does the pain experienced by the listener in hearing the truth of another impede safety, trust, and/or intimacy? How does the perception of remaining days, weeks, months, or years of life affect decision making? Through the development of studies such as this, there would be great value in developing a language with which to discuss "inner life", which would be appropriate to use in a pluralistic society, in contrast to traditional cultural and religions world views.

Fifth, one might develop a systematic evaluation of interventions such as those cited previously, guided autobiography and /or life review, therapeutic enactment, guided visual imagery, etc. Of special interest in this category of future research is the impact of touch with regard to sense of well being or healing. What is the psychology, benefit, or detriment of touch be it through reflexology, massage, acupuncture, or therapeutic and/or healing touch?

Sixth, it is important to develop assessment tools to determine the readiness for intervention when the patient experiences spiritual or psychological stress or distress.

Seventh, it might be of value to conduct some age-comparison and cross cultural studies with similar open-ended questions. And in the childhood age groups, there would be value in understanding the lived experience of the parents and siblings, as well as that of the child who has the terminal illness.

Eighth, any and all training programs ought to be evaluated so as to improve and integrate the most effective care into any programs. Once the skills are part of practice, measures of worker satisfaction, absenteeism, less avoidance of difficult patients and decreased blocking with regard to meaningful conversations would necessarily be incorporated into any program.

E. Conclusion

Like the patients, health care providers must be aware of all the emotions that encompass the experience, some of which include guilt, grief, loss, doubt, despair, fear, anger, and angst. Hollis describes these as “swamplands of the soul” and understands that they may actually provide opportunity to find “new life in dismal places” (Hollis 1996). Perhaps the time when one learns of having a terminal illness might be regarded as a swampland of the soul. Society would have one believe that it is the ultimate swampland and therefore exists as though it can be avoided. That in itself might result in suffering, in that it means one does not question one’s death anxiety, one’s personal reality and truth. In its place, one lives in the context of a frantic desire to be happy and untroubled. *Rather, one is unavoidably pulled down and under, frequently, painfully*

(Hollis 1996, p.11). It is not happiness, but meaning which delivers people from despair to integrity. Whether that occurs is based on choice, for the responsibility of movement rests in the one who has the capacity to choose. Often it involves *a more honest encounter with the shadow, some deepening of the journey into places we'd rather not go. Yet all of those psychic states have a soulful purpose. Our task is to live through them, not repress them or hurtfully project them onto others. What is not faced within is still carried as a deep personal pathology. To experience some healing within ourselves, and to contribute to healing in the world, we are summoned to wade through the muck from time to time. Where we do not go willingly, sooner or later we will be dragged...Soul work is the prerequisite not only of healing but also of maturation* (Hollis 1996, p. 15). The work of the soul includes insight, endurance and action; it is no different for those who know they have a terminal illness and those who don't wish to believe they are mortal, for the patient or the care provider, for the researcher or the co-researcher.

Man lives in three dimensions: the somatic, the mental, and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human (Frankl 1969, p. xvi). Medicine as a discipline addresses the somatic very effectively. However as physicians and health care institutions have become increasingly specialized in order to integrate the vast amount of medical knowledge into the care that is provided, the familiarity with patients has been compromised, especially as it pertains to the mental/psychological and the spiritual (Roy 1994, p. 11). For persons at the end of life, that means the care of themselves as 'whole' people may also be threatened or compromised. This could potentially result in a split in the components of self, and may

contribute to suffering as experienced by the persons who are experiencing all the emotion integral to having a terminal illness, to knowing that life as it has been known, no longer exists. These emotions certainly include anxiety and depression.

The task at hand is to merge the knowledge and skills which characterize the humanities, ethics, medicine, the spiritual dimension and the behavioural sciences. The issues surrounding the end of life are too complex and intricate to be left to a single discipline. We cannot only provide care for the body or only for the soul but must be prepared to address all the issues consistently and comprehensively. In addressing the issues of the dying, the appreciation of the fullness of life will increase with an enhanced ability to define our purpose, our values and our own life goals. In understanding the experience of dying, we will comprehend the purpose of living.

