SURVIVING WITHIN THE PERIMETER: HOW PALLIATIVE CARE PATIENTS

MAKE MEANING OF LIVING WHILE DYING OF TERMINAL CANCER

by

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Abstract

The purpose of this study was to discover how palliative cancer patients experience living while they are dying. A naturalistic approach, interpretive description, was used to identify and interpret themes. Data collection consisted of unstructured interviews with 6 patients with a prognosis of less than 6 months. Data was transcribed and analyzed systematically. Emerging findings were validated with participants and revealed 3 major themes: coping with a terminal illness, making sense of the situation, and surviving within the perimeter. Participants utilized a unique combination of coping styles and resources. Some reflected on the experience, while others ignored the psychological and spiritual aspects of the situation. All participants had a matter-of-fact acceptance that the situation could not be changed. They acknowledged their inevitable death but did not dwell on it. They maintained hope by being open to positive outcomes and using treatments that may make them feel better. Meaning related to doing what must be done in a bad situation while never letting go of the hope that the situation could improve. The participants focused mainly on staying alive (eating to maintain weight and gain strength) and accomplishing physical activities (by working around fatigue and other symptoms). Meaning was attached to physical accomplishments. Participants described themselves as surviving within a smaller perimeter of life.

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Dedication

To my husband, Kent, and my four children, Alison, Jason, Tim and Ted,
who endured and supported me for the past five years

and to my sister, Arlene
who has outlived her three month prognosis
and calls herself a survivor.

Also those patients and family members whom
I have had the privilege to journey beside during their last days.

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Chapter 1   Introduction

Background to the problem

Given the widespread prevalence of cancer, most people in our society will be affected by cancer-related experiences during their lifetime. In fact, one in three Canadians will develop some type of cancer at some point during their life (National Cancer Institute of Canada, 1997). A diagnosis of cancer is associated with death, so elicits fear in the affected individual, family and friends (Sontag, 1977). There is some basis for this fear. Cancer has been the leading cause of death in British Columbia since 1993. In 1997, one in four deaths in the province was due to cancer. Seven thousand, three hundred and eighty-six British Columbians died from cancer in 1997 (British Columbia Vital Statistics Agency, 1997).

Individuals with a diagnosis of cancer usually undergo surgery, radiation therapy, chemotherapy or a combination of these or other therapies in an attempt to cure or control the cancer. The trajectory for most cancers has changed in recent times from a steady decline to a chronic terminal illness that may last for several years (Halstead & Fernsler, 1994; Pattison, 1977; Pattison, 1978). Therefore the treatments, the stigma associated with having cancer, losses endured due to the disease and uncertainty about prognosis cause continual stress over a period of years for the cancer patient (Leigh, McCaffrey Boyle, Loescher, & Hoffman, 1993).

Palliative care is offered to patients and their families when active treatment of disease is no longer possible. Cancer patients constitute the majority of patients in palliative care programs (Victoria Hospice Society, 1990). When patients are

admitted into palliative care programs, they know that anti-tumor therapy is no longer effective for cure, and that they are likely to die of their disease. The goals of care at this transition point shift from cure to comfort and enhancement of quality of life. "Palliative care strives to meet the physical, psychological, social, and spiritual needs of patients and families, with sensitivity to their personal, cultural and religious values, beliefs and practices" (Ferris & Cummings, 1995, p. 16). These needs are reflected directly in the concept of "quality of life" .

Quality of life is "subjective well-being" (Cohen et al., 1997). It is a subjective and multi-dimensional concept that includes physical, social, psychological and spiritual dimensions. Quality of life can only be understood from the patient's perspective and can only be assessed by asking the patient about it directly (Cella, 1992; Ferrell, 1993; McMillan, 1996). Several studies have demonstrated discrepancies between caregiver evaluation and evaluation from the patient viewpoint (Cella, 1992; Loew & Lapin, 1994; McMillan, 1996). Although assessment of existential aspects of quality of life is critical (Cohen et al., 1997), the psychological and spiritual dimensions have historically been and continue to be difficult to assess and measure (Cohen & Mount, 1992).

Quality of life research with palliative care patients is limited. Most of the palliative care quality of life literature is focused on developing tools to quantify quality of life (Bullinger, 1992; Cohen & Mount, 1992) and establishing the validity of these tools, rather than exploring the quality of life of palliative care patients. Measurement of quality of life in the palliative care patient population has most

often been based on constructs identified by researchers as being important rather than constructs identified by the patients themselves. These constructs, therefore, may not all be valid. In-depth qualitative interviews could help determine the comprehensiveness and validity of quantitative measures (Johnston & Abraham, 1995). Qualitative methodology may be more effective for discovering individual subjective well-being (Cohen et al., 1997) than the quantitative tools currently in use.

Kubler-Ross (1969) first promoted the idea of "living until dying" to emphasize the importance of not limiting the identity of a terminally ill patient by relating only to the dying person. Palliative care patients find meaning by focusing on living and acknowledging dying and death (Davies & Oberle, 1990). There is continual tension between life promotion and death acceptance for terminally ill patients and their families (Downing, Braithwaite, & Wilde, 1993). Some patients focus more on living than others and some patients focus on living to the point of not outwardly acknowledging their dying. The perspectives of these patients are sometimes described in terms of having realistic or unrealistic hope (Dufault & Martocchio, 1985; Hendricks-Ferguson, 1997; Scanlon, 1989; Yates, 1993) or being in denial (Pattison, 1977; Weisman, 1984; Yates, 1993). Although these authors have identified the complementary and conflicting relationship of living and dying, most research has focused on the adjustment to losses rather than living aspects of the experience. One exception is a recent study by Davies, Reimer, Brown, &

Martens (1995), which begins to describe aspects of this tension between living and dying.

Although one of the goals of practitioners in palliative care settings is to help patients to live until they die, the reality is that patients are generally viewed as dying people. Patients' goals are acknowledged and much staff energy is put into helping patients reach these goals, when possible. At the same time, individuals are encouraged to talk about their thoughts and feelings related to dying. Communication and interventions are geared to help patients manage symptoms, adjust to losses associated with dying, and come to terms with dying.

Successful treatment of pain and symptoms and the holistic philosophy of palliative care programs allow greater opportunity for patients to reflect on the psychological and spiritual aspects of their lives. Nurses strive to enhance the individual's quality of life to enable individuals to live life as fully as possible for the time they have (Davies & Oberle, 1990; Degner, Gow, & Thompson, 1991) but interventions are generally based on the nurse's professional experience, common practice or research based on health care professionals' perspectives, rather than research with patients. The lack of research-based knowledge about the patient's perspective and meaning of *living* while dying of terminal cancer may interfere with the ability of nurses to ensure holistic and optimal care for patients near the end of their lives.

Statement of Problem

The high prevalence of cancer in general, and of cancer patients in palliative care programs, supports further research with this patient population. Palliative care settings provide optimal opportunities for holistic care and consideration of quality of life for dying patients and so are a suitable context for investigation of this phenomenon. Both the literature and clinical reports indicate that cancer patients do continue to focus on living during their final months of life. Previous qualitative studies, eliciting direct feedback from individuals about the experience of dying, have provided useful insight for caregivers about aspects of the dying process (Glaser & Strauss, 1965; Glaser & Strauss, 1968; Kubler-Ross, 1969; Martocchio, 1982; Pattison, 1977; Weisman, 1984). However, there have been no studies that investigate what living means to patients who are near the end of the dying trajectory. A better understanding of the experience of living at the end of life will contribute to a better understanding of the quality of life for these individuals.

Purpose of Study

The aim of this study is to address this gap in knowledge and understanding of the palliative care cancer patient's perspective of life and what is meaningful in life. The purpose of this study is to describe the palliative care patient's experience of living during the dying phase of cancer. This study will be directed by the specific research question: "How do palliative care patients make meaning of living while dying of terminal cancer?"

Definition of Terms

For the purposes of this study, the following definitions will be used:

- <u>Terminal cancer</u> - When the disease becomes so advanced that anti-tumor therapy will not cure the disease or stop disease progression. Anti-tumor therapy may be used to palliate symptoms.

- <u>Palliative care patient</u> - An individual with terminal cancer that is receiving supportive comfort care and has a life expectancy of less than six months.

- <u>Living</u> - The existential aspects of being alive and acting according to one's values. The process of engaging in physical, social, psychological and spiritual aspects of life.

Assumptions

The following assumptions are inherent in this study:

1. There exists a tension between living and dying that persists to the end of life.

2. People who are experiencing cancer and are dying are the best source of knowledge for understanding this phenomenon.

3. Individuals will be able to describe their thoughts, feelings and beliefs related to the experience.

4. An understanding of living with dying includes physical, social, psychological, and spiritual components.

5. A focus on living does not negate the work of dying in end-stage cancer.

6. "Living" can be distinguished from "dying" near the end of life.

