

The University of Calgary

A Phenomenological Study of Caregiver Loss by Death
of a Patient, Client, or Parishioner

by

George Willard Wagner

A Thesis

Submitted to the Faculty of Graduate Studies
in partial fulfillment of the requirements for the
Degree of Master of Social Work

Faculty of Social Welfare

Calgary, Alberta

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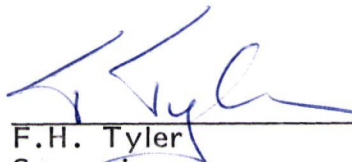
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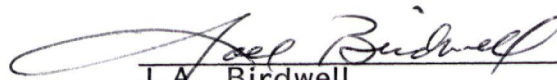
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled, "A Phenomenological Study of Caregiver Loss by Death of a Patient, Client, or Parishoner" submitted by George W. Wagner in partial fulfillment of the requirements for the degree of Master of Social Work.



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Abstract

This descriptive study examines the caregiver's experience of loss of a patient, client, or parishioner by death. The major emphasis is the various themes that have been drawn out of the transcripts presented.

Between July 2, 1987 and September 30, 1987 eleven respondents replied to the basic interview question: "What was the experience for you of losing one of your clients (parishioners, patients)? The eleven interviews produced 447 pages of verbatims ranging from 28 to 70 pages in length. The phenomenological-descriptive approach necessitates a reducing process which while reducing the number of pages of verbatim still captures the essence of the lived experience of the interviewees. Chapter five of the thesis represents those verbatims reduced to manageable transcripts. The results of the analysis of the data which are in chapter six are based on the reduced transcripts in chapter five.

Chapter two deals with a very brief history of the hospice movement. The hospice movement is the alternative movement with a rationale for suggested alternatives to the care of those who are dying. One of the key points of the hospice rationale is that the caregiver is also a significant element in the caregiving system. Attention must be paid not only to the person who is dying, but also the family unit. The third element is the caregivers in client system.

Chapter three is a brief literature review of numerous disciplines. What is noticed is the paucity of material

dealing with the caregiver as she or he continuously deals with death and the dying. On a continuum of greatest to least, the greatest research effort is directed towards the person who is dying, and the least research endeavour is paid to the caregiver and the long term effects of dealing with the issues involved in dying and ultimately death.

Chapter four describes the phenomenological-descriptive method used in gathering the data. The descriptive approach seems best suited to describe first-hand experiences caregivers experience. From data gathered in this way it would appear that all other research would be firmly grounded in the caregiver's reality.

Chapter six analyzes the data into a number of themes. While the literature notes the stress caregivers experience in dealing with death and the dying, and also suggests alternatives to cope with this type of occupational stress; the data gathered and analyzed suggests another phenomenon that occurs. It suggests in the existential encounter with death and dying a transformation can occur. A transformation in which a relationship occurs between the caregiver and the client. It is a relationship whose key ingredient is mutuality. It is a mutual relationship characterized by mutual care, caregiving and learning.

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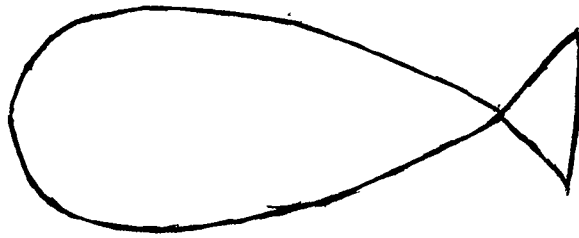
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Dedication



ἰχθυσ

ἰησοῦς χριστός θεοῦ υἱός σωτήρ

Table of Contents

Chapter I	Introduction	1
	Choosing the Parameters of the Research	2
Chapter II	The Hospice Movement	12
	Introduction	12
	Hospice Models	13
Chapter III	The Stress of Caregiving	25
	Introduction	25
	Fear of Death	25
	The Stress of the Caregivers	30
	Medical Doctors	35
	Nurses	37
	Volunteers	40
	Clergy	41
	Social Workers	43
	Occupational Therapists	46
	Teachers	46
	Suicide	48
	Helping the Professional Caregiver	49
	Categories of Help	50
Chapter IV	Methodological Approach	55
	(1) Subjectivity and Objectivity	64
	(2) Particularistic and Holistic Orientation	66
	(3) Reliability and Validity	67
	(4) Hypothesis Testing and Hypothesis Generating	68
	Application of Qualitative Method	70
	The Research Design	70
Chapter V	Synopsis of Data	74
	Val	74
	Cag	80
	Willie	86
	A Team	92
	Bettie An	96
	Joy Season	101
	D.K.	105
	Myrna	112
	Jim	117
	Sandra	128
	J.J.	134
Chapter VI	Observations and Conclusions	139
	The Theme of Relationship	143
	The Theme of Loss	150
	The Theme of Active Participation	156

	The Theme of Learning	166
	The Theme of Personal Transformation	172
	Conclusion	176
Appendix A		178
Appendix B		182
	Cover letter to participants	183
	Research procedure	184
	Research questionnaire	190
Appendix C		195
	Letter to Mr. Werner Pauls	196
	Letter to Judith Blythe	198
	Letter from Mr. Werner Pauls	199
Bibliography		200

Chapter I

Introduction

While participating in a recent seminar I observed many caregivers working in the hospice field seemed to experience a need to share some of their unresolved grief experiences. This observation prompted a brief search to see whether the literature addressed the needs of caregivers who experience the loss of a client, patient or parishioner by death. The brief literature search provided insight into the dynamics and experience of dying and dealing with death as experienced by the patient or client. It also dealt with how one can assist and work with the dying patient. It noted also the stressfulness of working in this area and the research evidence on coping mechanisms and strategies with that stress. There was, however, little mention of the personal or subjective experience of the caregiver. The question of what it meant to lose a patient, client, or parishioner by death was not addressed. Nor was the question of the effect on the caregivers loss of patient, client or parishioner by death addressed.

There were, however two recently published books which dealt with the caregiver's response to the loss of patients by death. Written from the personal or subjective point of view, they shared what death of patients meant for them and how it transformed them. They also mentioned how that change affected their working with their patients.

This observation and the resultant brief literature review validated for me the topic or area of research. The topic

would be the meaning, the lived experience, of the loss of a client, patient or parishioner by death.

Choosing the Parameters of the Research

Worden (1982), who authored Grief Counseling and Grief Therapy was the keynote speaker at the Sixth Annual Dealing with Grief Seminar in Calgary, Alberta, October 23 and 24, 1986. Sponsored by the Alberta Pastoral Care Association and the Alberta Funeral Service Association, day one consisted of an overview of loss, grief and mourning. Part of the day one program included a skills enhancement segment. Day two of the program dealt with bereaving children; complicated bereavements; and grief therapy. It again had a skills enhancement segment.

The seminar was a good overview of the topic and it provided information about the advances that occurred in the area of bereavement and grief therapy. It was observed by the author, however, during both small sharing group sessions and plenary sessions that there were a number of people who shared their grief over a recent loss by death of a patient, client or parishioner. These concerns varied from permission for a professional caregiver to grieve to open expressions of grief over a recent loss of a client, patient or parishioner. Those who shared their grief were comforted by the participants in the small groups, or when this occurred in the plenary sessions, people would come to the grieving person and provide help. One woman, whom I presumed to be a nurse, told our small

group session that through this seminar she resolved her grief over the loss of a patient that had occurred a long time before in her professional career.

This workshop experience brought into focus the occupational stress of professionals working with terminally ill people. Understandably, much of the treatment focus and current research is attentive to the patient, client or parishioner who is dying. Once death occurs there is usually a focus on the survivors and their bereavement and grief. What is noticeably absent are the unaddressed needs of the lay and professional caregiver.

This observation generated a number of questions. Where do professionals go for help when they lose a client, patient or parishioner to death? Have their respective disciplines prepared them for such losses? How do their disciplines help them now? Do the professions encourage and provide ongoing training and continuing education seminars to deal with this problem? Can this be addressed in one's formal education or can it only be dealt with as it arises in one's professional career? What is the existential reality one experiences when a client, patient, or parishioner dies? How does that experience effect the caregiver? What are the initial effects and the long term effects on caregivers?

The generation of these questions suggested an area of research. The literature was investigated in the form of a preliminary search for a thesis proposal to see if these ques-

tions had been or were being addressed.

Wentzel (1976) describes his three month stay at St. Christopher's Hospice in London. He observed, as a doctor, that only if one has found meaning and value in life can one die with dignity. He saw two axioms which characterized the caregiver's approach at St. Christopher's. The first is that dying patients need more attention not less. The second is to allow patients as much control over their life as possible. This counters the major fear of every dying patient which is the fear of dying alone. He goes on to mention that the dying can teach the living about their impending death. Finally, he noted that when a person dies, the staff gives opportunity for others in the ward to talk about it. What stands out in his otherwise excellent description is the fact that the dying can teach the living "if we are willing to listen." Implied is a shutting off process to insulate oneself from the dying patient. Also noted is the fact that the caregiver's needs are not identified or noted.

At no time does Wentzel deal with the dynamics that involve the caregiver. Kubler-Ross (1969) also comments on this avoidance process. Much, she stresses, is missed when we avoid patients. What, however, would be found?

If one is interested in human behavior, in the adaptations and defenses that human beings have to use in order to cope with such stresses, this is the place to learn about it. If they sit and listen, and repeat their visit, if the patient does not feel like talking on the first or second encounter, the patient will soon develop a feeling of confidence that there is a person who cares, who is available, who sticks around.

When they are ready to talk, they will open up and share their loneliness, sometimes with words, sometimes with little gestures or non-verbal communications. (p. 40).

Caregiver involvement as noted in this quotation implies learning a patient's adaptations and defenses.

In her later work Kubler-Ross (1975) comments on the therapist's outward display of emotions:

Display of emotion on the part of a therapist is like drugs. The right amount of medication at the right [115] time can work wonders. Too much is unhealthy and too little is tragic. (pp. 114-115)

Since her approach is interdisciplinary in nature she cautions against various disciplines maintaining their traditional roles. Ministers need to care about more than the spiritual needs and psychiatrists need to go beyond the psychic needs. Various aspects or concerns can be dealt with by whoever feels comfortable with the family or the patient. The avoidance pattern is noted and there is encouragement to overcome it. The narrow role boundaries should be avoided. There is little focus on the caregiver and his or her needs.

In the literature the focus is on the client or the client's family. Even the expressions of one's emotions must facilitate the dying patient in particular. Research continues to revolve around the patient and his or her family. Carolyn Cook Gotay in 1984 assessed problems, coping mechanisms and problem resolution in one hundred twelve individuals she investigated. There were two groups. Patients were either in an early stage of cervical cancer or precancer or in the advanced

stage of breast or gynecological cancer. Their respective mates were also part of the investigation. The results indicated more similarities than differences between the two groups. The similarity was the high amount of stress in both groups, not much change in coping mechanisms and above all little reduction of stress in the advanced group. The investigation was not expanded to include the patient's caregiver.

Our Western society is characterized by market capitalism. Goods and services become primary. In many ways the patient is a commodity that consumes services. The focus becomes one of serving the needs of the client. Services for the medical patient as consumer became primary. The intent is to facilitate an easy death. The caregiver is expected to be proficient in service delivery. Becker's (1973) The Denial of Death deals with the most basic of human terrors -- his or her death. He sees the fear of death as universal:

It haunts the human animal like nothing else; it is a mainspring of human activity -- activity designed largely to avoid the fatality of death to overcome it by denying in some way that it is the final destiny for man. (p. ix).

Dempsey (1975) states death is interdicted because the dominant ideology, of our Western progress oriented society, is that "life must be happy at all times." (p. 15).

Who, then, takes care of the caregiver when he or she loses a patient, client, or parishioner? What is the effect of this experience on the professional caregiver? What does the professional caregiver do to cope with the anxiety and the

threat of death? What occurs that enables the caregiver to transcend these fears and problems and enables him or her to respond effectively with client, patient, or parishioner facing eminent death?

Sol Goldstein (1986) in his book Michael's Ship, focuses on a young boy struggling with cancer and the feelings associated with that event, its treatment and its effect on his life. Goldstein goes on: "As Michael's psychiatrist and friend, I knew about his feelings and witnessed his struggle." (p. 11). Here was a piece of literature which could be characterized as very subjective or personal in nature. Goldstein shares through the medium of the printed page what transpired between he and Michael. He knew he broke a cardinal rule that medical people must not treat the patient's family. In his psychiatric training that rule was extended to include friends and acquaintances. At risk is the friendship and/or the success of the therapy. The success of the therapy, of course, is more important. Yet Michael's parents refused to consider any referral. Dr. Goldstein shares that decision process with us. He writes:

The late William Menninger was one of my favourite teachers. He exerted a profound influence on my life and my way of thinking. Though Menninger had been dead almost five years when Michael's father came to me, he was very much alive in my mind that evening....In a real way he helped me, for I recall the occasion when he said, "Sol, always remember your personal evolution. You were born a human being, then you became a physician, and now you are becoming a psychiatrist. When you deal with people and their emotional turmoil, first be the human being, then use your medical knowledge, and only at that time will you be a good psychiatrist." Now, I concluded, was the time

to be the human being. (Ibid., p. 31)

In a profound way Dr. Goldstein has taken us into his experience with Michael. How else can we understand what the caregiver experiences until finally he or she shares that event with us. In sharing the event we may learn how the caregiver sustains himself or herself and we may get some insight about the ingredients of a good and effective therapeutic interchange and intervention. What did Goldstein learn?

I think of how many people in our world look at what is wrong and what is lacking. We complain of what we do not have, of how we have been cheated. We fear death yet we do not live life. Michael taught me this: death is not to be feared; life is to be lived. I hope that my telling of his story might in some way similarly influence you and that you too may learn from Michael, as I did. (pp. 163-164)

Hatfield and Hatfield (1985) note also the element of the personal in dealing with death. They note:

We could provide better terminal care by trying to come to grips with death personally. (p. 78)

They note elsewhere: "I find that by helping, in the process I help myself." (Ibid., p. 88) There is even the element of the personal, the human in the practise of medicine. They close their book with the following:

Practising medicine is still, and always will be, human beings relating to human beings. In that, it's no different that anything else. Life is marvellously rewarding if you let it be; if you realize you're not the only one writing the script. (p. 141)

In order to investigate the caregiver's experience of loss through death of a patient, client or parishioner it is surely necessary to enter their subjective and experiential reality.

What is that experience? What meaning does the event or events hold for them? As we become familiar with the experience what can we learn that may assist the caregiver in coming to terms with the event and becoming more effective therapeutically in working with the terminally ill? A sample from various disciplines of individual caregivers suggested itself for examination. How would that experience be for a social worker or hospice program director? What is the experience of loss for a chaplain, a parish clergyperson, a registered nursing assistant, a nursing supervisor or the volunteer? Since there is very little literature on occupational stress as experienced by the caregiver related to work with the terminally ill a research project that focused on the subjective meaning of these experiences seemed to represent a worthwhile contribution. This data would help in delineating the parameters of a problem for future investigation.

This seemed to imply a review section on the emergence of the contemporary hospice movement as an alternative to the traditional patterns of dealing with the dying and death. It uses alternative methods of care which tend to be passive or palliative in nature and increases the focus of care. Not only the dying patient but family becomes the focus of care. In that context the concerns of the caregivers are also noted and dealt with and thus represents a literature that made this project sensitive to the kind of emerging themes and concepts that might be expected to arise from a study of caregiver

losses. Chapter two outlines the development of this movement.

Chapter three gathers information experiential from the literature. Here the intent is to provide a background that is attentive to the caregivers experience of the loss of a patient, client or parishioner through death. Preliminary attention is on first-hand lived-experiences of caregivers sharing their experience of loss by death. It will also focus on problems that caregivers experience and how they have dealt with those concerns.

Chapter four outlines the methodology used in obtaining data. It will be suggested that the open-ended single question interview best facilitates the gathering of phenomenological data. Second, since the data is personal or subjective in nature, the rationale for the use of the phenomenological method is outlined as a legitimate scientific endeavour. This theoretical method facilitates objectivity in the use of the subjective data.

Chapter five is a synopsis of the data. The verbatim transcripts range anywhere from twenty-nine to sixty pages. To include the eleven transcripts verbatim would produce a thesis of unmanageable length. Each transcript will be abbreviated into a synopsis. Each synopsis shall try to capture the essence of each interview. By essence is meant the predominant themes, reactions and comments of each co-researcher. Co-researcher indicates not only the active participation of each interviewee in the direction that the research proceeded, but

also the process of insight, growth, reformulization or conceptualization the interviewer might experience when dealing with the content of the event.

In chapter six, the last chapter, observations and conclusions will be presented. A number of themes that stand out in the transcripts will be outlined. We shall also see that the dominant mode of educating caregivers and their culturally acceptable practise raises some issues and concerns. The last portion of the chapter will deal with conclusions derived from the themes.

Chapter II

The Hospice Movement

Introduction

Professionalism can be characterized by a number of traits or characteristics. Professionalism characteristically takes on the qualities of being objective, assessment oriented, prescription giving, and a professional distance or manner maintained. In medicine skills and technology are used aggressively to maintain and prolong life. This curative ideology and the professional stance one has to maintain is becoming more unacceptable. People wish to have a good death which means dying with the least amount of pain surrounded by one's friends and relatives. This re-orientation to dying and death derives its impetus from the long standing tradition of the hospice. It is the hospice movement which provides a philosophical foundation on which to build this study. This chapter will look at the hospice movement and the suggested hospice models as they provide assumptions and a rationale that address the concerns about death and dying. It also gives guidance and impetus to the direction current research is going.

There is a long tradition in the western world, going back to the Crusades, of providing special places for those in need of provisions, shelter and special care. The service may be for pilgrims and the faithful, for the sick and maimed or for those with incurable diseases. By the end of the nineteenth century a wide range of hospices had been founded by charitable organizations associated with the Christian religion.

A new, modern movement attentive to caring about those facing death has emerged in recent years. During the last two decades this hospice movement has been revitalized in caring for a special group -- those with terminal illness. It began with the initiative of Dr. Cicely Saunders in opening St. Christopher's on the outskirts of London in 1967. Later, in 1971, the movement spread to the United States with the opening of Hospice Connecticut. Later, the hospice movement came to Montreal with the opening of a Palliative Care Unit at the Royal Victoria Hospital. By 1981 the Joint Commission on Accreditation of Hospitals identified over eight hundred hospice programs in operation or being developed in Britain, United States, Australia and other industrialized nations. These emerging hospice programs differ from hospitals in three ways. First, the patient and family are considered the unit of care, while active hospital treatment focuses on the individual. Second, the focus is on a multidisciplinary team attentive to the physical, psychological, social and spiritual need of the patient. Third, while pain is controlled, no heroic attempts are made to "cure" the patient. Active treatment becomes palliative care.

Hospice Models

While most hospice care for the terminally ill is either in-patient or at home, other models are frequently recommended including extension of hospital and nursing homes. As a rule in-patient care is guided by a policy, organization and struc-

ture which will distinguish between hospital and hospice care.

Butterfield-Pigard and Magno (1982) note:

Hospitals and extended-care facilities cannot simply cordon off a wing, rename it "the hospice" and include hospice work as just one of any number of clinical rotations for doctors and nurses. (p. 1259)

It appears hospital based programs are more prevalent in Canada. There are two primary reasons for this trend. The first is cost. Not much hard evidence is available to indicate that free standing hospices are cost effective; however, preliminary evidence shows that the hospice program is cost effective in a few places in the United States where an experimental program has been initiated. Second, there is the problem of third party reimbursement. Primary funding sources do not wish to consider this model as a viable medical option. An alternative model which is a hospital-based palliative care unit seems to work well in the Canadian scene. In the United States the trend has been to use a visitation based out-patient program for as long as possible before the patient is brought to an in-hospital hospice program. Sweetser's (1979) findings from the Royal Victoria Hospital in Montreal indicates a palliative care unit can be successfully incorporated into a hospital. The palliative care unit can utilize radiation therapy from the hospital for pain management as well as provide a wider spectrum of care utilizing hospital resources. It has been noted that having both units together improved both service areas. A comparable program to the Royal Victoria Hospital is St. Luke's in New York. It has successful programs

in the area of in-patient management, home care, clinical treatment, bereavement counselling and single consultation with attending physician. Coale (1979) states that it is cost effective to have an active treatment hospital offer palliative care. It is also cost effective in time and money to share resources. Slivkin (1976-77) states that another alternative to a palliative care unit is the Psychiatric Day Hospital. The advantage of this modality is the various forms of psychotherapy that can be made available to the terminally ill. Longo and Darr (1978) indicates those hospitals which have a palliative care unit or a hospice program need to emphasize the team approach to the problem plus weekly team meetings to exchange information and formulate therapeutic plans.

Besides the variation in hospice models other components or aspects have been suggested. Staff in-service education (Johnson and Smith, 1981) is also needed in a hospital-based program. A psychological consultant can be retained on an hourly basis to help staff deal with stress. Also an intra-hospital referral team or hospice liaison nurse may be used to solve communication problems between the various programs in the hospital that offers a hospice program. Nurses and social workers (Breindel and Boyle, 1979) can be used for in-house training, education and counselling for out-patients and their families. Adkins (1984) suggests the use of hospice programs for terminally ill children. Parents would be primary caregivers. Another advantage would be the company of brothers, sister, friends, pets and relatives. Lister and Ward, (1985)

describe a hospice that provided a training program to train youth hospice volunteers. The aim was to make these people available to peers that were grieving.

The recent emergence of the hospice movement for care of the terminally ill has brought into focus some important policy and program issues. The most basic is that of funding. Another is the use of drugs, heroin in particular, to relieve the pain so characteristic of many terminal illnesses. The case for euthanasia is an extremely controversial issue. However, the most basic issue is the dominant model of medical practice and the insistence that medicine must attempt to overcome the illness. This active intervention is clearly in conflict with the finality of terminal illness and death. Smyser (1982) quotes a nurse at St. Joseph's Hospital (London) who stated this dilemma very clearly:

... all too many terminal patients are allowed or made to endure avoidable, useless (sometimes constant) pain, nausea and vomiting, constipation, personal indignity, hospitalization, surgery, chemotherapy, injections, and harnessing to tubes and other disabling impediments.

She commented: "Torture is alive and well in the Western world." (p. 1261)

A further issue about care for the terminally ill is the inappropriate training where the focus is always on treatment intended to cure. Thus very little professional training is attentive to the inevitability of death for the terminally ill. The conflict between active treatment model and palliative care model brings about enormous stress and burnout on the part of those involved in caring for the terminally ill. Randolph

(1982) quotes an American Senator in introducing amendments to Medicare legislation stated:

... I have come to realize that those home health care professionals, who acted and reacted to their jobs and responsibilities for their patient in what appeared to be a cold and unfeeling manner, very probably did not do so because they felt no compassion or because they were uncaring. They were simply, and regrettably untrained in the unique care required by the terminally ill, and they were unprepared by their professional training to address and cope with their own stress -- stress born from intimate daily contact with people who were dying. (p. 1250).

The range of skills and competences required to practice within this hospice movement are exceedingly complex. A different approach to training seems to be required. The stress of caring for the terminally ill can be enormous. Death is seldom dignified or beautiful. We are confronted with our own mortality while trying to care for others. Our culture hides death and its finality by a cloak of institutional mystery. The structure of our society precludes the possibility of a spouse, son, daughter or friend being closely involved as a caregiver. These trends will likely continue. Even within the hospice movement with its emphasis on the family as a unit there is very little bereavement counselling. Klagsburn (1982) identifies four issues of particular concern when dealing with the dying. First, staffing of hospice services is a major area of concern. Second, the professional approach required is passive rather than interventionist. This contradicts most professional training. Control of pain rather than cure is the treatment objective. Third, the movement has not been able to recognize the family unit as the focus of care as much as the

terminally ill patient although the intent is there. Fourth, since death is an existential reality the spiritual needs of the family in coping with the inevitability of mortality cannot be ignored. It is this global, holistic approach to caring for the terminally ill that presents a unique and special problem in staffing.

Within the hospice movement there is a recognition that the spiritual, philosophical, existential domain is much more important than in other areas of the human services. Terminal illness is obviously very stressful for the patient and the caregiver. The goal as Klagsburn (1982) sees it is:

making a moment of fear into a more meaningful experience, presenting a patient and the family with an opportunity to provide a feeling of meaningfulness, historical, continuity, and even possibly a future goal at the end of life is a very special gift that only a properly trained and knowledgeable religious and spiritual figure can offer. (p. 1265.).

Professional training for palliative care is only now receiving attention. Students in the various medical disciplines need to be encouraged to contemplate their own inevitable death and have some understanding of how they might cope with it. This helps all health staff so trained understand that the primary task of a person facing death is to give meaning to their life as they come to terms with their death. A process of resolution and closure must be facilitated and staff must be open to this process.

Schowalter (1986) documents the growth in the literature of thanatology which is the scientific study of death. He notes the changes in the training and response of medical doctors in

particular. The taboo topic of death is now part of the professional vocabulary. He notes also that research is underway on a broad range of topics. While technology is still dominant there is a rising discourse and dialogue on the part of the professional as well as citizen community about the limits to the use of advanced technology.

Ultimately the hospice movement has a rationale of assuring everyone can face the inevitability of death as a personal experience of care and completion. This requires us to overcome the technological imperative and accept that death is a natural part of life and this process must be internalized within our own existential reality. Corbet and Hai (1979) quote Dempsey:

Man needs a sense of closure on his life. If obsession over "staying alive" by all means supplants the deeper meaning of life, man can never experience the transcendence that guides the spiritual side of his nature. It is only when we accept the inevitability of death that we attain meaning and balance in our lives. In performing miracles on the dying ... modern medicine is depriving man of a natural vision of death. And it is this vision that adds meaning to a life that is more than mere biological existence. (p. 39).

Within the rationale of the hospice movement drugs are administered to control pain rather than to overwhelm and confuse. Psychological and spiritual death need not precede physical death. With the focus on the patient and family, all intervention, including medical-technology, becomes holistic and integrative. This humanistic process is a basic hospice principle. The impact of the movement can be observed in hospitals, nursing home and home care programs. Increasingly there

is recognition of a holistic multi-disciplinary practice that is attentive to: the total patient needs, increased patient autonomy, open dialogue about impending death, role blurring of caregiver, a focus on the family unit and integration of facility, caregivers and community.

After nearly twenty years of research some generalizations can be made. The hospice approach or model is profoundly multi-disciplinary. It is grounded in modern ideas of communication dialogue and openness. It leads in giving recognition to the need for support and caring at both a professional and personal level. It gives recognition of the basic need for nourishment renewal and replenishment on the part of staff. The movement has also given leadership in recognition of the importance of the physical environment for both patient and staff; one in which all the participants can experience a sense of being welcome and being wanted.

Western society is a death denying culture: only recently, as part of the hospice movement have we been able to talk about death. Elizabeth Kubler-Ross (1969, 1974) has been instrumental in freeing us to undertake this dialogue. In a review article Schowalter (1986) documents the growth of the literature on thanatology in the last twenty years. He notes doctors almost never talked about terminally ill patients twenty years ago. Death, now is no longer a taboo topic. There are numerous areas of research underway including the costs and consequences of dying and death on the family.

The purpose of the hospice movement is to make dying a personal experience of care and comfort. Buckingham (1982-83) suggests:

Hospice is a symbol of the revolt against excessive specialization. It represents a return to humanistic medicine, to care within the patient's community, to family-centered care and the view of the patient as a person. (p.160).

As we examine the hospice movement we can suggest four general areas. First of all there are suggested models; second, there are specific issues; third, there are special skills and competencies. Fourth, there is the area that deals with learning and education.

The literature recognizes the correlation between death anxiety and the caregiver's proficiency in dealing with terminal clients. If death anxiety does interfere with professional ability it must be recognized and ameliorated. DaSilva and Schork (1984-85) indicate that there are significant differences between males and females in their perception of death. Females recall open talk about death about twice as often as males. Twice as many males as opposed to females remember such talk as painful or difficult. A larger portion of males to females reported remembering no talk about death. The sample was also broken down into Christian and non-Christian. The above results followed the same pattern for the Christian group. Religion played a bigger role for women than men again at a two to one ratio. Over half of the sample believed in life after death; more than a tenth were convinced there was no life after death. The difference between female and male was

in a ratio of two to one.

DaSilva and Schork's findings indicate that there is significant gender differences in attitudes about death. Remedial action would have to take these findings into account. Educational endeavours aimed at a male population would need to raise consciousness about death and to be more open to the topic.

A model that is relevant to death education is the development concepts of Erikson (1963). He postulates that the eighth and last stage of a person's life involves ego integrity versus despair. In a study investigating institutionalization of older adults, Goebel and Boeck (1987) noted those institutionalized who had less ego integrity had a greater fear of death than those living independently. High ego integrity did not differ in fear of death as a function of type of residence. This correlates with the finding that institutionalization had no bearing on the concept of fear of death. Rather it was the ego integrity level one was at. Low ego integrity was exacerbated by institutional experience.

Dickinson, Somner and Durand (1987) notes that the majority of medical schools have programs relating to death education. In the U.S. ninety-six per cent of medical schools, ninety-five per cent of nursing schools and sixty-eight per cent of the pharmacy schools offered death education programs. Medical schools (eighty-three per cent) and nursing schools (eighty per cent) integrated their death education programs in

other courses. It is suggested that when students actually face terminally ill clients this might be the best time to address their own anxieties about death. Morgan (1987) also describes an inter-disciplinary program of death education for medical students. This approach looks at the problem from different points of view. The learner then must do the integration in order to see the relationships among the various points of view.

The hospice movement is based on a number of assumptions and principles. See Appendix A for a detailed description. Some of those assumptions are: (1) issues are complex and involve psychological, legal, social, spiritual, economic and inter-personal topics; (2) the unit of involvement goes beyond the patient to include the family and significant others; (3) traditional professional boundaries must be expanded; (4) the issue of isolation must be addressed; (5) health care services must be highly coordinated; and (6) the environment must be conducive to the patient's well being.

Patient oriented assumptions include: (1) an aggressive curative orientation is inappropriate; (2) symptoms can be controlled; (3) needs change over time; (4) the best care involves maintaining the patient's life-style and philosophy of life; (5) patients are involved in the decision process; and (6) the greatest fear is the fear of dying alone.

Staff oriented assumptions include (1) there is a growing body of knowledge on symptom control; (2) emotional investment occurs in good terminal care; and (3) emotional commitment will

result in emotional exhaustion.

These assumptions and principles become the rationale and impetus to pursue expanded and alternative research which emphasizes the personal humanistic element in treating the dying patient and the family unit. More importantly, this perspective views the caregiver as important and therefore worthy of the research endeavour.

Chapter III

The Stress of Caregiving

Introduction

Work with the terminally ill is exceptionally stressful. Therefore somewhat special coping strategies are required. The alternative is inevitable burnout. Under the section entitled "Fear of Death" some general information on stress is provided. This is followed by brief comments on how fear of death is manifested in the young, middle aged and older populations. Next is an overview of the stress experienced by caregivers as an occupational group. A review of the literature follows with particular attention to occupational stress and fear of death among specific groups of caregivers; namely medical doctors, nurses, volunteers, clergy, social workers, occupational therapists and teachers. A brief reference to suicide is included since this can be the most profound loss a caregiver can experience.

The final section will look at some alternatives approaches to dealing with stress caused by the fear of death and dying.

The Fear of Death

In western culture the fear of death is quite stressful. That stress is exacerbated when it is met in ones occupation. But before we examine that occupational stress we must see how stress manifests itself.

Tache (1986) indicates there is a direct correlation be-

tween sickness and stress. Stress managed improperly manifests itself in disease. Stress patterns can be changed by attitudinal changes. This involves the "general adaptation syndrome" as discovered by Hans Selye (1986). The syndrome operates in a sequential pattern. First, the stressor initiates an alarm reaction. Resistance to disease falls below normal. If defensive mechanisms (in animals) are put into action, resistance to disease increases and remain above normal. The second stage is resistance. This is the heightened level of preparedness to the stressor. The final stage is exhaustion. Resistance is lower than normal. This pattern when invoked shortens the life span. This same pattern occurs in humans. What is damaging to humans is that this life threatening response may be elicited by non-life threatening situations. Life span would be shortened by stressor's which in reality do not threaten life. Thus one must learn to control the general adaptation syndrome so that it is evoked appropriately. Selye (1986) links severe sustained emotional stress (inappropriate general stress syndrome response) and cancer.

La Greca (1985) studied stress and survivorship. Stress can adversely affect the central nervous system (CNS), the cardiovascular system and the immune system. Working in high stress occupations results in higher cardiovascular disorders when compared to the general population. He notes that heavy smokers who cope well with stress do not develop lung cancer. He speculates that poor handling of stress in AIDS virus car-

riers may activate the syndrome.

He investigated six psycho-social factors that influence and induce stress. They are: (1) childhood experience, (2) personality hardiness, (3) expectations of stress, (4) compartmentalization of stress, (5) social support networks, and (6) general environment. He discovered that early childhood conflicts increase one's chances of developing cancer later on in adult life. The loss of significant others increases the chances of developing cancer. Developmentally, a poor coping style may take longer to develop into an effective coping style. While there are some positive effects on stress (e.g. challenges to increase coping strategies or adaptations to stress) one can increase survivorship by realizing that life is inherently stressful. The flight syndrome of the North American culture tends to cover or avoid the inherent stressfulness of life.

La Greca then lists nine stress reducing strategies. They are: (1) learning to prioritize commitments, (2) stress avoidance strategies, (3) sufficient rest and recreation, (4) exercise, (5) expanding interpersonal networks, (6) proper diet, (7) relaxation techniques, (8) biofeedback, and (9) hypnosis.

Bernardo (1985) confirms La Greca's finding that social relationships and networks are life-enhancing and contribute to longevity. Older people who lose a life spouse are susceptible to the "Broken heart syndrome." There is a greater risk for the surviving spouse to die within the first year. This risk

is higher for males than females. The cultural component known as the Protestant Work Ethic is also significant. It teaches us how to work hard but not how to relax properly.

When it comes to the fear of death and dying we have some tentative indicators of that process from the literature. Reeves (1971) studied parishioners who had children with cystic fibrosis. Clergy can experience much stress because the parents may indicate the child doesn't know the prognosis of the disease. However, when the clergy engage the patient, the child might be fully aware of the prognosis. What was noted was that children are very open and up front in their feelings about the disease. It was also noted there was less fear of death in children and adolescents in comparison to the adult population.

Florian and Har-Evens (1983-84) studied a sample of two hundred and twenty-five high school students fear of death. The results suggested young women fear loss of identity and self-annihilation while young men are concerned about consequences to family and friends and punishment in the hereafter. Religious beliefs clearly influence death fear. Those who internalize their beliefs often find comfort.

Kuiken and Madison (1987-88) discovered from a sample of young adults that contemplation of one's mortality apparently causes reformulation of personal goals and commitments. Apparently, there is a tendency to withdraw from commitments and re-evaluate life goals. This suggests that for this age group

there is a greater readiness for self-exploration.

Weisman and Worden (1976-77) describe what they call the "existential plight" cancer patients experience. This is a period approximately one hundred days in length that begins when the cancer diagnosis is positively verified. It is a period of high emotional stress. People who exhibit this pattern were also noted to have patterns of regret about the past, were pessimistic, came from multi-problem families and had marital problems.

Kasterbaum (1978) while not dealing with the fear of dying in an older population lists seven myths which people hold which supposedly indicate that the old have no fear of death.

They are:

- (1) old people are "ready" and "long" for death;
- (2) death is "natural" and "timely" for the old person;
- (3) it is inappropriate to extend life because of the "indignity" that may result or it is not "cost-effective";
- (4) The "social loss" of an old person is minimal and is not a factor to be taken seriously;
- (5) memorializations and rituals are not important, they may prolong morbidity;
- (6) little can be done to extend the life of the sick;
- (7) limited social and medical resources should be given to the young who have much to live for.

Lockwood (1978) suggest a concept of dying that involves a

process and a continuum. This enables one to see death as part of life. Stage one, represented by an upward curve, covers birth to adolescence. Stage two, is a plateau curve representing young adulthood to adulthood. Stage three, with a downward curve represents adulthood to death. The second curve represents "inner-growth." It almost parallels stage one, however in stage two and three it moves upward. This would represent a "living patient in the process of dying" (p. 83). This concept or model would counter a patient's fear of rejection, suffering and isolation when death occurs.