And the Lord (Higher Power) said, I have surely seen the affliction of my people...and have given heed to their cry...for I am aware of their sufferings. So I have come down to deliver them...and to bring them up from that land to a good and spacious land, to a land flowing with milk and honey. I will be with you. Exodus 3: 7, 8, and 12

New American Standard Bible

REFERENCES

- Advisory Committee on Cancer Control (1994). Bridging research to action: a framework and decision-making process for cancer control *Canadian Medical Association Journal*, 151 (8), 1141-1146.
- Aldridge, D. (1993). Is there evidence for spiritual healing. *Advances, The Journal of Mind-Body Health*, 9 (4), 4-21.
- Avis, W.S., Drysdale, P.D., Gregg, R.J., Neufeldt, V.E., & Scargill, M.H. (1983). *Gage Canadian Dictionary*. Toronto: Gage Educational Publishing Company.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, 2 (1)
- Beauchamp, T.L. & Childress, J.R. (1994). *Principles of biomedical ethics*, (4th Ed.) New York: Oxford University Press
- Berliner, P.M. (1992). Soul Healing: A model of feminist therapy. *Counseling and Values* 37: 3-14.
- Birren, J.E. & Deutchman, D.E. (1991). *Guiding autobiography groups for older adults exploring the fabric of life*, Baltimore: The Johns Hopkins University Press.
- Black, H.C. (1979). *Black's law dictionary*, (5th Ed.), St. Paul, Minnesota: West Publishing Co.
- Bonica, J.J. (1990). Cancer pain. In J.J. Bonica (Ed.) *The management of pain*, (2nd Ed.) (pp. 400-460) Philadelphia: Lea and Febiger.
- Braud, W. & Anderson, R. (1998). *Transpersonal research methods for the social sciences honoring human experience*. California: Sage Publications
- Breitbart, W. & Holland, J. (1990). Psychiatric aspects of cancer pain. In K.M. Foley (Ed.) *Advances in Pain Research and Therapy* (16: 73-87). New York: Raven Press, Ltd.
- Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal*, 311: 251-253.
- Brody, H. (1987). *Stories of sickness*. New Haven, Connecticut: Yale University Press.
- Buber, M. (1996). *I and Thou* as translated by Walter Kaufman. New York: Simon & Schuster.
- Buechner, F. (1991). *Telling Secrets*. New York: HarperCollins Publishers.

- Burge, F.I. (1995). Medical care of the dying Where do family physicians fit in? *Canadian Family Physician*, 376-378.
- Butler, R.N. (1997). *Don't Manage Me: I'm No Case* Lecture, New York: Citizen's Committee on Health Care Decisions, Inc.
- Callahan, D. (1993). *The Troubled Dream of Life*, New York: Simon and Schuster.
- Campbell, J. (Ed.) (1971). *The Portable JUNG*, Penguin Books.
- Cassell, E.J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306:639-645.
- Cassell, E.J. (1991). Recognizing suffering. *Hastings Center Report*, 24-31.
- Cassell, E.J. (1991). *The nature of suffering and the goals of medicine*, New York: Oxford University Press.
- Cassem, N.H. (1988). The person confronting death. *The New Harvard Guide to Psychiatry*, 728-758.
- Chandler, C.K., Holden, J.M., Kolander, C.A. (1992). Counseling for spiritual wellness: Theory and practice. *Journal of Counseling & Development*, 71: 168-175.
- Chapman, C.R. (1979). Psychologic and behavioral aspects of cancer pain. In J.J. Bonica & V.Ventafredda (Eds.) *Advances in Pain Research and Therapy*, (2: 45-56) New York: Raven Press.
- Chapman, C.R. & Gavrin, J. (1993). Suffering and its relationship to pain. *Journal of Palliative Care*, 9(2), 5-13
- Charlton, R.C. (1992). Spiritual need of the dying and bereaved--views from the United Kingdom and New Zealand. *Journal of Palliative Care*, 8 (4), 38-40
- Cohen, S.R., Mount, B.M., Tomas, J.J.N., & Mount, L.F. (1996). Existential well-being is an important determinant of quality of life. *Cancer*, 77: 576-86
- Cohen, S.R., Bultz, B.D., Clarke, J., Kuhl, D.R., McNeil, C., Poulson, J., Baldwin, M. & Mount, B.M. (1996). Dying healthy - palliative care: A psychosocial and spiritual research agenda from the patient's perspective. *A Report from the Sociobehavioral Cancer Research Network*.
- Cohen, S.R., Bultz, B.D., Clarke, J., Kuhl, D.R., Poulson, M.J., Baldwin, M.K. & Mount, B.M. (1997). Well-being at the end of life: Part 1. A research agenda for