<u>Significance of the Study</u>

More knowledge about how individuals experience and make meaning of living within the context of dying may provide better understanding of psychological and spiritual needs and resources, and concepts such as denial, hope and quality of life. It may help identify and ground valid constructs for measuring quality of life in the palliative care patient population. This knowledge may also illuminate factors related to common practical decisions made by patients about treatment and resuscitation. An investigation of the living perspective is necessary to ensure that additional aspects of the experience have been examined, providing a more complete and holistic understanding of the living-dying experience.

Chapter 2   Review of Literature

This review of literature is organized to provide an orientation to the bodies of literature related to the living and dying aspects of terminal illness in order to establish what is currently known and how it is known. An argument will be made for the relevance and importance of the study of the living aspect of the dying experience. The literature will be surveyed to provide an understanding of common beliefs and practice related to living and dying, as well as to synthesize the knowledge that has been derived from previous relevant research.

A summary of the literature about dying will be presented to establish an overview of the subject area. A general synopsis of coping and central concepts related to coping with terminal illness will follow. Living and coping with a terminal illness while receiving treatment will then be discussed, as most literature that focuses on living with dying describes living in relation to this phase of terminal illness. This will be followed by description of research related to living with dying during supportive treatment. Lastly, quality of life will be examined as it pertains to research done with palliative care patients, as this area of research fits most closely with examination of the meaning of life during the end-stage of cancer.

The Dying Process

The process of dying of a terminal illness has been conceptualized in terms of stages, phases, and elements of transition. Kubler-Ross (1969) explored patient perspectives of the dying process by interviewing terminally ill patients. She identified five stages of dying: shock and denial, anger, bargaining, depression, and

acceptance. Identification of these stages provided the beginning understanding of the psychological aspects of the process of dying. Unfortunately, these stages were interpreted by many as being absolute, sequential steps required for a "good death." This misconception lead to some misapplication of the theory to clinical practice and total rejection of the stages by some theorists and researchers. Kubler-Ross' research, however, precipitated more direct discussion with patients about dying and initiated an abundance of research about death and dying.

The process of dying has also been conceptualized as phases (Pattison, 1977; Pattison, 1978; Weisman, 1984). Pattison (1977; 1978) describes the process of dying from a terminal illness as the living-dying interval. This process is divided into three phases: acute crisis, chronic living-dying, and terminal. The process begins with the diagnosis of terminal illness and ends with death. In the initial phase, the individual reacts to the news of their impending death. During the chronic living-dying phase the individual deals with the illness and its problems over an extended period of time (likely years). During this phase, cancer patients are dealing with active treatment such as surgery, radiation, or chemotherapy. Individuals strive to maintain normalcy in their lives despite their uncertain prognosis, remissions and relapses. The terminal phase, according to Pattison (1978), begins when the dying person begins to withdraw. During this phase the type of hope changes. Pattison suggests that helping the individual to face and deal with the fears of dying during the chronic phase, enables the individual to let go of life during the terminal phase.

Although this framework of phases provides some structure and understanding of differing needs of patients over time, there is a significant gap in knowledge for the time-period between the treatment phase of terminal illness and the phase of imminent death. The framework does not provide any guidance in relation to patients who are receiving the supportive comfort care provided by palliative care programs.

Research on the dying process has been sparse between the mid-1980's and present. Current psychosocial care of the dying generally reflects the work of the classic researchers done during the late 1960's to the mid 1970's (Canine, 1996; Lair, 1996; Weisman, 1984). The process of dying involves a series of losses and adaptation to each of these losses (Canine, 1996; Pattison, 1978; Rando, 1984; Sourkes, 1987). Possible losses include: control, independence, productivity, security, various psychological, physical, and cognitive abilities, predictability and consistency, experiences, future existence, pleasure, ability to complete plans and projects, dreams and hopes for the future, significant others, familiar environment and possessions, aspects of the self and identity, and meaning (Rando, 1984). Common fears of dying include: the unknown, loneliness, sorrow, loss of body, loss of self-control, suffering and pain, identity, and regression (Pattison, 1978). Psychological coping mechanisms used to cope with losses include: regression, repression, denial, suppression, rationalization, depersonalization, projection, introjection, intellectualization, obsessive-compulsive mechanisms, counter phobic mechanisms, and sublimation (Rando, 1984). Different dying trajectories require

different coping mechanisms (Pattison, 1978). Nurses, social workers, spiritual care providers,. and other health care professionals working with dying patients help individuals to deal with their fears and losses, and prepare for death. The goal is that the patient have an "appropriate death" (Weisman, 1984); a death that is right for a particular individual, reflecting how that individual lived his life (Canine, 1996; Lair, 1996; Pattison, 1978; Weisman, 1984).

In contrast, Davies et al. (1995) conceptualize the dying process, within the palliative care context, in terms of a transition that occurs over time. Once the patient and the patient's family acknowledge that the patient will not recover from the cancer, the transition period of "fading away" begins. The transition includes several elements which occur over time. They may occur in any sequence, and may recur or overlap. The elements include: redefining, burdening, struggling with paradox, contending with change, searching for meaning, living day-to-day, and preparing for death. This view of the dying process includes both living and dying tensions, which have not been identified in other studies.

This overview of the dying process reveals a general acceptance of the dying process conceptualized in terms of losses and fears to be adapted to and coped with by the dying individual. Only the most recent research on the dying process has revealed evidence of the tensions between aspects of living and aspects of dying. This study will be discussed in more detail later, as it reveals evidence of the existence of a living - dying tension in the palliative care population, and a gap in knowledge about the living aspects of the dying experience.

Coping with cancer

"Cancer is more than a diagnosis: it is an all-consuming experience that alters the meaning of life for the patient and family" (Ferrell, 1993, p. 1471). Living with cancer or terminal illness is often described in terms of how the individual copes with aspects of the disease. A review of the literature on coping with terminal illness, may therefore, reveal some aspects of living while dying.

Lazarus & Folkman (1984) posit that the response of an individual to a potentially stressful situation is mediated by an appraisal of the personal meaning of the situation. This includes an appraisal of the individual's ability to deal with the situation. The individual may view potentially stressful situations as: (1) being irrelevant or having no effect on one's well-being, (2) preserving or improving well-being or (3) stressful. A stressful appraisal may include: harm or loss, threat of harm, and challenge/potential for growth.

Cancer is a stressful experience, and the appraisal of the situation influences the coping behaviors of the individual. Coping is affected by personality, the surroundings and the situation (Rustoen, 1995). Cancer patients often cope with their illness by using their life-long coping style (Scanlon, 1989). Thus, perception, attitude, personality, coping style, family support, and resources, as well as phase, length and trajectory of illness all affect how individuals view, adapt to and manage their illness.

Popular literature on coping with cancer focuses on using inner and spiritual resources to make changes to one's thinking and way of living. Authors promote

engagement in the processes of self-awareness and personal growth to fight the cancer and/or heal oneself (Siegel, 1986; Siegel, 1989; Siegel, 1993; Simonton & Henson, 1992; Simonton, Mathews-Simonton, & Creighton, 1978).

Relevant concepts related to coping include hope and spirituality. There is an extensive body of literature on hope. Hope is a complex phenomenon (Dufault & Martocchio, 1985; Hendricks-Ferguson, 1997). Dufault and Martocchio (1985) describe spheres and dimensions of hope. The two spheres of hope are generalized and particularized hope. Generalized hope is the abstract, broad sense of hope for the future, while particularized hope focuses on a particular outcome. Dimensions of hope include affective (sensations and emotions), cognitive (including the processes of thinking about and judging the aspects of the hope), behavioral (actions taken to bring about an outcome), affiliative (sense of relatedness and involvement with people and God), temporal (related to the experience of time - past, present and future), and the contextual dimension (related to the circumstances that activate the hope process).

Owen (1989), in her qualitative study of the meaning of hope in patients with cancer, identified the following attributes of hope: goal setting, positive personal attributes (courage, optimism and positive attitude), future redefinition, meaning in life, peace and energy. A limitation of this study is that these descriptions of hopeful cancer patients were obtained from clinical nurse specialists working with cancer patients, rather than the patients themselves.

Benzein and Saveman's (1998) investigation of hope among palliative care cancer patients found hope included: inner strength and energy, significant events, support from relatives, familiar environment, and confidence in treatment. Again, hope was described from the perspective of nurses caring for these individuals.

Post-White, et al. (1996) studied cancer patients to determine the patients' personal meaning of hope and strategies used to sustain hope. They identified five themes: finding meaning, affirming relationships, using inner resources, living in the present, and anticipating survival. Sub-themes included faith, family, friends, and future.

Hope is thought to play an important and positive role in coping with illness (Fryback, 1993; O'Connor, Meakes, McCarroll-Butler, Gadowsky, & O'Neill, 1997; Scanlon, 1989) and dying (Kubler-Ross, 1969; Scanlon, 1989). Hope changes over time, as illness progresses (Owen, 1989; Pattison, 1978; Scanlon, 1989). Preservation or loss of hope affects adjustment and participation in life (Hockley, 1993; Owen, 1989). Investigators have identified correlations between hope and spiritual well-being (Fehring, Miller, & Shaw, 1997; Mickley, Soeken, & Belcher, 1992; Reed, 1987), hope and quality of life (Carson, Soeken, Shanty, & Terry, 1990; Rustoen, 1995), hope and will to live (Hockley, 1993), and hope, well-being, and spirituality (Carson et al., 1990).