Momeyer (1985-86) writing from the existential point of view suggests that the fear of death is natural for it is part of our being. It is an ontological component. He differentiates fear of death and denial of death. Fear of death is a normal part of life; it is part of the human condition. Failure to cope with this fear may lead to denial of death. When this occurs how we deal with the dying and death may be less than satisfactory.

The Stress of the Caregivers

This section will look at the stress caregivers experience when they work with death and the dying. A brief summary of the literature is provided to see what has been studied and the findings contained in the literature pertaining to the topic. Finally an overview of occupational stress is provided.

Hatfield et al (1983-84) notes that attitudes effect care and treatment. The reality of the inevitability of the care-

givers own death is a source of stress a caregiver experiences. Unusual openness and honesty are needed to establish meaningful relationships between caregivers and patient.

Aday (1984-85) when correlating religious faith and death anxiety found a significant inverse relationship. The results of his study indicate that belief in afterlife is a function of religion and not fear of death. The variable of church attendance correlated with death anxiety. Those actively and regularly participating in the religious life had less anxiety about death. It was noted also that women had a higher degree of death anxiety.

Mor and Laliberte (1984) noted that burnout among hospice staff wasn't higher than other areas examined. However a higher average measure of burnout was noted among employees with higher educational levels, long tenure, and full time status. Paid staff in free-standing hospices experienced a significantly lower rate of burnout and also reported a greater sense of accomplishment than in other forms of hospices.

Lamers (1986) draws attention to the surrogate caregiver bereavement phenomenon. Friends and relatives not closely involved or gradually withdrawing from the dying patient abandon the dying person. Often the caregiver becomes over-involved. When the patient dies the surrogate caregiver exhibits grief patterns normally found in family members. Over-involvement may also occur with the survivors (Arnold, 1983) or when the patient is a child.

Barton (1977) notes the following list of feelings a caregiver might exhibit at the death of their patient:

Confusion, grief, helplessness, fear, anger, draining, loneliness, inadequacy, ambivalence, nameless feelings, intimacy, love, pity, needing appreciation, guilt, increased commitment, entrapment, needing release, superiority, lacking knowledge, intrusiveness, threatening, disintegration, wanting the person to live, wanting the person to die, protectiveness, abandonment, avoidance, alienation, lacking authenticity, intolerance, distance, vulnerability. (p. 72).

While these feelings may be noted in any caregiving setting they appear to exhibit a special type of intensity in the context of death. Because of the intensity, defensive maneuvers may result. Proximity to the dying elicit another set of feelings. They are often "nameless." Barton defines these as "feelings which are closely related to the subjective experience of the personal confrontation with death." (p. 74). These feelings are: a sense of fleetingness, transience, futility and estrangement. They may be experienced as fragmentation, disintegration, coming apart or not being whole. This basic constellation has been referred to as death awareness. This is the issue that the patient must resolve or is resolving. It is also evoked in the caregiver who is now confronted with his or her own mortality. If this is not resolved in the caregiver Lifton's concept "psychic numbing" may occur as a counter-measure to the stress.

If this process is not resolved in the caregiver, Barton notes that avoidance behaviour may occur. It may vary from actual physical distancing to emotional distancing via routin-

ized physical caregiving. The caregiver may choose the cognitive-technical rather than the emotional-experiential modality. Appropriate caregiving would imply the judicious use of both as modulated by the patient's agenda.

This unresolved stressful process may spill over into staff conflict, anger, conflict directed at team leaders, curt-ness with the patient or patient's family. Or it may be internalized as depression, fatigue, a general lack of interest in life and/or excessive acting out in social activities, alcoholism or other forms of escapism. Munley (1983) observes that the caregiver needs to know the potential sources of stress after his or her patient has died. There are four sources. First is the patient death. The second source is the deceased's family grieving. The third is intrapsychic with the people involved. The fourth is those present in or affecting their (medical) professional competencies such as co-staff, supervisors, hospital policy and other cultural and environmental factors.

The literature also suggests some solutions to the occupational stress that results from working with death and the dying. Barton (1977) has given a number of suggestions. He suggests the use of the "buddy" system. Experienced caregivers are matched or paired with the inexperienced. Thus the inexperienced may receive peer support. An alternative to pairing is a team approach to caregiving. The team approach uses team meetings to not only plan therapeutic strategies but also to

air grievances and problems. Self-awareness is also a process the caregiver can practise. The focus is on the emotions the stress produces. Finally one begins to address the concern and develop better, alternative, or stronger coping strategies.

Kasterbaum (1977) suggests that caregivers be given adequate time to form and maintain personal relationships with patients. He suggests the use of primary caregivers who would be assigned to specific patients and would be with them through their journey to the end. Kasterbaum's (1987-88) recent book review points out that in becoming sensitive to interpersonal interactions caregivers can negotiate the relational rules between themselves and their patients. This can facilitate effective communications. Being consistent in one's approach and openness to negotiate relational rules also helps enhance communication. Caregivers ought to maintain either a high or low relational intimacy being either a stranger or a friend but never an acquaintance. Patients should set the agenda for non-death and death-related issues. These techniques can enhance the communication process which may result in the patient experiencing a "good" death and facilitate caregiver mental health.

Pasnau and Hollingsworth (1977) notes that after the patient dies the process of mourning occurs in various degrees in the health care team. This needs to be recognized and permitted.

Medical Doctors

Jacobstein (1982) discovered that profession, gender, maturity and length of practise seem to account for much of the variance in attitudes towards death. Male physicians tend to inform, explain and reassure. Nurses, largely female, are more likely to explore and reflect feelings. Stress was more apparent in those thirty-three years and older given that the patient population was a group of fatally ill children.

Moore (1983-84) in an English study discovered that physicians rating of pain severity in terminal illness tend to be considerably lower than that of the family.

Kirkley-Best, Kellner and Ladue (1984-85) studied the attitudes towards stillbirth of seventy obstetricians and obstetrical residents. Most respondents felt a mother should see/hold the infant or be offered that option. This was seen as a significant attitudinal change. It was also suggested that this practise be continued because of its humanistic value.

Kane (1985-86) studied seventy-seven male physicians found an inverse relationship between repression and overt reports of death anxiety. What was significant was age, experience and death anxiety. The older a physician is the less death anxiety he exhibits. Kane also observed through this study that younger doctors were interested in the result and commented on their lack of training in this area.

Field and Howells (1986) studied medical students and their fears of dying. While not concerned about their own mor-

tality they were concerned about the patient's pain. They feared losing someone close to them. They also expressed concern over communicating with their patients.

Liberman et al (1983) examined behavioural and psychophysiological responses to patient death. The sample was twenty-five pediatric house officers. Reported reactions were similar to the loss of loved ones. Males seemed more likely to remain unaffected while with females it was the opposite. Females also tended to seek professional help to cope with death.

Eggerman and Dustin (1985-86) examined physician's attitude towards openness in communicating the prognosis of terminal illness. All felt the terminal prognosis should be shared if asked. While some felt uncomfortable with sharing the prognosis all felt the information should be given. A small group felt someone else could be delegated to share the information.

Klenow and Young (1987) in a review article concerning physician's willingness to share a terminal prognosis showed a significant shift compared to the 1950's. The shift was from a basic reticence to one of openness.

In summary we find a shift in attitudes and behaviours. Terminal prognosis information is openly shared. Problems in communication abound but the issue is recognized as a concern and is being addressed. Age and experience lessened the stress of dealing with the dying and also contribute to open communication styles. There seems to be significant differences between male and female physicians in how they deal with their

patients and how they cope.

Nurses

Four studies on attitudes were discovered in the literature review. Eakes (1985) examined nurses from nursing homes and their attitude towards their patients. Nurses with high death anxiety had significantly more negative attitudes towards the elderly. Thrush, Stewart and Paulus (1985) studied student nurses attitudes toward euthanasia. It was found that warm and permissive parental socialization significantly related to an attitude of acceptance of active euthanasia. It was also indicated that active euthanasia is acceptable so long as the respondents did not have to become actively involved in the termination of life. Active euthanasia was only acceptable when parents requested it of their physicians or when gross physical or mental deformities were involved with the newborn. Kurman (1984) studied nurses attitudes towards passive euthanasia for the severely handicapped. The results of the study were inconclusive. Nurses who had experience with passive euthanasia or had nursed a severely handicapped child were favourably inclined toward passive euthanasia. Campbell, Abernathy and Waterhouse (1983-84) in his study comparing nurses' and physicians' attitudes observed that roles rather than gender account for observed differences. Physicians tend to intellectualize their feelings and thus need minimal support. Nurses however, act as patients' comforters, patient-doctor intermediaries and doctor's assistants. The results indicated that

nurses see death as rebirth, tranquility and victory. House officers saw death negatively described as unsafe, alone, forgotten and cold. Gender did not significantly predict the nature of respondents' attitudes. When clustered the responses of house officers revolved around the theme of "one who is responsible" while the nursing group clustered around the theme of "one who cares."

Schowalter (1971) lists a number of role dilemmas pediatric nurses face. The first is the problem of discussing the prognosis with patient and family who are in constant contact with the nurse. Second, there is the professional-personal conflict. How personal does a pediatric nurse become? Young professionals often are ashamed of their grief. The third role conflict the nurse experiences is that of providing for the patient's needs and the psychosocial needs of both patient and parents. The fourth role conflict may be nurse-doctor, especially in a system heavily hierarchical in nature.

Schowalter (1975) noting the strong mutuality that develops between nurse and patient suggests some coping strategies for dealing with the doctor-nurse conflict. He suggests doctors listen to nurse's feedback and also incorporate nurses' suggestions into their treatment plan. Nurses should do self-care in their group times.

Drotar (1976-77) reiterates the point that group meetings can facilitate stress reduction. The stress of a pediatric intensive care nursery can be very intense. The nursing staff

bears the brunt of "permitting" the child to die but are also the first ones involved in comforting the family. The nurses felt inadequately trained to deal effectively with the family dynamics and the crisis of pediatric mortality. It was also observed that intensive care units can become a subculture unto themselves due to the nature of the care that is given.

Bader (1972) examining the personal aspect in the nurse-patient relationship notes that the personalization process contributes to excellence of care. A case example provides the data. A cancer patient was taught to self-monitor and self-administer part of her drug prescriptions and the staff made arrangements for her to receive her injections from another hospital. This self-care enabled the patient to visit her daughter which was the key ingredient to the "good" death she experienced. Davidson (1976) shows how this personalization helped manage a patient effectively. The patient was treated with respect and each staff person would talk with the client about his anger. His anger soon dissipated and he became quite manageable. Breuer (1976) however documents the reverse. Physician and staff were happy at the impending birth. After complications and a stillbirth physician and staff left the mother and escorted the father to the waiting room. The patient responded: "No one seemed to want to come near me. How I longed for someone to just hold my hand and be with me while I cried." (p. 759).

Bryant (1985) investigated nurses' religious faith as a

coping device. All nurses interviewed indicated their belief system was important in developing an effective coping strategy in dealing with patients dying. Two images of God predominated; one of a distant God and the other of a close imminent person. Jesus' life, death and resurrection was largely absent as the core of faith from the sample interviewed.

The literature is replete with methods for relaxation as a coping strategy to handle occupational stress. White, Gilner, Handal and Napoli (1983-84) studied groups using systematic desensitization and relaxation training. Groups receiving the above treatments showed significant reduction in death anxiety. Donovan (1979) used relaxation and guided imagery. Those whose scores indicated a paucity of coping skills benefitted from the two techniques. Babcock (1976) suggests nurses use Transactional Analysis to study the transactions between patients and nurses. They can also apply it to self-analysis. Stewart (1976) suggests relaxation and rhythmic breathing exercises. The breathing technique is the one developed forty-five years ago for delivery of babies. Cady (1976) suggests the use of journal writing and letter writing.

Volunteers

Patchner and Finn (1987-88) describe the general characteristics of volunteers. The average age was thirty-nine and predominantly female. They are Caucasian and married. A majority are Protestant and considered themselves moderately or fairly religious. Most had completed college. Reasons for

volunteering given were to be of service and programs worthy of support. Most felt their services were appreciated. Working with the dying and the bereaved seemed to be the most important reason for volunteering. Most believed in life after death and recognized the importance of grief and mourning rituals.

Chng and Ramsey (1984-85) note that the role of the volunteer is that of companion, friend, advocate and educator. Volunteers step in unhesitantly when families abandon the dying person. As advocates they may share with staff what the patient is unable to share. The volunteer must be "watched" so that "death saturation" does not occur. This is the volunteer's version of burnout. Suggested coping strategies are debriefing, relaxation techniques, limitations on time volunteers may volunteer, and change of duties.

Hayslip and Walling (1985) using a sample of volunteers studied focus of control and death anxiety. After eight weeks of training the group showed both less overt and covert fear. Fear of deaths of others rose. The group transcended its fears about the temporariness of life. However, fear over the loss of control over one's own death was heightened.

Clergy

Neale (1978) challenged Lockwood's (1978) definition of dying which implies that living and dying are on a continuum. He challenges this broad spectrum definition by stating the body can be aware of the impending physiological tragedy and

patients are aware of the fatal consequences. Second, the broad definition says nothing about hope; hope which shapes the reality of how one faces death. Third, he notes that theorist's like Erik Erickson and C.G. Jung deal significantly with the last part or stage of life. This deals with coming to terms with one's mortality. In essence impending death is the core of religion which, by nature, deals with the existential problems of life.

Lucan (1978) proposes a practise model for student clergy learning which may be used to engage the parishioner and assist in arriving at the "good" death. It revolves around the metaphor of drama. The six stages are: (1) the drama of shock: denial versus panic; (2) the drama of emotion: catharsis versus depression; (3) the drama of negotiation: bargaining versus despair; (4) the drama of cognition: realistic hope versus despair; (5) the drama of commitment: acceptance versus resignation; and (6) the drama of completion: fulfillment versus forlornness. This model recognizes the negativity of death and enables one to recognize that not all may achieve "good" death however it be defined.

Kushner (1985), famed author of When Bad Things Happen to Good People (1981), deals with the religious-ideological problem of why children get sick and die. He notes that often clergy fall into the trap of giving theological explanation rather than consolation when the tragedy of death occurs. He writes:

a person who is suffering does not want explanation, the person wants consolation. Not reasons, but reassurance. You help the person by helping that person to cry. (p. 72).

He goes on to note how children often are not afraid to die. He shares this fact because it counters caregiver burnout.

Sklar and Humeke (1987-88) addresses the issue of bereavement counselling and the church. They note the growing trend that this is being provided by sources other than the church. In his sample of clergy less than one tenth offered bereavement counselling on a one to one basis. Older clergy who often had no training in bereavement counselling strongly felt the need for bereavement groups while younger clergy who had seminary training in bereavement hesitated to initiate any programs. A possible reason for this is the exacerbation of the work load. Clergy have a tendency to task overload. Organized religious groups were encouraged to face the need for bereavement counselling.

Social Work

Pilsecker (1979) notes the role of the social worker in the health care setting. Social workers by the nature of their training are involved with patients and their family's communications skills. Social workers can address the psychosocial needs of the patient thus relieving the pressure often placed on nurses. The social worker's role is also expanded in that they may assist staff in dealing with their death anxiety concerns. The key role however, is to assist the patient with communications in order to facilitate coming to terms with

their impending death.

Tull (1975) noted three patterns of coping with the stresses of clinical social work. The first pattern identified was constricted defensiveness. Respondents were unwilling or unable to share feelings. They responded to questions asked but volunteered no further information. They inhibited positive feelings towards client and avoided the patient's family after the death of a patient. They also involved themselves with other clients immediately and intellectualized feelings. Feelings were often displaced on staff. The second pattern was active struggling. Struggling with the issues of death and dying were obvious. Their chief concern was how to maintain the appropriate emotional distance with their clients. They recognized countertransference reactions but were unable to resolve them. They openly owned their grief reactions. The third pattern was integrated coping. They showed openness toward the issues of death and dying and were able to form appropriate relationships. They dealt with clients as persons and resolved countertransference problems. They tended to talk with admiration about their clients' growth and felt gratitude for being allowed to enter the patient's life. They perceived that their own integration enabled them to function as effective caregivers. Their philosophy of life was one of giving and taking; sadness and joy; birth and death.

Parry (1983) researched communication style. Three settings were examined. The hospice had the most open communi-

cation style reflecting the hospice principle of open communication. The hospital setting and nursing home had the least open communication.

Lui (1983) in a Canadian study of social workers attitudes towards fear of death found three patterns. Pattern one was detachment from death and dying; pattern two was the challenge of death and the dying process; and pattern three personalization of death and dying. The majority of workers exhibited pattern two. They did not deny death and grappled with the anxiety death produces. Pattern one social worker's work style was characterized by withdrawal and disengagement. The work style of patterns two and three was interventionist. When pattern one is noticed in social workers it needs to be addressed immediately with professional consultation and supervision both out of concern for the patient but also for the worker.

Moore (1984) notes the two greatest fears dying patients exhibit. They are the fears of isolation and abandonment. He notes also eight areas of social workers intervention. They are: (1) family communication patterns; (2) patient's potential for suicide; (3) alcohol abuse by patient or primary caregiver; (4) persistent anxiety; (5) care of patient's children; (6) sexuality; (7) consultations with other health care professionals; and (8) racial, cultural, and ethnic issues. Emphasized also was the complexity of the family dynamics of the patient's surviving relatives.

Lusk (1983) also notes the importance of the dying pa-

tient's family and the dynamics involved. Special attention needs to be paid to the primary family and its coping abilities. Also the physical resources need in some cases to be addressed. Caution is urged in dealing with defense mechanism. They may be the only appropriate coping mechanisms available to the patient and client.

Occupational Therapists

The discipline of occupational therapy is becoming aware of its involvement with death and dying. Like the medical profession its ideology is basically a cure perspective. It also must change its ideology and procedures of active treatment to facilitate the terminally ill. Geizhals (1975) noted that nursing students had a greater death anxiety than any grouping of occupational therapists.

Teachers

Santiago (1987) reports on teachers working with children who are terminally ill. Two observations were noted. First there was no support from professional colleagues. Second the home didn't offer the security of the hospital environment. One can be sick in a hospital. The educational goal is also changed from one of achievement (e.g. passing to the next grade) to one of overall developmental growth and fulfillment of human potential.

Carter (1987) shares her experience about Barbara, an adolescent dying of cancer. Barbara wished to be treated as a person and not as a student who was dying of cancer. When

Carter began to treat her as person she became a resource Barbara used in moments of sadness.

Pratt, Hare and Wright (1985) studied the comfort level of early childhood educators discussing the topic of death with pre-school children. Most felt it was important to discuss death with children. Only a very small portion followed through on the discussion. Teachers who had training in death and dying issues had higher levels of anxiety. Paradoxically teachers with high rates of death anxiety were most comfortable in dealing with death issues in the classroom.

Chekryn's, Degan's and Reid's (1987) research verified Santiago's (1987) findings that children terminally ill with cancer wished to be treated in a normal fashion both academically by teachers and by their peers. Teachers experienced the dilemma of what is appropriate academic achievements for the dying student. There was a dilemma noted and that was with parents. The teachers needed information about the illness but felt cultural pressure not to ask the parent. This cultural pressure sees the illness as a family matter. There was also the classroom dilemma of determining appropriate discipline. Intrapsychically, teachers faced the dilemma of how much and what kinds of emotional support should be given especially since children are very reticent about their feelings and illness. It was also noted that the school nurse was not a resource for information and support nor was there any liaison work going on between school and health care institutions.

Suicide

Two recent studies are provided in the literature. Swain and Domino (1985) noted the complex nature of attitudes towards suicide. Second, clergy attitude is significantly different than any other group. There is a strong disagreement that suicide was an acceptable act. Third, physicians often see suicide as a form of manipulation. Fourth, psychiatric nurses and aides emphasize less the intrapsychic causes than other helpers. Fifth, professionals who have personal acquaintance with suicide are more likely to accept the concept of self-destructive drive. Last of all clergy were least empathic towards people who contemplated suicide. In the second study Limbacher and Domino (1985-86) examined the attitudes of attempters, contemplators and noncontemplators of suicide. It was found that attempters and contemplators were more accepting of suicide than nonattempters. Attempters see their attempt as a serious wish to die while nonattempters see it as manipulation. Attempters would be most understanding if used as therapeutic resource. Subjects least familiar with suicide felt that attempters lost self-control or were mentally ill. Attempters saw their suicidal behaviours as serious but impulsive. This study also noted suicide was more acceptable by males than females.

Neuringer (1987) studied professional ability to recognize suicide lethality. The order from highest to lowest was as follows: (1) psychiatrists, (2) psychologists, (3) crisis interventionists, (4) physicians, (5) social workers, (6) psych-

iatric nurses, (7) counselors, and (8) clergy.

Neuringer goes on to deal with the philosophical-theoretical component in suicide. Suicide of a caregiver's client, patient or parishioner is probably the highest form of stress one can experience. Suicide is an existential paradox. It runs counter to the homeostatic survival principles underlying all biological and psychological theories of human life. Suicide does not conform to any theory of evolution which postulates the survival of the fittest. It challenges many cultural myths. The myth of harsh life circumstances is challenged by those who have overcome and not succumbed. The inheritance myth is also challenged yet suicide does run in families and is imitative in nature. Nor is the natural causes myth (e.g. weather, moon) sustained. There are higher rates of suicide around Christmas time and spring. The greatest myth that needs dispelling is that those who talk about suicide won't do it. Those who don't talk about it also attempt it. Usually there is a psychological blindness to telltale signs. To call suicide a "coward's way out" is the ultimate trivialization.

McIntosh (1985-86) contains an excellent, current comprehensive bibliography on suicide that is also annotated.

Helping the Professional Caregiver

This brief review of the literature is meant to be attentive to the existential reality of working within the hospice movement working with terminally ill people; while also accepting the inevitability of personal death. While caregivers

need to help themselves they also need to learn how to express their need for help. Epstein (1975) captures this notion well.

In learning to help the dying patient and his family we must be careful not to overlook the fact that the nurse also needs help. If the inevitability of our own deaths is not so easy to deal with, neither is the possibility that we may one day have the illness we happen to be treating. And each dying patient becomes a reminder that we too, one day will be dying. (p. 181).

The literature reviewed suggests some helpful alternatives.

Epstein (1975) notes that caregivers may need to help themselves since no formal structure may be available that addresses the caregivers needs. Caregivers will need to learn how to express that need for help and to identify their modality preference of the help they want. Epstein (p. 183) suggests categories of help:

Categories of Help

Non-Verbal	Verbal	Activities	Just being left alone
-bodily contact	-explanations	-entertainment	
-listening	-reassurances	-help with the	
-kinesthetic	-advice	dying patient	
respond with-		and/or his	
out contact		family	
(body language)		-accompany to	
		eating, walking,	
		etc.	

Munley (1983) suggests the use of informal caring groups often with members derived from one's peers. The idea is to expand your exposure to the world in order to counter the feelings of anger, guilt and despair one experiences when working with

death and the dying. Avail yourself of in-service training and continuing education courses. Strengthen ties with family, friends and those people who do not present problems. Pursue aesthetic, creative and spiritual options. Use intrapsychic techniques such as talking it out. Meditation and professional counselling are also options. Finally, there is the whole area of physical activities. Poss (1981) reminds us that conflict or anxiety over death and dying issues need not be dysfunctional. Success will lead the caregiver to become highly effective in this stressful occupation.

Religious belief is also a factor which can assist the caregiver in this stressful area. It may also help the patient. The goals arrived at with an active religious faith is first the awareness and assurance of benign supernatural force or chance. Second, religious faith can give meaning to life and death and can also make the relationship clear between life and death. Belief in an afterlife may facilitate the death process. Finally, Harper (1977) proposes the following model professional social workers can use to address the anxiety of death caregivers face. As one progresses through these stages one begins to develop adequate coping abilities and strategies. It is suggested this model could have general application to all hospice occupations.

Harper's Model

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Profes- sional Knowledge	Increas- ing Pro- fessional Knowledge	Deepening of pro- fessional knowledge	Accept- ance of profes- sional Knowledge.	Refining of Professional Knowledge
Intellec- tualiza- tion	Less In- tellec- tualiza- tion	Decreas- ing In- tellec- tualiza- tion	Normal Intellec- tualiza- tion	Refining In- tellectual Base
Anxiety	Emotional Survival.	Depres- sion.	Emotional Arrival.	Deep Compassion.
Some Un- comfort- ableness	Increas- ing Un- comfort- ableness	Decreas- ing Un- comfort- ableness	Increas- ing Com- fortable- ness	Increased Comfortable- ness
Agree- ableness	Guilt	Pain	Modera- tion	Self-realiza- tion
Withdraw- al	Frustra- tion	Mourning	Mitiga- tion	Self-Awareness
Superfi- cial Ac- ceptance	Sadness	Grieving	Accommo- dation	Self-Actual- ization
Provid- ing Tan- gible Services	Initial Emotional Involve- ment	More Emo- tional Involve- ment	Ego Mas- tery	Professional Satisfaction
Utiliza- tion of Emotional Energy On Under- standing the Set- ting.	Increas- ing Emo- tional Involve- ment	Over-I- dentifi- cation With the Patient	Coping With Loss of Relation- ship	Acceptance of Death and Loss
Familiar- izing Self With Policies and Pro- cedures	Initial Under- standing of the Magnitude of the	Explora- tion of Own Feel- ings A- bout Death	Freedom From Con- cern A- bout Own Death	Rewarding Professional Growth and Development

Area of Practice				
Working with Families Rather Than Patients	Over-Identification With the Patient's Situation	Facing Own Death	Developing Strong Ties With Dying Patients and Families.	Development Ability to Give of One's Self
		Coming to Grips With Feelings About Death	Development of Ability to Work With, On Behalf of and for the Dying Patient	Human and Professional Assessment
			Development of Professional Competence.	Constructive and Appropriate Activities
			Productivity and Accomplishments	Development of Feelings of Dignity and Self-Respect
			Healthy Interaction	Ability to Give Dignity and Self-Respect to Dying Patient. Feelings of Comfortableness in Relation to Self, Patient, Family and the Job

(pp. 30-31).

Conclusion

In this brief review of the literature it will be noted that much of the material available does not directly give information on the meaning and experience of the loss of a client, patient or parishioner by death. The literature recognizes and deals with death and dying as a notable occupational stress. There is also some suggestion in the literature on how to manage stress. Little, however, pertains to the personal or subjective meaning and experience of the event for the caregiver. Field and Howells, (1986) noted that when studying the fear of dying of medical students they feared losing someone close to them. Kuiken and Madison (1987-88) noted that when young adults contemplate one's mortality they spend time reformulating personal goals and commitments. In the section entitled "Teachers" Carter shares her experience with Barbara an adolescent dying of cancer. She describes briefly the change that occurred in her that facilitated the teacher-student relationship. Thus the literature rather than being a foundation for this study, indicates this area of study has not been covered and is worthy of being studied.

Chapter IV

Methodological Approach

The approach to data collection in this thesis is grounded in the existential, phenomenological and humanistic tradition within psychology. The emphasis is on qualitative rather than quantitative approaches to documentation.

In part this humanistic tradition arose as a reaction to the perceived limits of both the psychoanalytic and behaviourist models as well as an alternative explanatory framework to that grounded in the natural sciences. Thus the general meaning of humanistic psychology includes both the existential and phenomenological orientations which have an European background. Humanistic psychology originates in the United States.

Humanistic psychology challenges the assumption that psychology should emulate the philosophy and procedures of the natural sciences. In addition it challenges the predominant view that humans respond primarily to, or are shaped by various external or internal determining influences (Shaffer, 1978). Some however, see it not as a school or discipline but an orientation towards psychology as a whole. It respects the worth of the person; it respects different approaches and is open to new methods. Humanistic psychology examines topics not covered in other areas of psychology or unable to fit into existing theories, e.g. creativity, self-worth, self-growth, self-actualization, being, becoming, spontaneity, transcendental experience, peak experiences and courage.

Schaffer (1978) identifies five principles that underlie humanistic psychology. The first point is that humanistic psychology is strongly phenomenological or existential. Second, it seeks as its starting point conscious experience. Third, it investigates the subjective experience. Fourth, it's philosophical underpinnings come from the phenomenological philosophy of Edmund Husserl. Any phenomenon can be analysed. Fifth, it is not limited by prevailing logical positivism which does not take seriously that which cannot be precisely and consistently measured, under standardized conditions in a relative number of people. Consciousness can be examined in its own right without further explanation or analysis. Humanistic psychology claims to avoid the error of reductionism. Reductionism seeks to explain complex phenomenon reduced to some all-pervasive subcomponents such as defenses or drives; it requires the observer to break down the whole into parts.

In the existential analysis of Binswanger and Boss (Rychlak, 1973) which is also known as Daseinanalysis not only the person but the person's world is also considered. Three worlds (German: Welt) are described. The first is Eigenwelt or the self world of inner feelings. These are all the things we experience within ourselves. Umwelt (world around us) is everything, animate and inanimate, we experience. Mitwelt (mid-world) is our social world or society. All these aspects constitute our present reality. Thus man's existence constitutes intrinsic and extrinsic factors.

Humanistic psychology insists on humanity's essential wholeness and integrity. It has learned from Gestalt psychology that the whole is greater than its parts. Rather than study eyeblinks or physiological reactions larger units or concepts are studied such as the self or self-actualization. This puts the person at the center of the investigation and recognizes the active component in personality. It is not that people cannot respond to given stimuli but that they can also shape their responses. Rychlak (1979) writes:

The reader may rest assured that there is absolutely no sound evidence proving that human nature is machine-like, or that people can be covertly controlled by purely psychological means to do the bidding of some Big Brother at the master controls. Quite the reverse is true. Human beings are manipulated more through personal convictions, conformities, and perceived advantages in the hoped-for future than they are by the blind needs in the present or environmental meditations from out of the past. Although these are still powerful sources of control they are telic in nature, final-cause determinations which cast an altogether different light on what it means to be a person. (p. 128)

Howard (1986) writes that he believes it is not the past or the present that shapes human behaviour but the future as imagined by the individual.

Emphasizing the concept of self, self-actualization and the person being in charge of their life; humanistic psychology tends to avoid traditional dichotomies such as mind-body; fact-value; conscious-unconscious; inner-outer; and thoughts-feelings.

The humanistic point of view, while acknowledging limitations inherent in human existence, insists that human beings

retain an essential freedom and autonomy. Humans have the ability to actualize themselves, that is to maximize their potential. The Freudian model which implies behaviour determined by unconscious impulses or the behaviouristic model which implies responses generated by external stimuli are basically reductionistic-deterministic models. In such models behaviour is predictable. Predictability stems from Newtonian physics which is a causal model. All behaviour is determined and results in patterned behaviour. "Reductionistic models can be applied to humankind but they produce only manipulated results." (Ouden, 1979, p. 156).

Existentialism is a reaction to this deterministic idea of behaviour. It stresses the human's potential to actualize himself or herself to various levels of being and the ability to relate beyond one's present state. It was the crucible of the Nazi occupation that probably popularized the existentialist point of view. In the midst of cruelty of the Nazi regime and its brutality, humans needed to make sense out of the absurdity, contingency, anxiety and despair war can cause. Humans are by nature creatures that live by meaning. Where hope is lost, despair reigns. Existentialism reverses a historic philosophy that deals with essence. "What are humans?" or "What is it to be human?" are questions that involves our essence. Existentialism's famous maxim is that existence precedes essence. To know what it means to be human is to study people as they live their life or express their existence. It is only within

this context that "human nature" can be studied or observed. The classical example in psychology would be Viktor Frankl's (1963) concentration camp experience. Those who chose to remain alive took their rations of food while those who accepted their "fate" chose rations of cigarettes. Greening (1971) concludes:

Responsibility, involvement, and action, plus a belief that man is capable of choosing and growing: these tenets link existentialism and modern humanism. (p. 8)

As previously noted humanistic psychology stems from the three broad areas of phenomenology, existentialism and the humanistic psychological approach of American psychologists. There is a point of disagreement between existentialism and the American point of view. As Weckowicz (n.d.) notes there is a kind of "Polyannaish optimism" about the goodness of human nature as propounded by the humanistic point of view. Existentialism's concept of dread, anxiety, and absurdity point to the complexities of life and the existential situation humans can find themselves in. Maslow in the humanistic tradition postulates a hierarchy of needs which need to be fulfilled. Primary needs are food, water and shelter. Until and unless these are met, humans cannot move up the hierarchy to fulfill higher-order needs. The experience of Viktor Frankl (1963) and Eugene Heimler (1959, 1966) would contradict this hierarchical postulate.

Another point Schaffer (1978) makes is that humanistic psychology is antireductionistic in its orientation. Existen-

tialists would consider themselves radical empiricists. The unconscious, for example, is not denied. The unconscious is, however, dealt with differently. First of all, it is a concept not especially helpful or relevant since by its nature cannot directly be known. Second, the concept of unconscious can be used to deny one's autonomy and to rationalize away one's responsibility. It would be easy to "blame" the unconscious rather than oneself for one's behaviour. Finally, the concept of the unconscious would make the human model a fragmented model. Existentialism prefers the concept of the irreducible wholeness of human beings. May (1958) notes two things. The existential-humanists are against splitting beings into parts. What is called unconscious is part of the person. Being in its core is indivisible. What he rejects of the unconscious is the "cellar view." The cellar view of the unconscious is "a convenient blank check on which any causal explanation can be written or as a reservoir from which any deterministic theory can be drawn." (p. 91). The unconscious should be seen as an enlargement of the depth that personality is. Beyond the voluntarism and rationalism of personality is also the irrational which include the repressed, hostile, unacceptable urges and forgotten experiences. May (p. 91) concludes: "The symbol for this vast enlarging of the domain of the personality was the unconscious."

In their treatment of the unconscious we see the stress on the holistic aspect and redefining the concept so that existen-

tialists recognize that things can be hidden yet humans are still responsible for the depth of their personality. It would be from the unconscious that the existentialist would see the feeling of dread arise; dread of the unknown, the meaninglessness one experiences and the fear of death come forth. Barrett (1958) notes that Freudianism and Existentialism arose in the same time period in history and in the same place.

The last point that Schaffer (1978) makes is that humanistic psychology, with its strong grounding in existentialism, believes human nature can never be fully defined. Existentialism differentiates between being and becoming. This is captured in the famous phrase they use to summarize their position: existence precedes essence. A mere catalogue of human capabilities cannot capture the essence of humans. This description may not capture the fullest capacities of humans nor conversely their limitations. A more accurate picture develops as humans act and do. It is this continuous process of choosing that humans use to express themselves authentically. Authenticity is that process of becoming; of facing reality and making decisions. This is acting responsibility. This final point of view takes note of the possibilities of expanding and transcending the self. This challenges the Freudian notion that humans are just a regression-oriented and tension-reducing organism. It is oriented towards the developmental point of view, represented by Erikson (1963), Jung (1933), Gleeson (1975) and Stokes (1983), which postulates an ongoing develop-

ment until one faces death.

Purists would differentiate between the phenomenological movement and existentialism. Phenomenology in psychology stems out of the philosophical movement attributed to Edmund Husserl. Phenomenology studies any phenomenon from the first person description of an experience. It is a method of studying subjectivity. This method of analysis is used by existentialism. Husserl was Heidegger's teacher. Existentialism used phenomenological analysis in its study of motivation and personality. Thus all existentialists use phenomenology, but not all phenomenologists are existentialists (Schaffer, 1978, p. 21).

The choice of the methodology used in the research thesis is based on humanistic principles especially on the existential point of view. The existentialist emphasizes man or woman as a unique individual who is known in the reality of his or her daily life who is becoming a centered being. He or she is both free and responsible for his or her actions. He creates himself, she creates herself through courageous decisions, made in encounter with the world and in dialogue with others. In the process, he or she learns to live constructively with anxiety, to find meaning in life, and to become a moral being. The existential approach meets the criteria for a psychological point of view which sees humans as: (1) a whole and unique person; (2) finding integrity and authenticity in his or her life; (3) legitimating the meaning he or she discovers in reality; and (4) he or she is able to function as a hopeful and responsible

person.

Pass (1987) argues cogently for the use of these qualitative research methods in child health care. Health care professionals mastering technological competencies and complex technologies may find themselves decreasing the number of supportive exchanges between themselves and their pediatric clients. Thus they might find themselves applying a technology which causes a violent reaction in some clients and not in others. What is the world view of the child that would cause either a favourable or unfavourable reaction? In order to address the needs of their pediatric clients the illness and health world of the child would need to be known. This could not be discovered by investigating the professionals who are involved with the pediatric client. Ultimately the world of the pediatric client must be broached. How else can those experiences be understood?