- psychosocial and spiritual aspects of care from the patient's perspective. *Cancer Prevention and Control*, 1 (5), 334-342.
- Conrad, N.L. (1985). Spiritual support for the dying. *Nursing Clinics of North America*, 20 (2), 415-426.
- Coope, C.M. (1997). Death with dignity. *Hastings Center Report*, 27 (5), 37-38.
- Corless, Inge, (1990). Assumptions and principles of spiritual care *Death Studies*, 14:75-81.
- Corr, C. (1993). Coping with Dying: Lessons that we should learn and should not learn from the work of Elisabeth Kubler-Ross. *Death Studies*, 17:69-83.
- Copp, L.A. (1974). The spectrum of suffering. *American Journal of Nursing*, 74 (3), 491-495.
- Coward, D.D. (1991). Self-transcendence and emotional well-being in women with advanced breast cancer. *Oncology Nursing Forum*, 18 (5), 857-863.
- Crabtree, B. & Miller, W.L. (1992). *Doing Qualitative Research*. California: Sage Publications, California.
- Crowley, V. (1998). *Thorsons Principles of Jungian Spirituality*. London: Thorsons.
- Denzin, N.K. & Lincoln, Y.S. (1994). Introduction Entering the Field of Qualitative Research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 1-17). California: Sage Publications.
- Demske, J.M. (1970). *Being, Man, & Death*. Kentucky: The University Press of Kentucky.
- Derrickson, B.S. (1996). The spiritual work of the dying: A framework and case studies. *The Hospice Journal*, 11(2), 11-30.
- Doyle, D. (1992). Have we looked beyond the physical and psychosocial? *Journal of Pain and Symptom Management* 7 (5), 302-311.
- Duffy, M.E. (1992). A theoretical and empirical review of the concept of suffering. In P.L. Starck & J.P. McGovern (Eds.), *The hidden dimension of illness: Human suffering* (pp. 291-303). New York: National League for Nursing Press.
- Dunphy, R. (1987). Helping persons with AIDS find meaning and hope. *Health Progress*, 58-63

- Eden, O.B., Black, I., MacKinlay, G.A., & Emery A.E. (1994). Communication with parents of children with cancer. *Palliative Medicine*, 8:105-114.
- Eissler, K.R. (1955). *The Psychiatrist and the Dying Patient*. New York: International Universities Press, Inc.
- Erikson, E.H, (1980). *Identity and the Life Cycle*. New York: W.W. Norton.
- Erikson, E.H, *The Life Cycle Completed*, W.W. Norton, New York, 1982.
- The Expert Working Group on Integrated Palliative Care for Persons with AIDS (1989). *Caring Together*, Ottawa: Health and Welfare Canada.
- Feifel, H. (1990). Psychology and death meaningful rediscovery. *American Psychologist*, 45 (4), 537-543.
- Ferrell, B.R. (1993). To know suffering. *Oncology Nursing Forum*, 20 (10), 1471-1477.
- Ferris F.D., Flannery J.S. (Eds.) (1995). Module 4 palliative care—A comprehensive guide for the care of persons with HIV disease. Ottawa: National AIDS Strategy, Health Canada.
- Field, M.J. & Cassel, C.K. (Eds.) (1997). *Approaching death Improving care at the end of life*. National Academy Press, Washington, D.C.
- Foley, K.M. (1985). The treatment of cancer pain. *New England Journal of Medicine*, 313: 84-95.
- Foley, K.M. (1989). Controversies in cancer pain. *Medical Perspectives Cancer*, 63:2257-2265.
- Frankl, V.E. (1959). *Man's search for meaning*. New York: Washington Square Press.
- Frankl, V.E. (1969). *The will to meaning foundations and applications of logotherapy*. New York: Penguin Books.
- Fulton, G.& Metress, E.K. (1995). *Perspectives on death and dying*. Boston: Jones and Bartlett Publishers, Boston.
- Gill, T.M., Geinstein A.R. (1994). A critical appraisal of the quality of quality-of-life measurements. *Journal of American Medical Association*, 272 (8), 619-626.
- Glik, D.C. (1986). Psychosocial wellness among spiritual healing participants. *Social Science and Medicine*, 22 (5), 579-586.