Spirituality is considered an essential component of well-being of individuals and of care of the terminally ill and dying. Reed (1987) found greater spirituality in hospitalized terminally ill patients than non-terminally ill hospitalized patients and

healthy adults. Finding meaning is one aspect of spirituality and is an important part of the experience of patients with a terminal illness (Conrad, 1985; Davies & Oberle, 1990; Kemp, 1994; O'Connor et al., 1997; Rutland-Wallis, 1996).

Fryback (1993) used a naturalistic study to determine how health is described by terminally ill individuals. Three domains of health and related essential components of health were identified. The mental/emotional domain includes hope, love and control. The spiritual domain includes belief in a higher power, recognition of mortality and self-actualization. Health promotion activities, feeling good, and relationship with physician were considered important aspects of the physical domain.

Kreitler, Chaitchik, Rapoport, Kreitler, & Algor (1993) investigated life satisfaction and health in cancer patients, orthopedic patients and healthy individuals. When compared to orthopedic patients and physically healthy individuals, cancer patients obtained satisfaction with life from more domains (ten rather than three). Health-related domains made less of a contribution to their life satisfaction, than other domains. Other domains included: health concerns, work, economic state, family life, parenthood, communication with partner, sexuality, getting help from others, social life and entertainment. Cancer patients were able to maintain satisfaction with life by inclusion of and appreciation for various aspects of their lives.

The literature on hope, spirituality, well-being and health related to individuals with cancer reveals much overlap in concepts and coping mechanisms.

The literature provides some insight into aspects of living and coping with cancer and some of the inter-relationships of concepts identified as important by researchers. Yet the focus on a particular concept precludes a full understanding of the whole of the experience of living with cancer. Examination of the total experience from the patient's perspective may reveal new insights and inter-relationships.

Living with dying during active treatment

The main body of literature found in relation to "living with dying" focuses on living with cancer (Fryback, 1993; Halldorsdottir & Hamrin, 1996) or HIV/AIDS (Allan, 1990; McCain & Gramling, 1992) over a period of years during which active treatment continues to be available. Some authors have studied mixed groups of patients with a variety of conditions (McIntyre, 1997). Individuals living with their life-threatening illness over a period of years live with uncertainty and use a variety of strategies to cope (Allan, 1990; Fryback, 1993; Halldorsdottir & Hamrin, 1996; McCain & Gramling, 1992; McIntyre, 1997). This section will highlight the research done in this area.

Halldorsdottir and Hamrin (1996) interviewed non-hospitalized individuals who had experienced diagnosis and treatment of cancer. This phenomenological study focused on the lived experience of having cancer. The overall theme discovered was "experiencing existential change." The sub-themes were: uncertainty, vulnerability, isolation, discomfort and redefinition. The results of this

study highlight the focus on adapting and coping with changes caused by the disease and treatment.

Allan (1990) used a naturalistic design to study individuals living with asymptomatic human immunodeficiency virus (HIV) to determine their responses to living with the uncertainty of a potentially terminal diagnosis. She identified five dimensions of self-care activities used by these individuals: diet, exercise, stress reduction, life-style changes and attitudinal changes. Attitudinal changes included (1) focusing on living, not dying and (2) establishing priorities for living. The participants of this study found that care of their physical selves made them feel better. They were able to decrease uncertainty by obtaining information and redefining the situation.

McCain and Gramling (1992) studied the lived experience of coping with HIV. Their sample included individuals with HIV positive status, AIDS related complex and AIDS. Phenomenological analysis revealed three processes: living with dying, fighting the sickness and getting worn out. The first stage begins with diagnosis and involves assimilating the diagnosis and then getting on with life. The second stage focuses on weight maintenance and physical appearance, while the last stage (close to death) involves dealing with physical problems and searching for meaning in life. Coping strategies used throughout these stages included: religious beliefs, living in the present, staying busy, thinking positively, and using distractions. Some participants also used drugs or alcohol.

The above studies provide information about coping with the effects of disease and each identifies a focus on aspects of living as an important aspect of coping. However, published information about the living aspects is limited.

McIntyre (1997) studied five women who had been involved for over one year with a serious illness experience of themselves or a family member, to explore their experience of being understood in relation to living with dying. These participants viewed their experience of dying as a part of living and felt others did not understand them because they viewed them as dying. Study participants advocated an approach where others would be open to exploring the possibilities of living while dying, which they viewed as very important to the dying person (McIntyre, 1997). If these individuals felt excluded from life, it is possible that palliative care patients feel excluded from living in some ways because they are seen as dying.

Patients who are no longer receiving active treatment for their cancer (and therefore have a short prognosis) have not been studied in relation to this living perspective. It is likely that the experience of living with dying during end-stage cancer is different than the experience of living with a terminal illness over a longer period of time, given the physical condition of the patient, many limitations and changes in lifestyle and relationships, and the certainty and nearness of death.

Living with dying during supportive treatment

Martocchio (1982)described social and interactional factors surrounding hospitalized dying adult patients and those interacting with them. Once the patient is labeled as dying, changes occur in the expectations of the patient and

interactions with others. Patients are expected to passively accept their death rather than fight it, to give up thinking in terms of the future and "to die within the expected time" (Martocchio, 1982, p. 140). This dying role is in conflict with the needs and desires of those who wish to live until they die. Dying is generally not viewed as a part of living in contemporary North American society (Martocchio, 1982). Martocchio's research suggests that more study is required to understand "the realities involved in living while dying" (1982, p. 138).

However, there is a paucity of literature available in relation to this area. The bulk of the literature focuses on practical management of physical symptoms and care with brief mention of psychological, social, or spiritual comfort (Carnevali & Reiner, 1990; Lindley-Davis, 1991; Saunders, Baines, & Dunlop, 1995).

Davies et al (1995) described the living-dying experience of patients receiving supportive care for terminal cancer and their family members. Using the grounded theory method of qualitative research, the researchers interviewed patients in the terminal component of advanced cancer and their immediate family members. Twenty-three families were interviewed both as a family unit and individually. The researchers found that the physiological changes experienced by the dying person change how the person experiences life. Individuals with advanced cancer redefine their identity as they change. The degree to which patients are able to redefine themselves influences their perception of being a burden to other family members. Patients who can redefine themselves to a greater degree are more concerned about burdening their loved ones. The researchers

describe the tension between living and dying as "struggling with paradox." Struggling with paradox refers to living with cancer and dying of cancer, including contending with the ups and downs of the disease, the limited time frame for life, the tension between fighting and letting go, hope, and decisions about accepting or foregoing treatment (Davies et al., 1995). Searching for meaning lead to satisfaction and a sense of usefulness. "Patients try to put their experience in context and endure the turmoil. They try to make sense of the situation by connecting with their inner and spiritual selves, connecting with others or with nature" (Davies et al., 1995, p. 43). Living from day to day involves a focus on the present and attempts to make the most of each day or keep things as normal as possible. As well, individuals prepare for death by taking care of practical matters, caring for family members, reminiscing, and communicating openly with family members. Further study of this area, focusing in detail on the patient's perspective of living while dying, could provide more depth and understanding of this perspective and thus enhance our ability to interpret the patient's needs.

Living in the Context of Dying - Stories of Individuals

Living and dying are inseparable. Death is a natural part of life (Jones, 1993; Kubler-Ross, 1969). Living with dying can only be understood in the context of the situation and setting (Martocchio, 1982). Jones (1993) used the case study method to describe one individual's dying process in the context of her life experience. Data collected through interviews over a three month period was analyzed using content analysis. The patient in this study reacted to her dying with the same pattern she

had lived her life. The meaning of a healthy life for this woman was having a sense of control and usefulness to others.

Health care professionals and laymen share stories of remarkable individuals who exemplify "living until dying" and reflect this need for control and usefulness. Bayer (1993) relates the stories of several women who "spent almost all of their time living and very little, until the last moments, actually dying " (p. 28). These women chose not to tell others that they were dying because they did not want to endure the negative consequences of being viewed as dying. These women spent their time actively helping others in small ways. They successfully overcame exceedingly difficult situations and so had positive effects on their own and others lives. Bayer (1993) concludes that these women "lived their attitudes and values through their choices and actions because doing so was personally meaningful, but it was the fact that their choices and actions could be of benefit to all people that made them personally meaningful" (p. 31).

Cooke (1993) identifies "the ability to acknowledge future events while not sacrificing the present experience" as the key that distinguishes her exceptional patient, a middle-aged man with AIDS, from other people. He was able to live each day fully, despite pain and other symptoms of his disease, through personal spiritual development such as giving thanks to loved ones, forgiving and asking for forgiveness.

These stories describe existential aspects of living while dying that add depth to the description of living provided in the previous studies. They also reveal the

shallowness of current understanding about living with dying, as revealed in the previous reviews.