Two concerns are expressed concerning quantitative results. First of all the information comes from predetermined stimuli (e.g. questionnaires or checklists). Secondly the results may be biased in the sense that the findings are based on adult perspectives rather than on the pediatric clients. The qualitative method enables one to remove the above biases. The pediatric client can speak for himself or herself. This type of personal, subjective data could not be elicited from standardized or researcher constructed, structured questionnaire or checklists.

In the literature dealing with qualitative and quantitative approaches four areas of differences and concerns about those differences can be noted (Bernheimer, p. 224). The four areas are: (1) subjectivity and objectivity; (2) particularistic and holistic orientation; (3) reliability and validity; and (4) hypothesis testing and hypothesis generating.

(1) Subjectivity and Objectivity

Quantitative research searches for facts and causes of behaviour by examining objective, observable, quantifiable data. In the process various variables are manipulated in order to find which variables enhance or cause change. The effect can be measured or counted out is know as the etic approach (Bernheimer, 1986). The success of a parental support group might be evaluated on the frequency count of attendees.

The qualitative methodology values subjectivity for it deals with the internal world of the person. This Bernheimer (1986) calls the emic approach. In researching the above example the participants would be interviewed to find out what the expectations of the parents are and how the group met their needs. It could broaden its investigation and talk with parents who didn't use the support group and why it failed their needs.

In qualitative research, the researcher's subjectivity is controlled by recognizing and making allowances for pre-determined stimuli. The researcher is cognizant of his or her bias and endeavours to bracket or suspend his or her biases or pre-

conceptions. However, since the researcher is aware of his or her point of view, he or she may not succumb to the point of view or views of the group being studied. This prevents the subjectivity of the researcher contaminating the results.

Existential psychologists (van Kaam, 1966) note four areas of subjectivity that may effect the researcher. The first is that the researcher may use methods exclusively used from the physical sciences. Second, only intuitive methods may be exclusively used. Third, only a few methods considered valid might be used. And finally, subjectivism in the form of dogmatic assertion that positive science is capable of providing all possible insights to human behaviour. Basically these four possibilities are subjectivistic because of their prior assumptions. Existential psychology demands that data be observed as they exist before analysis or interpretation proceeds.

This existential attitude when exercised will prevent the danger of subjectivism from occurring. This subjectivism is the constant danger of investigation into the human subject. One is aware of subjectivism when one limits the field of investigation into acceptable/non-acceptable territories. Thus phenomenology investigates any phenomenon. Nor does the existentialist restrict himself or herself to established theoretical constructs. Traditional science also attempts to discover "particular validities by examining universal ones." (van Kaam, 1966, p. 314). This is the deductive method. What one discovers is assumed to be contained within some general uni-

versal law. Often researchers may have a prior model or philosophy which when held may influence the explanation of the data.

Existential analysis uses the inductive method which goes from the specific to the general. It starts from the various data and then formulates a valid description from the data collected from the sample. Experience then becomes the primary data that in and of itself cannot be proven. Science from the existential point of view uses a process of explication. By this is meant that "implicit awareness of a complex phenomenon becomes explicit" (Ibid, p. 316). In this process there is a faithfulness to the things as they appear. By definition phenomenon means "that which appears." Some would charge this existential process with introspectionism.

In forming hypothesis, phenomenal psychology tends to start from an overall analysis of the human situation in its immediate givenness; whereas introspectionism started from "objects" which were supposed to be inside the mind, isolated from the total existential situation; and behaviorism starts from the external aspects of behavior, isolated from their experiential content. (Ibid, p. 340).

(2) Particularistic and Holistic Orientation

Quantitative research identifies and isolates variables for examination. This is usually done through the use of standardized tests, questionnaires and predesigned observational instruments. Causes and consequences of these variables are investigated.

Qualitative methods measure the interaction and processes which occur. The meaning of the data can only be inferred in

quantitative analysis. Qualitative analysis has no need to infer for it examines directly. It seeks to examine the context. It seeks the various forms the phenomenon takes and what variations occur. A frequency count may indicate which programs might be successful while the qualitative approach could provide the process that distinguish successful programs from non-successful ones. Van Manen (1984), for example, notes the large number of books on how to be successful parents. These "how-to" books avoid the topic of parenting. They shy away from describing the "whatness" or "isness" (essence) of parenting. When various accounts that express parenting are described one notices that his or her unique experience is recognized by others. Other become aware of the similarity of the experience.

As Gestalt psychology discovered that the whole is greater than its parts other are suggesting a systems point of view as an alternative paradigm for psychology. The systems point of view enables numerous interchanging variables and also levels of stratification to be studied. Manicas and Sécord (1983) note:

The acts of persons in life settings are open systemic events that involve an enormous range of codetermining structures and systems. (p. 407).

(3) Reliability and Validity

Quantitative methodology is more concerned about reliability than qualitative methodology which is concerned about validity. Reliability is concern about the researcher's abil-

ity to replicate or reproduce findings. Quantitative methodologists maintain that their findings can be repeatedly investigated and can be investigated separately to insure reliability. The intensity or the range of an experience is much like the range of scores.

Validity is the prime concern of the qualitative researcher. This is assured by the large amount of time spent in the setting with the person. Continuous data analysis also enhances the validity. Validity concerns itself with the meaning and meaningfulness of the data and instrument used (Patton, 1975). Time plus the assumptions of the phenomenological approach take seriously the data collected from the interviewee. The data is also "respected" in the sense that the researcher is cognizant of his or her bias or subjectivity. He or she uses the technique of bracketing to assure that the meaning or experience as perceived by the participants is brought out as clearly as possible.

(4) Hypothesis Testing and Hypothesis Generating

Quantitative methodology starts out with a hypothesis or predetermined notion of what will or will not be found. These are based on a theoretical framework. The danger as always is that predefined question and measure may inhibit the participant from sharing fully or even missing what the experience is actually like.

Qualitative research shies away from testing previous theories. The aim is to discover new concepts and theories.

This may be necessitated by the fact that some phenomenon may have been investigated on an atomistic level and the experience may need to be examined more holistically. The qualitative does not ignore previous research. Previous research may well contain insight which spurs further investigation.

Ellenberger writing about psychiatric phenomenology and existential analysis (May, 1958) illustrates the point whereby previous theory and knowledge was subjected to further analysis in order to better understand a phenomenon. Noting how the descriptions of certain pathological conditions at the turn of the century didn't facilitate diagnosis and treatment the phenomenologist used certain categories to analyze psychological states. Two categories in particular that were found to be fruitful were time and space. People with pathological conditions perceived time and space in a different manner than the ordinary person. Their descriptions were often convoluted or extremely restricted. Thus the concepts of time and space aided in differentiating pathological conditions. This was a result of letting the experience speak for itself. In the process of describing that experience as best one possibly can, insight would be developed. This insight would generate its own hypothesis which could be tested. This process would have a higher probability of producing something that would be relevant and functional.

Application of Qualitative Method

The focus of the research is the experience of selected caregivers working within the hospice movement, in particular the meaning of the loss of a patient, client or parishioner by death. The focus was on the caregiver and in order to maximize the interviewer's freedom to share that experience an open-ended, semi-structured questionnaire was used. Miles (1979) points out two limitations of qualitative methodology. First of all the method is highly labour intensive. From the sheer range of the phenomenon to the volumes of notes, recordings and transcripts can overwhelm a researcher. Secondly, methods of analysis are not well formulated and need to be improved. Noting the date of this observation (Miles, 1979) much work has been done on methods of analysis. However, since the caregiver appears least addressed in the literature a philosophical point of view and a methodology as illustrated above was chosen to discover as best as possible the nature of the phenomenon.

The Research Design

As indicated in Chapter I the area of research suggested the focus be on caregivers. While there is much research on death and dying involving the patient and his or her family not much research is directed at the caregivers. Dealing with dying and finally death of a patient, client, or parishioner is quite stressful as indicated in chapter three. The hospice movement notes also that quality care involves emotional commitment and emotional energy on the part of the caregiver.

This process must be recognized and dealt with. Failure to recognize and address this results in professional burnout. The preliminary literature search did not indicate that this issue was addressed in professional education.

The question asked was: "What had the experience of the loss through death of a patient, client, or parishioner meant for you?" A sample of one was suggested from the following categories of professional caregivers:

- (a) chaplain
- (b) parish clergy
- (c) social worker
- (d) counselor
- (e) medical doctor (resident)
- (f) medical doctor (practising)
- (g) hospice worker/director
- (h) registered nursing assistant
- (i) volunteer
- (j) nursing instructor

One category (social worker) was chosen for the pre-test. The interview (code named Joy Season) is a result of the pre-test. The pre-test interview was used to gauge whether the question asked would facilitate the interview process. It was judged that the question was valid in the sense that it did initiate the interview process and people would share their perceived experiences. The pre-test interview did suggest a slight modification of the question. Rather than the longer

version which included the phrase "patient, client of parish-ioner" one of the three words was chosen and used with the appropriate profession. Although volunteer is not a professional category that subgroup was chosen for two reasons. First of all since there are now significant fiscal restraints the use of volunteers has taken on a new significance. Secondly, many agencies rely on volunteers to do a significant amount of their mandate. In that process they have initiated training sessions and also use professions to coordinate and supervise volunteers. The volunteer for this research had the appropriate volunteer training and worked under a duly appointed chaplain supervisor.

The sample was extended to include a social worker working in a children's hospital, a police officer that lost a partner, a nursing attendant and a nursing supervisor. There was only one refusal and that was the category of social worker in a hospital setting. Efforts were made to contact a police officer who had lost a partner, however no volunteers came forward. Both a nursing attendant and a nursing supervisor were obtained for interview purposes. Most of the people sampled were acquainted with the researcher and readily volunteered to be interviewed. The hospice director at the Bethany Care Centre assisted the researcher in contacting three persons for the research.

Appendix B contains the package every person contacted received. While a majority of people did not hesitate to parti-

cipate, all were given the package and were asked to read it. No interviews were conducted until the historical data sheet and consent form was signed. All participants did not hesitate to sign the consent form. Some indicated a high sense of trust that the researcher would not abuse their verbatims, however, the researcher insisted that consent forms were needed since the ethics committee had the right to request these forms.

Appendix C contains the letters sent to the Bethany Care Centre. Four participants from that institution participated in the research. The last page from that institution indicates its approval and co-operation with the research endeavour. Before each interview was conducted each interviewee was asked to choose a code name which would be used when quoting their material in the body of the thesis. It was also suggested that when they shared personal stories that real names not be given. Many attempted to use false names when referring to their patients, clients or parishioners. It was noted, however, that segments of the verbatim that was highly significant, personal and existential often the real names were used. In order not to interrupt the interview process this was not pointed out nor checked. All real names, places and other personal data that might possibly identify a person has been changed. This is to maximize the confidentiality of the material and the people involved.

Chapter V

Synopsis of Data

Introduction

The total pages of verbatim number 447 pages. To reproduce this would make this thesis unmanageable. Nor would the phenomenological-exploratory method suggest this of the sample size of eleven case studies. Therefore, a reduction process has been applied to the verbatims. Two factors have been used to reduce the materials. First of all, the material included revolves around identifiable themes as they occurred. When that recurred or was elaborated or clarified, portions of the verbatims were included so that the theme was clearly explicated. Second, other quotations from the verbatims are retained which gives biographical material. This material enables one to grasp the event and pertinent circumstances which enable the flow of the story or event to occur. Thus, it is hoped that in the reduction process a portrait of sufficient worth is produced in order to capitalize the phenomenon. Fisher (1978) provides an example of this phenomenological reduction process. It is from these reductions entitled transcripts that validation quotations in chapter VI have been taken.

Code Name: Val
Age: 56
Profession: parish clergy person, male
Years practising: 32
Approximate time involved with parishioner: 4 years
Total pages of transcript: 29

Transcript No. 1

Val: I'll try to focus in on one death where I dealt with the patient from the month of April through the summer to September when the person died. ... She was dying of cancer. I found out she wanted this German for her mother's sake. She felt that at her funeral she needed to have her mother cared for in the language which she knew as ... as her mother language which was German. I had never met this person before and she was very curt, polite and kept me at an arms length until she determined that I could speak German well enough. My difficulty with this funeral or this death was that the patient didn't have a faith which could be verbalized. She had almost a negative attitude toward God at the point. And the question of God and her death was invoked by the fact that a well meaning person working at the hospital said to her, on one occasion, God must be very angry with you about something otherwise you wouldn't be suffering the way you are. I felt this was very judgemental and I had somehow helped her past that point. So we struggled with that and the whole relationship with God in her life during the visits....So this person who sort of started out as angry with God got to the place where she was willing to accept. Now the difficulty lay in the fact that her family also did not understand this. And her need was quite intense to have her family relate to the same God. So she put me with her brother and her mother with whom I would have to deal after the funeral. These were not parishioners now. All this happened because of the Lutheran Hospital service involved here.... Anyway the family has since then become closer and closer to the church. The brother ultimately allowed his two children to be baptized here, though he hasn't espoused any faith or any relationship to God in Christ....

Geo: Uh huh

Val: Now that describes the person and sort of the circumstances with which I had to deal. I guess the biggest difficulty I had with the whole thing was to work with her at the same time as to try to become a friend and trusted person for her family. There was some tension -- not grief but there was a lot of tension in my relationships between her family and me. They accepted me in the end and I believe trust me quite implicitly.

Geo: ...I'm wondering what was the meaning behind that.

Val: I guess I felt the same tension with the family that I felt with her and the difficulty in getting to the place where God mattered and God matters for them in their lives and ... my feeling was that the dying person wanted me so much to get the message across that she left me with a burden which was difficult for me to completely unload....

Val: Yes, because I felt she had laid a burden on me about looking after her family after she died. I think the first question, the first reason for contact, was not for her sake but for her family's sake. She was caring for the people who were going to be left behind.

Geo: uh huh

Val: and so the tension of that burden became how can I reach the people who don't want to be reached

Geo: uh huh

Val: and did not initiate a reaching to me for help

Geo: uh huh

Val: but were assigned to me almost by the dying person

Geo: uh huh

Val: and that was the tension I had to live with. And the fear that anything that I said or did might be misconstrued and a wedge would be driven or a gap would be created which meant I could not fulfill this dying person's wish.

Geo: Uh huh

Val: And so the whole process of care for the family became the burden rather than the care for the dying which was the initial contact

Geo: Uh huh

Val: and the initial concern but it wasn't the final concern. So that here is this dying person who was calling in somebody whom she would trust

Geo: uh huh

Val: to see if that person could care for the family in the way she wanted that done. I felt that this was because in most of the other cases of death that I've had it has just you know I am dying and make sure that my loved ones are cared for on the day of the funeral and that's about it. You know but this one had a longer agenda in mind, one that was not easy because the family also had trouble with God.

Geo: Uh huh

Val: and there were many other problems related to it, through the family's understanding of God. I think that those were the difficult things for me. I think that made that particular one significant for me. She asked for her family in such a way that I could be involved for a long time to come. As a matter of fact it is now four years since then and I still feel the burden of the family although in many instances in funerals like that I wouldn't feel the burden of family for more than a week or so after the funeral....

Val: She was asking me to look after her family and in those four years the mother also died so I've been able to care for her during that period of time and in fact needed to in German after she became more senile....

Geo: Uh huh so there was a profound expectation placed on you.

Val: Yah

Geo: She was giving you her work to do.

Val: She was giving me her work to do and it was very interesting because she was also the same age as I and she literally gave me a mother and a younger brother. In her own way she said ... build that kind of a bridge, she didn't say it in words but she said I'm leaving and they will need someone who cares for them and I have been their caretaker. She didn't say I'm leaving you that responsibility but that's how it's worked out. ... So you know the interesting thing is my relationship with her though uh it was extensive and difficult for those months of April till September. That was the beginning of something which has lasted and continued. (pause) I guess the most interesting aspect of that was the mother whom I had to care for, in the end in her senility related to me as if I were her husband.

Geo: Uh huh

Val: She used to call me papa which was the family name for her husband and I talked to the son about that and he said, "well there's a resemblance" and he brought a picture out of his father who had died when he was quite young and he also was sort of a biggish man with loss of hair and a big nose...

Val: I guess I don't have any feelings anymore of tension in dealing with the family. The tension is gone the burden is still there in the sense that I feel that responsibility that was given to me is still going to continue for years to come; that I will never be able to say that this is purely a pastor-parishioner relationship. I think that this particular death put me into a brother-brother relationship with the man and his family. And that's one of the most difficult relationships to build when there is no blood tie. (pause)...

Geo: Could you elaborate on that statement?

Val: Well ... brothers who are siblings you know have a blood tie and therefore you know, you did not choose them nor did they choose you it was something that happened. In this case now you have a brother relationship which is imposed by an older sister. She let you into the family to be the brother and son to her mother and she wants that to continue. Now if you feel like you have a burden to continue this then it is because you have allowed that relationship to be there although you don't have any kinship....

Val: ...Initially my contact with this lady in the hospital was purely clinical and then it became something in which she tied me to her family. Now the family and I have a deep relationship being that has been built over the years. If something should happen to that family now there would be real grief where with the initial patient it was purely a clinical relationship. So one thing led to a deeper involvement. That's where I think the deepest relationship is, not with the person that died but

with the person that she gave to me as a brother and his family.

Geo: It sounds like you might have been surprised that this would happen.

Val: I didn't believe that it could...initially. I felt that I was making a promise like so many promises about looking after my family which I would try to fulfill but would not be allowed to fulfill because there were no kinship ties....

Geo: You still sound surprised that this happened.

Val: Yes, because I don't believe he wanted it to happen. I think it happened in spite of him. As a matter of fact we had a very deep ideological difference at one point...

Val: So that's why that's part of the surprise. It has prompted me to do some research also so that, you know, what is a cliché and a glib answer in religious circles is never enough. It needs to be something which has more quality of research in it than just sort of the casual answer which I would give to another person. But it's become a good solid relationship. The problem is that now you know if either one of us were lost to the other there would be equal grief in that family or if I died there would be grief and the same thing would be true the other way....

Val: ...I have had many cases where the trust level has grown between me and the other people and the relationship has been more family than a clinical relationship. So I've had that experience before. I've never had somebody who has that close a relationship with me die. I do not know how I would handle that grief.

Geo: I wonder if you could elaborate on that

Val: I don't really know yet other than you know what kind of grief I would experience with the death of somebody who was very close to me....I don't know that you see I haven't really experienced grief in death. I have experienced grief in loss a lot because I build close relationships....and the parishioners that have died I have been able to handle those deaths very well because they were all clinical relationships...

Val: ...And this is why this instance is significant for me because it is so very really the one death that established the kinship relationship in this family for me ...

Val: I don't know but I think it would be different. In my mind grief and my position in life are really determined by the intensity of personal relationships and not by the clinical or the parishional relationship....

Geo: uh huh

Val: Then I think the pastor or the professional person would experience a whole lot of grief but it would have to be not on the basis of his position. It would be on the basis of his relationship with that particular person involved....

Val: You know George I'm almost surprized that I did that because I don't try ever to make that distinction between people and yet as we talk about this I realize that that's one of the things that has happened

Val: and it has happened in other relationships with other people

Val: and I have tried in my care for all the people not to distinguish one from another.

Val: And yet what I have done now is to say that there is a difference in my feelings between quite a number of the people in my parish...

Val: I've never talked about it with anybody until now....

Val: Now the most interesting thing about this is that family bond, that closer more intimate relationship,

Geo: uh huh

Val: was built with somebody outside the church.

Geo: uh huh

Val: I think that's significant and that's the first time in my life that that's happened. And it's also peculiar that it should have happened by the design by a person who was dying....

Val: Yes. So there were many surprizes there which I don't have an answer for you know. I don't feel bad about it. I feel good about the relationship that has grown between me and that family. I feel good about that. I think it has been good for them and it has been good for me.

Geo: uh huh

Val: And in that sense you know something very therapeutic took place for them and also you know it gave me an additional source of help for my life.

Geo: Uh huh

Val: And that young man and I go skiing together for instance and we enjoy each other's company

Geo: uh huh

Val: we're very, very, very much alike in many ways. Maybe that's one of the things that the sister saw as she got to know me

Geo: uh huh

Val: and that made it possible for her to sort of lay the burden on. And maybe that's one of the reasons why the mother called me "papa".

Geo: Uh huh, uh huh....

Val: I feel you know that the relationship is one that is most helpful, ... both ways, I find also that he is very helpful to me in dealing with people who have had very extensive surgery because he works at the local hospital...

Val: I think that this is about where the story ends. I don't want to experience that loss. Maybe that's why I keep it very much alive and I guess there's significance in wanting to keep that once it's established.

Code Name: Cag
Age: 46
Profession: Hospice Director, female
Years Practising: seven years
Approximate time involved with client: 11 months
Total pages of transcript: 28

Transcript No. 2

- Cag: OK, alright, and you want me to zero in on one because I have known many deaths
- Geo: Well, if there is one that stands out.
- Cag: Yes, OK, there is. Alright, This was a man who had a germ cell tumor in his chest. He was about 37 years old when it was diagnosed. When I took over I started counselling him and his wife, not together, they never chose to come together, they always came to see me separately. So I saw him once a week and I saw her once a week on a different day up to his death in October. Really it was a very close relationship in terms of death and dying issues and that kind of thing and I was really fond of him....
- Cag: He was open, there wasn't a thing that he couldn't discuss and it was really a nice relationship. His wife was the same way. There were times that she would say, I wish he'd die, I wish he'd die I'm just so fed up with it and so on and she'd share that with the girls and so on and so forth. She and I have remained friends even to this day
- Cag: ...you know we were very close with one another, I'd give him a hug and I'd tell him that I loved him and those kinds of things and how much I'd learned from him. (Pause) That's almost two years ago (voice breaks, some tears)....I have a feeling in death and dying that if the parents are doing a good job with the kids then you should leave that with them. I think it's very stigmatizing for kids to go for counselling for anybody to go for counselling but kids don't have the cognitive process to work that through. So I simply let them work through the things with the kids and she continued to do so and they are very well adjusted, very well indeed and she came to a bereavement group after and I meet with her individually and I meet with the group from time to time. We have lunch and have become sort of friends as opposed to a counselor and so on.
- Geo: It seems like it's a very significant story.
- Cag: Yes. I've probably not had anybody that I was closer to or that I learned more from than him....from him the learning was deeper, you know, because he was so open and so was his wife that I learned so much from them but particularly from him because there wasn't anything that was sacred anymore in terms of sharing so I missed him after

he died and uh then you know still his death is significant to me obviously. I could talk about most of my patients or clients or whatever you want to call them. I don't know of anybody else who would invoke tears in me now because generally speaking it has been a sad kind of thing. Now what do I want to say. You know really when you're working with cancer patients by the time they die I can feel some joy, because they're out of their suffering and I can see how they've grown....I can certainly say that about this man's death. But still I miss him sort of on a personal basis where I don't with the others I felt a little more detached from them somehow

Geo: Do you mean it was a personal relationship?

Cag: Yes, I still think of him very fondly too, and the others I do in a sense but not in the same way. Our relationship was on a little different plane and so it was interesting seeing his wife at the same time; the parallel things they went through and sometimes they would be on a slightly different plane and then they would reverse those. Just a very interesting case all around in terms of learning.

Geo: I'm wondering what you mean by learning?

Cag: Well, I guess learning about the feelings about dying. Women are pretty good about talking about feelings about dying, men are not so good. This man was very good, and he gave me insight into the male feelings about dying, that I really haven't had from most men. They tend to express that on a very cognitive level.

Geo: ...How has that experience affected you, your work and your learning?

Cag: How has it affected my work? Well, I think I have more expectations of the men I work with now. I don't know if it's more expectations but I guess I think in my own mind that men had that depth before this man now I seek that out a little bit more in men where I might not have before. I simply would have allowed them to operate at the cognitive level, now I dig a little bit more for the feeling level...just in terms of helping me to understand the feelings that men can have. I don't know that I should be generalizing to all men based on him. He was a bit of a rare bird, and I haven't found too many men since him even when you dig for feelings....Men are more capable of a whole lot deeper feeling than I think most counselors give them credit for but I guess the secret is to unlock whatever it is that is going to allow them to open up those feelings.

Geo: Are you any closer to that secret?

Cag: No I think just basic trust and openness and that sort of thing. Men are very socialized to keep those locked up so I think we have a responsibility you know to try and dig for those kinds of things....It has just led me to remain in this area, in the area of death and dying which

I consider to be a very significant area of bereavement. Cag: It was confirming in two ways for me. For me personally that was good work for me it also confirmed all the reading you do in death and dying and they say this is what happened and go through this phase and that phase. I went through all the phases with him and so it confirmed all the things in the literature so when I go to the literature now, I read through and that's like him. I remember that from him, you know, a lot of that was true for me. Another thing was, I realized how people use the workers in a system. These people used us very well indeed. They knew how to use us, they knew what we were there for. I'm including my student in this because they started with her. Right away when he was diagnosed they said, "We want some help, we want some psychosocial help. Now they didn't know the system and he was a businessman, he wasn't a counselor of any kind. He didn't know necessarily but they said "We need help." So we were called in right at the beginning of the thing and there was an opportunity to work through every one of the phases and they hung in there and they used us. She said "When he goes for surgery, I want you there and I want you there for the whole day so I just put aside the whole day which was appropriate because she was a bit of a wreck over that surgery....

Geo: Uh huh, uh huh

Cag: So that was good. So confirming in many respects. Affirming or confirming, whatever. (Pause)...Yes, I wasn't frightened it was always a very professional relationship. It wasn't a case where he was in a love relationship, I mean other than a humanistic kind of love, there was never any confusion about that although I told him that I loved him and he said the same thing to me. It was always a very good relationship. People are loathed to say that, he never would have said that to me nor I to him if he hadn't been dying but it was a very pure kind of nice thing and some real warmth between us and between he and his wife and between his wife and me. It was just a very different kind of thing and it is a shame that we hook all that up with sexuality somehow and are nervous and frightened of it and that kind of thing and there are very few people with whom you can have that kind of relationship and he happened to be one of them and it was great....It never stepped into a sexual realm or any thing like that. Just a super relationship....

Cag: Sure I think about him from time to time and of course whenever he and his wife, I mean his wife and I get together.

Cag: He was at peace when he died. We sat with him, his wife and I, in the coma, and talked with him and each of us, each of the family members and myself was given an opportunity to be alone with him in his coma and that was

really significant, that was really nice. So I know how important that is. The kinds of things that affected him, affected my work in that way because now if I'm working with someone who is dying I sort of suggest that each of the family members have time alone. In my position I have no right to it, it's a privilege that I ask for so in that sense it's different

Geo: Uh huh and yet for it to work it almost has to be, uh you almost have to be part of the family

Cag: You have to be close to the family.

Geo: There's that element of closeness that is key to the relationship.

Cag: Yes, that's right

Geo: That's something we talked about before. It's almost like there's a barrier you have to cross. You have to be invited in as a social worker to help, but for that help to be working, there's an intensity/relationship there which is not there in the same everyday life of normal circumstances. (Pause) Am I catching your drift.

Cag: Yes, I think so, that's right, you're invited in and I think the things you do help you to reflect directly on whether or not the relationship becomes intense or not and now I don't know what, exactly what you can do to make it more intense because relationships between clients and workers are the same as personal relationships, sometimes you click and sometimes you don't, I'm not sure it can't click with everyone....

Cag: Sometimes I get a little surprized as I was surprized today uh at the intensity of the feelings I still have for that relationship. So that's another thing I've learned, that I would rather work with younger people, who are dying, for whom the issues are very intense and significant, that for me is more meaningful work for me....and there are many, many more issues when you're young so the intensity of the relationship is going to be better and it is thereby going to be more satisfying for the worker....

Cag: But I think in psychology they are told that they can only go so far and I don't think that a psychologist would have gotten into as intense a relationship as I did with this gentleman. They would have seen it as completely unprofessional some of the things that I did because they are told you can go this far and no farther, you don't cross over the line. But I don't believe that there's an arbitrary line. I think that what you can do is you can have a professional relationship that is deeply intense and you can say the kinds of things that you want. There's something else that divides the professionalism from, that keeps it professional there's something else and I'm not sure I know what that is....

Cag: There was never any question of that, never. And yet the intensity was there. And yet any psychologist looking at

that would have said, "No, you were meshed, or this, or that, or the other thing or whatever."

Cag: ...I had a client commit suicide. And when I start telling that story I can get into some emotional parts. There's always that little element of surprise when that when the emotion comes and you think "Oh my God, I thought I could tell that story, I thought I was beyond that."

Cag: One of the things I thought you might ask about was whether or not my training prepared me for that. Was that one of the things we talked about or did I think about it myself? My training somehow allowed me to realize that people can feel deeply so in that sense I guess it did. I think training in death and dying is good but it can only help you on a cognitive level.

Geo: Uh huh.

Cag: I don't think people can describe to you, it's like trying to describe labor pains, you know what I mean you just have to experience them before really or describe dying or describe being ... I think every experience has to be felt, has to be known in order to accurately describe the feelings that accompany it....

Cag: I think you can only train people cognitively.

Cag: and that helps and there's no question about that, that helps.

Geo: Yah

Cag: I think that because one takes a lot of courses in Death and Dying, one still doesn't know what it's like to work with the dying....Nor does one know what it's like to have someone in your family diagnosed with something you know, I work with families that have been bereaved by suicide and they used to say to me, you don't know what it's like, and it was absolutely true, I didn't know what it was like, thank God.

Geo: Uh huh

Cag: I would acknowledge that to them and I would say "yes I know, but you can help me to understand" so I can at least affirm for other people what their feelings are

Geo: Uh huh

Cag: and that was how I share with other people, I never said to people "I know just how you're feeling." because they would cut me off at the ankles if I ever said that to them. That's not an appropriate thing for a social worker to say unless indeed they've had the experience.

Geo: Uh huh

Cag: If you've had a husband that's been diagnosed with cancer then you know what that feels like but if you haven't then you can only say "Well, I have another patient that tells me this."

Geo: It's sort of a personal learning that everyone has to experience in their own way and on their own time table.

Cag: Well, I think you can be helpful if you haven't exper-

perienced it directly by just, as I said, picking up the feelings from clients.

Geo: Uh huh

Cag: And then passing them on as their experiences not your's but their's. I think that's crucial.

Geo: Uh huh, uh huh. People are open to that?

Cag: Yes, very open to that and then you don't misrepresent yourself and they don't lose trust in you.

Code Name: Willie
Age: 51
Profession: Registered Nursing Assistant, female
Years Practicing: 15 years
Approximate time involved with patient: 8 years
Total pages of transcript: 43

Transcript No. 3

Wil: ...she had M.S. and of course it has its ups and downs at the beginning but they seldom die of M.S. as such
Geo: uh huh
Wil: they usually die of a complication of some sort.
Geo: Uh huh
Wil: But she was a beautiful woman and she was so appreciative of everything we did for her although she was severely handicapped she couldn't do a thing for herself. She still really always showed her appreciation and she would have episodes of going into a coma just like that suddenly you would be feeding her or doing something for her and she would just go right unconscious...
Wil: But we'd send her off to the Foothills to give her antibiotics and in a day or two they would send her back. It always frightened her so very much because she was not really frightened of dying but the process of dying.
Geo: Uh huh, uh huh.
Wil: and what would happen to her and how she would die and I got quite close to her and could talk to her very easily and tell her about you know how maybe possible ways that she might die that she would likely go unconscious and this is likely the way she would die and uh ...
Wil: To keep her here. This was one thing she didn't like was whenever she had to go to the other hospital...
Geo: Uh huh
Wil: And so anyway she went through this quite a lot during the eight years I looked after her and we all looked after her of course, but she went through several of those episodes and we always knew there would be, she would ask this too, if there would ever be a time when she wouldn't come out of it.
Geo: Uh huh
Wil: And I said yes there probably would be and that likely. I tried to be as honest as I could with her. Her family were not too supportive of her and it didn't bother her a lot because she understood that she had been sick at home for quite a while before she became institutionalized so it didn't bother her a lot that her family... She worried more about them and their conditions than they worried about her for some reason. I think they worried but they didn't know how to react to her and uh so um when her sister would get sick and always had this ritual of phoning every Sunday. They phoned each other. Either she

phoned them or they phoned her....

Wil: ...I myself really picked her as a favorite and spent a lot of time with her when I could and even off my duty hours...

Geo: Uh huh

Wil: because she was so alone and she had trouble with her speech so not everyone could understand so I spent quite a bit of time with her....

Wil: ...I tried to tell her that yes the chances were that she may not come back. We would look at it we tried to look at it in a positive way that she was going to get some help and that um, she would come back and uh...

Wil: ...and just as she got sort of a spurt of energy and she said "take the basket" and I said "O.K." So once she got over to the Foothills and I was off duty at three I went over to see her....

Wil: ...So I went out to the desk and asked if we could take it off and the nurse said no that her blood gases were very low and the Dr. wanted her to have the mask on. And I really felt bad because I felt that A----- in all her stress she never asked for anything much

Geo: Uh huh

Wil: and this was one thing that she was wanting you know not to have this mask on. I could see that she had deteriorated a lot and chances were not good that she would be recovering even at that point....And she was on my mind, I couldn't get her off my mind you know I just thought about her all the time, I came back to work the next day plus everybody was asking about her. And I went back again after work and um I noticed a real big difference in her and so I took the O2 mask off. I thought this is very much against the rules but even if its for a few minutes it's not going to make a big difference because that's what she was saying that that's what she...

Wil: And so I got those things hooked up for her and I had a hard time convincing those nurses that she could hear and that she understood completely what they were saying to her at all times. She may not be able to talk but she understood....

Wil: But it came right down knowing her so well to the last instance she didn't want it. She wanted me to take it away and take out the intravenous out of her hand and do all these things for her. She trusted me a lot...

Wil: and I wasn't with her when she died. I feel kind of bad about that but on the other hand maybe it was just as well I think I always have feelings yet that maybe it was just as well that I wasn't with her and on the other hand I would have liked to have been

Geo: Uh huh

Wil: but I don't have any deep set regrets about it,...

Wil: I feel that death is very special and it happens to special people. It's not everyone that can die and die

easily and are at peace with themselves and their surroundings....

Wil: How would I say what I mean, I think it's a part of living in a way because...I think you die the way you live. You live peacefully and I say a fulfillment time of life you feel satisfied with how things in your life have gone...

Wil: ...God has chosen her. That is how I feel in a way too. I'm not a church going person, I'm not a religious type of person but I feel that God does have a special thing for us to do. He's called us at that time....

Wil: ...the younger people we had a lady of about forty-two who died of kidney failure and she was very frightened because they weren't honest with her about her condition and the prognosis of her condition and uh the Dr. told her it wasn't good but then he didn't elaborate enough on it to satisfy her need and uh so therefore she died very frightened. She was very, very frightened when she died she um her she hadn't done all the things she wanted to do....

Wil: you kind of have to get to know her a lot. And I think that's where staff training needs to come in all areas is to zero in on that person where they're at and go with them from there and tell them it's O.K. to die. It's a real blinder with people that it's not O.K. to die

Geo: Uh huh

Wil: and I put myself and I've been to many workshops on Death and Dying. And one we went to in Banff that was, I just forget what the moderator's name was now but he was excellent and put us through exercises of your expected date of death and your life from the day you remember until you die. Go right past where you are now until the day you die. It was an excellent exercise because it really makes you think of you dying; your own self. So I went to that in the spring and while I was with A---, her attitudes and the talks we had together before dying helped me I mean yes it helped me and then it also helped me to help her

Geo: uh huh

Wil: because she was not frightened, she just didn't, wasn't sure of what was going to happen to her and uh the ability for me to talk to her...

Wil: ...I would want to know that somebody was going to be there for support for me while this was happening to me....

Wil: ...But I think it's O.K. because I think that if it was O.K. with him, it was O.K. with me and that's how I often look at it. You have no control over how the other person feels or thinks and I don't think you should take it on yourself....

Wil: ...I always wait for that clue...you wait for that clue and I think to pick up the clues is important because I

think the majority of people do want to talk about it sometime. They are the one's that have to open the door and they are the ones that have to choose who. Like it's not everybody that will talk to them they have to have your confidence and your sensitivity to all that....