- Good, B.J. (1994). *Medicine, rationality and experience An anthropological perspective*. Great Britain: Cambridge University Press.
- Guba, E.G. & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N.K. Denzin & Y.S. Yvonna (Eds.) *Handbook of Qualitative Research* (pp. 105-117). California: Sage Publications.
- Guyatt, G.H. & Cook, D.J. (1994). Health status, quality of life, and the individual. *Journal of the American Medical Association*, 272 (8), 630-631.
- Hall, J. (1986). *The Jungian Experience Analysis and Individuation*. Toronto: University of Toronto Press Incorporated.
- Hamel, R.P. & Lysaught, M.T. (1994). Choosing palliative care: Do religious beliefs make a difference? *Journal of Palliative Care* 10 (3), 61-66.
- Hardy, Lee (Ed.) (1987). *The Husserlian foundations of science*. Washington, D.C.: Center for Advanced Research in Phenomenology and University Press of America, Washington, D. C.
- Heaven, C.M., & Maguire, P. (1996). Training hospice nurses to elicit patient concerns. *Journal of Advanced Nursing*, 23: 280-286.
- Heidegger, M. (1996). *Being and Time* translated by Stambaugh, J. New York: State University of New York Press.
- Herman, J. (1992). *Trauma and recovery the aftermath of violence—from domestic abuse to political terror*. New York: Basic Books.
- Hiatt, J.F. (1986). Spirituality, medicine, and healing. *Southern Medical Journal*, 79 (6), 736-743.
- Highfield, M.F. & Cason, C. (1983). Spiritual needs of patients: Are they recognized? *Cancer Nursing*, 187-192.
- Hinton, J. (1998). An assessment of open communication between people with terminal cancer, caring relatives, and others during home care. *Journal of Palliative Care*, 14 (3), 15-23.
- Hollis, J. (1993). *The middle passage From misery to meaning in midlife*. Toronto: University of Toronto Press Incorporated.
- Hollis, J. (1994). *Under Saturn's shadow The wounding and healing of men*. Toronto: University of Toronto Press Incorporated.

- Hollis, J. (1995). *Tracking the gods The place of myth in modern life*. Toronto: University of Toronto Press Incorporated.
- Hollis, J. (1996). *Swamplands of the soul New life in dismal places*. Toronto: University of Toronto Press Incorporated.
- Hollis, J. (1998). *The Eden project In search of the magical other*. Toronto: University of Toronto Press Incorporated.
- Hopwood P., Howell A., & Maguire, P. (1991). Screening for psychiatric morbidity in patients with advanced breast cancer: validation of two self-report questionnaires. *British Journal of Cancer* 64(2), 353-356.
- Hopwood P, Howell A., Maguire, P. (1991) Psychiatric morbidity in patients with advanced cancer of the breast: prevalence measured by two self-rating questionnaires. *British Journal of Cancer*, 64 (2), 349-52.
- Johanson, G. A. (1991) Symptom character and prevalence during cancer patients' last days of life. *American Journal of Hospice and Palliative Care*, 8(2), 6-8.
- Johnston, G. (1995). The WHO objectives for palliative care: To what extent are we achieving them? *Palliative Medicine*, 9:123-137.
- Jones, R. (1995). Why do qualitative research? *British Medical Journal*, 311:2.
- Kagawa-Singer, M. (1993). Redefining health: Living with cancer. *Social Science and Medicine*, 37:295-304.
- Kastenbaum, R.J. (1977). *Death, society, and human experience*. Saint Louis: The C.V. Mosby Company.
- Kastenbaum, R. (1991). *Death, society, and human experience*. New York: Merrill, 1991, 101-103.
- Kaufert, J.M., Putsch, R.W. & Lavalley, M. (1999). End-of-life decision making among aboriginal Canadians: Interpretation, mediation, and discord in the communication of "Bad News". *Journal of Palliative Care*, 15 (1) 31-38.
- Kierkegaard, S. *Either/Or* (Vol. 1). Princeton: Princeton University Press.
- Klagsbrun, S.C. (1994). Patient, family and staff suffering. *Journal of Palliative Care* 10 (2), 14-17.

- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88:251-258.
- Kubler-Ross, E. (1969). *On Death and Dying*. New York: MacMillan Publishing Co. Inc.
- Kuhl, D.R. (1994). Ethical issues near the end of life: A physician's perspective on caring for persons with AIDS. *Journal of Palliative Care*, 10 (3), 142-150.
- Kuzel, A.J. & Like, R.C. (1991). Standards of trustworthiness for qualitative studies. In Norton, P., Stewart, M., Tudiver, F., Bass, M., & Dunn, E. (Eds), *Primary Care in Primary Care Research: Traditional and Innovative Approaches* California: Sage Publications.
- Lair, G.S. (1996). *Counseling the terminally ill: Sharing the journey*. Washington, D.C.: Taylor & Francis.
- Latimer, E. (1991). Caring for seriously ill and dying patients: The philosophy and ethics. *Canadian Medical Association Journal*, 144(7): 859-864.
- Latimer, E.J. (1995). Caring for the dying in Canada. *Canadian Family Physician*, 362-365.
- Laukhuf, G. & Werner, H. (1998). Spirituality: The missing link. *Journal of Neuroscience Nursing*, 30 (1), 60-67.
- Levine, S. & O. (1982). *Who dies? An investigation of conscious living and conscious dying*. New York: Anchor Books, New York.
- Ley, D.C.H., and Corless, I. (1988). Spirituality and hospice care. *Death Studies*, 12: 101-110.
- Lukoff, D., Lu, F., & Turner, R. (1992). Toward a more culturally sensitive DSM-IV psychoreligious and psychospiritual problems. *The Journal of Nervous and Mental Disease*, 180 (11), 673-682.
- Maguire, P. (1985). Barriers to psychological care of the dying. *British Medical Journal*, 291: 1711-1713.
- Manos, N. & Christakis, J. (1985). Coping with cancer: Psychological dimensions. *Acta Psychiatr. Scand*, 72: 1-5.
- Maslow, A.H. (1968). *Toward a psychology of being*. New York: Von Nostrand Reinhold Company.

- Maslow, A.H. (1970). *Motivation and personality*. (2nd Ed.), New York: Harper & Row Publishers.
- Massie, M.J. & Holland, J.C. (1992). The cancer patient with pain: Psychiatric complications and their management. *Journal of Pain and Symptom Management*, 7 (2), 99-109.
- Mays N., Pope C. (1995). Rigour and qualitative research. *British Medical Journal*, 31: 109-12.
- McCormick, T.R. & Conley, B.J. (1995) Patients' perspectives on dying and on the care of dying patients. *Western Journal of Medicine*, 63:236-243.
- McKee, D.D. & Chappel, J.N. (1992). Spirituality and medical practice. *The Journal of Family Practice*, 352: 201-208.
- McNeely, D.A. (1987). *Touching body therapy and depth psychology*. Toronto: University of Toronto Press Incorporated.
- Mermann, Alan C. (1992). Spiritual aspects of death and dying. *The Yale Journal of Biology and Medicine*, 65: 137-142.
- Merritt, D., Fox-Grage, W., Rothouse, M., Lynn, J., Cohn, F., & Forlini, J. (1998). State initiatives in end-of-life care Policy guide for state legislators. *The Center to Improve Care of the Dying*, Washington, D.C.
- Meryn, S. Improving doctor-patient communication. (Ed.) (1998). *British Medical Journal*, 316: 1922.
- Mickley, J.R., Soeken, K. Belcher, A. (1992) Spiritual well-being, religiousness and hope among women with breast cancer, *IMAGE: Journal of Nursing Scholarship*, 24(4), 267-272.
- Miller, Alice (1994). *The drama of the gifted child The search for the true self*. New York: Basic Books.
- Miller, W.L. & Crabtree, B.F. (1994). Clinical research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 340-352). California: Sage Publications.
- Millison, M. & Dudley, J.R. (1992). Providing spiritual support: A job for all hospice professionals. *The Hospice Journal*, 8(4), 49-66.
- Mishler, E.G. (1991). *Research Interviewing*. Massachusetts: Harvard University Press.