Quality of Life

The measurement of quality of life has developed from two essential aspects of the concept: (1) quality of life can only be understood from the patient's perspective, so data must be collected directly from patients and (2) the multi-faceted nature of quality of life includes several dimensions that must all be evaluated (Cella, 1992; Ferrell, 1993). The physical, psychological, social and spiritual dimensions are addressed by researchers using a wide variety of groupings and questions.

Cohen & Mount (1992) have led Canadian research about quality of life in the palliative care population. The development of the McGill Quality of Life Questionnaire (MQOL) resulted from specific concerns about available quality of life instruments. These include: inadequate inclusion of existential concerns, excessive focus on the physical domain, the need to include positive influences in addition to problems, the need for an instrument that fits the needs and abilities of terminally ill patients (Cohen, Mount, Strobel, & Bui, 1995).

The current version of the MQOL includes five dimensions: physical well-being, physical symptoms, psychological symptoms, existential well-being (concerns about death, freedom, isolation, seeking meaning) and support (Cohen et al., 1997, p. 4). The MQOL includes seventeen questions and uses a Likert scale of 1 to 7 for each question with descriptors to identify the endpoints. For example,

My personal existence is:

         utterly meaningless   very purposeful
         and without purpose ....and meaningful
                                                          (Cohen et al., 1995, p. 218).

The questionnaire includes questions about physical symptoms (the patient

chooses the three most troublesome for him/her), general physical wellness,

depression, anxiety or worry, sadness, fear of the future, meaning, achieving goals,

worth of life, control, support, self-esteem, general perspectives of the current day,

a general perspective of the world, and an overall rating of quality of life during the

past two days only. Existential well-being has been proven to be an important

determinant to quality of life in patients with a life-threatening illness (Cohen, Mount,

Tomas, & Mount, 1996).

         The MQOL was developed using a combination of clinical experience, a

literature review, unpublished qualitative data from a longitudinal study of 50

patients, and conceptually based questions from another quality of life index (Cohen

et al., 1995). Researchers have recently completed an extensive study confirming

validity of the MQOL (Cohen et al., 1995) but results of measurement of quality of

life have not been published.

         McMillan (1996) developed a Hospice Quality of Life Index (HQLI) with

twenty-five questions covering physical/functional, psychological/emotional,

social/spiritual and financial dimensions. The social spiritual dimension includes

support from family, friends, hospice and medical staff, meaningfulness of life,

relationship with God, involvement in own care and surroundings. The

psychological/emotional dimension includes questions about feelings (angry, lonely,

sad, worried), sleep, pain, feeling masculine/feminine, feeling about whether each day holds some good. The physical/functional dimension includes constipation, activity, work, fatigue and eating. Financial choices include worry about living expenses and cost of medical expenses. Each item is rated on a scale of one to ten. The tool was developed based on a literature review and consultation with content experts. Reliability and validity for the tool was established by factor analysis that confirmed the four sub-scales used. However, patients were limited to giving feedback only in the selected areas within these sub-scales. They did not have an opportunity to identify other factors that influenced their personal perspective of quality of life.

McMillan (1996) conducted a descriptive study using the HQLI, and found that the home care hospice patients (who all had a prognosis of less than six months) rated their quality of life higher than expected. There was no clear explanation for this finding. Patients were least satisfied with the physical/functional aspects, particularly the amount of usual work they were able to do. They were most satisfied with social/spiritual aspects, such as support from family, friends, physician and hospice team. They were fairly satisfied with their surroundings which contributed to their emotional well-being and relationships with God. During the three week study, quality of life scores remained stable. I was unable to locate other studies that described findings related to quality of life of palliative care patients.

Limitations of instruments that measure quality of life include the fact that these tools have been developed by healthy, well-educated, middle-class

individuals with a limited variety of cultural or ethnic perspectives (Ferrell, 1993).

Although a single item scale avoids the potential biases about item selection and

definition of constructs (Cohen et al., 1997) it only provides an overall sense of

quality of life and does not provide any specifics. Quality of life instruments can

provide some useful information about *predetermined* aspects of the individual's

well-being, and impetus for exploring some aspects further. However, care should

be taken in linking outcomes of quantitative measurements with actual experiences

of individuals with chronic illness or cancer, as their experiences are much too

complex to easily quantify (Thorne & Jillings, 1996). There are some aspects of

quality of life that cannot be captured in discreet measures (Cohen et al., 1997;

Loew & Lapin, 1994; Roy, 1992). The quality of life literature, at present, provides

little insight into the experience and meaningful aspects of living during the last

months of life.

In conclusion, a review of the literature revealed several references to living

with dying, but surprisingly little knowledge about the living aspects of the dying

experience. Much of the literature related to dying and care of the dying is not

research-based. Most references to living with dying are directed towards

individuals living with a chronic life-threatening illness. Individuals dying of terminal

illness are generally described and discussed in terms of the dying process,

although the intent to assist patients to "live until they die" is readily accepted by

palliative care practitioners. One recent study provides a beginning understanding

of life as experienced by palliative care patients. Research into quality of life in this

population remains focused on outcome measures for research purposes and does not provide information about what it is like for these individuals to live during their final months of life. There is clearly a gap in knowledge about palliative cancer patients' experiences of living during the last six months of life. The best source of information about this phenomenon is the patients themselves. To investigate this phenomenon, a naturalistic approach will be taken, in keeping with the nature of the research question, the philosophy of palliative care, and the vulnerability of individuals at this time of their lives.

Chapter 3   Research Design

Qualitative research involves "broadly stated questions about human experiences and realities, studied through sustained contact with persons in their natural environments, and producing rich, descriptive data that help us to understand those persons' experiences" (Munhall & Oiler Boyd, 1993, p. 69-70). A qualitative or naturalistic approach has been taken in this study as there is need for more in-depth description, clarification and understanding of the whole of the experience of living while dying of cancer in a palliative care setting.

The choice of the research method must be based on the fit with the research question and the paradigm followed by the researcher in relation to the "nature of reality and the nature of knowing" (Bunkers, Petardi, Pilkington, & Walls, 1996, p. 33). Naturalistic inquiry is based on the following beliefs: (a) realities are multiple, constructed, and must be studied holistically; (b) research is an interactive process in which the knower and the known are inseparable; and (c) truth is time-bound and context-bound (Lincoln & Guba, 1985, p. 37). These beliefs are congruent with the palliative care philosophy and the research question (Clark, 1997). They provide the underpinnings for this study.

Nurse scholars continue to debate the merits of various qualitative approaches. Some are committed to rigid adherence of traditional qualitative methodologies to ensure credible research (Thorne, 1991). The methodologies most frequently employed are phenomenology, grounded theory and ethnography, which are based in the philosophical underpinnings of other disciplines. Some nurse

researchers have attempted to modify or combine these methodologies in an attempt to better answer their clinical research questions (Thorne, 1991). These researchers have sometimes been accused of "sloppy research" (Morse, 1989). Other researchers advocate use of multiple methods or modification of traditional methods to adequately address and add to nursing knowledge (Dreher, 1994). Still others claim that qualitative researchers are doing legitimate research for which there is no name (Morse, 1989). Thorne (1991) suggests that nursing-based methodologies are necessary to meet the needs of nursing science.

The method used for this study is interpretive description, a new methodology proposed by Thorne, Kirkham, and MacDonald-Emes (1997). Interpretive description has been developed based on philosophical perspectives of the discipline of nursing. The goal of interpretive description is "to develop clinical knowledge with significant nursing science applications" (Thorne et al., 1997, p. 173). This method involves an inductive and interactive process of inquiry. It was chosen because it promotes in-depth description of the phenomenon, as does the phenomenological method (Munhall & Oiler Boyd, 1993), but goes beyond description to provide structure for interpretation of nursing knowledge and practical application of findings (Thorne et al., 1997).

Nursing has a unique body of knowledge and is grounded in practical application of knowledge (Thorne, 1991). The focus of nursing, therefore, differs from other disciplines from which nursing has traditionally borrowed knowledge and research methods. Building nursing knowledge can best occur if nursing research is

built on the philosophical underpinnings of nursing science (Thorne et al., 1997). Interpretive description is a methodological approach based on nursing science that provides a means for nurse researchers to study individual cases in detail, extract common themes from these cases, and produce new knowledge that can be applied back to other individual cases. It supports nursing's emphasis on the uniqueness of individual perspectives while systematically identifying similar themes and differences among aggregates (Thorne et al., 1997).

Interpretive description provides "a coherent set of strategies ... to develop knowledge about human health and illness experience phenomena without sacrificing the theoretical or methodological integrity that the traditional qualitative approaches provide" (Thorne et al., 1997, p. 169). Following general principles of qualitative research, the interpretive description method incorporates structure related to analytic frameworks, sample selection, data sources, data analysis and rigor. This structure provides the methodological rigor necessary for credible nursing research.

Sample Selection

Qualitative research requires much time and effort to collect an abundance of comprehensive and detailed data in the form of verbatim notes, therefore sample sizes are always small (Morse, 1986). In qualitative research, a small sample with depth of data is understood as an appropriate way to produce significant results (Morse, 1986; Sandelowski, 1995b). The actual number of participants required for the study would ideally be determined by data saturation. Saturation refers to (1)

repetition of information previously discovered and (2) confirmation of previously collected data. At the point in data analysis at which no new themes are identified, no new participants are interviewed (Streubert & Carpenter, 1995).