Wil: Most times they will ask right out. The majority of people will say am I going to die, How long do you think it will be before I die?...

Wil: um How will I die? Some of them will say, I hate my condition so much I hate the way I am that I would like to go and jump over that balcony

Geo: uh huh

Wil: and it's a clue that they are troubled about this

Geo: Uh huh

Wil: They are very troubled about it and they have come to the stage of being almost suicidal

Geo: Uh huh

Wil: before they will within themselves they are at that state before the will actually say it....

Wil: But they've come to that state and um also they will say um I may as well be dead ...

Geo: You were saying I may as well be dead 'cause that's the way I am or something like that.

Wil: Yes I may as well be dead as the way I am because they are very handicapped or they are very ill very distraught about their own condition so they want to be out of it.

Geo: Uh huh

Wil: They say isn't there something you could give me that would just put me out of this misery

Geo: Uh huh, uh huh

Wil: I say well I can't do that how do you think I would feel if I were to give you something or what do you think the consequences would be. (laugh)...

Wil: ...but the people I think that are really in trouble are the ones that say I would rather be dead as the way I am and I feel like jumping over the balcony. They are sort of at a desperate situation and I am not altogether sure always of how to cope with because they want to kill themselves as far as I am concerned and perhaps that is a way some people would like to do it....

Wil: You know the loss of their functions is very devastating to most people....

Wil: I sometimes think that nurses should all be patients in hospital before they ever look after patients and this really makes you think and once you're in the place of looking after people in this state and I think you should have to know that the acceptance of a change in your that other people accept you the way you are no matter what state you're in...

Wil: you know if you go in to them with a nasty attitude this is all they need, it's another added thing to what's already happening to them....

Wil: ...But I think the concept of treating others like you'd like to be treated....

Wil: You know she's still special to me to this day, my memories of her, she's a special person. I think that goes to show you (laugh) that there was a special relationship and I think you get special relationships when you look after people for long periods of time....

Wil: ...I don't ever envision leaving level four because they are like my second family....

Geo: Can you elaborate more on what special means, what does the word special mean to you.

Wil: (pause) let me see, well, she was like I say, she was so dependant on you and she was so appreciative for all that you did for her and like she was always concerned about you too like did you get away on your coffee break on time or did you have good days off...

Wil: she was so understanding

Geo: uh huh

Wil: of everything that happened and it made you want to go to her

Geo: uh huh

Wil: you know her personality

Geo: uh huh

Wil: as a whole was such that you wanted to spend time with her, you liked her as a whole person...

Wil: It just makes me feel good that I was able to be a part of A----'s life.

Geo: Uh huh

Wil: You know, to be able to take care of her, to know her as a person and just that I was one of the lucky ones that got to know her so well...

Wil: ...I think of her in that way you know, how lucky I was.

Geo: Uh huh, uh huh

Wil: And someday I would like somebody to say that about me (laugh)...

Wil: ...I would like to think that others could learn what I learned from her, you know. I learned a lot from her, a process is, is maybe very special, or I keep saying the word special, but I guess I do mean that it's, I would like others to experience the same thing and be able to have the feeling that I have about it because it's such a scary situation to most people, like they don't want to talk about it at all....

Wil: ...But going back to A----, it is special for me and I would like for everybody to have the same feeling if it was at all possible.

Geo: uh huh

Wil: About dying. It's O.K. to die.

Geo: Uh huh

Wil: I think this is important...

Wil: ...A lot of these things help like the book you read on

death and dying and it all helps but these, the actual thing...

Wil: ...That's for sure and the exercises, the workshops and the sessions I've been through too, there's nothing like the experience. It does not replace it maybe gives you ideas and coping mechanisms to a certain extent.

Geo: uh huh

Wil: but the actual happenings that's where you get the experience...

Wil: ...because I'm very much into listening...

Wil: and I never really did have a problem with it although there were times when you know it was iffy whether I could deal or not but I always managed by just being honest and straight forward with the person....

Wil: ...I learned from him much about it being O.K. to die he said because I was so young and I was young, I had all the skills to look after him but not those skills and he told me that it was alright. That he was ready to die...

Wil: ...so I think your young experiences do sort of mold the foundation for how you feel in the future and I think I've seen a lot of cultural differences like some cultures have very strange attitudes to death like rituals...

Wil: Yes, they sort of have an idea that they should stay in bed and they shouldn't get up in the chair and I say "why not?" Well because he's dying. Well I don't see, there's no reason to be kept in bed because you're dying. If a person wants to get up, I mean, and he's able to talk and he wants to see all the people he's been with, why not....

Wil: And the young girls are especially very kind of frightened of the dying person, I think this needs to be I don't know the training or just the experience, your experience there is no replacement for that you know, we will notice a great change in time and people telling them it's O.K....

Wil: Oh yes, more acceptable, you know this has always been such a big myth of the past, it's not acceptable to die. It's a natural living process, I think. It's natural to die, my own death, I'm not frightened a bit about my own death. I don't want to die yet, but I'm not a bit frightened about it....

Wil: ...I like to look after them and care for their needs and support them, I enjoy working in that, I enjoy working in any capacity but that is a favourite spot of mine and our supervisor is good, if there is a person dying on our unit then I have the opportunity to work with them. Say if I haven't had that group for a long period of time...

Wil: If you should ask me if any one thing that I missed about the death, A-----'s death, I kind of would like to have been there when she died

Code name: A Team
 Age: 48 male
 Profession: Hospital chaplain
 Years practising: 21 years
 Approximate time involved with patients: NA
 Total pages of transcript: 34

Transcript No. 4

- A.T.: ...my experience of loss through deaths of patients I visit is very different from patient to patient, depending on the kind of relationship I have had with the patient. Also depending on the relationship that the patient has had with other volunteers and staff. And depending very much on the kind of relationship the patient has had with the community of faith.
- Geo: Uh huh
- A.T.: I find that the people who have had little or no relationship with the community of faith are not very demanding, the patient himself, not demanding of other people not demanding of me in terms of any kind of support, religious, what ever. They appreciate us visiting and so forth but the demands aren't great for the most part, but their families are. And I think this has something to do with the idea of guilt, atoning for the guilt of the person who has not had a relationship with the faithful....
- A.T.: For those people I don't become emotionally attached as such when they die, it doesn't make a lasting impression upon me, it doesn't effect me emotionally, it doesn't cause me to go into a grief process....
- A.T.: When I worked with these people active in a real faith over a period of time then in the moment of death, or in the process of death, in the times after death, it makes an indelible impression upon me and it does have affect on me....
- A.T.: You visited them on Wednesday, you go back to the hospital Friday, and they're gone. What's happened, you don't even know. Have they been discharged, have they died so there's this feeling of being held in suspension. I guess if you get enough of those suspensions it kind of causes some stress, especially if you have a group of them over a period of time within a couple of weeks. I began to feel some tension, not having things resolved, not knowing with the ones that I come to know very well through on going pastoral care for a long period of time, who may have gone through a conversion experience or who I become involved with up to the point of burial. I'll be doing the funeral and so forth, I'm deeply touched by these people, especially if they are young, children, young people, young adults. Some how that touches me very deeply, and I

become emotionally involved in their lives, when they die. I too need caring....

A.T.: ...AIDS. And that's a whole new ball game. There you see death walking, literally. For me the first time I visited a person that had AIDS, that I knew he had AIDS, it was quite a frightening experience. You know the person's dying, the person knows they're dying, it's literally death walking.

A.T.: ...I've had to talk to people about that, I needed somebody to talk to immediately as soon as I got finished making my visit....

A.T.: Yes, a part of it had to do with my own vulnerability. I have done some reading on AIDS, listened to some of the things being done on radio and T.V. and so forth and yet it is still very scary.

Geo: Uh huh

A.T.: I was quite well assured afterwards or during the process that I was visiting that there wasn't any chance of me catching this disease....

A.T.: ...because you're handled so differently by the hospital staff, they're very protective of anyone visiting there...

A.T.: And yet, my sense of mission and calling said, You've got to do this. This patient is also a child of God and called himself a Lutheran, though had no connection with the church for a long time, but had been baptized a Lutheran, grown up as a Lutheran and even that person is a child of God and was in a position that he needed to have the assurance of God's grace, in spite of his life style which neither I nor the church approved. This person has a need of God's grace. So I had to struggle a little bit about my sense of calling. I often get called into situations there where through accidents, dead on arrivals, suicides, things like that where you don't know the patient they may have no religious connection what so ever but because it an hospital policy that the call the chaplain in on the time of death or imminent death that your there

Geo: Uh huh

A.T.: and those cases it's sometimes really frustrating experiences to try and offer some sort of consultation and a caring to people who had distained the church

A.T.: ...this is our prophetic part where we call out of people the questions on what's going on in their life but with others you just never know and it's the ones you don't know that you have a kind of a sense something being unfinished. I guess I need to finish things up a bit and when I feel that things are unfinished it's a bit uncomfortable...

A.T.: ...I see death you know as the gate to eternity rather than as an empty pit or darkness or no exit.

Geo: Uh huh

- A.T.: So I'm able to celebrate that conclusion with them or with the family and all it's unfinishedness I think that troubles me the most is not knowing, if something isn't finished....
- A.T.: There was a child abuse case and when I went to the hospital it was late, late at night it was almost midnight. I had the baptism and then the life support was withdrawn and the child died in just a few minutes but I was already gone....
- A.T.: ...I called the hospital chaplain I said, you know, what's the status of this child? Well he said, "I don't know anything about it." I said, "well I was not on call but the on call chaplain called me,..." "Well," I said, "would you get it," and he said, "well I'll check on it." Two days later I saw him, he said, "No, I don't have anything," And I said "would you check on it?"...
- A.T.: ..."What kind of support is being offered to the family?" And he said, "That's all taken care of." I said, "Well, share with me."
- Geo: Uh huh
- A.T.: "Well what's going on I need to know." "Well," he said,...
- A.T.: ...Just to go to the hospital and find the persons name is no longer listed on the Lutheran list I don't think is enough and I've heard others say the same thing. I follow the newspapers and many times that's the only way I know what has happened if the person died if they're local, I'll see the name in the paper....
- Geo: What about this nurse who was there for one day?
- A.T.: I raised that question at the hearing you know and they said the hearing is about the patient not the staff.... "if the chaplain had been notified it would of been the chaplains duty to immediately go to the unit and offer consolation and care for the people who were involved in that child's death and life and the caring. That's what I would of done as chaplain...
- A.T.: ...well there's some need for improvement there perhaps in the service but I know from talking with staff in various hospitals, in various situations that they just don't want to go to anybody who is part of the system....
- A.T.: The unfortunate thing is I see change being negative and it falls right in the lap of Marvin Moore, I'm afraid, and the department of hospitals where pastoral care is officially recognized but in actuality, not recognized. In the province each hospital receives one dollar a year for pastoral care from the provincial government and the provincial government will not even dialog with anybody about the importance of pastoral care...
- A.T.: I think if we work on people's life styles and thing

like that we could probably clear out about 60% of people in the hospital and save the government a lot of money and taxpayers as well and the people would be a lot happier,...

A.T.: Yes, I think my satisfaction comes not that I have had the relationship with the person but that through my relationship with the person they now had a new relationship with their church or their Lord or have come into contact with their faith again....

A.T.: ...yet I do find many young people, they're brave, they die well so to speak, they're much more able to cope with and handle death than adults. I find that among children what becomes inevitable they accept and they work it through. I guess that's basically it especially in suicides and things like that. Very often you'll find those people back in the hospital the parent and family of those who committed suicide...

Geo: Uh huh. Back in the hospital

A.T.: As a patient suffering from I would say some suicide related disease. Medically speaking there probably isn't such a thing but I see people coming in later with cancer and things like that...so I find that people who have unresolved guilt or unresolved problems and so forth they will develop a particular disease now that may have been dormant there the whole time or just needed something to stimulate it. Maybe the endocrines are out of wack or whatever because of the stress they're going through and as the result of that they develop a disease....

A.T.: I know the one thing we do have available to us in Calgary,...we have every year a fantastic grief seminar that's on going...but one thing that really concerns me. It's evident in the kind of people who don't attend, the medical doctors avoid this kind of seminar and opportunity for skill development and I think probably medical doctors are the worst ones for handling death of any of the caring people. Doctors ought to be there we have like 150 to 160 people attending the last meeting and only two doctors...It's hard to break into the medical community, very hard

Geo: That medical community, are you limiting it to just doctors?

A.T.: Yes, I found in hospitals where I work the nurses are just thirsting for opportunities to talk with pastoral care. We rate the same in Myers-Brigs and so forth we have an understanding to one another...and to be a care person for the caregiver...

Code Name: Bettie An
Age: 44, female
Profession: School secretary (hospital volunteer)
Years practising: 3.5 years
Approximate time involved with patient: NA
Total pages of transcript: 37

Transcript No. 5

- Bet: ...Probably the ones that I can relate to and have more experience with are the long ones, ones like the cancer patients that we deal with at Tom Baker you get more depth because there is a longer time frame there. But also I've had my father who went through heart surgery and never really came out of it. That took about four months and I've had an uncle just recently who also went the cancer route...They're all the same and they're all different...
- Bet: Um I think you get into a relationship where normally if it was just you and I visiting we would be threatened probably. But because one of us is dying we have thrown all these guards aside and we have nothing to lose and we must get on with this and the death and the dying is foremost...and what I'm thinking as a dying patient, I want to know those answers and I'm going to skip all formality to get at them and now we feel safe with one another...
- Bet: They have to give you permission and it has to be done with dignity and they have to feel that this won't make them any less a person. Most times they just want a sounding board. They really aren't too interested in your opinion on things...but they need to talk. I don't think they need guidance because I think they sort it out as you go along and they go along...and towards the end they give you the gift saying hey when your turn comes it's O.K....don't be afraid. So in the end the gift you have given them by just being there they are returning to you. Many times over...
- Geo: to you also
- Bet: ...one thing I observed from these people probably in the latter stages, I don't know if you've noticed this also, they like a light on at all times. I don't really know what the significance is in that but they feel comfortable having a light on day and night...
- Bet: ...from the volunteer's point of view a lot of times you are forced to deal with feelings you thought you had resolved but really hadn't. Each person as they're dying will give you the same story but a different story. We're all alike but we're all different and as you walk down the path with them they will touch on something that maybe you hadn't thought about before and you thought in

your grief you had covered all the bases and yet this opens up a new door and sometimes it's a pretty big door and sometimes it's just something you can yah, you can acknowledge and say this is certainly true...maybe one of the significant ones is how when I was dealing with a patient I thought back on how I had walked down this road with my father and also with my neighbor and things we had talked about and thought that we had talked about everything when in fact you know really we hadn't maybe to the full measure that I could have with someone else or some one else chose to do with me....my father's situation was different in...we went from mid July until he passed away at Halloween...so it was very long and very drawn out. It was more one sided as, it was us by the bedside trying to deal with our feelings and not much of his because he couldn't give us anything

Geo: Uh huh

Bet: but with my neighbor and with my uncle it was two sided, you know, hopping in and out. So you're getting different aspects I felt I was holding an empty plate after they died you know, like we had been celebrating together and they got the reward and here I stood after they died. Like they had been able to go on and it's pretty empty and that surprised me so dealing with patients from that time on I think the first little while I probably held back...but with the dying you get very at least I get very involved and when they are able to die I feel a tremendous loss, I'm very happy for them

Geo: Uh huh

Bet: but on my own I feel like I'm standing there with the empty platter

Geo: What did you lose?

Bet: It's what I haven't gained. I have not died and they have...I have to continue on and they've been able to step through to the other side or what ever terminology you want to use. Yes this has definitely happened. After going back into life again or into routine again you get so you can use this gift that this last person has given you for others and that's where you get your fulfillment. You must be very careful with this gift because if you give it too soon you'll ruin it. It has to be given at the right time and in the right way. But these people also teach you that

Geo: O.K. Can you elaborate by what you mean by this gift?

Bet: A gift of them letting you walk with them as they go through all their frustrations and all their feelings of saying Hey I'm dying and what does that mean....

Bet: ...if you can spend time with them they will allow you to spend with them will walk through the various stages and I'm sure you know the stages, some not all and some go through them several times

Geo: Uh huh

Bet: but it's a basic pattern and they'll allow you in on their feelings: Where they are, what today's problems are...and there's a gradual releasing of the world around them and their world is their room. Sometimes their family will visit with them and they object to the family telling them what's going on at home because they've already blotted that out of their minds and this is their here and now and they've decided somehow, I'm not going to be a part of that anymore, I can't worry about that anymore and this is my here and now they tell you how glad they are to see you, something generally trivial about how the nurses don't have enough time for them or something and then they zero in on their thoughts where they are. Most times they don't have any formal requests for you, physical things, you can do for them, it's just the being there. The family again is something different

Geo: like what

Bet: particularly with men. Men are very shy and awkward with their mothers and their fathers and sometimes with their wives but particularly with their parents as to where they might step in because in stepping in they're afraid to acknowledge for fear that that's not what the patient wants....men especially are very timid about it, maybe because they have to show their feelings...some men for some reason our society has said you must never cry, which is perfectly natural for us at a time like that...these people are dying. They don't have time to play around with the formalities and social games we play sometimes...It doesn't seem to be all that important, the age of the patient either....

Bet: ...it's O.K. they've probably built up some sort of screen or blockage which eventually somewhere down the line they take down...

Bet: They will be dying and this will be happening and some people it seems that until they grab a hold of one thing they cannot let go of the other and in letting go they are saying yes I'm dying...

Bet: Absolutely, they don't easily let you cross the threshold. One to one but when you walk into the group in a room they don't. This is their club and they feel that you don't know how they feel about a situation and until you can build up to a point where you can say to them, Yah you know I really don't. They know that you don't know how they feel, then they will share their feelings with you how this actually felt, but it's a very tight little, it's a club

Bet: One to one they'll let you, but you must be a very quiet visitor. You get to know the technique. This course that we take is excellent. It teaches you how to be an active listener, it teaches you how to encourage people and I don't know if they realize how little you have said and how much they have said, I don't think they realize

this. And life teaches you, each patient teaches you something in addition...

Bet: ...you learn never to make inquiries. You may start out and you must go with their agenda and they will...they'll let you know what their agenda is. You must also not leave the patient with the feeling that you're just a nosy old bag, you're there for each nitty, gritty little detail. You must assure them that you're there to help them and that you're feeling these things with them ...Another thing they want to know is that they're not speaking to their family members....They want exclusive rights to you. It's almost a possession...I think they are on an altogether different level with us than they are with their family members a lot of them along the way will verbalize that they are helping you, they're teaching you how to die and it's not uncommon for them to tell you that, which gives the relationship a new aspect for them as well,...

Geo: ...It sounds like you enjoy this work, it's right for you to do this.

Bet: It's a very humbling experience because people will let you into their lives you must, you must make yourself trustworthy

Geo: Uh huh

Bet: ...When I first started it was frightening because you're walking in to a stranger. This is their house and you're invading their territory. It was quite threatening and frightening but as you became more comfortable with it and realize that they are just as frightened as you are it puts you kind of on an even keel, as the patients teach you more and you can help that patient but more than that they help you, a lot of time they are ministering to you and somehow you must keep that even...At times when I go, when I've had a busy week and something has happened and I think I don't want to visit today. Those are generally my most rewarding days, the days that I am ministered to...and I come out thinking, Thank you.

Bet: Not many people in the critical situation can have the other attitude you know hey, God is aware that this has happened he was aware before it happened and he already knows the outcome...we are the winners no matter what but sometimes it's hard to see the situation

Geo: Is there a difference in the people who have no religious faith

Bet: Sometimes it's a hindrance if you have a religion because you're having these feelings and as a Christian you don't think you should be having these feelings. Sometimes it's easier to come as the non-Christian...and most times the patient is far ahead in the process than the family. Like we talked about before, they've had more time to get into it and you really don't have time to walk through each step with each individual family member.

- Bet: Your prime concern is the person who's dying because as far as we know they have less time than the rest of us...they need someone to walk with them. And if the family is not ready, it's not only that the family is not ready um but they are doing their own walk so they have two things to do, their own walk plus that of the patient. It makes it pretty complex for the family....
- Geo: Uh huh. Are you suggesting that maybe another part of the program could be for a volunteer to visit with the family
- Bet: I don't know, that would certainly be a lot of quality for it if it was just a spiritual need. Probably a person could but if there were other things that have to be worked out, I don't know that we would ever be qualified. You know if there is a whole life and problems to resolve before you can get to any of this, I don't think we would be qualified
- Geo: Are you saying then that the relationship between you and the patient that the territory you cover is more spiritual
- Bet: most times, most times it's about 90% spiritual
- Geo: Whether that person is a practising Christian or an unbeliever it ends up on spiritual
- Bet: Because when we leave this life that's what we're going to, we're going to the life beyond and this is what they're working through. What is that life beyond going to be, do I qualify for that life beyond, What does Jesus expect of me, Did he really die for me, How can this be a free gift, I must have to qualify. And if they have enough time they want to give this gift back to their family and let their family in on this Good News....
- Bet: ...the patient generally tends to be very truthful with you, sometimes the family will lead you to believe things that later on you find out they were doubting and are doubting,...

Code Name: Joy Season
Age: 38, female
Profession: social worker
Years practising: 18
Approximate time involved with client: 15 years
Total pages of transcript: 30

Transcript No. 6

Joy: ...I have had a lot of clients, a lot of losses of clients. I don't find it to be that traumatic or difficult, but I'm not usually sad when someone died at ---. I see so much suffering and what not that they have, that I'm usually feel more, thankfulness, and concern for the family but also thankfulness 'cause I know they're ambivalent, they've got the sadness and the grieving but they also let out a sigh of relief and say, "it's been a long hard road." My clients are more often the family, my clients aren't as much the actual patient...So I'm one step removed from the death although um that sometimes, I've had people that have been counselling on individual matters....But usually it seems like its a release and a relief for the most part. The people don't want to move here, if they had their drothers. They, I mean it's the last place they'd be coming to if they didn't have to come, so for them it's just a very difficult ordeal and there's the ones that I can be counselling individually...

Joy: You know they're waiting, they're asking, you know, please make me I'm ready, why, why, why are young people being killed and I'm still living, you know, let me die I'm ready....And they wanted to go they were ready. So I go to the many funerals and that feels good. And I've shed a few tears, but I probably am more concerned about how the family is going to do, especially if there's a spouse still living, how are they going to go on, when so much of their life has been tied up with coming and visiting, their purpose in life is suddenly no longer there. It's a shame for them, some very devoted spouses, it's a release for them as well, 'cause then they can know they did everything they could and they can get on with their life now.

Geo: Right

Joy: And they'll never be the same and they are sad and but they can get on with things, it's very draining for them to come to the hospital every day or every second day or whatever they've been doing....it's sad watching someone go downhill, for me that's more difficult, than to actually have them die....

Joy: ...I guess I don't see my role as doing psychoanalysis. I take my cue from them in terms of whether they want to talk about it, and if they want to open those doors, if

- they don't, I don't push...
- Joy: ...I want and need someone that I can do some interactional kind of work with, and that can be done with someone who has some cognitive deficits, but as they get more and more, the amount that they can transfer from one session to another or they can put into practise gets less and less....So it gets to be more working with the system and working with families...
- Joy: ...the systems work is working with staff....The system makes the quality of life for the patients, enhance it or detract from it, so that's the work that's done there and it's maybe through education, or helping the staff understand the client's particular situation so they can be more supportive of the person, so that's the work there. A lot of it's on that level....I'd say expectations and the guilt are probably a really common theme....
- Joy: We'd previewed some films of Sexuality in Aging. Sexuality within an Institution, How do we as an organization and staff, confine that, and limit it?...
- Joy: ...We have a lovely group here that the social work department originated and that I have responsibility for. Myself and Pastoral Care Worker, run it jointly, it's a spouse group called Family Idea Exchange, F.I.E. group, they developed the title for themselves and it's been running for six or seven years. It's almost become a self help group now. Our leadership is very minimal, we're a resource. It's a long term group initiated as more of a therapeutic group, looking at their own issues and their own commonalties and discussion around those; so they are connected very closely with each other over the first few years....
- Joy: It's better than family contact, the church, the social work; it's someone who's either been through, it very recently or not so recently or is about to go through it, they are in the same boat....a sub group even got together for Christmas Dinner instead of with their families, who had made other plans for Christmas dinner...
- Joy: I think the lack of judgement is there they really feel understood
- Geo: Uh huh
- Joy: ...I guess it's with any situation; another family member just doesn't know what it's like, and these are all very committed spouses for the most part many of them with spouses whose diagnosis is Alzheimer's or some other dementia. It's the younger group of spouses too, it's not the spouses who are in their 80's, like the average age at ---
- Joy: When people are expecting it, I think people are ready for it, you know, at some point the people I come in contact are ready. They're frightened and everything as well but their also ready for it. It depends on what

- kind of person they've been probably all through life....
- Joy: ...I think our challenge is to touch that part of them, that isn't just their reactions like there's more to that person than just their external behaviors and I think we as a staff, care givers, we tend to pigeon hole people, expect that and treat that and where as that person, if approached in a very different way, can surprise us too....
- Joy: Usually it's the institutionalization not a freeing aspect though. People don't see moving in here as a liberating, opening experience. It's restrictions, they're being constricted.
- Geo: But in the adapting process is there an accepting process or a freeing
- Joy: No, I don't think so myself there's an adapting process for most but not even for all. Adapting is probably a good word because I don't think it's really accepting. I think people, who are cognitively aware, realize the realities of their body; their needs why they need to be here and what they need to put up with.
- Joy: And so they adapt but to me that's usually a sad process because there's real grief around that and there's anger around that, I don't think many people ever resolve that one if it is resolvable. Just by nature being in an institution, the privacy's limited, they're usually sharing a room, they can't bring in their own special mementos, the things that are significant to them, there are indecencies too. Some people may call them Dear or Granny and maybe to someone that's just a slap in the face. So for most people it's a very difficult, pill to swallow: institutionalization and that's usually how it is. I don't see many people going through that period and the flourishing. There's a few but not very many, most people it's a resolution, adapting continually, trying to conform to the norms of an institution and depression is very common. I've heard that close to 1 in 3 extended Care Residents are clinically depressed so to me that's not an acceptance, they are trying to adapt, and not adapting all that well....
- Joy: It's something we start thinking about; I'm thinking about now as I would rather think about death than institutionalization, I can't avoid death. Death is something I'm going to face but I might be able to avoid institutionalization. I'm going to form my own, co-op housing or what ever. I'm going to have some friends and we will beat the system but I won't beat death so I might as well start thinking about that one and examining that whole concept. But I refuse to accept that I in forty years, would be in an institution.
- Geo: Has that happened since you're here, since you've seen what's going on?
- Joy: ...maybe it's altered my views of death as well....

- Joy: So my work will be with families and the system, the team, but I think I will feel the loss of the patients a bit more, I'm not sure, it will be interesting to see....
- Joy: ...In terms of staff, again our formal mandate isn't to work with staff on grief issues related to patients, hospice program would have more a mandate in that area....
- Geo: But how do professionals in this institution deal with that whole process? It sounds like there's no formal way of handling it.
- Joy: No formal way, no. Is that the best, you know, is that the optimum way. I'm not an expert on Hospice, is having a formal way better than an informal ways?...It's an interesting question, what happens to all the grief? ... I don't like to think of myself...
- Joy: I guess it's been good for me to review again to see how truly comfortable I feel with death in an aging population and that there's no boogy men there that I've been kind of putting a lid on, it feels fine and it's been good confirmation for myself....
- Joy: ...I wish there were ways we could be of more help to after death as a social work department we're not very involved unless we choose to call them up, someone that we've been seeing,...
- Joy: ...What more could we be doing for the families, to me that more the question of for the staff, it's for the families, the sons and daughters cause some things you know with the F.I.E group I guess there's some support but most of the families don't know each other, so how are they, you know, I'm not sure....
- Joy: I'd be curious. I think it's something our society as a whole. You know we do as much for the family and patient as we can up to the point of death, what do you do after, do you acknowledge the grief, the feelings or what not, I would hunch it's an area that needs addressing....You're not going to get that family going for family counseling. We're talking about extended family, who are O.K. and doing quite well in life but if things get stirred up with death sometimes quite volatile issues around finances, around dynamics in the family, it could be anything from family origin stuff, to current stuff that all gets stirred up again then it's just dropped. I think that they had more that way than staff, staff can have a different perspective, the families, their whole life as a family is right there in that instance. I think that to me would be my major concern.
- Joy: I'm very aware that there's some very heavy duty dynamics going on, that the family is in extreme crisis at that point both with the death and their own family situation and there is no help. No help given other than a kind of supportive help which when you're talking about that kind of active family difficulties it needs more than just support.

Code Name: D.K.
Age: 33, male
Profession: physician (resident pediatrician)
Years practising: 1
Approximate time involved with patient: NA
Total pages of transcript: 59

Transcript No. 7

- D.K.: Well George, I read over your stuff and it's hard, it's hard to pick out one person whose death has meant more or less than anyone else, partly because of my position certainly during my clerkship I didn't get close enough to anyone who was dying to make an impact. I was able to keep my distance and worry about learning stuff full time; that's my last year of medical school, They brought me in and showed me how to pronounce someone dead and make sure they weren't alive (laugh)
- D.K.: My first month on the wards I was awakened twice on two consecutive nights on call, to pronounce babies dead, one was 3 months and one was 8 months. I had known they were a no code that is they were expected to die and weren't to be resuscitated. It wasn't a big deal for me, I wasn't taking care of them on a day to day basis, I was just told they were expected to die, neither were expected to die on the nights that they died but they died anyway....
- D.K.: My first intimate experience with a death was a baby that was born at 26 weeks gestation. I was the junior resident in ICU and...it was one of my first nights on in ICN my first nights covering life and death situations. I went there and didn't know the first damn thing to do. (laugh) Luckily, the nurses up there are very well trained and covered me until my senior resident got there and he took over and kept the kid alive until the attending physician got there, the neonatologist. The baby died subsequently but it was all a downhill course and it was clear that the kid didn't have the lungs to survive in the real world. I was quite upset after that death and R----- came over to console me but the thing I was upset about was not knowing what to do I had no idea what I was doing when this happened and the fact that the kid died was no big thing, he was obviously not meant to make it....
- D.K.: ...Essentially I got kicked out by the dad, didn't you know, don't poke at him if you don't have to...we came out of his room and sat down at my desk and the atmosphere was very charged especially since the nurses had known this kid for a year and a half now...They were all in tears and this is my first time with him and I think the thing that struck me was writing, "Do not resuscitate." This kid is going to die and T----, the unit

clerk, (the unit secretary) came by and gave me a hug. The oncology unit is a very warm, touchy, feely place to work...and um for a matter of a few minutes I was quite choked up. I really choked on that one and um darn near in tears over a kid I didn't know....

D.K.: I was mad at the beginning because all of a sudden this, the doc disappeared, where did he go? I could look across the courtyard of the hospital and see into the DAT centre, here he was getting his coat on and tearing out the door. What he was trying to do was to get to the liquor store before it closed, this kid liked screwdrivers and he wanted to let the kid have his last drink....Well the mother said she had some Vodka at home and she would go home and get it for him. And so that night, the big emotional things there was the switch from full code to no code status, that from now on we were treating this boy to make his death comfortable instead of prolonging his life. So we so we got him a screwdriver, had the pharmacist to come in and prepared and oral liquid called a Brompton's cocktail...from then on my job became quite clear, to make sure the kid didn't hurt....

D.K.: ...Once we decided that he was to be allowed to die he was much more calm with things. The father was much quieter and the mother was very easy to get along with, in my point of view and they were all quite supportive of this boy.

D.K.: But the third guy that made a big impression on me was a boy named J-----....Here again was a boy that I had known over the course of about two and a half months, met him in January, and he died in March and um I had been there when he came in in relapse um saw him when therapy was withdrawn....Here was a very nice boy, and a terrific family, I really liked that boy.

D.K.: There was a fourth boy that I really liked,...He was a terrific guy, just a terrific kid. Everyone liked him: a friendly guy, very bright, musical, had everything going for him except cancer....My feelings were kind of screwy there. One was why the hell did this have to happen to this kid. Two, was that tumor there when I was covering him, should I have felt it two or three months earlier. Needless to say I ran and checked them, we had done an ultrasound and the ultrasound was clear at that time....But here was a kid that was everyone's favorite, everyone really liked him and he died....

D.K.: the fifth kid I want to tell you about was a little baby that was born while I was in the nursery...

D.K.: ...they have a little grieving outfit that they dress the babies in when they're going to die, or when they're dying or when they're letting them die, so here is a kid and I was really surprized at my reaction; that I would find it very sad and tragic because the parents were

holding him for the first time and this kid was two or three weeks old. They were finally getting to hold him and see him with clothes on and all this and he died within a couple of hours. That was a very touching for me for some five minutes or so felt that's really sad you know. Those are probably the five kids whose death has meant the most to me, or gotten the most reaction out of me.

D.K.: I've worked on oncology now for three months and you get to know some of the kids really well,...in two cases kids I have followed over the course of three months or so and none of their deaths have kept me awake at night....For the first part of the year it was, how did I do my job as a doctor...I haven't seen kids in my practise die so it's been more or less "That's the way it goes, he was a really nice kid, you know, I really liked J----, or D----, or C---- or whoever it was..." I know other residents, like some of the women who were much more openly emotional...I remember a friend of mine saying, watching a TV show, some guy had died and gone into this bit, you know, gave all his last, last words and then died and slumped over and someone had just died that afternoon and she was still having a lot of tension. "Damn, why doesn't someone tell those writers that they don't turn their heads when they die." My approach has been to keep myself insulated a little bit....

D.K.: ...Occasionally you see your own children in them....

D.K.: ...but I also spent three of the last six months on oncology where the kids are basically normal kids, they just happen to have cancer that's all...

D.K.: ...so those kids touched me more, I see kids the same age as my own children dying...

D.K.: and you know there's this one little girl, I laugh, she's the second cutest three year old in the entire world after my own daughter M---, she acts just like M--- and laughs a lot and I can play the same jokes on her...

D.K.: I said, Yah, she's the second cutest girl in the entire universe and my staff looked at me and said, "Don't say that about her (laugh). You know, (laugh) don't get too personal with her. He's a guy that you always see crying, he always come in with his eyes full of tears, he's either very emotional or he has allergies,..."

D.K.: ...I'm satisfied with my approach right now a mixture of getting personal and getting to know the kids and getting to like them but excepting their death as once I've done my best, something I can't control...

D.K.: ...I would expect to go to the funerals of the kids,...

D.K.: but I think I'm as detached as I'd want to be and I think it would be, I think it would be dangerous to get any closer....you're just going to see so many die. If you're going to allow the assault to go on your psyche everyday, I think it would be hard to come to work every

day....You see, I don't want to portray myself as someone who is stifling feeling or someone who is repressing feelings of grief, I think that so far my approach has been to say, "that's really too bad..." and on the two occasions I had to choke back a tear,...and interestingly they were the one's I knew the least...

D.K.: ...but for these kids I liked a lot I haven't had a chance to go through the actual dying of the child in the same room, although I would avoid that anyway because it's not my place, the parents are in there and they know he's dying and they don't want an extra jerk like me hanging around...I don't think I could have cried for those guys.

Geo: Why not I don't understand?

D.K.: I don't think I could have had a more emotional response I guess not long ago reading Kubler-Ross stuff about death and the stages of death, you know it's usually clear to the physician involved that the death is imminent before we go over with the parents and so having to go through any anger or denial of the death or what ever the other stages four

Geo: I don't understand at this point, who's going through these stages

D.K.: Well, if I as their resident involved with them, those stages aren't part of it because most of the time I got them and the death has been imminent and there's nothing to do but accept it. You know, if we've done the medical things and well the parents will be angry with you and angry with everyone or they'll be denying or even accepting you know, I've seen it all the thing to do with them is to be patient. If they're angry with you, I haven't felt any need to come back at them or anything except to say "well, you know, I'm sorry..." They're the ones that have to go through all that stuff I haven't

Geo: That stuff?

D.K.: That stuff, the five stages, the Kubler-Ross stuff

Geo: Uh huh

D.K.: By the time I've got a kid he's already in relapse, they have already failed their therapies or whatever.

Geo: What does D.K. go through, What stages does D.K. go through?