- Mtalane, L.J.T., Uys, L.R., & Preston-Whyte, E.M. (1993). The experience of terminal illness among Zulu speaking patients and their families. *International Journal of Nursing Studies*, 30(2), 143-55.
- Moyers, B. (1993). *Healing and the Mind*. New York: Doubleday
- Novack, D., Plumer, R., Smith R., Ochitill, H., Morrow, G., & Bennett, J. (1979). Changes in physician's attitudes toward telling the cancer patient. *Journal of American Medical Association*, 241:897-900
- Nuland, S.B. (1994). *How we die Reflections on life's final chapter*. New York: Alfred A. Knopf
- Oakley, A. (1981). Interviewing women: a contradiction in terms. In Roberts, H. (Ed.) *Doing feminist research*. London: Routledge and Kegan, 30-61.
- Oken, D. (1961). What to tell cancer patients. *Journal of American Medical Association*, 175:1120-1128.
- Osborne, J.W. (1994). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychology*, 167-189.
- Padilla, G.V., Ferrell, B., Grant, M.M., & Rhiner, M., (1990). Defining the content domain of quality of life for cancer patients with pain. *Cancer Nursing*, 13(2), 108-115.
- Payne, R. (1990). Pathophysiology of cancer of pain. In K.M. Foley, et al *Advances in pain research and therapy*, (16: 13-26) New York: Raven Press, Ltd.
- Penfield, J. (1992). Pain syndromes in HIV infection. *Canadian Journal of Anesthesia*, 39(7): 724-730.
- Pivcevic, Edo (1970). *Husserl and Phenomenology*, London: Hutchinson University Library.
- Pope, C. & Mays, N. (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal*, 311: 42-5.
- Portenoy, Russell K. (1989). Cancer pain epidemiology and syndromes. *Cancer*, 63(11), 2298-2307.

- Ptacek, J.T., Eberhardt, T.L. (1996). Breaking Bad News. *Journal of American Medical Association*, 276(6), 496-502.
- Randall, F. & Downie, R. S. (1996). *Palliative Care Ethics A Good Companion*. New York: Oxford University Press.
- Reed, P.G. (1986). Death perspectives and temporal variables in terminally ill and healthy adults. *Death Studies*, 10:467-478.
- Reed, P.G. (1987). Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing and Health*, 10:335-344.
- Reed, P.G. (1991). Preferences for spiritually related nursing interventions among terminally ill and nonterminally ill hospitalized adults and well adults. *Applied Nursing Research*, 4(3), 122-128.
- Roy, D. J. (1987). The "Spiritual Need of the Dying" (Ed.). *Journal of Palliative Care*, Vol. 2(2), 3-4.
- Roy, D. J., Williams, J.R. & Dickens, B.M. (1994) *Bioethics Canada*. Ontario, Canada: Prentice Hall.
- Sackett, D.L., Haynes, R.B.& Tugwell, P. (1985). *Clinical Epidemiology A Basic Science for Clinical Medicine*, Little Brown and Company, Boston, 1985
- Sackett, D.L., Rowenberg, W.M.C., Gray, J.A.M., Haynes, R.B., & Richardson, W.S. (1996) Evidence based medicine: what it is and what it isn't. *British Medical Journal*, 312: 71-72.
- Saunders, C.M. (1978). *The Management of Terminal Disease*. London: Edward Arnold Publication.
- Saunders, C. (1988). Spiritual pain. *Journal of Palliative Care*, 4(3), 29-32.
- Schofferman J., Grody R. (1990). Pain in far-advanced AIDS. In K.M. Foley, *Advances in Pain Research and Therapy*, (16: 379-386) New York: Raven Press, Ltd.
- Schulz, R. (1978). *The Psychology of Death, Dying and Bereavement*, Massachusetts: Addison-Wesley Publishing Company.
- Schwandt, T.A. (1994). Constructivist, interpretivist approaches to human inquiry. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of Qualitative Research*, California: Sage Publications.

- Sevensky, R.L. (1979). Religion and illness: An outline of their relationship. *Southern Medical Journal*, 74(6), 745-750.
- Sevensky, R.L. (1983). The religious foundations of health care: A conceptual approach. *Journal of Medical Ethics*, 9:165-169.
- Shields, C.E.(1998). Giving patients bad news. *Primary Care*, 25(2), 381-390.
- Singh, Kathleen Dowling, (1998). *The grace in dying how we are transformed spiritually as we die*. New York: Harper Collins Publishers Inc.
- Smith, D.W. & McIntyre, R. (1982). *Husserl and intentionality*, Holland: D. Reidel Publish Company.
- Smith, D.C. (1993). Exploring the religious-spiritual needs of the dying. *Counseling and Values*, 37: 71-83.
- Spiegel, D., Bloom, J. & Yalom, I. (1981) Group support for patients with metastatic cancer. *Archives of General Psychiatry*, 38: 527-533.
- Spiegel, D. & Bloom, J.R. (1983) Group therapy and hypnosis reduce meatastatic breast carcinoma pain. *Psychosomatic Medicine*, 45(4), 333-339.
- Spiegel, D., Bloom, J.R., Kraemer, H.C., & Gottheil, E. (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *The Lancet*, 888-891
- Soros, G. (1998) *Reflections on death in America*. A speech for the Alexander Minger Fisher Lecture Series at Columbia Presbyterian Medical Center, November 30, 1994 in Project on Death in America, New York: Open Society Institute.
- Stedeford, A. (1984). Psychological aspects of the management of terminal cancer. *Comprehensive Therapy*, 10(1), 35-40.
- Strang, P. & Qvarner, H. (1990). Cancer-related pain and its influence on quality of life. *Anticancer Research*, 10:109-112.
- Strang, P. (1992). Emotional and social aspects of cancer pain *Acta Oncologica*, 31(3), 323-326
- Sykes, J.B. (1976). *The Concise Oxford Dictionary of Current English*. Oxford: Oxford University Press.