The sample for this study was obtained by purposive sampling in order to maximize the ability to obtain comprehensive and insightful data. Purposive sampling means that individuals are chosen to participate in the study according to their knowledge of the phenomenon being studied and their ability to share their knowledge in depth (Streubert & Carpenter, 1995). Participants are purposely selected to obtain a maximum variation on the themes identified during analysis (Morse, 1994a; Sandelowski, Davis, & Harris, 1989; Thorne et al., 1997). Variables are chosen to provide breadth of variation in the sample. When other critical variations are identified during the analysis, the researcher actively seeks participants with the required characteristics to provide a more complete interpretation of the phenomenon (Thorne et al., 1997).

Selection Process

Participants were chosen from patients registered in the Burnaby Palliative Care Program, who were either in the palliative care unit, on a hospital medical unit, or at home. Individuals: (1) were 19 years of age or older (2) had a diagnosis of cancer (3) had a life expectancy of less than six months (4) had their symptoms controlled well enough that they were able to participate fully without undue fatigue or discomfort and (5) understood and spoke English fluently.

The focus on cancer reflects the fact that cancer patients make up the largest percentage of the palliative care population (Victoria Hospice Society, 1990). The last six months of life were chosen to limit the influence of change over time and to focus on the group of patients who were most imminently dying. The prognosis given by the primary physician or the Palliative Care Medical Coordinator was used to estimate life expectancy. Given the content of the interview and fragility of the population, the last two criteria allowed for optimal data collection with minimal stress to the participants.

Potential participants were identified by members of the palliative care team and home care nurses. The hospital nurses did not identify any potential participants. The home care nurses asked potential participants for permission to have me contact them by telephone to explain the study. I explained the study, requested participation in the study, answered questions about the study, and provided information to help participants prepare for the initial interview. I emphasized the voluntary nature of participation, and reinforced the fact that the individual's nursing and medical care would not be affected, regardless of the decision to participate or not.

Description of the Sample

There were six participants in this study; three men and three women. Patient demographic data were elicited during the interview. The participants' ages ranged from 51 to 78 years old, with a mean age of 67 years. Patient diagnoses included cancers of the: breast , tonsils, pancreas (2), and lung (2). Four individuals were

married, one was widowed and one was divorced. All participants were Caucasian, except one with some aboriginal heritage. Two people had immigrated to Canada from other countries, one from Italy and one from England. Educational level ranged from high school graduation to university undergraduate degree. Occupations included homemaker, telegrapher, carpenter, office assistant, mechanical engineer and boilermaker. Five of the participants had retired prior to their palliative diagnosis. All participants had adequate income levels except one. This individual lived in a low cost housing development and pushed herself beyond her physical limitations due to financial constraints. For example, she did not have a car so she walked to the store for groceries. One participant had saved money to travel during retirement, but was unable to do so due to the cancer, so had the financial ability to use expensive alternative therapies. Religious affiliations included: Anglican, Mormon, Roman Catholic, Protestant and none (2). Family members were involved in the physical care of four of the six participants. Family members provided emotional support to all except one person. Four participants were considered "palliative" at the time of diagnosis. One person was diagnosed 11 years before the interview but had a recurrence 5 months prior to the interview. Another individual was originally diagnosed 2.5 years before the interview but had a recurrence of the cancer about 3 months prior to the interview. Time since diagnosis with advanced disease or recurrence ranged from 2 months to 12 months, with a mean of 6 months. Time since admission to the palliative care program ranged from 1 week to

42 weeks, with a mean of 11.5 weeks. No additional relevant variables were identified during the study.

Demographics were included to describe each research participant in the context in which they were researched (Morse, 1989). The demographic data reveals some variation amongst participants in relation to all areas described. However, no extreme variations occurred in the group studied.

Data Collection

Data were collected in face-to-face interviews of individuals with terminal cancer. Qualitative interviews are an appropriate means of data collection for palliative care patients. In using a naturalistic or qualitative approach, there is recognition that the interaction between the researcher and participant is an acceptable and necessary part of the research approach, and that the researcher and participant influence each other in the process (Lincoln & Guba, 1985; Munhall & Oiler Boyd, 1993). The process of "being with" a person, listening to his or her story, and asking thought-provoking questions can in itself be a therapeutic intervention for that person. It is a common intervention in the palliative care setting (Davies & Oberle, 1990). The individual is likely to work through feelings, thoughts, and concerns and may come up with new insights or perspectives. This introspection and making of connections can affect the individual's adjustment and well-being (Streubert & Carpenter, 1995). This interaction influences the data collected.

At the outset of the first interview, informed consent was obtained, as well as permission to tape the interview. Ongoing consent was obtained as the interviews continued. All interviews were tape-recorded and transcribed immediately following the interview.

Open-ended interviews were conducted in the participants' homes. The initial interview lasted approximately twenty minutes to two hours, depending on the physical limitations and desires of the participant. It was my experience that patients often wanted to speak for long periods of time. Demographic data were collected directly from the patient during the initial interview or from the chart, using a Demographic Data Sheet (Appendix A).

The initial interviews began with an open-ended statement, then I followed the lead of the participant, so that I did not influence the direction of the participant's thoughts. Silence and probes were used to promote more detail of description. Sample trigger questions for the initial interview are included in Appendix B to give an indication of the areas that were covered.

One or two interviews were conducted with each participant to ensure complete description of the experience and verify information collected. All the participants, except one, participated in a second interview. During the second interview, information collected during the initial interview was confirmed, clarified and expanded. In addition, emerging research findings were checked for accuracy.

I kept a reflexive journal to aid in critical reflection about my assumptions, values, beliefs, impressions and feelings, and their influence on the research

process, in order to offset researcher bias (Lamb & Huttlinger, 1989; Lincoln & Guba, 1985; Thorne et al., 1997). Reflexivity was used to integrate the process and product of research into the understanding of the phenomenon (Lamb & Huttlinger, 1989). The journal also chronicled decisions made about methodological issues and the rationale for these decisions (Lincoln & Guba, 1985). Written notes were entered into the journal immediately following each interview and when thoughts occurred at other times. In addition, field notes were kept to record data about the context of the interviews and to identify links between the context and the phenomenon (Dreher, 1994; Morse & Field, 1995; Thorne et al., 1997).

Data Analysis

Data collection and data analysis occurred simultaneously so that analysis could guide data collection and maximize the amount of relevant data collected (Morse, 1994a). During analysis of qualitative data, I became deeply immersed in the data (Streubert & Carpenter, 1995). This occurred during data collection and at the end of the study. Alternating immersion in the field and immersion in the data enabled me to compare individual participants to emerging common patterns (Thorne et al., 1997) and thus test conceptualizations as they were developed (Strauss, 1987). The goal of analysis was to identify commonalities among aggregates related to the phenomenon. In order to do this, I discerned idiosyncrasies from commonalities in relation to both process and outcome (Thorne et al., 1997).

Analysis was inductive and promoted in-depth, meaningful interpretation by using strategies to understand the whole of the phenomenon (Giorgi, 1985; Knafl & Webster, 1988; Thorne et al., 1997). I focused on synthesizing, theorizing and reconceptualizing, rather than sorting and coding (Morse, 1994b). I looked for layers of meaning, identifying meaning units and themes reflected in passages or units of text, rather than using line by line coding procedures. This was done according to the following steps. First, the entire description was read several times, to get a sense of the whole. Then I identified "meaning units" in context, focusing on genuine meaning rather than visible content, to enable depth of understanding. I used "reflection and imaginative variation" to identify and describe themes and sub-themes (Giorgi, 1985, p. 18). This required constant back and forth comparison amongst the original transcript, the significant statements, the meaning units or themes to verify the conclusions drawn. The criteria used for developing categories and determining the contents of each category was recorded in the reflexive journal. I constructed an interpretation of the phenomenon as a whole, providing a new view of the phenomenon, beyond lists of themes and sub-themes (Giorgi, 1985; Knafl & Webster, 1988; Sandelowski, 1995a). I then returned to the participants to refine and clarify those constituents that emerged in a patterned way, and checked for accuracy and fit with the individuals. This ensured that the constituents fit the experience of the participants in the context of the whole (Streubert & Carpenter, 1995).

Data were managed using a word processing program. The taped interviews were transcribed using Microsoft Word ®. Each interview was assigned a numerical identifier. All personal information was removed prior to the transcription so that no identifying information was included in the transcription. Relevant units of text were identified. A computer file was created for each code to group the data and enable retrieval of related quotes and meaning units (Morse & Field, 1995).