D.K.: All I've seen in myself associated with these deaths is the feeling at the time of death or the no code pronouncements is just a feeling of sorrow or something not, a bad feeling, it has never lasted more than a few minutes and generally feeling that, if I may put it simplistically, it's really crummy that this had to happen to this kid, this nice kid, and in a in a few cases I've had like I said the one kid that looks like M--- and when that baby died and the parents finally got to hold it. I've entertained the thoughts of how would I feel if it was my own child but I've had to explore that feeling more es-

pecially with the oncology kids more...

D.K.: I don't know if I could watch it. I do entertain these things, my identification goes more to that aspect of it. You know, if my child had to go through the bone marrows and the spinal taps...but it gets to be a fear, could this be cancer, could this be cystic fibrosis, could this be any number of bad things, that we see and so my fears are more towards getting a bad diagnosis on one of my children or my wife and when I meet a child say in the oncology unit where they all have life threatening diseases. Some of the ones that have really touched me and the ones where I've lost the most sleep over have been the ones who have been in for diagnosis not the ones who have died....

D.K.: Well getting into the question of how emotionally attached I want to be to my patients um the emotional attachment for me has come either because I've gotten to know the kids or because they remind me of my own children. When they remind me of my own children I've had the most fears, the most disturbing thoughts to deal with every time I ever look over the history of a kid with that. The kid has had a history of a week or so of things that my kids complain about all the time but that's the thing that's been tougher on me than the actual deaths of the patients, is the worry that a disease like this might happen. Perhaps I've been lucky because the kids I've seen die have had things that we've been able to predict it or at least be known that death is imminent for a while...it's generally quite clear to the people who are working on the case that this kid is going to die and you might as well accept it.

Geo: Who is You?

D.K.: Me, the residents that are working on the case and in here it's the nurses that grieve a lot more that we do. You know they show a lot more sadness than we do.

Geo: I wonder why?

D.K.: Well, in most of the kids that did die like I said, I haven't been involved in any sudden deaths, accidents or anything. The oncology patients we have, the oncology unit, the nurses take care of them...

D.K.: ...and the nurses there are specialized in cystic fibrosis and they know the kids, they know the parents and they've known them for ten, fifteen years...Some of these cases, so the nurses are almost without fail clearly sad, and more attached than the residents are

Geo: It still sounds like it's not O.K.

D.K.: What?

Geo: to be sad, to grieve, to be involved

D.K.: Well I don't agree with that I don't know how the other guys handle it but I think I'm as involved as I could be given the time I've known the kids and the longest I've known any of these kids is five months but, I'd seen that

kid for two weekend trips...He's got pain in his shoulders, it hurts so much for him to roll over so that he doesn't roll over at night so that his shoulders ache in the morning. So all he wants to hear about is the morphine. So he's a nice guy, how involved can you get. I think there's only so much you can get involved, you know him as a nice kid and you have some nice memories of him and you see him as a sense a normal kid he seems a nice kid but when he's your patient you take good care of him and try to make sure he's not vomiting too much, you want to make sure he's satisfied with his control. You control the vomiting or the pain or what ever.

Geo: He's a nice kid with a fatal problem

D.K.: Yes, so you take good care of him and how emotional a base can you have to a relationship like that I guess I try to think of who I know who would really make me grieve, like Kubler-Ross writes about. Who would make me grieve or who in my life, if they came up to me and told me that they had a terminal illness, would cause me to go through with them stages of death. I don't think outside of my family, outside of the seven people who live in this house and my parents would cause that. Maybe if I was to try to summarize how I feel about it. The tragedy is their's not mine and I can try to be compassionate about it and I think I'm successful at it, I've had good responses from my patients when they've talked to me about that or other things later on, they seem to like me as a person and as a doctor and I try to be compassionate and sensitive but...

Geo: It would blow you apart if you would have to treat them like you would treat M---

D.K.: Oh heck yes, I try and think that, you know I see guys coming in and out of the place, they go to work and you know they drop their kid off for chemotherapy. They go to work and they come in after work and sit there till bedtime and the kid goes to bed and they take off. You know if one of my children were in that unit and I had to work in the same hospital, I don't know how I could function...or if they were dying, I don't know how I could possibly do my job with the next kid you know. Another kid's problems would seem so trivial that it just wouldn't be worth the effort to get involved or else it would remind you so much of your own kid's problems that it would be difficult to stay involved. I don't know how they do it. You got to get a balance between that job and your life...

D.K.: I'm still more haunted or nagged by my roll as a physician and doing a good job as a physician than by anyone who had died...

D.K.: ...we all think about our mortality, and how we're going to handle it and we think about our family's mortality and stuff now what would happen if K----or L----showed up with peticii all over, that's little small bleeds,...so I

think about stuff like that and in most of those fantasies or day dreams and times when we try and rehearse things that might happen there is a lot of sorrow and almost a feeling of paralysis with it. But those fantasies have not come at the deaths of the patients, they have come at other stages of the course of the diseases....

Geo: Is it a matter of relief when you see the patient reach the point where death is imminent?

D.K.: Yes, there has definitely been relief there and I definitely see relief in the parents and in the staff working with them, there's certainly a lot of relief when the patient that we've whispered about Code status for a couple of days has gone to that status and finally gets it over with and you know when you see an acceptance type of thing in someone else who's going through it and is actually dying or the parents of someone who is dying...

Geo: It's been a difficult interview

D.K.: I've played over the interview in my mind a couple of times since I first heard about it, largely because I didn't think I had anything solid to offer you, I didn't see any solid stories of grieving. I've talked over all this stuff with S---- on occasions, not related to this interview. She's heard all this stuff before except relief. The residents get together informally quite often especially when someone has died, and talk it all over...

D.K.: ...you've got to have some approach to death. Now, we've all been involved with the staff guys who aren't good with death. The case in point is this kid I mentioned a couple of times the child abuse thing and the resident involved there, said she just, she just felt like she was alone the whole time, the attending physician, who just happened to be the one on the roster that day and the kid came in through emergency to the ICU so he didn't really have anything to do with him. The ICU physician, and the child, and in this case the child abuse team, wasn't involved yet and there was no one there to, to help her talk to the parents...

D.K.: and uh I'm please you came up with the concept of relief that is new, is something that I hadn't conceptualized.

Geo: That sort of surprized you, the concept of relief

D.K.: Well it was there, we've talked about it in terms of other people, that relief occurs but you know, it's a bitter/sweet concept, the relief that comes up when you decide that you are only going to aggressively treat pain and other things and then ends when a patient dies. All the deaths I've seen this year have been of that, that category, and that sort of justifies ones feeling of not having a lot of sorrow with the death doesn't it. You've already gone through your sorrow, you're right, you're absolutely right there....

Code Name: Myrna
Age: 49, female
Profession: Registered Nursing Assistant
Years Practising: 24 years
Approximate time involved with patient: 5 years
Total pages of transcript: 34

Transcript No. 8

- Myr: O.K., now we're going to talk about S---- who is a patient at ----- and I had known her for five years as a patient, she was a Jewish lady, and she had one son who didn't pay much attention to her because she was a very lonely lady. And at times she was confused. But she was really unique because you know when she was confused she seemed to make sense.
- Geo: Uh huh
- Myr: S---- was very special she was a lady not just a lady, but she was a fine lady had her manners and she was a really superb person. Spiritually I always felt a great concern for S----because I was trying to make sure she knew Christianity and she was trying to teach me to be a good Jewess and like I said before she somehow in her mind got confused that I was her son's wife there was no way of showing her differently...it didn't matter because I was her son's wife and that was it. My name is Myrna but to her I was Merva which is a Jewish name and she was always planning trips for her son and I and herself to fly back to England to visit the relatives because it is time the relatives knew me and all the rest of this crazy thing...
- Myr: ...Up until the time that she died I think she became extended family. I know this is something you're not supposed to do with patients, you're supposed to put up a barrier, and not let patients cross that but I don't think there are many nurses who work in a place like the ---- that don't have a special patient
- Myr: ...you know the girls always promised me that I wouldn't have to be with S---- when she died but S---- did die in my arms. It was the first that I ever ran out of a room where I was to look after a patient but for some reason I could not remain in there. It seemed so cold and distant. In fact it took me a long while to go back into that room even after the rabbi came and took the body away. I really don't know why I reacted that way but ... it was like losing a loved one a member of your family, a good friend, a close friend, I really wonder now when I look back whether it's because being a Christian I wanted to make sure S---knew the Lord, knew Christ and I didn't know that and she just wasn't having any part of that, she knew her Jewish faith and that's where she was at and I think basically it's far easier when somebody is a Christian and you know they're going to a better place,

it's far easier to let them go. But if they're not a Christian and you know they're not going home...

Myr: And I really believe that if a nurse is solid in her faith and really believes I don't think there is anything wrong with saying to a patient could I pray with you, especially if they are dying.

Myr: I guess that's where my whole hangup with S---- was and I think that really bothered me....

Geo: this was not a patient but this was a person

Myr: My friend, yes, she was more like a mom to me. There's lots of things that bother me, about not only S----but older people, ... when they're dying, they're lonely ... and somehow I think it's great the care they get, but I think there should be more care on the spiritual level the older they get. Bodily and healthwise their just about finished. There's great care in the world to make sure they can move their arms and have all their, you know freedoms but there's not much emphasis on the spiritual. I'm not saying there's none...

Myr: I knew she was a fine Christian lady and solid and she died. But all the night before she died she would say "Sing to me Myrna, sing to me." And I sound like a frog, I have no voice, but I sang every hymn I could think of and B---- was with me. And B---- was so touched, she said: "Wouldn't it be great if all patients could go that way. And I really think this would be. Basically I think every nurse wants their patient to be comfortable and at peace and you know by looking at your patients you know if they're uncomfortable, if they're in pain and you know if they're afraid. I mean you can look at patients and see naked fear and over the years you try to find ways to calm them. In the last few years like I've only been a Christian 12, 14 years it's really been impressed upon me that everybody tries to do so much for them bodily and emotionally but there isn't an awful lot of emphasis on the spiritual and that's the only thing that will take away the fear. You know S---- isn't the only patient I have had that I have sensed this fear, that I could do nothing about. But she was the one, I guess, because we were very close, that it bothered me the most. That somehow I failed to reach her ...

Geo: Wasn't it a mutual affair. She also chose not to

Myr: Oh definitely, I guess what I'm saying, is there are a lot of people that die but nobody really cares whether spiritually they're headed in the right direction, it's something that isn't cause for worry in the medical profession because you're not supposed to bring up prayer or anything, the patient is supposed to. If the patient asks you to read the Bible, that's fine but you're not supposed to be the one to instigate it...

Myr: ... Where S---- had that cold naked fear and you just wanted to hold her like a child and try to comfort her and yet there was no comfort for her. Do you know what I

mean? It didn't matter that you held her tight because there was nothing else you could do, her faith blocked out the peace

Geo: You mentioned a couple of times about the naked fear, the cold naked fear. I'm wondering if you could elaborate on that or make it clear?

Myr: O.K. Just cold naked fear um ... have you ever seen somebody who is out walking and they come upon an object that terrifies them like a snake or a woman who is terrified of a mouse. Well that's about it, her eyes were big, you know just naked fear.

Myr: ...She was calmer with me than with any of the other girls. As long as I was with her, she was a little calmer but I couldn't get her to relax. I couldn't get at that fear.

Myr: ...Like I say she isn't the only patient that I felt this but because she was close it's bothered me because it's your last thing on earth you're going to do for a patient...

Myr: I've had a lot of surgery before I was a Christian, I've had major surgery since I was a Christian and I could not believe the difference....I had major bowel surgery for diverticulitis, I was a Christian then and that was the one I should have been afraid of. I think that this is the thing that I really wanted to give S----, "Don't be afraid," you know and basically I felt like I had really let S---- down. I had not completed what I had wanted to do, I knew I could if I could make her understand.

Geo: As a nurse you'd like to give not only your best but all which includes the spiritual aspect

Myr: Right, that as a nurse, you have a walk with the Lord, you should be able when you see patients struggling or even if the patient isn't struggling to speak openly that there is a loving and a caring Father. I feel really strongly on that but I don't think you should be dictatorial on that and say "Hey do you know the Lord get to know him now."

Myr: You know there are ways you can share. There are many things you can share with people, show them through love and your everyday living and you know I've had patients say to me why are you so different or how can you be so happy when you're working nights all the time and where do you get your strength from and regardless I have said "From the Lord" it's past time, I think the spiritual aspect should be taught or as well as, well I shouldn't say it's taught but accepted if you're going to try to help heal the whole man then spiritually that's part of the whole man. But where is emotional support without spiritual support. If you have a sound spiritual mind you're not going to have any problems emotionally really if you've got it all where it should be. I'm not saying hey become a Christian and everything will be rosey, that isn't what I'm saying but I'm saying you can face things

because you will never face it alone at least that's how I'm finding it in my own life,...

Myr: ...with Mrs. S-----, I can say what I want because I'm no longer her nurse but with S---- she was my patient and there was a code of ethics to follow and I had tried to follow that one but this one is my friend and I will share Christ with her every chance I get, if I can get her calm that way because I think it's really important and I think not only is it important for the patient but for the nurse too because then you've done your work well. If you can have someone calm then you know you've done your work well...and I can't see why people in higher places cannot see it, why can't administration see that it is really one area that is lacking. Surely there are many middle age and older people in the churches right across Calgary who would be willing to go in on a one to one basis; retired clergy, retired missionaries, but even just letting a free hand on putting the spiritual in there as well as emotional. I think it would do wonders. Maybe I'm becoming radical, I don't know I feel that there should be a lot of emphasis on the spiritual when you're working with dying people. If families are around you should be able to speak out in comfort to them and to me when you're trying to comfort somebody who is losing a loved one you speak in a word from the Bible you don't use your words because they're no good, they're empty, they're hollow, but God's word isn't empty so if you can do that then you've served the purpose....

Myr: ...I remember when I had my bowel surgery I was on a cancer ward, just 20 of us there and everybody had cancer. Talk about praising the Lord. I was the only person out of 20 who came back without cancer and there was a Mennonite lady across the hall from me and she was dying and you know George, 300 people took turns, she was never alone but they prayed around the clock with her and when she died, my bed was in this room across here and I could look and see her in her bed, she just raised up her hands like this and said "Jesus" and she died with the biggest smile on her face. I thought the peace that woman had and if you really believe you know that you have that peace and so why are we not allowed. What I am saying is you know the Lord and you know the peace and the Bible is the oldest book ever, Christianity isn't new...

Myr: Maybe people would say that I am becoming really radical, I don't know, but I think that spiritually we have neglected our patients. I really feel it's a neglect and I believe more nurses would share if it was an open thing and I believe that through that sharing you would be able to give your patient peace and hope...it's a hard situation to get into because there are so many faiths, so many beliefs and unbeliefs. It's my right now and it's in the Canadian Constitution "I don't have to listen to you..."

- Myr: You'd have the satisfaction that you knew that you had done all that was possible, mentally physically and spiritually, and I think there are a lot of people, nurses, doctors, who really wonder if they have failed spiritually, and all we have to do is look around at our world and know that this is what's lacking in every facet of life it gets worse and it gets worse and here I go again, "if my people will humble themselves and pray" and I think this is the thing you have to get back to whether it's in the hospital or not, it doesn't matter where you work, I firmly believe that especially dealing with people you have to look to the spiritual as well as the emotional and the physical...
- Myr: ...I thought my dad was just a shell and he thought I was blotting out death and so he insisted I go and see my father but my father had a smile on his face, just a beaming smile, I said you knew he met the Lord, it was there, that peace, you know big smile on his face, you knew there was peace and I compare his face to S----'s rigid fear that's what I would like to blot out. If there is one thing I can do in my earthly walk I would like to blot out that fear to be able to if I'm ever able to go back nursing this is one aspect I would like to be free to...
- Geo: Is there anything you feel you should say or want to say or could say?
- Myr: No, I think I've said it over and over again, the thing that bothered me most as well as losing a friend, I thought I had let her down...
- Myr: ...I think there's a low key movement where they try but it to me I think you should put their spiritual problems up there with their emotional and physical and maybe if they got the spiritual sorted out first the other two would be far easier...

Code Name: Jim
Age: 58, male
Profession: medical doctor
Years practising: 29 years
Approximate time involved with patient: NA
Total pages of manuscript: 70.

Transcript No. 9

- Jim: I think that varies to some degree with the kind of responsibility that one has and the degree of responsibility that one has with the individual patient, and I'll speak about patients because that's the relationship in which I'm involved with palliative care and with death. Because if you in fact are writing the orders then I could see that one might have a somewhat different response than to some other professional who in fact felt no or very little sense of responsibility as to the actual death itself...
- Jim: straddling the patient pushing down on the chest and mouth to mouth breathing and I did this for I don't know for fifteen to twenty minutes and there was no response what so ever, so that I found myself not sleeping well that night in fact I stayed awake that night and I remember seeing the dawn and I had a lot of questions, could someone with more skills have actually saved that young man, because if we had gotten him through the initial insult he would have survived almost certainly. But the fact was that I was the doctor on call and on service, at least he had me and I did "the best that I knew"...
- Jim: ...I can think of two people where we stopped respirators and I quickly developed the policy that if I wrote the order I also had to stay around and implement it. It was not appropriate, I would even say ethical for me to write the order and then for me to walk off and expect a third year nursing student or even the charge nurse to have to go pull the plug, knowing full well that death was going to ensue within a matter of minutes....
- Jim: ...Another one that's again particularly in the final analysis a doctor-patient one is the decision to abandon treatment, the cancer patient who had been getting chemotherapy. And you finally say let's stop chemotherapy we're not getting response and it's making sure that the patient is totally informed. So that I think the impact there is a great deal different without having been in the experience of say a social worker who is dealing with emotional problems, with inter-family problems but who in fact is not writing any order that is significantly altering when the death will occur but is dealing with things around that death. The answer to that question has to be qualified a great deal, how it affects me depends again in part on all of the other features, is this somebody that I've never known until two days before

death, they're in coma when I first meet them,...so that I could support the family physician who had the major contact with the family...

Jim: She was a brand new unit clerk on who said well we haven't got anybody by that name. And I said "well that suggests to me that she died over night"...

Jim: ...I subsequently worked with this oncologist several times with situations where she in essence said I can't handle this and you seem to be able to handle that scenario better than me eventhough you're not primarily a cancer specialist, would you take over and she solved those situations on her own level for her own needs by getting out. Superb young woman who did excellent work but when she reached that point she was undone and she couldn't deal with it.

Jim: ...she had three brothers, she was the only girl in the family and I think had sort of become the apple of father's eye....the malignancy appeared and this brought out sort of the latent "Well I don't give a damn anyway" ...and so now it had become a convenient way to escape everything, I will die....

Jim: ...She and I became pretty good friends.

Jim: We stopped, C---- and I making the decision alone without mother's input although mother and I had become pretty good friends by now and I kept insisting with mother, now look C---- must have absolute trust in me that what ever she want's to be kept confidential will be and that if I talk with you it's with her permission. And we as I say we established pretty good relationships. Well, when C---- and I finally said O.K. let's quit, we could give you twelve cycles but we don't really know if twelve is any better than six and we better just stop now, a delightful period ensued. This was about March. By summertime she really felt better,...

Jim: ...then she began complaining of a little soreness in her neck and her speech wasn't quite as good. All within a matter of a couple of days we realized she's got bumps... ...I sat down with C---- and said, "C----, this is the way it is." And in essence the two of us looked at each other and I said, "I can't in good conscience urge that you start chemotherapy again because I don't think it's going to do a darn." She said, "I don't want to."...

Jim: ...So in essence we sat down with the staff and had a quick cram course on "Reactions to Dying"...

Jim: ...I felt very badly because I had almost become a surrogate father to C---- and I just felt badly that I should have been more perceptive and stayed and been with her at her death....several of the young adults, here's the Flatsome and Jetsome of teenage, they took turns staying with her, they didn't do anything but they stayed, they comforted C----'s mother and she's talked to me many times about this....The resident, one of the residents, who was a medical resident not a psychiatric resi-

dent and had treated C----through some of her medical admissions was not on the floor and C---- seemed to be getting worse and the psych. floor needed a doctor who knew C---- to give them some help. They had to do something to make it easier. So they put out an overhead page in the building, Dr. So and So Unit 22 stat. C---- through her cancer had made friends with several other people, young people, who had other cancers,...The stepfather of one of those young men, is a personal friend of mine and a patient, was up on one of the other medical units. He recognized the name over the intercom. So he just got up and came down to, because I had kept him appraised and through his step son he knew a little bit about Cindy as a person. He came down to the unit, the resident arrived on the unit, and she quickly said, "Well let's give her a little intravenous morphine, it should help take the pain and maybe ease her breathing slightly. Well it did, and in fact in a matter of minutes she died. So this chain of people collected. And the mother was tremendously impressed by this chain. They phoned me, I felt badly, so I found out where mom was staying with another relative. After work I drove up there and sat down with her and we talked a little about the afternoon and some of her feelings and then I started probing gently, "Well what are you going to do." "Well, it's been so long and dragged out, I think we'll have a quiet little service we won't have a funeral" and I didn't hit the roof but got very directive which don't I often do, and I said "Look you're having a funeral." ...So she said, "Well I'll cry." I said, "that's fine that's part of it and if I may make a bold suggestion, Dad had died before C---- died and I had learned this through practical experience,...and you'll experience a sense of physical support eventhough nobody will lay a hand on you during the service and I've gone through it and experienced it

Jim: and sure I cried but I also had an easier time with my tears than I would have if I had been clustered off in a side room and there had been just me and my wife and a few family members and we'd have been no great help to each other because we'd all have been in the same sad state to the same degree at the same time. So I'm urging you do that way." Well, reluctantly they had a funeral. I phoned her because they were about a hundred and some miles away, I didn't drive down, I just felt jeepers, my contribution has in a sense been made and yes I've got my own grieving needs but in a sense I'm working them out by being useful to the family. So I phoned her that night, I said, "How are you?" She said, "It was triumphant." Those were her opening words. I said "Hey, you weren't going to have a funeral." She said, "Oh I can't help it." She said, "Can you imagine, there were six hundred people there, the place was jammed." And she said, "Oh, yes and it was the right thing to do." And I said "Well I

- am so pleased because you almost denied yourself those feelings if you hadn't had that service and you make me feel better because vicariously through your words I can appreciate what went on and I sort of knew it would."...
- Jim: ...and then pursued a few more questions with her after she had viewed the tape with me and with the class. And quite intriguing, after we finished that and in front of the people, she turned to me and she said, "I won't be back next year, I don't need it anymore." ...our grieving has reached a state where we're comfortable."...I firmly believe the truth of the teaching probably Kubler-Ross more than anybody about identifiable phases of response.
- Jim: And that the caregiver in this instance myself as a physician/caregiver, we all become part of every dying person whom we contact and we in saying we become part, we become part to those reactions and with some patients it will be to a great degree and depth as with C---- mine were quite obviously. And with other people as with the lady I mentioned the last couple of days and whose death I could comfortably confirm by a phone call only, to a very minimal degree, but we're part of it. And so at any given time I am involved in literally dozens of impending deaths and grievings to varying degrees. But I'm also receiving strength and support for each of those from number of other people who are part of each scene....
- Geo: Could you elaborate on that the number of people...?
- Jim: Well, this will be a strange answer to that but I became a grandfather today,...I missed the birth, the nurse who was helping my daughter was superb. She was the kind of nurse giving not terminal care. In this case it was brand new life care not end of life care, but it's the same principles. She touched people, she and I hugged each other, we stood several times at the foot of the bed and put an arm around each other and she did this with other members of our family in a very natural, unaffected and yet in an unembarrassed way. She did her job efficiently. She looked for little things like there was some blood on a sheet made sure that that got tucked under especially when she knew that our first little granddaughter who is two and a half was coming in to see mom and the new baby sister. The same kind of nurse doing the same kind of things with me as a collaborative team with someone dying help each other, the resident who came on a quick emergency call was comfortable to make the decision, "Sure I'll order some morphine, she didn't wait, and say "Oh I can't do that I'd better phone Dr. Jim or somebody else," no, she just did it. She and I have become good friends and she is now a practising physician in Calgary in this hospital and we still every now and again sort of update with this particular family because she's interested. Well she helped carry me with my grief and I helped carry her as we both watched C----get closer to death and then she took over and carried me

totally. The afternoon of the death itself, a social worker and a chaplain and physiotherapist, a nurse, all of us do that with and for each other. So if I've got people like that and maybe I'm involved with a dozen potential deaths at any one time but I've got all sorts of support coming back to me to help me with those,...So that's what I mean by helping each other, carrying each other. Oh Lordy if it didn't happen then of course a professional would in fact put on what in the old days was called the Professional Attitude, you don't get involved, you don't show emotion, it's just your role to be efficient, capable, and no tears and no undue emotion, don't get involved. Well to me the whole emphasis is just the other way around, it is be human, be natural, be involved, which will mean at some time being sad, and maybe wondering off and having a quiet cry,...and maybe not having a quiet one, having a cry and one of the other professionals, not necessarily your own rank or kind will come along and say "Hey you've really gotten a lot of emotional involvement with this patient haven't you, go ahead, let it out. I hope that makes sense.

Geo: ...Does it ever happen that way between you and the patient, do you get something from the patient?

Jim: Absolutely, and often unexpected things one of the things I was thinking about for reasons that escape me now, the other day was the recurring but not common experience where a patient will make some sort of connection by which they feel their death is useful. Let me explain. A gentleman who was actually a couple of years younger than me and again I can't help identify in those scenes saying, "jeeppers how would I be feeling if my life would knowingly going to end in a matter of days."...And I was feeling pretty sad for him, what a waste, cancer of the stomach....I was saying how are you feeling, "Well not too bad." "How do you feel about the whole thing, about the cancer and about the fact that we have reached a point that we are literally saying we can't do anything to hold it back...and I don't know if the words, "You are dying" were used that day or not, certainly we were very clear that that's what we were talking about, sort of searching about how he was getting his support, I said "um you're married, your wife, she's holding up." "Oh yes, she's a real help to me." I said, "do you have children?" He said, "No, no children." And then he stopped and said "You know that's ..." And I was immediately thinking, "Ah, too bad", because children can be so helpful to the surviving parent let alone to each other and as a father of five I sort of feel very rich, and I think of somebody with none as impoverished (laugh). And he was saying "No, I'm very pleased about that." And I said, "I, I don't understand." He said "Well, my father died of cancer of the stomach, and now I'm dying of cancer of the stomach, but we don't have any kids." And I twigged and

said, "There's no worry that somehow through dad, through you, someone else has been fated to die of cancer of the stomach, you've sort of snuffed that out with you having it and you keeping it and no one else in the family." He said, "Yes."...

I said, "Well, yes I can see how that would be almost a comforting thought to you." He said, "Yes, it is." So here he was as he faced death gaining a comfort out of a connection that I frankly, I don't think would have made....

Jim: I've really appreciated that you've been my doctor and my friend. Well hey, what higher praise is there than to be called a friend,...sad that this friendship physically had to end very shortly because of the death, but that's, well to me that is extremely significant, strengthening, but I guess it's whatever you want to make it, to someone else it might be well, thanks very much, well big deal somebody called me a friend that's what I'm supposed to be a good doctor. They have gained nothing out of that, I doubt that however, I honestly doubt that, I think that almost any professional gains a great deal when any human being takes the time to say thank you, whether it's a life-death situation or just an illness recovery situation. So we get a lot of things back

Geo: ...does it take a special person to deal with these situations. Is it something that grows over time?...

Jim: ...most people can probably develop a degree of comfort so that they can function well enough to extend that kind of help but it's a growing thing...and then getting all those experiences for instance the one about sitting in the church and feeling strong enough to start telling people I really urge you to do that I wasn't doing that the first five years of my practise. No. And then study, starting some years ago with and I'm not really quite sure why I did it but going to a conference called the International Symposium on Death and Dying sponsored by the Royal Victoria Hospital Palliative Care Unit. And I went their third such international conference, they hold them every two years, and that really stimulated a great deal of interest, aware that there was more than just anecdotal kind of experience to tap into but that people like especially Kubler-Ross and Cicily Saunders, Dame Cicily Saunders of England. Well as one starts to look at material you then start to get a little analytical about the situations oneself is in, I found myself doing that, and then I found myself as it were almost testing some of the ideas...I think that one of the other things in my own instance that helped has been my own strong involvement in my church community so that I haven't been shall I say scared off by the thought that some of this is well less medical and perhaps pastoral let alone even theological...but I just adopted the attitude that doctors aren't the only ones who as it were

treat people medically, and pastors aren't the only one's that dispense pastoral care and nurses aren't the only ones that nurse, we all transgress professional lines if you will all the time....good palliative care is to deal with the whole person, and the person's relationships, the person's state of health meaning the person's relationship with God, their theological and belief system with fellow man, other humans, family, caregivers, community, and to deal with their knowledge, their intellect, their brain, their being, and their emotions. Well there it is Luke 2:52,...based on Jesus but we're all little Jesus'...

Jim: ...then the second thing is that openly one can quickly recognize, hey it's the way everybody wants to be treated....whether they're sick or healthy, whether they're in hospital or in their home, whether they're at work or play, and with specifically sick people that's the way we should be treating everybody whether they've got an easily curable pneumonia or whether they've got a totally incurable amyotrophic lateral sclerosis and we know that we're dealing with impending death. It becomes more poignant with the dying patient because we don't have much time left and surely to goodness we can make an extra effort and can try and gear other people to make an extra effort to at least give that person in their last few days on earth the kind of wholesome, whole, healthy, spiritually based concern that ideally we all would love to have every day of our lives....

Jim: So a calling, no, a reminder that this is the ideal of life and then the uniqueness that I have as a doctor of being able to be involved in the last days of life of many more people...it's a natural outgrowth of a life long teaching and philosophy and the whole Christian message. I've long subscribed to the idea that people are no different in their work than they are in their play than they are in their home and "non-working" situations. Now many people try hard to put on a facade or a face or an attitude and that's their professional or their working demeanor and then they're gonna be totally different they're going to be real at home, I venture the observation that what they really wind up being is the same way in both places.

Jim: ...I want to be useful, and in fact I want to have the satisfaction of knowing that at least one human being will say at some time, "Hey am I ever glad that you came into my life." Not that another human being turned up or that a doctor was available to give me the right antibiotic but that you uniquely, Jim, turned up, because you uniquely as a person and with your training and your interest and whatever. And even for a fleeting instant that I'm that useful...I have been uniquely useful to another human being....

Geo: ...Can this be taught to the young doctors...

Jim: I think it can, yes, and I'll go further, it desperately needs to be taught to young doctors and young professionals of all kinds...what's important is the doctor as perceived by the doctor and the doctor being encouraged from day one to stay human, because without planning it because of the tremendous complexity, the exploding technology, we take these very highly motivated intelligent young people, eager to learn, it's fascinating to see them on day two. And we start pouring information into them, oh man do we pour it in and by the time they hit the ward as a clinical clerk, which is just two and a quarter years later in our faculty, they're talking about the gall bladder in room 563 not Mrs. Thompson, and they're getting hardened and hardened and it's sad to see because again on day two they're just really wanting to be human and be doctors and help...we keep looking for ways to reinforce that these young doctors hang on to their own personal feelings and humanity that they have teaching about concepts and they're getting some like communication skill and interviewing skills which I never had...But I think an attempt is being made and it's particularly coming out now in a totally different fashion that is because of the technological abilities to delay death, because of the exciting potential for things like transplanting more and more organs and thus shall we say bigger and better band-aids for things that used to be universally lethal for example like end stage kidney disease. We are being more and more forced into ethical considerations and this business of medical bioethics decision making and you can't get more raw and personal and challenged than when you are forced into this kind of bioethical concerns. Oh yes, we can teach it, the same way we can teach logic. I think our students are getting much more exposed to social sciences, I didn't....

Jim: ...and because we are being pushed so much now with rationing of money, rationing of resources, the life/death issues are pushed aside.

Geo: Uh huh

Jim: We're rediscovering the humanity of medicine, the art of medicine, and we're talking about it, one of the things too that is difficult for the student is that even though some people may be talking about it, they don't very often see too many models and a lot of medicine is still almost the old apprentice, I won't say method as much as influence. For instance I can quickly identify three major influences in my medical life, they happen to all be men, and I have deliberately taken on some aspects of each of those three men because they were such powerful models to me and yet in no way was sort of apprenticed to any one of them anymore than a whole bunch of other people, and certainly none of them lectured to me. They were people with whom I did ward work, stood at the bedside, watched them deal with parents, spouses, watched

them go through their own decision making processes and investigative techniques and that sort of things and as I think it self evident I strongly believe in this fact that we can teach the young students of the health care professions and I try to devote a little of my time and we can teach the community and that's why I'm into this "Living/Dying" course which includes a mix of professional and community people, non-professionals, that's interesting each year who comes, a fascinating mix and very few men I might add. Very few the most we have had is about three out of thirty and some years we've had none...

Jim: and I'll just treat men and women as it were the same then I tend to feel that I get the same responses back, the other thing though is to funny I harken back to a teaching of a psychiatrist preceptor of mine back thirty years ago who said, "People don't use Iron bars to cage mice."...if I encounter a man who really just won't lose the stereo-typing that to me is an iron bar or a cage of iron bars and that means that man has a lot of lions inside not mice...He's being the stereotypic quiet tough guy because for whatever he is it's an absolute necessity that he stay the quiet tough guy...and I may just have to say, O.K. I may just have to leave you this way you're doing it for personal needs and although it's awkward for me to deal with you that way because that's not me. I can let you know that there's other ways to be, male or female, like being a little more vulnerable, open, and warm, and risky but if you can't take that I'm not going to spend a whole bunch of time trying to change you. You need to be the way you are, I need to keep being the way I am we'll just have to keep on and uh I can't solve, I can't take everybody's monkey on my back,...

Jim: ...I think palliative care, or to change the setting slightly, being privileged to be part of an experience when a person is in their last few day or months of life, is a precious time in that it's a time where most often people can in fact let down somewhat and be normal, be, be more human. Poor term, be normal, be more human. The same way that many people do in old age, they may be retired, they don't have to dance to company tunes,...

Jim: ...some people become more like themselves to use a peculiar phrase, under those circumstances. Then if an illness comes along that confirms it, they can even be more free, I almost said loose, loose is not the word, and they can be more open, they can have a conversation with someone that they's never dare have before because it sounded kind of schmaltzy and mushy.

Geo: Is there something that needs to be built into the system in a formal way to help deal with the problem of people dying, your problem of grief, or is the best method an informal networking amongst the other people?

Jim: I think there's a value in a formal mechanism, the imple-

mentation of that will vary from place to place, hospital to hospital, community to community, depending not just on dollars available, but on the cultures, the availability of people with special interest. By identifying a formal mechanism be it a team or a unit or designated beds or whatever, it makes it possible that the rest of let's say the hospital to ignore good palliative care. "Oh well we've got a tough patient get him off to the specialists and we don't have to deal with it." Which does nothing to enhance the everyday care of everybody or to confront some people who have trouble with this to possibly grow in their own wisdom and maturity with regard to dealing with death to being confronted by their own mortality, to perhaps being made aware that they have some unfinished grief that they haven't resolved, many of us do....In fact there are some intriguing articles in the medical literature coming out of late suggesting that a significant percentage of people in hospitals are there primarily because of illness and distress resulting from unresolved grief....These then are some of the valid reasons for having some sort of formal mechanism, but not letting the formal mechanism be it a team, a person, a library, resource, a educational program, or a whole unit or ward take away from the value of increasing the awareness about reactions to dying, grief responses, pathological grief, grief and illness connections throughout the whole build-ing...But putting it another way, you're not going to get that kind of awareness developing throughout the institution unless somebody is given that responsibility to develop it or can model it, and there become part of the major model of having the people or the place or both to serve those many roles.