- Toombs, S.K. (1992). *The meaning of illness A phenomenological account of the different perspectives of physician and patient*. Boston: Kluwer Academic Publishers.
- Vachon, M., L.S., Kristjanson, L., & Higginsons, I. (1995). Psychosocial issues in palliative care: The patient, the family, and the process and outcome of care. *Journal of Pain and Symptom Management*, 10(2), 142-150.
- Vachon, M.L.S. (1998). Psychosocial needs of patients and families. *Journal of Palliative Care*, 14(3), 49-56.
- Valle, R.S. & Halling, S. (Eds.) (1989). *Existential—phenomenological perspectives in psychology exploring the breadth of human experience*. New York: Plenum Press.
- van der Poel, C.J. (1981). Suffering and healing: The process of growth. *Hospital Progress*, 42-47.
- van Manen, M. (1990). *Researching Lived Experience Human Science for an Action Sensitive Pedagogy*, Ontario, Canada: The Althouse Press.
- von Eckartsberg, R. (1998). Introducing existential—phenomenological psychology. In R. Valle (Ed.), *Phenomenological inquiry in psychology* (pp. 21-62). New York: Plenum Press.
- Wachterhauser, B.R. (Ed.) (1994). *Hermeneutics and Truth*. Illinois; Northwestern University Press.
- Wanzer, S.H. (1989). The physician's responsibility toward hopelessly ill patients. *The New England Journal of Medicine*, 320(13), 844-849.
- Webb, M. (1997). *The Good Death The New American Search to Reshape the End of Life*. New York: Bantam Books.
- Webster's New Collegiate Dictionary, (1981) Toronto, Ontario: Thomas Allen & Son Limited.
- Widerquist, J. & Davidhizar, R. (1994). The ministry of nursing. *Journal of Advanced Nursing*, 19: 647-652.
- Wilber, K. (1979). *No boundary: Eastern and western approaches to personal growth*. California: Center Publications.
- Wilber, K. (1983). *Eye to eye The quest for the new paradigm*. New York: Anchor Press/Doubleday.

World Health Organization. (1990). *Cancer pain relief and palliative care*. Technical report series 804. Geneva, Switzerland: World Health Organization.

Wu, Kitty K.Y. (1990-91). Family support, age, and emotional states of terminally ill cancer patients. *Omega*, 22(2), 139-151.

APPENDIX A

CRITERIA TO DEFINE VERY GOOD/EXCELLENT STUDIES

Appendix A

Criteria to Define Very Good/Excellent Studies

Descriptive Surveys

- research question and objectives clear;
- sample selection appropriate;
- response rate adequate;
- analysis faithful to the data

Qualitative Studies

- purpose of the study clearly defined in terms of the available literature;
- sample selection appropriate;
- method of data collection described in enough detail to be reproducible;
- method of data analysis described in enough detail to be reproducible.

Correlational, Quasi-experimental, Experimental Studies

- clear research question or testable hypothesis;
- recruitment method and participant characteristics appropriate;
- adequate sample size (reasonable and defensible);
- psychometric properties of instruments adequate and established for the palliative care population;
- appropriate statistical analysis.

Scientific Reviews and Meta-analyses

- clear focus;
- method for determining inclusion or exclusion of articles clearly specified;
- studies discussed in terms of scientific criteria.

APPENDIX B
LETTER OF INVITATION

Exploring Spiritual and Psychological Issues at the End of Life

**Principal Investigator: Dr. David R. Kuhl
(604) 682-2344**

Dear

I am inviting you to participate in a research project. I am a physician who, for the last 10 years, has been involved in palliative care.