Rigor

The goal of rigor in qualitative research is to accurately represent the experience of the participants (Streubert & Carpenter, 1995). Rigor can be achieved by ensuring the following four criteria are met: credibility, auditability, fittingness and confirmability (Lincoln & Guba, 1985; Sandelowski, 1986). Credibility refers to strategies that increase the probability of credible findings being generated. Participants must recognize their experiences in the final description and interpretation of findings. As well, lay people and professionals should recognize the experience from the description (Sandelowski, 1986). Fittingness is the ability of the description to reflect the typical and atypical ambient factors of the experience, and to provide meaning in situations outside the study. Auditability refers to documenting the process of ensuring consistency so that other researchers would arrive at similar conclusions. Confirmability is "freedom from bias in the research process and product" (Sandelowski, 1986, p. 33). It is established when the first three criteria are met.

The following strategies were employed to meet these criteria. Purposive sampling was used to ensure representativeness of the information. Saturation of data was attempted to ensure completeness and thoroughness. No new themes were discovered as new participants were added to the study. However, true saturation of data cannot be confirmed with this small sample size. An audit trail included documentation of the research process, and showed how decisions were made during the collection and analysis of data. I kept a reflexive journal to make explicit my thoughts, feelings and beliefs which could have introduced bias during data collection and analysis. All interviews were conducted by myself to ensure building of trust with participants and consistency in interviewing. I validated and clarified data provided by the participant with the same participant, to validate or refute interpretations and descriptions of the phenomenon developed by the researcher. I also took a draft of descriptions of themes, sub-themes and conceptualizations of the phenomenon, developed from the contributions of *all* participants, back to five of the six participants to validate the final description of commonalities.

Ethical Considerations

The rights of participants were addressed by inclusion of the following considerations and strategies to ensure informed consent, confidentiality, participant safety and appropriate fit of researcher and clinician roles.

Consent

Potential participants were provided with written and verbal information about the purpose and nature of the study. Participants provided voluntary consent by signing a consent form at the beginning of the first interview. (Appendix C). Participants were informed of their right to end participation at any time and to have audio-tapes or parts of audio-tapes erased, at the their request. Ongoing consent was obtained as the interviews continued. Participants were also sent a summary of the study results.

Confidentiality

The amount of detailed description collected when doing qualitative research makes it difficult to maintain anonymity of participants (Ramos, 1989). Participant confidentiality and anonymity were ensured by removing identifying information from the transcripts and documenting verbatim comments separately from descriptions of the participant. During the study audio-tapes were kept in a locked cupboard. Access to data was limited to the researcher and her thesis committee. When publishing study results, special care was taken to exclude information that could be linked to a particular patient.

Safety of participants

Research on palliative care patients is difficult because these patients are in a state of physical decline and are emotionally vulnerable (Ananda, 1995). All psycho-social research has risks regarding emotional discomfort, fears, anxieties, and revealing inner secrets (Davies et al., 1995; Ramos, 1989). Therefore, during

interviews, I was sensitive to individual needs and circumstances. The individuals in this study found it beneficial to participate. They appreciated the opportunity to share their thoughts, feelings, beliefs and experiences and be heard.

All interviews were conducted in a relaxed, informal, and sensitive manner. Care was taken not to over-tire patients. Patients were reminded that they could choose not to answer particular questions and could stop the interview at any time. I informed patients that they could be referred to the Palliative Care Program social worker for further exploration of issues or intervention, if they wished. None of the participants requested this referral.

Written approval to conduct the study was obtained from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects. Written approval was also obtained from the Simon Fraser Health Region Clinical Investigation Committee.

Researcher versus clinician role

I chose to conduct research in my work setting for several reasons. First, conducting research is an expectation related to my clinical role. Secondly, I hoped to promote more emphasis on psychological and spiritual care with palliative care patients. Doing research in this area has promoted awareness, interest, and discussion amongst staff and team members. Thirdly, having a broad overview of the program provided good access to nurses in both hospital and community settings of the program. Despite this fact, it was still difficult to obtain participants for the study. Both home care and hospital nurses were very protective of their clients'

well-being. They determined which clients were mentally and physically fit to be interviewed and so were selective about which patients they told about the study.

The research approach was grounded in the belief that, when conducting qualitative research, the nurse role (to protect and nurture the patient) and the researcher role are "inextricably linked" and do not need to be separated (Robinson & Thorne, 1988, p. 73).

I was alert to situations when intervention might have been necessary, but no such situations occurred, so no special measures were required (Robinson & Thorne, 1988).

Morse (1994a) cautions against taking on the researcher role in one's work setting. The advantages of entering the setting as a "stranger" are that the researcher can view the setting with sensitivity and without bias, and any clashes between employee and researcher roles and responsibilities for dealing with information can be avoided (Morse, 1994a). For this study, potential problems related to familiarity with the setting and conflicts between the nurse practitioner and researcher roles were minimized. My usual clinician responsibilities do not include direct physical patient care so patients and staff did not have the expectation that I would be doing this. Participant sharing of information regarding desires and needs could have lead to expectations by the participant that I would use the information in relation to their current care. Therefore I clarified with participants, at the beginning of each interview, that all information would be kept confidential and not shared with the nurses or the palliative care team. I also clarified the intent and wishes of the

participants when information was revealed that could have affected the participant's current care. Participants were directed to share the information with their nurse or physician if they wanted the information acted upon.

All participants, except one, were unknown to me prior to the first interview. This avoided confusion about the researcher role. I had met one patient briefly, prior to the research interview. This meeting included an introduction to the palliative care program and verification that appropriate arrangements had been made for his discharge from hospital. Expectations were clearly laid out prior to the interview with this individual and no role confusion occurred.

In summary, interpretive description was chosen for this study in keeping with the nature of the research question and the philosophy of palliative care. The advantage of this qualitative approach is that it provides for detailed description of the phenomenon and maintains methodological rigor while being based in nursing science. The participants were chosen according to set criteria, with the aim of maximal variation of the sample. Data collection proceeded concurrently with analysis, providing systematic analysis and verification of evolving conceptualizations with participants. Ethical considerations were incorporated into the research design.

Chapter 4   Presentation of Findings

The purpose of this study is to describe how palliative care patients make meaning of living while dying of terminal cancer. The findings in this study reflect several striking commonalities among participants related to how they experience living. Individual differences were captured within these common areas. The three main themes that emerged from the data include: (1) coping with terminal illness, (2) making sense of the situation, and (3) surviving within the perimeter. These three themes do not represent distinct theoretical categories, but rather provide a useful way to examine the situation and organize clinically relevant knowledge. All three themes describe different aspects of coping with a diagnosis of terminal cancer and a short time to live. The first theme includes only coping strategies and styles that were unique to each individual. The second theme includes attitudes and outlooks employed by all the participants to create a manageable perspective of the situation. The third theme describes the whole of the physical experience of life. These three themes together comprise the essence of the participants' experience of life at this point in time.

Coping with terminal illness is discussed first as this theme reflects the uniqueness and variations in individuals. An understanding of the individuals is established in this theme, then the commonalities of the experience are described within the other two themes, making sense of the situation and surviving within the perimeter. An outline of this conceptualization, including the sub-themes is presented in Table 1.

Table 1   Palliative cancer patients' experience of living while dying ·

1. Coping with terminal illness
    a) Using coping strategies
    b) Reflecting or avoiding reflection
2. Making sense of the situation
    a) Acknowledging death while not dwelling on it
    b) Accepting the reality of the situation
    c) Maintaining hope
3. Surviving within the perimeter
    a) Surviving
    b) Staying alive
    c) Working around fatigue
    d) Attempting physical accomplishments
    e) Narrowing of the perimeter

Coping with Terminal Illness

Each of the study participants was dealing with a unique set of diagnoses, symptoms, limitations and resources. To cope with the terminal illness, people relied on past coping strategies. Their personalities, attitudes and beliefs affected how they faced and adapted to the problems and deterioration of their physical capabilities. The framework for discussion of this theme is divided into two parts. The first part describes the differences and individuality among the participants in relation to coping strategies. The second part describes the commonalities among the participants according to two contrasting approaches. This sample showed an even division between those that reflected on the experience and those that

avoided reflecting on the experience. The sub-themes are: (1) using coping strategies and (2) reflecting or avoiding reflection .

Using coping strategies

Each individual had his or her own assortment of strategies for managing problems and difficult situations. I will present information about coping strategies by describing this aspect in relation to each of the participants. The purpose of approaching the data in this way is to provide some depth of understanding about the uniqueness of each individual prior to describing commonalities.

The first participant relied primarily on herself and her family for support. She described her way of dealing with adversity.

> I've always been a pretty strong person. When I was brought up and you got a problem you deal with it [sic]. We were never allowed to really sit around and feel sorry for ourselves. You just always made the best of a bad situation and that's what you do [sic]. And what's the point? What's the point of feeling sorry for yourself? It doesn't get you anywhere. It makes you feel lousy.

The attitude of this individual toward dealing with cancer and its effects influenced how she lived her life.

> There's no point in focusing on the bad stuff because it's gonna happen when it's gonna happen. It's just that I've more of an idea that it might happen a little bit sooner than somebody else might think about. But, I don't know. I think I will be all right.

> --

> Sometimes I get a sharp pain or something but I mean, heck! When I felt good I had pains! Everybody gets a pain in the belly or a sore leg or a twisted arm. Everybody has something that bothers them. And some people make a big deal about nothing. You know, some people go on and on and on and I think, man! If that was my biggest problem I would be happy. But I don't say anything. I let them ramble on because it's obviously important to them. But there is no point. Everybody's got a problem. Some are worse than others and there's no point in dwelling on it.