Geo: Yah

Jim: And then that allows the community also to tap into that resource, community people, not necessarily a sick patient, it allows educational ventures to come out of the hospital to the community, and raise public awareness,... probably no more than a quarter to a third of the deaths in that community will have a great deal of need of the specialized services of the team....those resources that the teaching would be available for the young professionals, the student professionals, nursing, social work, pastors, pastoral education, physicians, medical students, to get teaching right at the beginning of the profession and that way you get everybody in the profession and if you get everybody, you gradually over a decade or two you cut down the need for the highly specialized services. 'Cause you're getting good solid compassionate whole care for virtually everybody. That's the perfect world. (laugh)

Geo: Uh huh

Jim: I think we're as a society and in particular now as Calgary, the rest of the world can look after itself at

the moment, we're moving and we're trying to come to grips with the needs that people have as they reach this stage of life, the final stage of the physical life as we know it and this heartens me when I think back to when I first started practise in 1959, boy it's a totally different world and for the most part it's a better world, medical world, no question and that's not reflecting on the technology part. I'm impressed with the willingness and openness of the young professionals and with many people in the community who become the volunteers in this whole system of caring one for another and I'm just hopeful that we can respond to that willingness and that openness of these large groups of people and that we can better integrate everybody so that we can get away from any concept of trying to give better health care it must always be by professionals because what we really emphasized is that the humanness of the care is what counts, well you get humanness from humans not from "professionalism." The second last comment would be...as we talk about death and dying, as we look at terminal care, palliative care, the more we can look at that and the more we can define what it is that that constitutes that quality of care, what we're really talking about is living, and fullness and richness of life,...and so the emphasis is not death it's life. And of course the more we capture that and believe it then we don't have to wait for a terminal illness to help us all get living and that's one of the joys that comes to people who've risked getting involved. Sometimes they're challenged saying isn't this terribly, terribly draining on you to deal with dying patients and grieving families. And the answer is no, because it constantly is making you focus on what's life. WOW, I'm thinking of living not necessarily dying." That takes a little while to get to that but that's really what it's all about and you're back to the old cliches like "Well, I've learned to live one day at a time," and oh how often have we heard that, we want to choke somebody who says it to us, or "remember today is the first day of the rest of your life." And we say "Ahh tell me another one," but the plain fact is that there's a tremendous truth in that and so that to me has become the richness of being involved in this, is helping people really look at living....

Code Name: Sandra
Age: 52, female
Profession: Professor of Nursing
Years practising: 30 years (1 year professor)
Approximate time involved with patient: 8 years
Total pages of transcript: 45

Transcript No. 10

- San: ...Now when I was thinking about who I would talk about, and the person that comes into mind most often through out the years, was a young man who died very suddenly. He was not specifically a client he was actually in a class I had....but in a sense he was the person who really helped me develop my career interests in this area so he's a special person....his name could be deleted in you're transcript but it's more natural if I call him by his name....
- San: As I say he was when I went to do my Master's work, it was during that spring that he died very suddenly and he was a very important person to me and it was just at that time that I was trying to think what direction to take my work and he has become really an important theme throughout, so I think he's a good person to talk about.
- Geo: uh huh, sure
- San: He was a kindred spirit. He was much younger than I at the time and full of vim and vigor and was risk taker.
- San: And very athletic and very able in many ways but he did tend to live on the edge. And, he was so full of life, that this is I think again why he keeps staying with me, it was just so unexpected, it was like he should live forever kind of thing because he had so much vitality so it came as a real shock when I found out that he had died in a scuba diving accident and of course I was just absolutely stunned and it actually affected our whole family so it very much brought the fact that death could happen to the young into our whole family situation....
- San: I don't think it's off topic altogether, I was talking with a colleague last night who is a professional in the area as well and most of his practise has been in the area of bereavement. And his own grandmother died, just yesterday, well the night before, and he was saying, "I almost get hung up now on what's appropriate like because I'm so quick to label my different stages and am I doing them appropriately or whatever." And it's really getting in the way so perhaps the non-professional is in some sense better off because they're not strung out on that.
- San: ...my family all dealt with it differently, I went to the kitchen and made lasagne...So we all handled it in slightly different ways,...first of all, I was amazed that it could happen to someone so young, I still believe that even after lots of practise....It still seems more

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difficult to put that together in my thinking...The interesting thing about this is that although I do workshops and talk about this a lot, the experience is really reflective of it, like sometimes theory and practice and what you say tends not to necessarily fit so well with what you actually do. The thing that has been helpful to me and has even been helpful to his folks a little bit is that a lot of the work I've done ever since has really been because of that death that hit me so suddenly at a turning point time of my own life...So I tell his story in a lot of workshops when it seems appropriate or whatever, so he still lives on in that regard and has had an influence on whatever work I've done and the way I've been in that work. So there is that positive side always, there's something to salvage...It has most often been the situation when I've been with someone who is dying or with a bereaved person that although I feel as if I sort of go into some awful place with them that maybe those memories have given me a lifeline out to the surface you know. I can sort of go down with them with that feeling that although it's awful sometimes there is that other side. The positive kinds of things that can come from the intensity of that experience I see time and time and time again and it's that that I pull and salvage and hold somewhere when I go back into a situation again with a person. I suppose it's Victor Frankl's notion in a sense that there is good in suffering it keeps one going.

Geo: But this experience is still special is it?

San: yes

Geo: It helped you focus

San: yes

Geo: in an area that you pursued

San: Yes. It doesn't quite capture it though, I know that's what I said but it doesn't quite capture it. I'm sure that's true on one level, but there's a different level where it's truer. (pause) It goes beyond career actually, it was deeper than a career choice or a master's project or thesis or anything like that it was fundamentally a turning point for me, I think in the way, I view my faith, my belief in good and bad, my ability to salvage some sense out of something that seems senseless,...

San: ...I mean it was all just part of being two human beings together. The professional role sometimes dissolves in the situations that I may have had in other situations working with different people through different experiences. This is a different kind of experience for me as a nurse and part of it is very nice and human....

San: ...I would say they're not just dissolved or blurred, perhaps they go in stages, they dissolve, they blur, and then they're not there, they become irrelevant, if indeed they are there.

Geo: Uh huh

San: There's something that comes from working with a person in a hands on way that can at a certain stage turn death into a friend....the loss is assimilated through touch even if it isn't spoken about, one feels the change in the person's body, one feels the disease is going to be the winner, and then one comes to the place where one feels that yes this is O.K. then one becomes more the comforter in a physical sense like the back rub, it can be comforting in some situations, but very confusing when it's sudden and takes a young person. Yes, it's different

Geo: uh huh

San: Now I agree, that was a harder one to put together, and to come to some sort of place where one could see the good in it or that there might be some good that could come from that...

San: Well, I'm finding it difficult to keep J---- in my thoughts because that triggers off so many different experiences with other people from the past who died in, like oddly enough things that are coming to mind are nursing context rather than psychology context,...The hardest ones do definitely seem to be the younger ones, the children and I do have real trouble putting that in place so I can live with it. It takes more time and more experience to pull those together. All those experiences are helpful to add together to give some depth to pull from. I think it very much too depends on what you do with it because I would say before, as a beginning nurse, as a student, I handled it in quite a different way from how I do now that I am older and have more life experience to put it into a different kind of context. I've been doing more reading, more thinking more experiencing actually, where I've let it come into myself, where I actually felt it as opposed to being able to keep it out there as a professional, as was my initial way of managing. So I think, and I'm not quite sure where that turning point came, or whether J---- was that turning point, I don't know. But I do know that the last few years I've been, in one way, paradoxically taking it in more deeply and in another way being able to move away from it more quickly. Not away from it but put it together, and get some peace around it....

San: ...The main quality is being a good listener, to be able to talk these things out with and piece them together in the telling of the story there's healing and there's a way through that comes.

San: I spend a fair bit of time each day in well, I guess it's accurate, in reflection and in thinking about rather deep sorts of questions about how I fit into the scheme of things, sort of a probing, reflective time each morning. And I think that's helpful as well. I read a lot, often times in the area of philosophy, and that kind of thing as opposed to things that are directly related to that

even. I try to associate with those great thinkers in that way, which is helpful. It kind of gives a context that way or a broader picture, so I don't get bogged down maybe as much as I would otherwise. I'm really a sounding board rather than an advice giver. It's more important to have someone there who is attentively listening so that I can tell the story and understand in the telling of it. As opposed to somebody patching me up or whatever in this really stressful time....

Geo: Understanding what? Can you clarify that?

San: The understanding, there are two levels really, one becomes immersed in the theory and you know that people, including caregivers, will feel certain things if one has experienced loss. That's fine. On another level, there is a need to make that personal and make it real, because it is real so one needs to change from the one out there to being less me, I am and I think it comes from that ...

San: ...And they need to resolve it both professionally and personally, probably the personal being the more important...

San: ...and so we did become very familiar with handling the body but very little was said about how we might be feeling as young people.

Geo: Uh huh

San: It was so poorly done in those days in terms of what might be going on with us. So I think that definitely there has been some movement to the good.

Geo: Uh huh, yah.

San: In those areas but we didn't know what we were lacking or missing at that point of time which I would say I do now after many years of experience

Geo: O.K. What was missing, what was lacking?

San: Well, the significance of death and the implications for the family and the implications for ourselves as well. And not so much the negative implications but the positive like attaching I think it would have been quite good to have to attached it to life in a more important way, to my mind that would have been helpful and maybe would have speeded up the process of having to discover it myself.

San: I suppose the most important writers or thought invokers would be people like Mother Theresa, and Victor Frankl and people who are able to work with who are surrounded by death and dying and are able to see it in the context of life a natural process without trivializing it;

Geo: ...it's a personal encounter.

San: Oh yes, oh yes...

Geo: Maybe that's what happened with J----, that this personal encounter was now broken, when you do something, maybe that's when you begin to understand it...

San: ...I think I can go either way. I think it can go so you never want to enter a relationship again because it's too painful to have the break or if it can be understood,

understood is not quite the right word, it sounds cognitive and it's not quite cognitive, it has that component, as part of my life and my purpose, and my work, my development as a person, all those things, then I can not be afraid to enter potential loss...

Geo: Does it become easier all the time, maybe that's not the word, not easier but willing to risk, to risk ...

San: I much prefer willing to risk than easy. Easy doesn't go down, and I know you recognized that right away too. Willing to risk I think for me is the wrong connotation too, it's more like, because that sounds like one chooses in a sense and I suppose that one does at a certain level. But on the other hand it become more uh like that person is on your path

Geo: but until you've experienced that loss then the searching begins and the answering of the question the feeling of the emotions and all that.

San: I agree with you I think that's one of the things I was getting at in terms of the faddishness, and the...you know a lot is written a lot is talked about and maybe some of that does some good, I'm quite sure it does I'm quite sure that it cracked open something that needed cracking open back whenever it was but then it sort of steamrolled on. A lot of that has been helpful but there's something more and I'm not sure how that something more is taught it's a real conundrum to me I really don't know 'cause one has to be open to it and the timing and how do you approach that in a curriculum is beyond me, I don't know.

Geo: Uh huh. I think you're pointing to something that I have a suspicion about too the text books don't match up to the reality

San: No....

San: ...I think Kubler-Ross herself, I've heard her speak and she has said that those stages were only theory and were meant to be helpful and not to be so rigidly adhered to as of course is what always happens. The disciples are always more rigid than the master and I think she's fallen into that trap, not she but we have fallen into that trap of taking it more seriously than she herself had taken it so that's just my tipping of the hat to Kubler-Ross because I think she had done some very important work. And it is helpful to have labels if they are not used slavishly...

San: I sometimes think that stories, maybe novels do the best job that describe the experience as opposed to ...

Geo: Yah uh the literature, the poetry, the sacred scriptures of many different religions, philosophy books, biographies, autobiographies those kinds of things, they seem to be a real slice of life. And you can identify with them either yes or no, I've had a similar experience or mine's the exact opposite I did this, I did that.

San: I have a feeling that that may be the textbook or this

curriculum that we were talking about or at least a good piece of it or at least not devalued as we do about just a person's story. This whole work is made up of stories.

Geo: And then the other half of the curriculum is the actual event of that encounter, the significant encounter

San: And how we can make that real is a real conundrum for me too and it can't really be quite phoneyed up. We can do scenarios, case studies which is maybe the best shot because somehow those significant deaths make us do our homework the stuff that we need to do for ourselves, that triggers that, there is no way you can schedule that in a semester. The part of that I bring to them is the importance of being open with the patient to the place where they do have some feeling about what is happening and that they hang in there through the tough patient and that they can be helpful at the same time. I have this theory of reciprocity

Geo: Uh huh

San: I believe that one receives and one gives and that's very much part of this work too...

Code Name: J.J.
Age: --, male
Profession: counselling psychologist
Years practising:
Approximate time involved with client:
Total pages of transcript: 38

Transcript No. 11

- J.J.: Well maybe we should set a... set the stage for this because I'm not sure I'm not the typical subject you're going to have....I'm somewhat different that way. But I also suspect somewhat different because I received the majority of my training working with suicides in the States; just the fact that first of all I received any training I suspect that makes me different than most of the professionals you've talked to...
- J.J.: ...part of that training was what happens when your client or little brother commits suicide and also I received training from the suicide hotline in ----....
- J.J.: There was a lot of, a lot of gang activity and as a result having to deal with gang warfare, lots of abuse and subsequently lost of suicide attempts for lots of reasons. Well as at that time if you'll think back, 1970 that was right in the midst of lots of drugs,...so we really had to learn and know how to deal really well with overdoses which is just another way to suicide.... and you are going to have to be ready for that eventuality because the more you see the more likely you are to have somebody who's going to follow through
- Geo: Right. Did that happen?
- J.J.: It did but not for a long time but it finally happened to me in 1980, a good six years ago, almost seven years ago actually.
- Geo: Uh huh
- J.J.: I had a very bright individual, a lot of fun to work with but had some definite psychoses along with a lot of depression and suicidal ideas, and a family history of suicide,...perhaps in a way unfortunately was referred to me kind of at the height of depression and suicidal behaviour. It's too bad I wasn't involved with him previous to that, however that's sort of retrospective thinking...
- J.J.: ...it surprised me from the standpoint that we had set up everything really well, or maybe I should say I thought we had...We really reached the point prior to the suicide where quite a bit of progress had occurred however and I think this is important in terms of how it affected me. It had occurred over a long period of time, a lot of real tough sledding....
- J.J.: ...So I suppose in a way one could say I had a little bit of personal reputation at stake....
- J.J.: ...It's a bad area for anybody to get into who doesn't

have the confidence there to work with someone who is suicidal....

J.J.: ...his attitude through out was being very mistrustful at first which we worked on and again it was kind of tooth and nail and the trust really developed and at first my attempts to develop it for him that he was really O.K. and really as a reality based individual it was met with a lot of personal scepticism....But he established a good relationship and a good friend...that's not so much part of what you want to hear but my personal reaction, but I think that it's important that you know that....because something that I had learned in developing skills in working with suicide when somebody does successfully commit suicide as quickly as possible you get everybody together which I did and it was a good thing in that the family was able to get together, in a sense I suppose the family was quite concerned about me and vocalized that. They were worried about what affect this would have on me because they were quite aware of how much effort I had put into it, and on a regular basis I called his mom and dad who lived back east...

J.J.: ...and it was quite clear he had full intent to kill himself there was no question about it, he used a piano wire and he used a special knot that tightened, it was self tightening so there were no options...so as he was choking to death there was no way for him to say "hey wait a minute no I don't want to do it and pull it apart..."

J.J.: ...that week there was an unusually high number of suicides, there were nine altogether in that week, the majority of them by hanging. But it's rather interesting that nine people in a week like it's an incredibly high number, here in Calgary

Geo: Here in Calgary

J.J.: Yah,

Geo: Incredible as to what, what would be the

J.J.: You mean the average (laugh) I suppose the expectation would be more like one or two

J.J.: ...My own immediate reaction was of course sadness, I felt very badly. I don't like not helping somebody (laugh)

Geo: I'm not sure I understand what you mean by that.

J.J.: Well, it's part of the way I looked at it, it wasn't like a big defeat but it was somewhat like a defeat. I realized that there was no way for me to control everybody every minute. And I'll be honest too it was a little bit of perhaps resignation too to the fact that well for as many years and as many clients as I've worked with who were suicidal and well it finally happened, and I was sorry to see it especially in this particular client because everything else I told you about. I think it's really important for anyone to understand is that there was perhaps a lot of inclusion because as I went

through things in my own mind I went back thinking well O.K. now did I miss something and what could it have been, and in fact I probably did far more than most but then that was in terms of what I was trained to do. In retrospect even at that time I think I was good with myself as far as also acknowledging the fact that I had everything in place so besides the sadness and perhaps a little bit of self doubt, I came back and said, "gee did I miss anything," it was also the kind of the interest in seeing, "hmmm, now how could he have done that under the circumstances," the wanting to know so I was very similar to the family in that way, that desire to understand to know why he would do a suicide to himself...but still we're in a situation where part of the need to know leads us to start to speculate. That same day that I found out the he had suicide that he had successfully committed suicide I had gone to the office, I shortened the day and set up a time within this case with --- because that was also part of my training that when this occurs don't isolate yourself. It's too easy to blame yourself...

J.J.: I got together with --- and went over the case, "now what do you think did I in fact miss anything" and that's that very first evening when B--- and I talked about it, that's when he gave me the feedback very quickly that in his opinion I had probably done more than most....

J.J.: there were different feelings, sadness and loss

Geo: Uh huh

J.J.: I like this one he was a fun client to work with. He was interesting having the kind of background he had, so yah there was a feeling of loss

Geo: Uh huh

J.J.: I'm sure it's not the same loss that his family might feel but maybe in other ways too I was, and I think that this is important for professionals too to realize, I may have been closer to him too than the family....

J.J.: where he might not do that with his family. I had a lot of concern for his parents as part of the family session I called back to their home town in Ontario and got them in contact with a support group of families...

J.J.: and like I said, they were highly supportive of me (laugh) the reason I chuckle is that they were that supportive and quite concerned both his mom and dad and sister called me back on a couple of occasions over a long period of time to find out how I was doing (laugh) I think part of that might have been perhaps even stimulated by: first of all obviously they were concerned, felt concern about how I was doing right away and some of that was just reciprocity, they really did appreciate the fact that I had been very informative with them all the way through and never held anything back...

J.J.: So, well for sure I knew a fair amount of disappointment

Later on, a fair amount of anger toward him because of what we were just talking about he was appearing to make steady progress it was kind of like, why would he do that....I used my professional friends as my support system. Like I said, I knew from my training that you don't isolate yourself. One of the first things you want to do is sort that out, how would you call it, what's the word, post-..., I can't think of the right terminology, B---- came up with a real good term but it's kind of like, definitely after the suicide sitting down with a fellow professional that knows about suicide and going through the case, making sure you get some validation and that sort of thing and that helped a lot. Talking to --- on a regular ongoing basis for a little while...

J.J.: ...that it was a case of me saying well "you can't be perfect forever." You know sooner or later it had to happen it's unfortunate that it happened this way, it's unfortunate that it was this individual but it's kind of like me being my own coach, "come on guy you know you're in a high risk area the fact that in all this time and all the suicidal clients you dealt with still you've only had one client successfully commit suicide, that's a pretty enviable record." So one could say, you know there is a little bit of professional ego at stake. It's kind of like saying God damn it I didn't fix him....

J.J.: as part of the training it was really emphasized, if you're going to get into this area and stay in it, don't try to be perfect because the first time somebody succeeds you're going to be all over yourself...

Geo: ...You mentioned a couple of times that you were really appreciative of that initial training

J.J.: Oh yah, I don't think there is any question, that set me up to succeed if the eventuality which I finally experienced did occur...no question in my mind that there should be training, the kind of training, of course I'm biased because it was the kind of training I received but yah a very similar training

Geo: Uh huh, do you think it should be put into the curriculum? Can you teach that kind of thing in a course?

J.J.: Oh yah, that's the way I learned it, however it's in a context of additional training I sought out....

J.J.: ...oh I failed to mention too that was part of what I did, I didn't allow myself to be isolated in that I didn't allow him to see me as his sole professional resource, I set up other identifiable resources with him, and that again is part of the training I received, don't isolate yourself with a suicidal client because you can end up in a sense being, from their perspective, the cause because after all if he felt suicidal when he called you and your spouse answered the phone and you in the bathroom and because you weren't available they

decided "well fuck you and killed themselves."...

J.J.: ...the interesting thing is that there's still not a training component even with the suicide resource education centre, there's still is not a specific kind of course or workshop for the professional to deal with themselves in terms of the suicide...

J.J.: ...we are forgetting something here and that's eventually when you work with suicidal people somebody will succeed and what are you going to do when that happens not so much with them but what are you going to do with yourself...

J.J.: recognize in the case of the telephone you have distinct limitations and you can only do what you can under the circumstances. Ultimately I think that's one of the most significant messages anybody can have working with suicidal people, you can only do the best you can under the circumstances and if you have a client whose really convinced themselves if they choose to disregard your advice, homework, or whatever you ask them to do, there's your limitations. There's no way to sort of following somebody around for twenty-four hours, there is no way to make somebody do something and besides that you're not creating, and helping a person create a good healthy attitude of being able to be their own therapist.

Geo: right, right

J.J.: 'Cause somewhere you need to be teaching them to do something where they're not depending on you which is no matter what concern I think you're dealing with in any human being I think that's probably anybody's goal who is in the business of helping people to learn to help themselves...And there's no way to isolate yourself from it on a client like that, that's not good for either of you and I think that's part of my ideology. The bottom line is somebody can make a choice and set up circumstances where there's no way to intervene. Some people do really mean to die.

Chapter VI

Observations and Conclusions

The data that was collected in the eleven interviews all revolves around the open ended question: "What was the meaning of the experience of the loss of a patient, client, or parishioner by death for you?" The phenomenological method is an intensive exploratory and descriptive method. It seeks to describe as accurately as possible the lived experience of the person. The open-ended question facilitates the interviewees response. He or she is given the widest possible parameters to explore and describe his or her personal experience. This process generates much descriptive data which translates into an extensive amount of pages of verbatims. Once the verbatims have been transcribed the process of analysis occurs. Various themes, concepts or processes described are noted. One begins to notice that these recur or are elaborated or clarified during the interview. Then one notes not only the frequency of these themes, but also an intensity or depth of a theme. Finally, one begins to see that these themes begin to recur in other verbatims. This leads us then, to list the general overall themes found in the data. These themes in various depth and intensity supposedly would occur in another sample if conducted along the same parameters.

Each transcript which is an abbreviated form taken from the verbatim accounts gives a sample of the predominant themes, comments and reactions of the interviewees. Some-

times themes or concepts included many lines of verbatim. A sample of lines has been chosen to illustrate that point or theme. Sometimes larger samples of lines from the verbatim are chosen to illustrate a process that is being shared. Some topics or comments that had already been noted in other verbatims were left out to reduce redundancy. In a few instances some issues touched upon would need clarification and elaboration first before they might become a major theme or concept.

This illustrates the nature of the phenomenological or descriptive approach. Two processes occur. As the interviews progress and the number of interviews grows the interviewer begins to modify the question or ask additional questions which clarify and elaborate the interviewee's response. As the interviewee reflects on the incident new meaning and clarification take place. Two examples will illustrate this phenomenon. Val talks of relationship really having no distinction for him. However, as he reflects on the incident he notes the distinction between clinical relationships or acquaintances and the personal relationship that evolved with the incident he shared. What made this event so meaningful was that a very personal relationship evolved, a relationship that had the qualities of kinship or blood ties. (See Val, transcript no. 1, p. 77, lines 25-32.) D.K., the young resident describing the loss of his young patients discovered the meaningfulness of the concept of relief. Concerned over using his newly acquired skills to preserve life when the stage is reached where these

skills cannot preserve or enhance life relief sets in. Death is ensuing and inevitable. The change to "no code" symbolizes the acceptance of the inevitable. There is now no heroic effort to save life, but now the effort is made to facilitate death so that the patient can experience a "good" death -- interpreted as issues having been resolved and maximum effort given to reduce pain. This definition we see embodies the rationale of palliative care. (See D.K. transcript no. 7, p. 107; lines 20-22).

To maximize this process one ought to interview a number of residents or parish clergy, or whatever caregiver group one wishes to investigate in order to reach a saturation point. One interviews enough people so that no new dimension of the themes can be observed. This is the saturation point or method that might be used in phenomenological or descriptive studies. My sample consisted of caregivers and samples of one were used. This process enables the selection of representative themes rather than describing as fully as possible a particular theme. Some themes occur over and over again in the various interviews. This method indicates some common themes no matter what disciplines sampled. While this method is not exhaustive it does supply themes, themes that are the concern of the interviewees. While the characteristic of exhaustiveness is missing in this method, it does give a sample of themes to be expected and gives sufficient grounds to pursue further research that has the characteristic of being grounded in lived

experience.

Initially, as the interviews were conducted a richness of content was observed. As each interview was conducted this vast array of content sparked panic in the researcher. The element of commonness or themes seemed to be totally absent. This researcher entertained the notion of redesigning the whole research project. After the fifth interview was conducted some time was taken to reflect on the data and whether the remaining scheduled interviews would be conducted. A period of serious reflections began. While the diversity of content seemed initially to predominate, slowly the concept of relationship began to occur. Over and over again the diversified content rebounded with the umbrella theme of relationship. Usually experience of an intense relationship was the response to the question: "What was the meaning for you of the experience of the loss of a client, patient or parishioner by death?" The following transcripts identified by their code names revolve around a predominant and significant person. They are Val, Cag, Willie, Bettie An, Myrna, Jim, and Sandra. In their professional life there stands out one client, patient or parishioner whose death was significant and transformational. Although Jim sees significance in a number of losses his experience in one portion of his transcript revolves around a recent episode that appears significant. The other four refer to multiple incidents which also appear significant and transformational; although the apparent intense personal aspect seems to

be missing.

The Theme of Relationship

The first broad theme and perhaps the most important is that of relationship. While all the incidences fall within the professional purview, except possibly the volunteer, the professional and volunteer parameters seem to be transcended and develop an intensity described in terms of being special, or in terms of friendship or in familial terms.

Val, as a parish pastor, given a family to take care of as a request by the dying person, describes the relationship in non-clinical or pastoral-parishioner terms:

Val: I feel the responsibility that was given to me is still going to continue for years to come; that I will never be able to say that this is purely pastor-parishioner relationship. I think that this particular death put me into a brother-brother relationship with the man and his family. And that's one of the most difficult relationships to build when there is no blood tie. (pause) (Val, transcript No. 1, p. 77, lines 25-32.)

Val continues and tells us the implication of that relationship :

Val: Initially my contact with this lady in the hospital was purely clinical and then it became something in which she tied me to her family. Now the family and I have a deep relationship being that has been built over the years. If something should happen to that family now there would be real grief where with the initial patient was purely a clinical relationship. So one thing led to a deeper involvement. That's where I think the deepest relationship is, not with the person that died but with the person that she gave to me as a brother and his family. (p. 77, line 43 - p. 78, line 2.)

Cag describes her relationship with her client in personal terms.

Cag: Really it was a very close relationship in terms of death

and dying issues. and that kind of thing and I was really fond of him. (Cag, transcript No. 2, p. 80, line 10-13.)
 ...it was really a nice relationship. His wife was the same way. (p. 80, lines 15-16.)

...we were very close with one another, you know I'd give him a hug and I'd tell him that I loved him... (p. 80, lines 21-22.)

Willie describes her relationship with her patient in these words.

Will: ...I myself really picked her as a favourite and spent a lot of time with her when I could and even off my duty hours... (Willie, transcript No. 3, p. 87, lines 2-4.)

Willie continues and describes the intensity of that relationship:

You know she's still special to me to this day, my memories of her, she's a special person. I think that goes to show you (laugh) that there was a special relationship and I think you get special relationships then you look after people for long periods of time. (p. 90, lines 3-8.)

...you liked her as a whole person... (p. 90, line 26.)

It just makes me feel good that I was able to be a part of A-----'s life....You know to be able to take care of her, to know her as a person and just that I was one of the lucky ones that got to know her so well. (p. 90, lines 27-32.)

Jim describes the personal relationship between himself and his patient.

She and I became pretty good friends. (Jim, Transcript No. 9, p. 118, lines 22.)

...I had almost become a surrogate father to C---... (p. 118, lines 45-46.)

Sandra describes her special person as a "kindred spirit.":

... he has become a really important theme throughout.... He was a kindred spirit.... (Sandra, transcript No. 10, p. 128, lines 14-17.)

Myrna describes the relationship this way.

...But she was really unique because you know when she was confused she seemed to make sense....S--- was very special...she was a fine lady...it didn't matter because I was her son's wife and that was it.... (Myrna, transcript No. 8, p. 112, lines 5-17).

...up until the time that she died I think she became like, you know, extended family....but I don't think there are many nurses who work in a place like the --- that don't have a special patient...it was like losing a loved one, a member of your family, a good friend, a close friend... (p. 112, lines 23-38.)

My friend, yes, she was more like a mom to me. (p. 113, line 10.)

...as well as losing a friend... (p. 116, line 28)

As we closely examine the above sample of quotations we see three broad frameworks used. We see words which describe the relationship in terms of personhood. This patient or client was a person or a lady or was special to me. Then, there are those terms which accentuate the personal relationship as a friendship. "She" became my friend or "we" were friends. Probably the strongest relationship terms are terms used to describe the familial. She was like a "mom" to me and I became her daughter. I became a "father" to her.

While we note that the caregiver relationship broadens and expands into the personal or relational the professional aspect is still there. From a purely professional relationship the relationship is expanded into the personal with no loss of the professional and its professional obligations. Val addresses the religious needs in that relationship.

... my feeling was that the dying person wanted me so much to get the message across that she left me with a burden

which was difficult for me to completely unload. (Val p. 75, line 47-50.)

Cag notes this also

...Another thing was, I realized how people use the workers in a system. These people used us very well indeed. They knew how to use us,...Right away when he was diagnosed they said, "We want some help, we want some psycho-social help. (Cag, p. 82, line 10-15).

...it was always a very professional relationship... (Cag, p. 82, lines 29-30).

It would appear that when the professional relationship is expanded into the person this process enhances the professional relationship also. It would appear that the role of the volunteer is one in which certain needs that can't or won't be met by the dying patient's family will be met in the volunteer relationship. One could postulate that this phenomenon, the phenomenon of the family's reticence in dealing with the family member's impending death, that results in the dying person becoming very intimate and personal with the caregiver. Necessity to resolve important personal issues around the impending death causes one to reach to those who are near. In this case the nearness is the caregiver. We note Bettie An's comments:

...they need someone to walk with them. And if the family is not ready, it's not only that the family is not ready um but they are doing their own walk so they have two things to do, their own walk plus that of the patient. It makes it pretty complex for the family. (Bettie An, transcript No. 5, p. 100, line 4-8).

Jim makes his professional judgements and obligations in the framework of a personal relationship. As mentioned above, the professional relationship is expended to include the personal. Now, professional decisions are made jointly under the guise of

the personal relationship.

We stopped, C---- and I making the decisions alone without mother's input... (Jim, transcript No. 9. page 118, lines 23-24.)

This personalizing, humanizing or relational aspect comes out in how we use our technical abilities and skills. Jim describes the nurse who was conscious of the blood on the bedsheet. The nurse folded the sheet to cover up the blood-stain because a two and a half year granddaughter was coming to see her baby sister. (See Jim, transcript No. 9 p. 120, lines 32-41). This process, as Jim notes, brings humanity back into medicine (p. 124).

Young doctors are encouraged to hang onto their humanity and personal feelings (p. 124). There is more emphasis on communication skills. There are options such as philosophy, ethics and the social sciences which address the personal, the relational aspect in the caregiver-patient relationship (p. 124).

Two other things which contribute to the openness of a personal or relational style are modelling and the complexity of medical technology. One can learn by modelling peers or mentors. These were professionals with various years of experience who were able to deal with their patients in a humanizing relational manner (p. 124). Second, the profound technological capabilities often require assessment and judgement whether treatment is used to merely prolong life or the complex procedures are stopped since death is inevitable (p. 124). When

that decision is made it must be made with the patient, family and significant others. This necessitates and facilitates communication. In the context of dying and impending death we are entering the personal. As someone has said death is the most individualizing process we meet in life. No one can die on our behalf. We do it alone.

This would suggest fruitful areas of research. One area would be what characterizes good and effective communication between patient and caregiver. What makes for good communication? Phenomenologically we would need to describe the essence of the encounter. Another area of research is how does the professional learn to use his or her craft in the face of the loss of a patient or client by death? As we have noted, the skills of medicine are based on the rationale of preserving or enhancing life. While palliative care doesn't suggest a diminished use or the absence of the use of these skills, it's rationale says that these same skills can be used to minimize the pain of death. It may mean the diminishing use of certain skills such as those that prolong life minimally when death is inevitable, but rather a wider rationale which makes possible the enhancement of life or the facilitation of death. This double emphasis needs to become prevalent as Jim describes his first death (page 117). Was there anyone who could have taken time to show him that he did what he could, that death is inevitable and overpowers even our best efforts? D.K. describes how residents use peer networking to deal with the losses they

experience. This indicates the need to deal with inevitability of death when one's professional skills training is only or the predominant emphasis is on enhancing or saving life. The use of peer groups is an effective coping strategy, however, it indicates also that there are an area for further research. What coping strategies are available or are currently being used by young professionals. (page 111). Willie describes her initial experience of the loss of a patient. It began a process whereby she overcame her fear of death and dealing with the dying. She was able to work in this area effectively. She says:

...I learned from him much about it being O.K. to die, he said because I was so young and I was young; I had all the skills to look after him but not those skills and he told me that it was alright. That he was ready to die... (p. 91, lines 15-18).

...so I think your young experiences do sort of mold the foundation for how you feel in the future... (p. 91, line 20-21).

While the literature suggests that there is a large amount of occupational stress involved with death and dealing with the dying, this data suggests that there are caregivers who have bridged the gap and have become successful in dealing with their patients, clients or parishioners. While the literature may suggest a discrepancy we might conclude that the data suggest the possibility of a successful resolve of the stress of working with death and the dying because we have examined the care-giver-client relationship. Caregivers would be the best source of information whether caregivers eventually become immobilized or they are able to transcend the loss of patient,

client, or parishioner and therefore, maintain effective caregiving.

The Theme of Loss

As we have seen above, the professional relationship can be transcended into a intense and personal relationship. But what happens when the patient, client or parishioner dies? When death occurs there is a sense of loss. A sense of losing a friend or a member of the family. Val, referring to the intense relationship between himself and the sister's brother states:

Val: ...I don't want to experience that loss. Maybe that's why I keep it very much alive. (p. 79, line 47-49).

Cag expresses it this way the personal loss also:

Cag: ...But still I miss him sort of on a personal basis where I don't with the others I felt a little more detached from them somehow (p. 81, line 10-12)

Myrna as we indicated above lost a friend. More profound than the loss of dying person is the fact that a loss is experienced if the caregiver cannot be there for the deathwatch. Willie regrets not being with her special person (p. 91). Jim regretted not being at the death of his patient whom he describes himself as being her surrogate father. A Team describes what he experiences when he buries one of his chaplaincy parishioner:

...I'll be doing the funeral and so forth, I'm deeply touched by these people, especially if they're young, children, young people, young adults. Somehow that touches me very deeply, and I became emotionally involved in their lives, when they die I too need caring.... (page 92, line 40 to page 93, line 2).

While death of a friend, who was a patient, client or parishioner, would engender feelings of loss, sadness, regret there are other things that come under the banner of loss. Bettie An outlines what she describes as the empty plate.

...I felt I was holding an empty plate after they died you know, like we had been celebrating together and they got the reward and here I stood after they died. Like they had been able to go on and it's pretty empty and that surprised me... Page 97, line 20-24.

She goes into greater detail explaining what the "empty plate" means to her.

Bet: ...but with the dying you get very, at least I get very involved and when they are able to die I'm happy for them...but on my own I feel like I'm standing there with the empty platter

Geo: What did you lose?

Bet: It's what I haven't gained. I have not died and they have...I have to continue on and they've been able to step through to the other side or what ever terminology you want to use.... (page 97, line 26-36).

Jim describes a patient a few years younger than himself and the impending loss.

Jim: ...A gentleman who was actually a couple of years younger than me and again I can't help identifying in those scenes saying, "jeeppers how would I be feeling if my life would knowingly going to end in a matter of days."...And I was feeling sad for him, what a waste, cancer of the stomach. ...I was saying, "how are you feeling," "Well not too bad." "How do you feel about the whole thing, about the cancer and about the fact that we have reached a point that we are literally saying we can't do anything to hold it back." I don't know if the word, "You are dying" were used that day or not, certainly we were very clear that that's what we were talking about, sort of searching about how he was getting his support, I said "Um You're married, your wife, she she's holding up." "Oh yes, she's a real help to me." I said, "Do you have children?" He said, "No, no children." And then he stopped and said "You know that's ..." And I immediately thinking, "Ah, too bad", because children can be helpful to the surviving parent let alone to each other and as a father of five I sort of feel very rich, and I think of somebody with none as

impoverished (laugh). And he was saying "No, I'm very pleased about that." And I said, "I don't understand." He said "Well, my father died of cancer of the stomach, and now I'm dying of cancer of the stomach, but we don't have any kids." And I twigged and said, "There's no worry that somehow through dad, through you someone else has been fated to die of cancer of the stomach, you've sort of snuffed that out with you having it and you keeping it and no one else in the family." He said, "Yes." (Page 121 lines 29 - page 122 line 5).