The Palliative Care Program at St. Paul's Hospital began in May, 1989. Through this program, care is provided to persons with a terminal illness when cure or prolongation of life are no longer paramount. The interdisciplinary palliative care team addresses concerns of a physical, emotional and spiritual nature.

In order to enhance our ability to address concerns and issues experienced by persons with a terminal illness it is important to hear from those persons about their experience. That is the purpose of this research project. I would like to spend some time with you to talk about the experience of this illness. I will talk to you for a period of one hour once a month as long as you are willing to participate. The conversation will occur at your convenience in your home or in the place in which you are receiving care. With your permission, the conversation will be either audio and/or video taped. After the interview the conversation will be transcribed. I will review the transcripts with you and discuss the themes which might be present in a subsequent one hour interview.

The talks would occur on a monthly basis until you chose to discontinue them or until you are too sick to participate.

I will also request permission to discuss your care with your family members, to have access to your medical records and your permission to discuss your care with your physicians and nurses at St. Paul's Hospital for use in this study.

You are under no obligation to participate in this study. Your decision whether or not to participate will have no effect on the care you or your family members receive at St. Paul's Hospital. You may withdraw at anytime.

The status of your ability to participate in this study may change through the course of your illness. There may be value in observing you in place of an interview at such a time. You may consent before such a time to be observed or you may designate an individual who would make that decision for you. This person would only decide about participation in the study and would not be the person to decide about medical care.

The information you provide will be used in conjunction with information given to me by others with a terminal illness to further develop the palliative care that is provided through St. Paul's Hospital.

If you require further information please feel free to call me at 682-2344 ext. 2099. I would be pleased to discuss this with you. If you have questions about your role as a participant in research you may contact Dr. Richard Spratley, Director, Research Services, University of British Columbia. His phone number is: (604) 822-8598

Sincerely,

David R. Kuhl, M.D.

APPENDIX C
CONSENT FORM

Informed Consent Form

Exploring Spiritual and Psychological Issues at the End of Life

Principal Investigator: Dr. David R. Kuhl
Palliative Care Program
Department of Family and Community Medicine
St. Paul's Hospital
(604) 682-2344 ext. 2099 pager 4266

Background:

I understand that I am being invited to participate in this study because I have a terminal illness, either cancer or AIDS. (Persons who are intravenous drug users are excluded from this study) Dr. Kuhl will be interviewing me with regard to the impact this illness has had on me physically, emotionally and spiritually.

Purpose:

The purpose of this study is to increase the understanding of the experience of dying as it pertains to the physical, emotional and spiritual components of the human experience.

Study Procedures:

Persons will be invited to participate in this study by letter. If I agree to participate in this study I will be interviewed by Dr. David Kuhl for a period of one hour once a month as long as I am willing to participate. The conversation will be taped by audio as well as video recorders. The information from the tapes will be transcribed onto a document. Themes which occur through the course of the interview will be identified and confirmed with me.

Participants:

As a participant in this study I understand that the illness I presently am experiencing will likely be the cause of my death. While it is difficult to assess how much longer I might live, my life expectancy may range from one to twelve months. I am able and willing to have discussions about the effect of the illness on my life. I am able to speak English well.

Risks:

This study will not involve any medical procedures (e.g. blood letting). While no side effects are anticipated, I recognize that some persons may experience strong emotional reaction to some of the discussion.

Benefits:

The benefit of participation might be to recognize unresolved concerns within a time period such that they could be addressed and resolved.

Confidentiality:

Any information from this research study will be kept strictly confidential. No information will be provided to my family members, hospital staff, or others without my permission. All documents will be identified only by code number and kept in a locked filing cabinet in a locked office. I will not be identified by name in any reports of the completed study. Features which might make it possible for others to identify me will be excluded.

I may refuse to participate or I may withdraw from the study at any time without any consequences to my continuing medical care.

I understand that if I have any questions or desire further information with respect to this study, or if I experience any adverse effects, I should contact Dr. David Kuhl at (604) 682-2344 ext. 2099. If I have any concerns about my treatment or rights as a research subject I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598.

Patient Consent:

I understand the nature of this study. All of my questions at this time have been answered to my understanding.

I understand that participation in this study is entirely voluntary.

I have received a copy of this consent form for my own records.

I consent to Participate in this study.

Patient Signature	Date
-------------------	------

Witness Signature	Date
-------------------	------

Investigator's Signature	Date
--------------------------	------