She relied heavily on her nuclear and extended family and friends. Her family and friends provided practical assistance such as cooking, cleaning and doing errands. They also provided emotional support. She had a family member with whom she could discuss death and dying. Being with family members made her life very full. "They all come. But obviously they've always come .... It's always been that way. It's just how our family is." She felt better when she was with people and when she went out. She said, "I like being with people and I eat better when I'm with other people too, I eat more." This participant also spent a good deal of time reading and incorporating knowledge, ideas and suggestions from her reading into her daily life.

Another participant relied mainly on herself and her faith in God. She related her coping strategies to her upbringing. "That's very much the way I was raised. Well, you have got it, now get on with it and do something about it or don't complain ... It taught us a lot of self reliance in those days." Her current approach to life was summed up, "So there's your hand and you're dealt with it, so now what do you do? You learn to handle it the best way you can." She said, "I've come to the conclusion that the only person who is gonna help me is me." It was also important to her that she handled life in a positive and moral way, as her ancestors had done. Her sense of humor also helped her cope. "I can see the funny side of tragic situations, not exactly tragic situations, but when we are personally [involved], I can always see a funny side to it." Her faith in God provided her with much strength and comfort, enabling her to cope well with her circumstances. She summed it up this way,

> You know, God loves you. He's there to help you. All you've got to do is ask for it ....You're never given more than God gives you the strength to stand. And He does expect you to help yourself .... If it's necessary for your comfort I think God will send you comfort. It's almost like somebody putting their arms around you and just giving you a hug. And sometimes after you have had a few days of quiet desperation you need a hug.

This woman was interested in learning and growing as a person, so she read books and watched documentaries about a wide range of topics including spirituality, religion, multi-culturalism, and self-awareness. She also had supportive daughters and friends, whom she spoke to regularly.

A third participant had little experience in dealing with adversity. He had been healthy all his life and his family had prospered. He belonged to the Roman Catholic faith but stated he had gained no strength or assistance from his beliefs during his illness. He sometimes had difficulty focusing on the present, as his mind tended to wander to thoughts of his condition and how he used to be. He said, "I talk but ... [at] the same time ... I am thinking, I say why I am in this condition [sic]? (pause) So then when the people talk you don't understand, because you [sic] mind is not concentrated." He relied mainly on his wife for practical and emotional support. He said, "She [wife] really help me in every way. (pause) If it was not her I was dead already. Because I don't have appetite and nobody push me and that's it. But she push me and she help me lots. Lots." His wife organized all his appointments and enrolled him in a weekly cancer support group which they both attended. He and his wife searched for new medicines and treatments for cancer and this seemed to help him cope with each day by providing some hope that things could change.

Another participant had always relied mainly on himself.

P: I'm not really what you call a team player or a team leader. I'm sort of a lone wolf that does his own thing.
R: So, that's the way you deal with this too?
P: Yeah.
R: And does that feel okay?
P: Well, it's the way I've always been.

He used the coping strategy that had worked for him throughout his life. "A problem comes up and you cope with it then and there. You do whatever's necessary to work your way around it." He tried to work his way around his inability to concentrate or drive by trying to reduce his morphine intake. In order to handle his pain with less morphine, he had a nerve block done. Unfortunately, this block was ineffective. He had to rely increasingly more on his wife, as he was oxygen dependent and physically unable to do many things. He stated,

> Well, some things you learn to become more dependent on in your, on your wife for than you did before [sic]. You know you were saying you fight for every bit of independence but then there's also certain areas where you're dependent on them and (pause) you really appreciate them for it.

Although he described himself as "religious, but not religious" because he did not attend church, he did say that his belief in God was comforting and helped give him strength to get through what he needed to.

The fifth participant also relied mainly on himself. He denied any belief in God or a hereafter. His wife worked full-time and his daughter provided some practical support. He did not comment on emotional support. His past coping style was to ignore problems and this was what he continued to try to do. He said, "I do the things I need to do."

The remaining participant viewed "everyday as a challenge for everybody, if you're healthy or, or unhealthy." She was a voracious reader. On her kitchen table,

she had stacks of articles, books, jotted questions and thoughts. She asked me

many questions prior to the start of our interview. She felt very strongly that having

knowledge helps people cope. She explained,

> Information, education, uh, information of what's happening and be able to, to have hands on knowledge of what's happening instead of groping in the dark. That to me is *so* important. Like I'm very lucky I have an inquisitive mind. I've got most of this stuff from libraries and the Cancer Clinic, and if people were more fully informed of what's really happening ... they could cope better.

She also felt strongly that goals were necessary before she could accomplish

anything:

> Before you have that ability to accomplish something physically in, in my, in my case, to me it's, it's, it's a blessing and a plus to be able to *know* what I have to do. I just don't want to cope [*sic*] around all day and figure by the time ten o'clock comes, gee I should have done that. I - to me I like to know, I like to know and I always ask Heavenly Father what - give me the ability to focus on my priority, be able to choose what's important, instead of wondering all day what is it gonna be?

Having a goal motivated her to attempt physical activities despite her lack of energy.

For example,

> What makes me happy is I had, I had enough gumption say, to go out there and clean it up today. But it was out of necessity. I had to have a goal ... I have to have a goal. I, just to get up and do the dishes or what am I gonna have for breakfast or lunch, that's not enough. People have to have, have a goal or something to look forward to.

This woman relied on setting goals and priorities to get her started with her days.

She said, "If it wasn't for my cat J_ I wouldn't even get my feet on the floor to get up.

But have to get up to go to the bathroom and feed J_ and let her out."

This participant believed that "every mind is capable of, of almost healing

itself and when you can't handle it, find your own way to dissolve it [negative

thought]." Her method of getting rid of negative thoughts involved writing the

thoughts on pieces of paper, sleeping on them for three days, then burning them in her "burning pot."

This woman wanted more practical and emotional support from people because she had little support from her family and friends. She confided, "But everybody is so, so busy in their own little world. They [her two children] care but they don't care enough to see me." The hospice volunteer and home care nurses seemed to be her main social and emotional supports. She drew strength from her faith in God and her religious practices.

This narration has highlighted the differences in personalities, approaches and resources used by the participants, each facing living near the end of a terminal illness. Each participant used a style of coping that was consistent with prior values and experiences. In addition, participants approached the experience by either reflecting on it or ignoring it as much as possible.

Reflecting or avoiding reflection

Participants in this study reflected two distinct patterns in terms of how they dealt with psychological and spiritual aspects of the illness experience. Half of the participants ignored or avoided thinking about the experience and the other half reflected upon the experience. These strategies reveal significant coping styles in relation to living with a terminal illness.

Avoiding reflection.

The three men focused on physical aspects of their illness and getting through each day. They did not want to think about or consider psychological,

emotional or spiritual aspects of the experience. This conscious choice to avoid thinking about the illness experience was apparent in comments such as, "I try not to think about it" or "just passing the time, letting the time flow by," or "I don't dwell on it."

These participants talked about ignoring some aspects of the situation by trying not to think about the situation. This approach typically reflected how they had always dealt with problems in the past.

> P: I've had lots of different pain - back problems, other things over the years.
>   I just ignore it and carry on as best I can.
> R: Is that what you're doing now?
> P: Yes. I do the things that I need to do.

Two participants used television as a distraction from the situation. This was a new strategy for each of these individuals. They had previously been very active with a variety of activities, so had spent very little time watching television. Their present physical limitations prevented them from participating in their previous activities.

All three participants were able to talk openly about physical concerns and possible solutions. However, psychological and spiritual aspects of the experience were difficult to verbalize. One person stated, "Physical symptoms is pretty [sic] (pause) is a lot more straightforward than being able to talk about feelings and thoughts." These participants did not volunteer information about beliefs or meaning related to their current situation. When asked direct questions, they often did not have answers. For example, in an interview with one person,

> R: So how do you get strength to get through this?
> P: I don't know. I don't know myself.

In another interview,

> R: Do you believe in an after life?
> P: I don't know whether I do or not. (pause) I don't think about it.

One person elaborated on his non-response, "I don't know. I haven't really thought about that ... You're asking me to put into words things that I never really think about. I just do them." However, one individual, when directly questioned about whether he had found a way to make meaning of this experience, related meaning to what he could physically accomplish. This man paused frequently during his interview due to dizziness caused by his efforts to speak with a tracheotomy. He said, "No ..... how can I?..... If I could ..... just do..... more."

These individuals talked about bad days in a matter-of-fact manner, indicating that they had no choice about how things were. They lived each day as it came and did what they were able to do. I asked questions related to what the participants thought would improve their quality of life, bring a little more joy or some small pleasures to their lives, given their limitations. They answered with comments like, "I think, not really", or "I can't think of anything", or "I really don't know at this point, you know."