Behind the loss of the person at his or her death is the possibility of the tragedy of meaninglessness. A person's life cut short may be meaningless if there is no sense of accomplishment. There are, no doubt, regrets over leaving family members alone to fend for themselves. However, to find meaning in one's own death is rather significant but somewhat paradoxical. This would appear a significant area of research. How do people make meaning out of their own deaths? What do caregivers experience when they are confronted with this meaning-making process? After one transcends the Kubler-Ross stage of acceptance does one enter into a stage of reconciliation and meaning making? It would appear that caregivers might experience this meaning-making process.

As Sandra experiences the loss of her clients she also experiences a salvaging of something, a process of making or receiving meaning, some good out of suffering.

San: The positive kinds of things that can come from the intensity of that experience I see time and time and time again and it's that that I pull and salvage and hold somewhere... (page 129, line 22-25)

San: ...my ability to salvage some sense out of something that seems senseless,... (page 129, lines 40-41)

Loss however, brings about fear. D.K., the resident

shares this:

D.K.: All I've seen in myself associated with these deaths is the feeling at the time of the death or the no code pronouncements is just a feeling of sorrow or something not, a bad feeling, it has never lasted more than a few minutes and generally feeling that if I may put it simply, it's really crummy that this had to happen to this kid, this nice kid, and in a few cases I've had like I said the one kid that looks like M---- and when that baby died and the parents finally got to hold it. I've entertained the thoughts of how would I feel if it was my own child... (page 108, line 42-52).

While one regrets the loss of a patient especially if it is a baby, child or adolescent, the experience translates itself into specific fears. The ultimate fear being that what if this were to happen to one of the members of my family. This would suggest an area for further research. Does this identification process with one's patient client or parishioner occur? How often does it occur? How does one deal with it?

Loss may also mean that professionally we may not help our patient completely and fully. One's professional skills and professionalism may come under question. In Myrna's case she was unable to help her patient with the spiritual dimension.

Myr: ...Basically I think every nurse wants their patient to be comfortable and at peace and you know that looking at your patients you know if they're uncomfortable, if they're in pain and you know if they're afraid. I mean you can look at patients and see naked fear and over the years you try to find ways to calm them. In the last few years like I've only been a Christian 12, 14 years it's really been impressed upon me that everybody tries to do so much for them bodily and emotionally but there isn't an awful lot emphasized on the spiritual and that's the only thing that will take away the fear. You know uh S---- isn't the only patient I have had that I sensed this fear that I could do nothing about. But she was the one, I guess, because we were very close that it bothered me the most. That you know somehow I failed to reach her... (page 113, line 26-

42).

Myrna continues:

Myr: ...Where S---- had that cold naked fear and you just wanted to hold her like a child and try to comfort her and yet there was no comfort for her... (page 113, line 51-53)

Myr: ...basically I felt like I had really let S---- down.... (page 114, line 26-27).

Myr: ...If you can have someone calm then you know you've done your work well... (p. 115, line 11-12).

We can see Myrna's consternation stemming not from role conflict but from a wide spectrum definition of caregiving. The traditional roles would be that chaplains deal with spiritual care and nurses deal with physical care. Psychosomatic medicine has shown that often, behind the physical needs in medicine lie some very important psychosocial components. Also there is a trend to view medicine and the patient holistically. As Kubler-Ross (1975) indicates roles are crossed and expanded. Nurses are front line caregivers who see their patients realistically and holistically. Thus we can see why the spiritual concern is just a portion of a whole or total person's concern.

Myr: Maybe people would say that I am becoming really radical, I don't know, but I think that spiritually we have neglected the spiritual in our patients.... (page 115, lines 44-46).

Myr: You'd have the satisfaction that you knew that you had done all that was possible, mentally, physically and spiritually. And I think there are a lot of people, nurses, doctors, who really wonder if they have failed spiritually,... (page 116, line 1-5).

When Myrna lost her patient she not only experienced failure as a professional caregiver, she also lost a friend.

Myr: No, I think I've said it over and over again the thing

that bothered me most as well as losing a friend, I thought I had let her down... (page 116, line 27-29).

The ultimate loss a caregiver can experience is when a patient commits suicide. The suicide J.J. experienced didn't occur at a low point in therapy.

J.J.: ...it surprised me from the standpoint that we had set up everything really well, or maybe I should say I thought we had... (J.J. transcript No. 11, page 134, lines 34-36).

J.J.: ...we really reached the point prior to the suicide where quite a bit of progress had occurred however and I think this is important in terms of how it affected me. It had occurred over a long period of time, a lot of real tough sledding. (page 134, line 37-42).

The trauma of the event call may call into question one's professional competency.

J.J.: ...So I suppose in a way one could say I had a little bit of personal reputation at stake. (page 134, line 43-44).

One feels not only the loss of a person but also the nagging possibility of professional failure. This is different from Myrna's experience because the concerns occurred simultaneously.

J.J.: ...My own immediate reaction was of course sadness, I felt very badly. I don't like not helping somebody (laugh). (Page 135, line 39-41).

By it's nature, suicide is very devastating and even if professionally trained for that eventuality one still asks: "Did I go wrong?"

J.J.: ..."now what do you think did I miss anything" and that's that very first evening when B---- and I talked about it, that's when he gave me the feedback very quickly that in his opinion I had probably done more than most. (page 136, line 22-27).

It would appear crucial that training would be vital for

suicide crisis workers, social workers, psychologists and other professionals who work in this area. How do crisis workers deal with the tragedy of successful suicide? More importantly, are caregivers being cared for either by training or through support after the event occurs? Is this the only kind of suicide that occurs -- in therapy or a crisis event? Are there suicide crisis that may stem from terminal prognosis or as a side effect from long term illnesses? Or is the suicide of a patient, client or parishioner qualitatively different from loss that occurs naturally over a long period of time?

Theme of Active Participation

We have seen how the caregiver-patient, client, parishioner relationship transcends professional role boundaries and enters the personal or humanistic relationship area. When this occurs it is only natural when death occurs that one experiences a profound personal loss.

There seems to be a process that occurs when the caregiver-client relationship expands into the personal area. It is a process that is initiated by the patient, client or parishioner. The caregiver however, also participates in this process. The caregiver begins the process by noting clues that the patient wishes to deal with the issues of death and dying. The client appears to test the receptivity of the caregiver. Will he or she listened to the client's concerns? The caregiver while remaining passive becomes an active listener. He or she lets the client bring up the topic and set the ground

rules for engagement. Then the caregiver proceeds. From active listening the process grows until the caregiver-patient, client or parishioner relationship expresses joint empathy. The relationship intensifies to the point where there is mutual empathy with his or her client and deals with the concerns of the client. The client however, also empathizes with the caregiver and is concerned about the caregiver. The client not only receives but also gives to the caregiver. The client shares with the caregiver how it feels to go through the process of dying and shares the issues that concern the dying patient. The client also teaches the caregiver about death and enables the caregiver to face his or her own mortality.

Willie describes how the process begins.

Will: ...I always wait for that clue... you wait for that clue and I think to pick up the clues is important because I think the majority of people do want to talk about it sometime. They are the ones that have to open the door and they are the ones that have to choose who.... (Willie, p. 88, line 51 - p. 89, line 3).

It is the patient, client or parishioner that initiates the process. But the caregiver also has qualities that help initiate and maintain the relationship. The initial quality is one of active listening. Willie notes:

Will: ...because I'm very much into listening...

Will: and I never really did have a problem with it although there were times when you know it was iffy whether I could deal or not but I always managed by just being honest and straight forward with the person.... (Willie, p. 91, lines 9-13).

Cag describes how for her relationships begin. It does not begin automatically. There is always the possibility it may not

come to fruition.

Cag: ...you're invited in and I think the things you do help you to reflect directly on whether or not the relationship becomes intense or not and now I don't know what, exactly what you can do to make it more intense because relationships between clients and workers are the same as personal relationships, sometimes you click and sometimes you don't, I'm not sure it can't click with everyone. (Cag, page 83, lines 20-27).

Yet our cultural mores and professional training remind us that the professional ought not to become too personal.

Cag: But I think in psychology they are told that they can only go so far and I don't think that a psychologist would have gotten into as intense a relationship as I did with this gentleman. They would have seen it as completely unprofessional some of the things that I did because they are told you can go this far and no farther, you don't cross over the line. But I don't believe that there's an arbitrary line. I think that what you can do is you can have a professional relationship that is deeply intense and you can say the kinds of things that you want. There's something else that divides the professionalism from, that keeps it professional there's something else and I'm not sure I know what that is....And yet the intensity was there. And yet any psychologist looking at that would have said, "No, you were meshed, or this, or that, or the other thing or whatever." (Cag. page 83, line 38 - p. 84, line 2).

Another key ingredient is that one also avoids any hint or comment of knowing how it feels or what the client is experiencing. As Cag explains:

Cag: and that was how I share with other people, I never said to people "I know just how you're feeling." Because they would cut me off at the ankles if I ever said that to them. That's not an appropriate thing for the social worker to say unless indeed they've had the experience.

Geo: Uh huh

Cag: If you've had a husband that's been diagnosed with cancer then you know what that feels like but if you haven't then you can only say "Well, I have another patient that tells me this." (Cag, page 84, lines 40-49).

Bettie An notes also that the seriousness of death removes

boundaries that normally would inhibit communication. Boundaries which are culturally or professionally produced. She says:

Bet: but because one of us is dying we have thrown all these guards aside and we have nothing to lose and we must get on with this and the death and the dying is foremost...and what I'm thinking as a dying patient, I want to know those answers and I'm going to skip all formality to get at them and now we feel safe with one another... (Bettie An, page 96, lines 12-18).

The patient, client or parishioner has their own agenda that needs to be worked out. They choose who they want to assist them. They need someone to listen to.

Bet: They have to give you permission and it has to be done with dignity and they have to feel that this won't make them any less a person. Most times they just want a sounding board. They really aren't too interested in your opinion on things...but they need to talk. I don't think they need guidance because I think they sort it out as you go along and they go along... (Bettie An, page 96, lines 19-25).

The listener doesn't remain passive. One comes into contact with one's own feelings. The mutuality is expressed on the common ground of dying. For the caregiver it is the inevitability of his or her mortality. For the patient it is the impending death that is to occur.

Bet: ...you are forced to deal with feelings you thought you had resolved but really hadn't... (Bettie An, page 96, lines 36-38).

The common element is that both parties are dealing with grief. The grief may be over different people but they are a mutual process. That enables the joint personal venture to occur.

Bet: Each person as they're dying will give you the same story but a different story. We're all alike but we're all different and as you walk down the path with them they will touch on something that maybe you hadn't thought about before and you thought in your grief you had covered

all the bases and yet this opens up a new door and sometimes it's a pretty big door and sometimes it's just something you can yah, you can acknowledge and say this is certainly true... (Bettie, An, page 96, line 38 - p. 97, line 4).

The dying also form strong relationships with those who are suffering from the same malady. It takes on the characteristics of an A.A. group. Entry is not permitted. The patient will only admit you to a personal relationship. This one to one basis seems to be characteristic of the caregiver-patient relationship.

Bet: Absolutely, they don't easily let you cross the threshold. One to one you can but when you walk into the group in a room they don't. This is their club and they feel that you don't know how they feel about a situation and until you can build up to a point where you can say to them, Yah you know I really don't and they know that you don't know how they feel, then they will share their feelings with you how this actually felt, but it's a very tight little, it's a club. (Bettie An page 98, line 38-46).

Bettie An gives details of this process of the caregiver which would be worthy of any textbook illustration.

Bet: One to one they'll let you, but you must be a very quiet visitor. You get to know the technique. This course that we take is excellent. It teaches you how to be an active listener, it teaches you how to encourage people and I don't know if they realize how little you have said and how much they have said, I don't think they realize this. And life teaches you, each patient teaches you something in addition...you learn never to make inquiries. You may start out and you must go with their agenda and they will ...they'll let you know what their agenda is... (Bettie An, page 98, line 47 - p. 99, line 5).

Yet realistically to achieve this depth in communication there can be hinderances. These seem to stem from the professional obligations and purview. As a profession chaplains and clergy deal with the spiritual realm. Val's intense relationship

with the son started with the sister who had a negative attitude toward God. (See Val, transcript no. 1, page 75, lines 12-13). A Team, a chaplain notes also that people who have little or no relationship with the community of faith make little demands. (See A Team, transcript No. 4, page 92, lines 9-15). Being on call and ready to assist but because people are distanced from the church the relationship just on a professional basis cannot begin. (See page 93 lines 32-42). Joy observes that her clients are the family for many of her patients have profound cognitive deficits. Thus the client is unable to initiate the patient-caregiver relationship. (See Joy, transcript No. 6, page 101, lines 9-10). Jim notes this also. A lady who has dementia or the patient who is comatose leaves little room for relationship to begin. However, there may be a relationship generated as professional peer act in consultation. The specialist may support his or her conferee to deal with the issues of death or dying. It appears that what can happen in the caregiver-patient relationship can happen in a peer relationship. The one peer becomes the caregiver to the other peer. This would be an area for further investigation. (See Jim transcript No.9, page 118, lines 1-3). D.K. notes how relationship cannot occur or is retarded by the physical symptoms of intense pain or constant vomiting preclude any kind of verbal relationship.

D.K.: He's got pain in his shoulders, it hurts so much for him to roll over so that he doesn't roll over at night so that his shoulders ache in the morning. So all he wants to hear about is the morphine. So he's a nice guy, how

involved can you get. I think there's only so much you can get involved, you know him as a nice kid and you have some nice memories of him you see him as a sense a normal kid he seems a nice kid but when he's your patient you take good care of him and try to make sure he's not vomiting too much, you want to make sure he's satisfied with is control. You control the vomiting or the pain or whatever.

Geo: He's a nice kid with a fatal problem
(D.K., page 110, lines 1-13).

While we have examined how one begins the relationship that may end up profoundly personal and also noted barriers which inhibit or minimize it, there are other events which are germane to this theme of actively engaging the patient, client or parishioner.

One such sub-theme is the males inability to share feelings. There is some indications of this in the literature in the area of attitudes of medical students to their patients.

Cag had observed this.

Cag: How has it affected my work? Well, I think I have more expectations of the men I work with now. I don't know if it's more expectations but I guess I think in my own mind that men had that depth before I worked with this man now I seek that out a little bit more in men where I might not have before. I simply would have allowed them to operate at the cognitive level, now I dig a little bit more for the feeling level... (Cag, page 81, line 31-38).

However, Cag didn't want to generalize whether all males seem to be emotionally secretive or can achieve the emotional depth and ability to share as her client did. (See page 81, lines 39-42). Jim notes men do not often attend a course that addresses the issues of death and dying. (See Jim transcript No. 9, page 125, lines 6-9). Jim meets people where they are and doesn't initiate his agenda.

Jim: and I'll just treat men and women as it were the same then I tend to feel that I get the same responses back, the other thing though is to funny I harken back to a teaching of a psychiatrist preceptor of mine um back thirty years ago who said um, "People don't use iron bars to cage mice..."if I encounter a man who really just won't lose the stereotyping that to me is an iron bar or a cage of iron bars and that means that man has a lot of lions inside not mice...He's being the stereotypic quiet tough guy for whatever he is it's an absolute necessity that he stay the quiet tough guy... (Jim, page 125, line 13-23).

Yet he can model for that person the possibility of openness and vulnerability, characteristics of the personal encounter which essentially is mutual in nature.

Jim: ...and I may just have to say, O.K. I may just have to leave you this way you're doing it for personal needs and although it's awkward for me to deal with you that way because that's not me. I can let you know that there's other ways to be, male or female. like being a little more vulnerable, open, and warm, and risky but if you can't take that I'm not going to spend a whole bunch of time trying to change you. You need to be the way you are, I need to keep being the way I am we'll just have to keep on and uh I can't solve, I can't take everybody's monkey on my back,...(Jim, page 125, line 23-33).

This suggests a fruitful area for further research. Is the stereotype "macho" male purely cultural bound or are there other factors which generate and maintain this stereotype? What is the process that might remove or modify this modality of presenting the self?

The next issue stems not so much from the nature of personal relationship, how one enters it, and the loss experienced from the death of a patient or client but from the parameter of the relationship. The focus of the data so far has been on the caregiver and his or her patient, client or parishioner. However, it was noted in chapter two of this thesis that the hos-

pice movement has some presuppositions which challenge current service delivery. It sees the dying patient in a larger context. The context is one of family. Most often the dying person has a family. Older adults placed in institutions often experience family disengagement. (See Willie, transcript No. 3, page 86, lines 34-35). Myrna also notes this. (See transcript No. 8, page 112, lines 3-4). There is however another form of familial disengagement which occurs. It occurs when the person dies. The family now has no formal connection to an institution or services. Joy notes this.

Joy: ...I wish there were ways we could be of more help to the family after death as a social work department we're not very involved unless we choose to call them up, someone that we've been seeing,... (Joy, page 104, lines 20-23).

Her institution has an informal spouse group that has the characteristics of a self-help group. Joy delineates some of the issues that the death may generate.

Joy: Yah. You know not going to get that family going for family counselling, you know, I mean, we're talking about and extended family who are O.K. and doing quite well if life but if all things get stirred up with death sometimes quite volatile issues around finances, around dynamics in the family of, you know, could be anything from family origin stuff, to current stuff so yah, that all gets stirred up again then it's just dropped....(Joy, page 104, line 34-40).

Cag notes another possibility. The wife of her client has become a friend and they meet for lunch. Personal relationship endure over time. (See Cag transcript No. 2, p. 82, lines 46-48). Jim transcended his professional obligations and helped his client's mother have an open funeral. He says:

Jim: ... "I think we'll have a quiet little service we won't

have a funeral" and I didn't hit the roof but got very directive which I don't often do, and I said "Look you're having a funeral..." (Jim, page 119, 26-29).

The mother followed Jim's advice and was very appreciative of it because she followed through with the advice.

Jim: So I phoned her that night, I said, "How are you." She said, "It was triumphant." Those were her opening words. I said, "Hey, you weren't going to have a funeral." She said, "Oh I can't help it." She said, "Can you imagine, there were six hundred people there, the place was jammed." (Jim, p. 119, line 47-52).

Jim continues:

Jim: And she said, "Oh yes and it was the right thing to do." And I said "Well I am so pleased because you almost denied yourself those feelings if you hadn't had that service and you make me feel better because vicariously through your words I can appreciate what went on and I sort of knew it would." (Jim, page 119, line 52 - p. 120, line 4).

He continued that relationship until the mother's grieving needs were met. Here professionalism and the personal meld to meet a human being's need.

This process can be reversed. The family of J.J.'s client who committed suicide was concerned about the caregiver and his reaction to this tragedy.

J.J.: ...because something that I had learned in developing skills in working with suicide when somebody does successfully commit suicide as quickly as possible you get everybody together which I did and it was a good thing in that the family was able to get together, in a sense I suppose the family was quite concerned about me and vocalized that. They were worried about what affect this would have on me because they were quite aware of how much effort I had put into it and on a regular basis I called his mom and dad who lived back east... (J.J., page 135, lines 12-21).

There was the common concern of all involved.

J.J.: ...the wanting to know so I was very similar to the family in that way, that desire to understand to know why

he would do a suicide to himself... (J.J. page 136, lines 11-13).

This also suggests areas to be researched. What happens to families after the death of the significant person? What should be or can be changed in the system to address these needs? But if, as the data suggests, some families which need help no longer meet the requirements of the system, how does the family engage the professional caregiver? Who assists them?

Most institutions do not have any formal structure to assist the caregiver. Like families mentioned above they become lost in the system. The data suggests at times this happens informally. Joy notes:

Joy: ...In terms of staff, again our formal mandate isn't to work with staff on grief issues related to patients, hospice program would have more a mandate in that area.... (Joy, page 104, lines 4-6).

D.K. notes how often the residents get together to deal with their grief. (See D.K. transcript No. 7, page 111, lines 24-25).

Should there be formal structures or programs which addresses the caregiver's needs? What would be the best format? What would be it's goals? What is the need for this? We have seen how the data gathered strongly suggests the attention needs to be paid the caregiver's needs.

The Theme of Learning

Another theme suggested by the data is that of learning on the part of caregivers in the process of engagement with the

terminally ill. It seems it is the dying person who teaches the caregivers something significant about death as universal human experience. In the process the caregiver learns how to handle his or her death in the future.

Cag learned this:

Cag: ...from him the learning was deeper, you know, because he was so open and so was his wife that I learned so much from them but particularly from him because there wasn't anything that was sacred anymore in terms of sharing... (Cag, page 80, lines 39-43).

Willie learned about the feelings that occur between the caregiver and the patient.

Will: I would like to think that others could learn what I learned from her, you know. I learned a lot from her, a process is, is maybe very special, or I keep saying the word special, but I guess I do mean that it's, I would like others to experience the same thing and be able to have the feeling that I have about it because it's such a scary situations to most people, like they don't want to talk about it at all. (Willie, pages 90, lines 37-44).

And she learned that it was alright to die.

Will: ...I learned from him much about it being O.K. to die he said because I was so young and I was young, I had all the skills to look after him but not those skills and he told me that it was alright. That he was ready to die... (Willie, pp. 91, lines 15-18).

Willie suggests that role-reversal as a teaching technique might be a good method to use to learn what the patient is experiencing.

Will: I sometimes think that nurses should all be patients in the hospital before they ever look after patients and this really makes you think and once you're in the place of looking after people in this state and I think you should have to know that the acceptance of a change in your, that other people accept you the way you are no matter what state you're in... (Willie, page 89, lines 40-46).

Bettie An learned to be an active listener.

Bet: One to one they let you, but you must be a very quiet visitor. You get to know the technique. This course that we take is excellent. It teaches you how to be an active listener, it teaches you how to encourage people and I don't know if they realize how little you have said and how much they have said, I don't think they realize this. And life teaches you, each patient teaches you something in addition...

Bet: ...you learn never to make inquiries. You start out and you must go with their agenda and they will...they'll let you know what their agenda is... (Bettie An, page 98, lines 47 - p. 99, line 2).

Again they are teaching you how to die.

Bet: a lot of them along the way will verbalize that they are helping you, they're teaching you how to die and it's not uncommon for them to tell you that, which gives the relationship a new aspect for them as well,... (Bettie An, page 99, lines 14-18).

Initially, as one begins to be involved with the dying one is frightened. They are afraid and after that is noted mutual learning occurs.

Bet: ...It was quite threatening and frightening but as you became more comfortable with it and realize that they are just as frightened as you are it puts you kind of on an even keel,... (Bettie An, page 99, lines 27-30).

Ultimately one can raise the question whether what is learned in these intense personal relationships can be reproduced in the classroom for the benefit of young professional being trained. While some of the data suggests an affirmative answer there is a caution. This learning has an experiential aspect which suggests some of the learning must occur in the actual relationship and after death has occurred. Willie observed this process in herself.

Will: ...A lot of these things help like the book you read on death and dying and it all helps but these, the actual thing...

Wil: ...That's for sure and the exercises, the workshops and the sessions I've been through too, there's nothing like the experience. It does not replace it maybe gives you ideas and coping to a certain extent mechanisms

Geo: uh huh

Wil: but the actual happenings that's where you get the experience... (Willie, p. 90, line 51 - p. 91, line 9).

There is a developmental aspect to this learning.

Wil: ...so I think your young experiences do sort of mold the foundation for how you feel in the future and I think I've seen a lot of cultural differences like some cultures have very strange attitudes to death like rituals... (Willie, p. 91, lines 19-23).

and

Wil: And the young girls are especially very kind of frightened of the dying person, I think this needs to be I don't know the training or just the experience, your experience there is no replacement for that you know, we will notice a great change in time and people telling them it's O.K.... (Willie, p. 91, lines 31-36).

Cag notes the cognitive-experiential continuum and the role that experience plays in it.

Cag: I don't think people can describe to you, it's like trying to describe labor pains, you know what I mean you just have to experience them before really or describe dying or describe being...I think every experience has to be felt, has to be known in order to accurately describe the feelings that accompany it. (Cag, page 84, line 17-22).

Jim's learning occurred over a period of time. It involved models who displayed medicine with a human face. It involved what was being said in the literature and the hospice or palliative care movement. (See Jim, transcript No. 9, p. 122, lines 29-43). In this learning process professional lines are crossed and one is in the area of the personal again. (See Jim p. 123 line 1-12). Sandra describes it this way.

San: ...I mean it was all just part of being two human beings together. The professional role sometimes dissolves in

the situations that I may have had in other situations working with different people through different experiences. This is a different kind of experiences. This is a different kind of experience for me as a nurse and part of it is very nice and human....

San: ...I would say they're not just dissolved or blurred, perhaps they go in stages, they dissolve, they blur, and then they're not there they become irrelevant. (Sandra, page 129, line 43-51).

But there are memories about the way things used to be done but were painful. For in the past the professional stance was used to deal with issues of death and dying. While the dying were placed throughout the ward there were breaks then which ameliorated the stress. Today the stress is constant when dying patients are grouped in certain wards.

San: I think very much too depends on what you do with it because I would say before, as a beginning nurse, as a student, I handled it in quite a different way from how I do now that I am older and have more life experiences to put it into a different kind of context. I've been doing more reading, more thinking, more experiencing actually, where I've let it come into myself, where I actually felt it as opposed to being able to keep it out there as a professional, as was my initial way of managing. So I think, and I'm not quite sure where that turning point came, or whether J---- was that turning point, I don't know. But I do know that the last few years I been, in one way, paradoxically taking it in more deeply and in another way being able to move away from it more quickly. Not away from it but put it together, and get some peace around it.... (Sandra. page 130, lines 27-42).

Even in this intense personal learning process the aloof or stoic professional stance and manners makes itself conscious. Professionalism requires some distancing.

Cag: There was never any question of that, never. And yet the intensity was there. And yet any psychologist looking at that would have said, "No, you were meshed, or this, or that, or the other thing or whatever." (Cag, page 83, line 51 - page 84, line 2).

The stressful work with suicide necessitates training. Probably no other aspect or concern about the caregiver is as important as this item. However, as we examine the literature this too seems to be a neglected aspect of concern about the caregiver's needs. J.J. notes this.

J.J.: I'm somewhat different that way. But I also suspect somewhat different because I received the majority of my training working with suicides in the States; just the fact that first of all I received any training I suspect that makes me different than most of the professionals you've talked to... (J.J., page 134, lines 3-8).

Can this area be dealt with and be taught in the classroom? Sandra states:

Geo: but until you've experienced that loss then the searching begins and the answering of the question the feeling of the emotions and all that.

San: I agree with you I think that's one of the things I was getting at in terms of the faddishness, and the...you know a lot is written a lot is talked about and maybe some of that does some good, I'm quite sure it does I'm quite sure that it cracked open something that needed cracking open back whenever it was but then it sort of steamrolled on. A lot if that has been helpful but there's something more and I'm not sure how that something more is taught it's a real conundrum to me I really don't know 'cause one has to be open to it and the timing and how do you approach that in a curriculum is beyond me, I don't know.

Geo: Uh huh. I think you're pointing to something that I have a suspicion about too the text books don't match up to the reality

San: No.... (Sandra, page 132, lines 15-33).

She continues to struggle in explaining that learning process.

San: I sometimes think that stories, maybe novels do the best job... (Sandra, page 132, lines 45-46).

Still there is an experiential component that is emphasized.

San: ...because somehow those significant deaths make us do our homework the stuff that we need to do for ourselves, that triggers that, there is no way you can schedule that in a semester. (Sandra, page 133, lines 8-12).

While learning takes place in the actual experience of

losing clients, patients or parishioners through death it is obvious that this learning or part of it needs to be put into the caregivers educational requirements. This then becomes a relevant research area. If these relationships can be shared through literature or first hand accounts the initial encounters of death and dying might be mollified for student nursing and medical personnel.

The Theme of Personal Transformation

The final theme to be examined is that of personal transformation. As we delineate the themes above we note that while they seem separate and distinct they also blend into each other. That blending indicates that we are dealing with a process. We saw how in the relationship between caregiver and patient, client or parishioner learning occurred. Yet we saw associated with that some of this learning could occur in one's professional training. It probably is a learning that begins in one's professional preparation and continues throughout one's professional career. As the data suggests, when the caregiver relationship transcends into the personal there is a transformation that occurs. One aspect of that transformation is confirmatory in nature. One begins to become aware that it is alright to work with death and dying. Individuals learn in which areas they wish to express their professional skills. There is something reciprocal in the experience.

Cag observes this in herself.

Cag: It has just led me to remain in this area, in the area of death and dying which I consider to be a very significant

area of bereavement. (Cag, page 81, line 51 - page 82, line 1).

This confirming aspect parallels some of the literature when read.

Cag: ...it also confirmed all the reading you do in death and dying and they say this is what happened and go through this phase and that phase. I went through all the phases with him and so it confirmed all the things in the literature so when I go to the literature now, I read through and that's like him. I remember that from him, you know. a lot of that was true for me. (Cag, page 82, line 3-11).

This confirming aspect helped Cag determine which areas she prefers to work in.

Cag: So that's another thing I've learned, that I would rather work with younger people, who are dying, for whom the issues are very intense and significant, that for me is more meaningful work for me.... (Cag, page 83, line 30-33).

Willie also had this confirming experience.

Will: ...I like to look after them and care for their needs and support them, I enjoy working in that, I enjoy working in any capacity but that is a favourite spot of mine and our supervisor is good, if there is a person dying on our unit then I have the opportunity to work with them. Say if I haven't had that group for a long period of time... (Willie, page 91, lines 43-48).

Bettie An observes this also:

Geo: ...It sounds like you enjoy this work, it's right for you to do this.

Bet: It's a very humbling experience because people will let you into their lives you must, you must make yourself trustworthy (Bettie An, page 99, line 19-23).

And she receives as she gives. While the process is confirmatory in nature there also the aspect of reward or satisfaction. The intense personal relationships are not one sided but there is the element of mutuality. It is not only the patient, client or parishioner that receives something but also the

caregiver. This suggests that the concept of synergism might describe what occurs in the caregiver-client relationship. Both people are enhanced in the process. This would indicate another area fruitful for research.

Bet: At times when I go, when I've had a busy week and something has happened and I think I don't want to visit today. Those are generally my most rewarding days, the days that I am ministered to...and I come out thinking, Thank you. (Bettie An, page 99, line 33-37).

Transformational processes seem to enable one's personal expression of one's humanity through the professional skills. For in transformation one wishes to use the personal or humanistic modality. Jim says:

Jim: ...I want to be useful, and in fact I want to have the satisfaction of knowing that at least one human being will say at some time, "Hey am I ever glad that you came into my life." Not that another human being turned up or that a doctor was available to give me the right antibiotic but that you uniquely, Jim, turned up, because you uniquely as a person and with your training and your interest and whatever. And even for a fleeting instant that I'm that useful... (Jim, page 123, lines 43-51).

Death can be profoundly transforming. Sandra's experience led her into the area of death and dying as a career change.

San: ...but in a sense he was the person who really helped me develop my career interests in this area so he's a special person.... (Sandra, page 128, lines 5-7).

She continues:

San: The thing that has been helpful to me and has been helpful to his folks a little bit is that a lot of the work I've done ever since has really been because of that death... (Sandra, page 129, lines 6-9).

That transformation enables one to go into the suffering but also enables one to come back. It not only enables one to be personalistic or humanistic in approach, it also enables a per-

son to suffer and to come back as a "wounded healer." (Nouwen, 1972).

San: It has most often been the situation when I've been working with someone who is dying or with a bereaved person that although I feel as if I sort of go into some awful place with them that maybe those memories have given me a lifeline out to the surface you know. I can sort of go down with them with that feeling that although it's awful sometimes there is always that other side. (Sandra, page 129, lines 15-22).

While it confirms one's area of vocation it has more depth because it deals with the meaning of life. Death's agenda is called us to make it meaningful.

Geo: But this experience is still special is it?

San: Yes

Geo: It helped you focus

San: yes

Geo: in an area that you pursued

San: Yes. It doesn't quite capture it though, I know that's what I said but it doesn't quite capture it. I'm sure that's true on one level, but there's a different level where it's truer. (pause) It goes beyond career actually, it was deeper than a career choice or a master's project or thesis or anything like that it was fundamentally a turning point for me, I think in the way, I view my faith, my belief in good and bad, my ability to salvage some sense out of something that seems senseless,... (Sandra, page 129, lines 29-42).

Death paradoxically can become a friend once we let it begin to transform us and we begin to experience growth.

San: There's something that comes from working with a person in a hands on way that at a certain stage turns death into a friend....the loss is assimilated through touch even if it isn't spoken about, one feels that change in the person's body, one feels the disease is going to be the winner, and then one comes to the place where one feels that yes this is O.K. then one becomes more the comforter in a physical sense like the back rub, (Sandra, page 130, line 1-8).

Sandra describes that process of personal transformation.

San: ...I think it very much too depends on what you do with it because I would say before, as a beginning nurse, as a student, I handled it in quite a different way from how I

do now that I am older and have more life experience to put it into a different kind of context. I've been doing more reading, more thinking more experiencing actually, where I've let it come into myself, where I actually felt it as opposed to being able to keep it out there as a professional, as was my initial way of managing. So I think, and I'm not quite sure where that turning point came, or whether J--- was that turning point, I don't know. But I do know that the last few years I been, in one way, paradoxically taking it in more deeply and in another way being able to move away from it more quickly. Not away from it but put it together, and get some peace around it.... (Sandra, page 130, line 27-42).

Transformation is ultimately a personal growth experience.

Geo: Understanding what? Can you clarify that?

San: The understanding, there are two levels really, one becomes immersed in the theory and you know that people, including caregivers, will feel certain things if one has experienced loss. That's fine. On another level, there is a need to make that personal and make it real, because it is real so one needs to change from the one out there to being less me, I think it comes from that ...

San: ...And they need to resolve it both professionally and personally, probably the personal being the more important... (Sandra, page 131, lines 10-21).

Jim suggests this also. A key aspect of the personal transformation is personal.

Jim: ...Good palliative care is to deal with the whole person, and the person's relationships, the person's state of health meaning the person's relationship with fellow man, other humans, family, caregivers, community to deal with their knowledge, their intellect, their brain, their being, and their emotions. Well there it is Luke 2:52, based on Jesus but we're all little Jesus'.... (Jim, page 123, lines 2-12).

Conclusion

This thesis is basically an exploratory piece of research. Qualitative methodology gives recognition to both the objective and subjective perception of the respondents as well as the researcher. For this researcher this tended to be a research exercise filled with surprises at what occurred. The depth of

personal relationship that can develop between caregiver and the dying person as well as the family was not expected. A second surprise was the conscious understanding that the pain and suffering often result in significant learning on the part of the caregiver. Clearly the death of a person can bring deep meaning about death and dying to others including caregivers. While the literature suggests death is associated with terror in western society, it is quite clear there can be a profound transformational process of deep meaning to those who continue to live.

This exploratory research suggests an important place for phenomenological inquiry as a method to legitimate and give meaning to lived experience. Much more needs to be undertaken so we can all more clearly understand the experience of working in the hospice movement, the desirable training for it and the support structures needed to genuinely help the dying person as well as those who choose to offer their services in this environment.

Appendix A

GENERAL ASSUMPTIONS AND PRINCIPLES
Assumptions **Principles**

- | | |
|--|--|
| <p>1. The care of the dying is a process involving the needs of the patient, family, and care-givers</p> <p>2. The problems of the patient and family facing terminal illness include a wide variety of issues--psychological, legal, social, spiritual, economic, and interpersonal.</p> <p>3. Dying tends to produce a feeling of isolation.</p> <p>4. It has been the tradition to train care-givers not to become emotionally involved but in terminal the patient and family need to experience the personal concern of those taking care of them.</p> <p>5. Health care services customarily lack coordination.</p> <p>6. A supportive physical environment contributes to the sense of well-being of patients, of families, and of care-givers.</p> | <p>1. The interaction of these three groups of individuals must constantly be assessed with the aim being the best possible care of the patient. This cannot be accomplished if the needs of family and/or care-giver are negated.</p> <p>2. Care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussion with a common purpose.</p> <p>3. All that counteracts unwanted isolation should be encouraged. Social events and shared work that include all involved should be arranged so that meaningful relations can be sustained and developed.</p> <p>4. Profound involvement without loss of objectivity should be allowed and fostered, with the realization that this may present certain risk to the care-giver.</p> <p>5. The organizational structure must provide links with health care professionals in the community.</p> <p>6. The environment should provide adequate space, furnishings that put people at ease, the reassuring presence of personal belongings, and symbols of life cycles.</p> |
|--|--|

PATIENT-ORIENTED ASSUMPTIONS AND PRINCIPLES

Assumptions

1. There are patients for whom aggressive curative treatment becomes increasingly inappropriate.
2. The symptoms of terminal disease can be controlled.
3. Patients' needs may change over time.
4. Care is most effective when the patient's life-style is maintained and philosophy of life is respected.
5. Patients are often treated as if incapable of understanding or of making decisions.
6. Dying patients often suffer from helplessness, weakness, isolation, and loneliness.
7. The varied problems and anxieties associated with terminal illness can occur at any time of day or night.

Principles

1. These patients need highly competent professionals, skilled in terminal care.
2. The patient should be kept as symptom free as possible. Pain should be controlled in all its aspects. The patient must remain alert and comfortable.
3. Staff must recognize that other services may have to be involved but that continuity of care should be provided.
4. The terminally ill patient's own framework of values, preferences, and outlook on life must be taken into account in planning and conducting treatment. [126]
5. Patients' wishes for information about their condition should be respected. They should be allowed full participation in their care and a continuing sense of self-determination and self-control.
6. The patient should have a sense of security and protection. Involvement of family and friends should be encouraged.
7. Twenty-four-hour care must be available seven days a week for the patient and family where and when it is needed.

FAMILY-ORIENTED ASSUMPTIONS AND PRINCIPLES

Assumptions	Principles
1. Care is usually directed toward the patient. In terminal illness the family must be the unit of care.	1. Help should be available to all those involved--whether patient, relation, or friend --to sustain communication and involvement.
2. The course of the terminal illness involves a series of clinical and personal decisions.	2. Interchange between the patient and family and the clinical team is essential to enable an informed decision to be made.
3. Many people do not know what the process of involves.	3. The family should be given time and opportunity to discuss all aspects of dying and death and related emotional needs with the staff.
4. The patient and family need the opportunity for privacy and together.	4. The patient and family should have privacy and time alone, both while the patient is living and after death occurs. A special space may have to be provided.
5. Complexity of treatment and time-consuming procedures can cause disruption for the patient and family.	5. Procedures must be arranged so as not to interfere with adequate time for patient, family, and friends to be together.
6. Patients and families facing death frequently experience a search for the meaning of their life, making the provision of spiritual support essential.	6. The religious, philosophical, and emotional components of care are as essential as the medical, nursing, and social components, and must be available as part of the team approach.
7. Survivors are at risk emotionally and physically during bereavement.	7. The provision of appropriate care for survivors is the responsibility of the team who gave care and support to the deceased.

STAFF-ORIENTED ASSUMPTIONS AND PRINCIPLES

Assumptions

1. The growing body of knowledge in symptom control, patient- and family-centered care, and other aspects of the care of the terminally ill is now readily available.

2. Good terminal care presupposes emotional investment on the part of the staff.

3. Emotional commitment to good terminal care will often produce emotional exhaustion.

Principles

1. Institutions and organizations providing terminal care must orient and educate new staff and keep all staff informed about developments as they occur.

2. Staff needs time and encouragement to develop and maintain relationships with patients and relatives.

3. Effective staff support systems must be readily available.

Taken from Foster, Zelda (1979).
Assumptions and Principles.
4, No. 1, 124-128.

Standards for Hospice Care:
Health and Social Work, Vol.

Appendix B

Cover letter to participants	183
Research procedure	184
Research Questionnaire	190

George W. Wagner
8624 - 47 Ave. N.W.
Calgary, AB.
T3B 2A2

Dear

As you know I am in the Masters program at the University of Calgary in the Faculty of Social Welfare. I am now completing my research for the thesis. The topic I have chosen to investigate is the topic of loss. Professional caregivers lose their clients to death either naturally or deliberately. While the literature and research abounds in information how to deal with death and dying and how to help the survivors little has been done to deal with professionals who loose their clients, patients or parishoners. This area seems to me an area for fruitful investigation.

As a professional in your area I would like you to assist me in my research endeavours. Please find enclosed a copy of my procedure and also the questionnaire I shall be using. Please read the material which includes a historical data sheet and consent form. If my endeavour is acceptable please let us arrange an initial appointment so that we may formally begin our work.

I thank you for your time and attention. I also thank you for your willingness to consider and participation in my thesis research. If you have any questions please call me at my home number which is 247-1963. We will then set up an appointment to meet.

Yours truly,

George W. Wagner

Thesis
Research
Procedure

Area of Research

The topic or area of research is the loss through death (accidental or deliberate) of a client, patient or parishioner that a professional may experience. This experience will be investigated by the openedended interview. This interview will last one and a half to two hours.

After the interview, which will be taped, it will be transcribed verbatim. It will be returned for correction, clarification, modification, elaboration or any other revision the interviewee wishes to make. This corrected version shall be the data used in the writing of the thesis.

Data Use

Obviously the data from the interview will be used in the thesis. Concepts from the interviews and quotations from that data will be utilized. Your consent will be asked for that use. Secondly, copies of your verbatims will be kept on file for two years in case it may be used for publications or journal articles. Your free and voluntary consent will be required.

To assure your privacy, a code name will be chosen to identify your material in the thesis and in any possible publication.

Audio tapes will be erased once the thesis has been completed

Arrangement for a copy of your audio tape and transcript can be made.

Procedure

Your consent to act as a subject shall be obtained before any interview appointment is scheduled. However, if at any time before the interview or during the interview you wish to stop proceeding and withdraw

your involvement you may without any consequences to you.

If there are any indications of possible enduring grief or unresolved problems from the event you're describing, arrangements will be made to refer you to competent counsellors that can deal with grief and loss through death.

Upon completion of the thesis all participants will have the opportunity to privately read the thesis or will be invited to a public presentation of the results obtained.

The interviewer shall be open to and deal with all concerns you may have not only at the initial appointment but during the interview process.

Consent will be asked also for a typist to hear and transcribe audio tapes if not transcribed by the interviewer.

Transcripts for possible future use will be kept safe and secure from the public. If in the event that material will be used in publication, the interviewee will be informed about the same. Also interviewees may request their verbatim transcripts to be forwarded to them so that they can destroy them.

No appointment for the interview will be made until interviewees feel they can give free and voluntary consent and that the data obtained and its use will assure their confidentiality and anonymity.

Name _____ Age _____

Code Name (to be used in this thesis) _____

Mailing Address _____

City _____ Postal Code _____

Telephone: Home _____ Work _____

Profession _____

Years practising: Years _____ Months _____

Approximate length of time that you knew the subject as a client, patient
or parishioner.

Years _____ Months _____

I, _____ hereby voluntarily and freely covenant with George W. Wagner, a Masters student in the Faculty of Social Welfare at the University of Calgary the following:

- (1) I of my own choice and volition agree to participate in the thesis research project. After the initial appointment to sign the consent form and set appointment date there will be two appointments. The first interview shall last approximately $1\frac{1}{2}$ hours and the final appointment approximately $\frac{1}{2}$ hour. If more time is needed it shall be my responsibility to extend the time committment as I choose.
- (2) The cost to me shall be the time involved. Due to the nature of the research, no monitary reward can be expected. It is assumed that my committment to scientific research and the scientific endeavour shall be sufficient reward.
- (3) I hereby give consent to have the sessions audio-taped.
- (4) I hereby agree to permit quotations from my sessions to be put into the body of the thesis.
- (5) I may borrow the tapes to make personal copies.
- (6) A copy of the verbatim will be corrected by me. All changes will be initialled.
- (7) I will be provided with a copy of the final verbatim.
- (8) I understand that audio-tapes will be kept in a secure place, confidentiality and anonymity respected, and finally erased upon completion of thesis.
- (9) The verbatims can be kept for up to two years and may be quoted in journal articles or related research materials. After two years they will be destroyed.
- (10) It is incumbent upon me to keep my sources used as example confidential.
- (11) I shall indicate a code name to be used in the thesis when quotine my material.
- (12) I consent also to permit any people working on the thesis (e.g. typist, thesis committee) to look at the material.

- (13) I understand that if there are any problems of unresolved grief that George W. Wagner will assist me in obtaining the professional help necessary to resolve the problem.
- (14) I shall be permitted to examine the results of the research and read the completed thesis.
- (15) While voluntarily and freely consenting to participating in the research project I have the right to terminate proceedings at any time without consequence to me.
- (16) Mr. George W. Wagner will explain all unclear items in the consent form and/or in the research procedures to my fullest satisfaction before any interview(s) be scheduled. I will endeavour to ask for that clarification.

Date

Print Name

Signature

George W. Wagner

Thesis
Research
Questionnaire

Introduction

My name is George W. Wagner and I am currently in the Masters of Social Work program in the Faculty of Social Welfare at the University of Calgary. I am also an ordained clergyman of The Lutheran Church -- Missouri Synod. After five years of parish ministry I entered the Faculty of Social Welfare to pursue further studies for the parish ministry. I graduated in 1983 with my Bachelor of Social Work. The research for this thesis will fulfill all the requirements for the Masters program with the view of completion for graduation in 1988.

Area of Research

The area of research interest is dying, death and the grieving process. This area has received much research impetus in the last few years. Much insight has been gained to assist people in facing their own death and to assist the living in their grieving-process. There is, however, one area that seems to need more research. That is the area of the loss of a client, parishoner or patient. How do we as professionals, viz., pastors, social workers, chaplains, doctors, nurses, nursing assistants and even volunteers deal with the loss of a person in our professional care? What is that experience for us?

Qualitative Analysis

As I ponder my area of interest there are a number of hypothesis that I could generate. One such hypothesis is that the loss of a client

(parishoner, patient) has a transforming aspect upon a person. Initially it may have a numbing effect. As the numbness or shock wears off one confronts one's own mortality. In the process of confronting the death of one's client (parishoner, patient) one formulates one's own philosophy or ideology of life. This enables one to deal with future losses and eventually one's own mortality. An alternative hypothesis is that when this event is not dealt with it may lead to ineffectiveness, stress or even burn out.

Another area of concern is what portion of one's professional education has been directed to this concern. As a professional has your profession devoted any amount of its formal training to dealing with loss? Is it now addressing the issue? What have you done through informal learning or continuing education to help yourself deal with this professional problem? What would you like to see happen in your professional education to address this problem?

Also another area for possible exploration is the network of friends, relatives and other professionals we use to help us deal with the grieving process. My hypothesis is that in lieu of any formal education or fellow professional caregivers one develops a personal informal system to deal with the losses one experiences.

There are numerous other hypothesis one could generate. Along with the above mentioned ones one could develop a definite and precise questionnaire and interview schedule. One could verify the various hypothesis one generates. There is, however, an alternative method

of investigation. That is the qualitative or naturalistic approach to generating data. This procedure maximizes input from the person being interviewed. They share their experience to the fullest. In essence the interviewer and interviewee become co-researchers. Verifying hypothesis in new areas of research may limit the area of investigation and future research may take longer to uncover significant data and insights.

Qualitative research emphasizes the experiences or the event. In order to understand the loss of one client (patient, parishoner) one needs to explore it in its fullest depth. Once that depth has been shared it can be studied. It is best studied in an open ended fashion. Rather than looking at it piece meal it is researched in a wholistic fashion. Comparison then of a number of these shared experiences will indicate commonalities and themes. These can at a future date be verified by other methodologies. As the experience is shared, hypotheses are generated from the data. These in effect would be more profitable to persue that verifying the hypothesis of the reseacher.

The question then, to be investigated is this: What was the experience for you of loosing one of your clients (parishoners, patients)?

Interview Procedure

The interview procedure will be as follows. After the initial appointment in which the research project will be explained, any questions of clarification answered and a consent form signed; a date, time and

place shall be selected for the interview.

At that time the interview shall revolve around the question indicated above. The interviewee shall choose the experience of a loss of a client (natural, accidental, homicide, undetermined or suicide) most significant to him or her. The interview shall deal with that event and its meaning.

Upon completion of the interview a verbatim transcript will be made. The person interviewed will be asked to read it and make any corrections, omissions or addendums as he or she feels necessary. Alternatively, if the interviewee would prefer to hear and study the audio tapes that alternative will be exercised.

At a future date the result of the thesis research will be shared with all those who participated in my research.

Appendix C

Letter to Mr. Werner Pauls	196
Letter to Judith Blythe	198
Letter from Mr. Werner Pauls	199

July 1, 1987

George W. Wagner
8624 - 47 Ave. N.W.
Calgary, AB.
T3B 2A2

Mr. Werner Pauls
Administrator
Bethany Care Centre
916-18A St. N.W.
Calgary, AB.

Dear Mr. Pauls:

First of all let me introduce myself. My name is George W. Wagner. I am a clergyman in The Lutheran Church-Missouri Synod. I am currently on a sabbatical and am completing my Masters degree in Social Work at the University of Calgary. My area of research is in the area of death and its effects on professional caregivers. My thesis is dealing with professionals, e.g. social workers, front line nursing staff and volunteers who experience the loss of their clients, patients or parishoners through death. That death may be natural, accidental or deliberate.

What I hope to do in my thesis is to get as accurate a picture as possible of the event and the meaning of the event to the caregiver. Also related to this is how the caregiver coped with the experience of the death in their professional capacity of a caregiver.

The methodology is qualitative (descriptive or naturalistic) in nature. It shall revolve around two unstructured interviews. The first interview shall last approximately $1\frac{1}{2}$ - 2 hours and the concluding interview $\frac{1}{2}$ - 1 hour in length. The content of the interviews will form the data I will work with in my thesis. There are a number of professionals I wish to interview. They are (1) social worker, (2) parish clergyman, (3) chaplain, (4) nursing supervisor, (5) registered nursing assistant, (6) nursing attendant, (7) medical doctor, (8) medical doctor - resident, (9) hospice director, (10) nursing instructor, (11) volunteer, (12) police officer (loss of fellow officer), and (13) counsellor.

I have shared my thesis research with Ms. Judith Blythe. She has consented to help me arrange contacts at Bethany that would be interested in participating in my research. She also suggested that I get your permission to conduct my research at Bethany Care Centre with Judith Blythe as the official contact person. She has indicated that she would act in this capacity.

Two other items of note. I am looking for three of four persons from Bethany Care Centre to be involved in my research. Secondly,

due to the nature of my research anyone involved in the interviews would do them on a mutually acceptable time on off hours or days off.

Also when the research is completed and thesis accepted I would be willing to avail myself to Bethany to give an in-service seminar on my findings.

I thank you for your time and attention. If there are any questions or if you wish to arrange an appointment please call me at 247-1963. Please find enclosed two items. The first is entitled "Thesis Research Procedure" and the second "Thesis Research Questionnaire." Everyone who participates in my research will receive both items. Please note also that the last two pages of the Research Procedure are consent form to be signed by anyone who wish to participate in my research.

Yours truly,

George W. Wagner

cc Ms. Judith Blythe
File copy

July 1, 1987

George W. Wagner
8624-47 Ave. N.W.
Calgary, AB.
T3B 2A2

Mrs. Judith Blythe
Hospice Director
Bethany Care Centre
916-18A St. N.W.
Calgary, AB.

Dear Mrs. Blythe:

Enclosed find a copy of a letter to Mr. Werner Pauls. I've also sent you a copy of the two items each prospective interviewee will receive. It is hoped that I will be able to have all my interviews done by the end of July.

I would be looking for people in the following areas: Social Worker, Hospice director, Nursing supervisor and nursing assistant. Possibilities for social worker is Joyce Elliot, and Mrs. McKinnon or Mrs. Brack for Nursing Supervisor. I haven't discussed your involvement yet. It would be contingent upon whether you've experienced the loss of a client through death.

I think it would be expedient for us to get together after you've perused the enclosed materials and we could formalize some strategies.

Again thank you for your time and attention in assisting me in my thesis research.

Yours truly,

George W. Wagner

Bethany Care Centre



- Auxiliary Hospital
- Nursing Home
- Senior Citizens Home

916 - 18A Street N.W.,
Calgary, Alberta T2N 1C6
Telephone (403) 289-3701

Owned and Operated by
The Lutheran Welfare Society
in Alberta

199

July 9, 1987

Mr. George Wagner,
Faculty of Social Welfare,
University of Calgary,
2500 University Drive,
Calgary, Alberta. T2N 3Y9

Dear Mr. Wagner;

Re: Research

Thank you for the very complete submission you prepared. The research topic you have identified, and the method of handling it looks most interesting. The information learned from your research project will undoubtedly be of considerable interest to organizations such as Bethany Care Centre.

We will be pleased to work with you in your preparation for the Thesis. Our Hospice Co-ordinator, Judith Blythe, has agreed to work on our behalf as your contact person within Bethany Care Centre.

In any research projects involving our organization, we are always concerned about confidentiality of information, consent processes, workload and time involvement for staff, and appropriateness of the subject matter. In this case as well, we ask that you work closely with Judith Blythe in identifying the three or four individuals that you will be interviewing. We further ask that a clear time frame be established for the duration of the interview times, and an overall time frame be set for the interview portion of the research project.

I would like to wish you success in your preparation for your Master's Thesis. Upon its completion we will look forward to further discussing its applicability to our caregivers.

Yours truly,

W. Pauls,
Executive Director.

WP/dfm
cc: J. Blythe,
Hospice Co-ordinator.

Bibliography

- Aday, Ronald H. (1984-85). Belief in Afterlife and Death Anxiety: Correlates and Comparisons. Omega, 15, 67-75.
- Adkins, Lynn (1984). Hospice Care for Terminally Ill Children. Child Welfare, 63, 559-562.
- Arnold, Joan Hagan and Gemma, Penelope Buschman (1983). A Child Dies: A Portrait of Family Grief. Rockville, MD: Aspen Systems Corporation, p. 130.
- Babcock, Dorothy E. (1976). Transactional Analysis. American Journal of Nursing, 76, 1152-1155.
- Bader, Madelaine A. (1972). Personalizing The Management of Pain for the Terminally Ill Patient. Journal of Thanatology, 2, 757-766.
- Barrett, William (1958). Irrational Man: A Study in Existential Philosophy. Garden City, New York: Doubleday and Company, Inc.
- Barton, David (1977). The Caregiver. In David Barton (Ed.), Dying and Death: A Clinical Guide for Caregivers. Baltimore: The Williams and Wilkins Company, p. 72.
- Becker, Ernest (1973). The Denial of Death. New York: The Free Press.
- Berardo, Felix M. (1985). Social Network and Life Preservation. Death Studies, 9, 37-50.
- Bernheimer, Lucinda P. (1986). The Use of Qualitative Methodology in Child Health Research. Child Health Care, 14, 224-232.
- Bettelheim, Bruno (1982). Freud and Man's Soul. New York: Alfred A Knopf.
- Breindel, Charles L. and Boyle, Russell M. (1979). Implementing a Multiphased Hospice Program. Hospital Progress, 76, 42-45.
- Breuer, Judith (1976). Sharing a Tragedy. American Journal of Nursing, May, 759.
- Bryant, Cullene Evelyn (1985). Nurses and Their Religious Faith as a Coping Mechanism In Dealing With Patients and Their Death. DA8519736
- Buckingham, Robert W. (1982-83). Hospice Care In the United States: The Process Begins. Omega, 13, 160.

- Butterfield-Pigard, Helen and Magno, Josephina B. (1982). Hospice the Adjective, Not the Noun: The future of a National Priority. American Psychologist, 37, 1254-1259.
- Cady, Jane Wood (1976). Dear Pain American Journal of Nursing, 76, 960-961.
- Campbell, Thomas W., Abernathy, Virginia, and Waterhouse, Gloria J. (1983-84). Do Death Attitudes of Nurses and Physicians Differ? Omega, 14, 43-49.
- Carter, Susan L. (1987). Barbara. Death Studies, 11, 63-65.
- Chekryn, Joanne, Degan, Marion and Reid, Jean. (1987). Impact on Teachers When A Child Waith Cancer Returns to School. Child Health Care, 15, 161-165.
- Chng, Chwee Lye and Ramsey, Michael Kirby (1984-1985). Volunteers and the Care of the Terminal Patient. Omega, 18, 237-244.
- Coale, Jack G. (1979). The Hospice in the Health Care Continuum. Quality Review Bulletin, May, 22-23.
- Corbet, Terry L. and Hai, Dorthey M. (1979). Searching for Euthanatos: The Hospice Alternative. Hospital Progress, March, 38-40.
- DaSilva, Anthony and Schork, M. Anthony (1984-85). Gender Differences in Attitudes of Death Among a Group of Public Health Students. Omega, 15, 77-84.
- Davidson, Margaret Pratt (1976). T.L.C. for Oscar. American Journal of Nursing, November, 1782-1783.
- Dempsey, David (1975). The Way We Die: An Investigation of Death and Dying in America Today. New York: Macmillan Publishing Co., Inc.
- Dickinson, George E., Sumner, Edward E., and Durand, Ronald P. (1987). Death Education in U.S. Professional Colleges: Medical, Nursing and Pharmacy. Death Studies, 11, 57-61.
- Doherty, Kathleen, Stein, Shayna, Linn, Margaret M. (1982). An In-Service Guide for Death Education. Gerontology and Geriatrics Education, 2, 191-197.
- Donavan, Mary Ivers (1979). Assessment of the Impact of Relaxation with Guided Imagery of the Reduction of Stress Among Cancer Nurses. DA7924708

- Drotar, Dennis (1976-77). Consultation In The Intensive Care Nursery. International Journal of Psychiatry In Medicine, 7, 69-81.
- Eakes, Georgene (1985). The Relationship Between Death Anxiety and Attitudes Towards the Elderly Among Nursing Staff. Death Studies, 9, 163-172.
- Eggerman, Sinda and Dustin, Dick (1985-86). Death Orientation and Communication With The Terminally Ill. Omega, 16, 255-265.
- Epstein, Charlotte (1975). Nursing the Dying Patient: Learning Process for Interaction. Reston, Virginia: Reston Publishing Company, Inc. p. 81
- Erikson, Erik H. (1963). Childhood and Society: Second Edition. New York: W. W. Norton and Company Inc.
- Field, David and Howells, Kevin (1986). Medical Students' Self-Reported Worries About Aspects of Death and Dying. Death Studies, 10, 147-154.
- Fischer, William F. (1978). An Empirical-Phenomenological Investigation of Being-Anxious: An Example of the Meanings of Being-Emotional. In Valle, Ronald S. and King, Mark. Existential-Phenomenological Alternatives for Psychology. New York: Oxford University Press. pp. 166-181.
- Florian, Victoria and Har-Even, Dov (1983-84). Fear of Personal Death: The Effects of Sex and Religious Belief. Omega, 14, 83-91.
- Frankl, Viktor E. (1963). Man's Search for Meaning: An Introduction to Logotherapy. New York: Washington Square Press.
- Geizhals, Judith Susan (1975). Attitudes Towards Death and Dying: A Study of Occupational Therapists and Nurses. Journal of Thanatology, 3, 243-269.
- Gleason, Jr., John J. (1975). Growing Up to God: Eight Steps in Religious Development. Nashville: Abingdon Press.
- Goebel, Barbara L. and Boeck, Bruce E. (1987). "Ego Integrity and Fear of Death: A comparison of Institutionalized and Independently Living Older Adults." Death Studies, 11, pp. 193-204.
- Goldstein, Sol (1986). Michael's Ship. Scarborough, Ontario: Prentice-Hall Canada Inc.

- Gorden, Raymond L. (1980). Interviewing: Strategy, techniques and tactics. Homewood, Illinois: The Dorsey Press.
- Gotay, Carolyn Cook (1984). The experience of Cancer During early and advanced stages: The view of Patients and their mates. Social Science Medicine, 18, 605-612.
- Greening, Thomas C. (Ed.) (1971). Existential Humanistic Psychology. Belmont, CA.: Brooks/Cole Publishing Company.
- Harper, Bernice Catherine. (1977). Death: The Coping Mechanism of the Health Professional. Greenville, South Carolina: Southeastern University Press, Inc.
- Hatfield, Bob and Bruce (1985). Matters of Life and Death. Winfield, B.C.: Wood Lake Books, Inc.
- Hatfield, C.B., Hatfield, R.E., Geggie, P.H.S., Taylor, J., Soti, K., Winters, L., Harris, A. and Greenley, N. (1983-84). Attitudes about Death, Dying, and Terminal Care: Differences among Groups at a University Teaching Hospital. Omega, 14, 51-63.
- Hayslip, Bert and Walling, Mary L. (1985). Impact of Hospice Volunteer Training on Death Anxiety and Focus of Control. Omega, 16, 243-254.
- Heimler, Eugene (1959). Concentration Camp. London: Corgi Books.
- Heimler, Eugene (Ed.) (1966). Resistance Against Tyranny. New York: Fredrick A Praeger, Publishers.
- Howard, George S. (1986). Dare We Develop A Human Science? Notre Dame, Indiana: Academic Publications.
- Jacobstein, Diane Moira (1982). Professional Distance and Involvement of Doctor and Nurse and Response to Emotional Concerns of the Fatally Ill Child. DA8223845
- Johnson, Barbara A. and Smith, Howard L. (1981). A Strategy for Integrating Hospice, Hospital Care. Hospital Progress, 62(11), 52-62.
- Jung, C.G. (1933). Modern Man In Search of a Soul. W.S. Dell and Carl F. Baynes, translators. New York: Harcourt Brace Jovanovich.
- Kane, Anne C. (1985-86). Death Anxiety in Physicians: Defensive Style, Medical Speciality, and Exposure to Death. Omega, 16(1), 11-22.

- Kastenbaum, Robert J. (1977). Death, Society, and Human Experience. St. Louis: The C.V. Mosby Company, p. 222.
- Kastenbaum, Robert (1978). Death, Dying and Bereavement in Old Age: New Developments and Their Possible Implications for Psychosocial Care. Aged Care and Services Review, 1(3), 3-10.
- Kastenbaum, Robert (1987-88). Book Reviews. Omega, 18(2), 163-164.
- Kirkley-Best, Elizabeth, Kellner, Kenneth R. and Ladue, Terry (1984-85). Attitudes Towards Stillbirth and Death Threat Level in a Sample of Obstetricians. Omega, 15(4), 317-375.
- Klagsburn, Samuel C. (1982). Ethics in Hospice Care. American Psychologist, 37(11), 1263-1265.
- Klenow, Daniel J. and Young, Jr., George A. (1987). Changes in Doctor/Patient Communication of a Terminal Prognosis: A Selective Review and Critique. Death Studies, 11, 263-277.
- Kubler-Ross, Elizabeth (1969). On Death and Dying. London: The Macmillan Company.
- Kubler-Ross, Elizabeth (1974). Questions and Answers On Death and Dying. New York: Macmillan Publishing Co., Inc.
- Kuiken, Don and Madison, Gregory (1987-88). The Effects of Death Contemplation on Meaning and Purpose in Life. Omega, 18, 103-112.
- Kurman, Elaine Cooper (1984). Nurses' Attitudes Toward Passive Euthanasia for the Severely Handicapped Child. DA8411274.
- Kushner, Harold S. (1981). When Bad Things Happen To Good People. New York: Avon Books.
- Kushner, Rabbi Harold S. (1985). When Children and Adults Suffer. Child Health Care, 14(2), p. 72.
- LaGreca, Anthony J. (1985). Social Networks and Life Preservation. Death Studies, 9, 23-36.
- Lamers, Jr., William M. (1986). Hospice Care in North America. In Stacey B Day (Ed.). Cancer, Stress, and Death: Second Edition. New York: Plenum Medical Book Company, p. 145.

- Liberman, Marla Beth, Handal, Paul J., Napoli, John G. and Austrin, Harvey R. (1983). Development of a Behaviour Rating Scale for Doctor-Patient Interactions and its Implications for the Study of Death Anxiety. Omega, 14, 231-239.
- Limbacher, Mary and Domino, George (1985-86). Attitudes towards suicide among attempters, contemplators, and nonattempters. Omega, 16, 325-334.
- Lister, Larry, and Ward, Dona (1985). Youth Hospice Training. Death Studies, 9, 353-363.
- Lockwood, Josephine A. (1978). From Life to Death. Social Work In Health Care, 4, 81-84.
- Longo, Daniel R. and Darr, Kurt (1978). Hospital Care for the Terminally Ill: A Model Program. Hospital Progress, 84, 62-65.
- Lucan, Sister Monica Ann (1978). Praying with the Terminally Ill. Hospital Progress, March, 66-70.
- Lui, Yee-Wah (1983). Death and Dying fear patterns of Children's Hospital Social Workers. The Social Worker/Le Travailleur Social, 51, 7-10.
- Lusk, Mark W. (1983). The Psychosocial Evaluation of the Hospice Patient. Health and Social Work, 8, 210-218.
- McIntosh, John L. (1985-86). Survivors of Suicide: A Comprehensive Bibliography. Omega, 16, 355-370.
- Manicas, Peter T. and Secord, Paul F. (1983). Implications for Psychology of the new philosophy of Science. American Psychologist, , 399-413.
- May, Rollo, Angel, Ernest, and Ellenberger, Henri F. (Ed.) (1958). Existence: A New Dimension In Psychiatry and Psychology. New York: Basic Books, Inc.
- Miles, Matthew B. (N.D.). Qualitative Data as an Attractive Nuisance: The Problem of Analysis. Administrative Science Quarterly, 24, 590-601.
- Momeyer, Richard W. (1985-86). Fearing Death and Caring For the Dying. Omega, 16, 1-9.
- Moore, Kathleen (1984). Training Social Workers To Work With The Terminally Ill. Health and Social Work, 9, 268-273.
- Moore, W. R. (1983-84). Perception of Terminal Illness By Family Physicians and Relatives. Omega, 14, 369-375.

- Mor, Vincent, and Laliberte, Linda (1984). Burnout Among Hospice Staff. Health and Social Work, 9, 274-283.
- Morgan, Mary Ann (1987). Learner-Centered Learning in an Undergraduate Interdisciplinary Course about Death. Death Studies, 11, 183-192.
- Munley, Anne (1983). The Hospice Alternative: A New Context for Death and Dying. New York: Basic Books, Inc., Publishers, pp. 190-215.
- Neale, Robert E. (1978). A Theologian's Response. Social Work In Health Care, 4, 85-88.
- Neuringer, Charles (1987). The Meaning Behind Popular Myths About Suicide. Omega, 18, 115-161.
- Nouwen, Henri J. (1972). The Wounded Healer: Ministry in Contemporary Society. Garden City, N.Y.: Doubleday & Company, Inc.
- Ouden, Bernard Den (1979). The Fusion of Naturalism and Humanism. Washington, D.C.: University Press of America, Inc.
- Parry, Joan Kaufman (1983). Social Workers and the Terminally Ill: Social Workers' Feelings about Clients, Job Satisfaction, and Organizational Settings. DA8405488.
- Pass, Cleo Massicotte (1987). In my opinion ... qualitative research will enhance the care of children. Child Health Care, 15, 214-215.
- Pasnau, Robert O., and Hollingsworth, Charles E. (1977). Mourning in the Health Care Team. In Charles E. Hollingsworth and Robert O. Pasnau, The Family In Mourning: A Guide for Health Professionals, New York: Grune and Stratton, Inc., pp. 161-165.
- Patchner, Michael A. and Finn, Mark B. (1987-88). Volunteers: The Life-line of Hospice. Omega, 18, 135-144.
- Patton, Michael Quinn (1975). Alternative Evaluation Research Paradigm. Grand Forks, N.D.: University of North Dakota Press.
- Pilsecker, Carleton (1979). Terminal Cancer: A Challenge for Social Work. Social Work In Health Care, 4, 369-379.
- Poss, Sylvia (1981). Toward Death with Dignity: Caring for Dying People. London: George Allen and Unwin, pp. 43-57.

- Pratt, Clara Collette, Hare, Jan and Wright, Cheryl (1985). Death Anxiety and Comfort In Teaching About Death Among Preschool Teachers. Death Studies, 11, 417-425.
- Randolph, Jennings (1982). A Federal Role in Hospice Care? American Psychologist, 37, 1250.
- Reeves, Jr., Robert B. (1971). Pastoral Care of Cystic Fibrosis Patients and Their Families. Journal of Thanatology, 1, 360-365.
- Rychlak, Joseph F. (1973). Introduction to Personality and Psychotherapy: A Theory-Construction Approach. Boston: Houghton Mifflin Company.
- Rychlak, Joseph F. (1979). Discovering Free Will and Personality Responsibility. New York: Oxford University Press.
- Santiago, Eileen (1987). Education and the Terminally Ill Child: A Teacher's Experience and Perspective. Death Studies, 11, 378-381.
- Schowalter, John E. (1971). Death and the Pediatric Nurse. Journal of Thanatology, 1, 81-89.
- Schowalter, John E. (1975). Pediatric Nurses Dream of Death. Journal of Thanatology, 3, 223-231.
- Schowalter, John E. (1986). Twenty Years of Pediatric Thanatology. Children's Health Care, 14, 157-162.
- Selye, Hans (1986). Stress, Cancer and the Mind. Cancer, Stress and Death: Second Edition. New York: Plenum Medical Book Company, pp. 11-19.
- Shaffer, John B.P. (1978). Humanistic Psychology. Englewood Cliffs, N.J., Prentice-Hall, Inc.
- Sklar, Fred and Huneke, Kathleen D. (1987-88). Bereavement, ministerial attitudes and the future of Church-sponsored Bereavement Support Groups. Omega, 18, 89-102.
- Slivkin, Stanley E. (1976-77). Psychiatric Day Hospital Treatment for Terminally Ill Patients. International Journal of Psychiatry in Medicine, 7, 123-232.
- Smyser, A.A. (1982). Hospice: Their Humanistic and Economic Value. American Psychologist, 37, 1260-61.
- Steward, Elizabeth (1976). To Lessen Pain: Relaxation and Rhythmic Breathing. American Journal of Nursing, 76, 958-959.

- Stokes, Kenneth (Ed.). (1983). Faith Development in the Adult Life Cycle. New York: W.H. Sadlier.
- Swain, Barbara J. and Domino, George (1985). Attitudes Towards Suicide among Mental Health Professionals. Death Study, 9, 455-468.
- Sweetser, Carlton J. (1979). "Integrated Care," Quality Review Bulletin, May, pp. 18-21.
- Tache, Jean (1986). Stress as a Cause of Disease. In Stacey B. Day, (Ed.). Cancer, Stress, and Death: Second Edition. New York: Plenum Medical Book Company, pp. 1-10.
- Thrush, John C., Stewart, Cyrus S. and Paulus, George S. (1985). Effect of Parental Socialization on Student Nurses' Attitudes Toward Euthanasia. Death Studies, 9, 395-415.
- Tull, Anne (1975). The Stresses of Clinical Social Work with the Terminally Ill. Smith College Studies in Social Work, 45, 137-158.
- van Kaam, Adrian (1966). Existential Foundations of Psychology. Garden City, New York: Image Books.
- Van Manen, Max (1984). Curriculum Praxis Monograph Series, Monograph No. 7, "Doing" Phenomenological Research and Writing: An Introduction. Edmonton: University of Alberta, Faculty of Education, Department of Education.
- Weckowicz, T.E. (n.d.). The Impact of Phenomenological and Existential Philosophies on Psychiatry and Psychotherapy. A paper prepared for the Center for Advanced Study in Theoretical Psychology, The University of Alberta.
- Wentzel, Kenneth B. (1976). The Dying are the Living.. American Journal of Nursing, 76, 956-957.
- Weisman, Avery D. and Worden, J. William (1976-77). The Existential Plight in Cancer: Significance of the First 100 Days. International Journal Psychiatry In Medicine, 7, 1-15.
- White, Pamela Diane, Gilner, Frank H., Handal, Paul J. and Napoli, John G. (1983-94). A Behavioural Intervention for Death Anxiety Nurses. Omega, 14, 33-42.
- Worden, J. William (1982). Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner. New York: Springer Publishing Company.