All of these participants were "feeling down" when I spoke to them and had not found a successful way to overcome this. They spoke predominantly about their inability to participate in the enjoyable and meaningful physical activities in which they had been involved before their illness. Through their comments, posture, expressions and tone of voice, they communicated a profound sense of loss. Two individuals spoke repeatedly about treatments and plans to gain back strength and

energy to enable them to regain ability to participate in some past activities. In contrast, one person had given up hope of ever being able to participate in any of the activities he had previously enjoyed. He said, "this is no life..... there's no purpose ..... in anything ..... to me ..... anymore." However, despite their discontent with their current physical abilities and life, these men continued to carry on satisfactorily from day to day.

In summary, these three participants dealt with the physical aspects of their existence but consciously chose to avoid reflecting on the psychological, emotional and spiritual aspects of their illness and life. The approach of ignoring what one cannot change had worked for them in the past. Although they seldom spoke directly about meaning in their lives, meaning and purpose in life seemed to be closely tied to physical accomplishments. Given their severe physical limitations at present, they were unable to find positive aspects or purpose in their current circumstances.

Reflecting.

The three women reflected on the illness experience, in addition to dealing with the physical aspects of the situation. Meaning was attached to trying to understand the experience on a different level, through solitary contemplation or discussion. One person stated, "The cancer. Probably the knowledge that you've got it does change your thinking a lot, you know." These individuals spent much time thinking, reading, and discussing psychological or spiritual aspects of living

with terminal cancer, such as meaning, purpose, coping strategies, attitude, and self-growth.

These individuals described several aspects of thoughtful reflection. One participant described the role of thinking in her life. She said, "But sometimes I just have plenty of time and I sit and think and maybe I sit and think too much. (pause) It's only since now that I've plenty of long hours and I think. I think a lot. I don't know whether I come to too many conclusions." This time spent thinking involved deliberation about one's self and the experience of terminal illness. For example, one woman shared the following thoughts,

> Most of these thoughts are random and I just kind of process them and reject the ones I don't want and put the other ones far as I want to, away somewhere and try and make sense out of the whole ugly mess.

> --

> It's not something I really sit there and consciously do and say, well, now I'm going to grow, it's just that I have a thought, a random thought. (pause) I've tried meditation. I'm not too good at it but at least I do get myself down to a quiet spot and then I let my mind wander.

> --

> But I say, it is all those things sitting in the back of your mind and you - kind of grist for the mill and it all gets fed in and it makes you what you are and who you are.

Having somebody to discuss a variety of existential topics was important to these participants. For example one person commented,

> Anyway, my cousin that brings the cookies, he's got quite a few degrees, I think actually, but his latest - he's a family therapist. He has all the training in it. So he is a good person to talk to about dying and stuff like that. We talk about all kinds of weird things, J_ and I. So my husband says, "What do you and J_ find to talk about." I've a lot of things to talk about. 'Cause he's interested in that kind of stuff.

These individuals had belief systems that helped provide meaning, understanding and opportunities for self-growth. For example, they offered interpretations such as, "I think it's an experience that I have to go through" and "I think that it must be happening to me for a reason and I just want to (pause) be able to help other people with my reaction." One participant elaborated on how she found meaning in learning and giving in her current situation. She saw value in accepting the situation as a challenge or test, which she could learn to handle in a positive way and show others how to do the same. She stated, "The most important thing in my life is to accept the sentence and hopefully learn how to cope with it ... so I can be sort of an example, not just to my family, but to other friends I know who haven't got as much faith as I have." Another participant also had a spiritual goals in her life. She said,

> You get up in the morning and you put one foot in front of the other and carry on until it's time to go to bed. One day the supreme being, whoever he is, will say well, okay, you can let go now. Until that time you just carry on doing what you know is good, honorable and moral.

One woman placed her present situation within the context of life in general and related her view of how self-growth provides meaning in living, and commented,

> One keeps growing, I think. You know, I say I grew until I became somebody's wife and then I grew into that and then grew in my role as a mother. Now I'm growing in my role as a widow (pause) mainly because I have to, not because I want to, but you can't stay static (pause) you can't just be.

A common focus of thought for these participants, struggling with issues in the context of their poor prognosis, was finding a purpose and integrating the purpose in their lives. One person said, "I don't need peace and quiet. I need a reason for

living. That's what it boils down to." Another person said, "So I guess I'm still doing

the things I have to do and when I'm finished doing the things I have to do, and then

it will be time and I'll go [die]." A third participant made this statement about

purpose.

> I never want to lose the, the ability to help people or do something for them or be an example. I would really love to have the, have the power to be a *real* example. Say, say they beat this, this horrible thing behind my, my, my breastbone here. That would be really a plus for me to be able to talk about it while it's gone ... that would really make it all worth while and maybe this would give me a reason. Well, that's why I had to go through this ugly situation.

All three of these individuals found meaning and satisfaction in helping family

and friends. For example, one person spent time listening to her daughters'

problems and offering advice. Another individual provided emotional support and

advice to friends who were also ill. The third participant looked after her

grandchildren or attended their activities when she could.

These three participants also described the experience of having bad days

or "feeling down" but were able to explain how they worked through this. For

example, one woman dismissed the limitations and problems she dealt with: "I've

probably only had about two or three [bad days] since the whole thing started and

they are not really all that bad. So you just pull yourself up and get going." Another

participant shared the depth of the "down" part of the experience and some specific

strategies for overcoming the depression and continuing to cope.

> You ... get down low and depressed where you dig a hole and climb in and pull it in after you and stay there 'til you feel better and then come out. I guess you're strengthening yourself while you are down there. You're building up your resistance to whatever it is you've got to face when you come back out ... the majority of us I think we can just climb into our little

holes, stay there for three or four days and work it out. Think of what it is you want to do, have to do, how you want to do it and then come out and go ahead with what it is you decide you're going to do.

Sometimes you do just go right down to the bottom and one day you look at yourself in the mirror and you say, "Well straighten up kid, for heaven's sakes you're getting on your nerves."

Another woman described how she kept herself going.

That's what I'm trying to say, is you look around and see your friends and other people who is really, really suffering and they haven't got ... they don't hang on. They, they let go very easily and you can't, you can't, you can't do that. You've got to hang on .... And how I hang on to it is ...sheer determination.

One participant described dealing with problems in the larger context of life.

So then you retreat a little and work your way through that and come to accept this new thing that's come along, and as soon as you've accepted that, well then carry on until the next thing comes along. So it's the life of constant acceptance and ... changing. You know, as I say, changing what you can change and accepting what you can't change. And don't try and change what you can't change because you're not going to do it and you're only going to wind up frustrated.

Participants who chose to reflect on the experience explored many aspects of themselves, their beliefs, attitudes, purpose and meaning in relation to the experience of having a terminal illness with a very short time to live. They were able to find some meaning and purpose in their experience of living with terminal cancer.

In summary, although all the participants in this study had their own unique coping strategies and resources for coping with their terminal illness, it was interesting that the group was divided equally in relation to whether they chose consciously to reflect upon or avoid reflecting on psychological and spiritual aspects

of the experience. The sample was also divided equally between men and women. Those individuals that chose to reflect on the experience found meaning and purpose in their lives. Those individuals who chose to avoid reflecting on these aspects dwelt more on physical losses and could not share any positive aspects or sense of purpose in their current way of living. The approaches of reflecting or avoiding reflection on the experience reveal two styles of coping with a terminal illness.

Making sense of the situation

Although there were unique ways each individual coped with their terminal illness, there were clear similarities in how individuals made sense of the situation. Participants exhibited clear commonalities in how they faced the news of an incurable illness and poor prognosis and made sense of what was happening to them. Some dealt with the facts more directly than others, but it was clear by their comments, implicit remarks, tentative language, and non-verbal behavior, that they understood the reality that had been presented to them by the physicians and nurses. As individuals with incurable cancer, their common approach to making sense of the situation included: acknowledging death while not dwelling on it, accepting the reality of the situation, and maintaining hope.

Acknowledging death while not dwelling on it

All the participants understood that their cancer was not curable. Some spoke indirectly about their poor prognosis. For example, one person said, "That's another thing you know. You can't believe it. But it's happened." Another stated,

"You say geez, I am sick. I'll never be better anymore." All the participants knew that the doctors had determined that they had a short time to live. Some participants referred to the incurable diagnosis indirectly. For example, one woman said, "But then I got dozens, and dozens, and dozens of lesions and that's why they can't do anything." Another individual commented, "Why am I going through this with a, a death sentence on my head?" A third person said, "can't operation. Can't do nothing." He also spoke about a one month improvement after radiation treatments, followed by the tumor beginning to grow again. Participants knew the facts about the progression of their cancer and the absence of effective treatment.

Some participants also made indirect comments acknowledging the nearness of death. For example, one person stated, "I don't think they expect me to be around very long." Another individual commented, "Thought I'd have more time." A third person said, "I don't have all that much time to be what I want to be because opportunity for that has past." This awareness of limited time was reflected in the way participants approached planning for the future. For example, one woman said, "My daughter wants me to go on a cruise with her. Well, you book up the cruise six months ahead and sometimes the thought crosses your mind. Well, will I be here, will I be here in six months? So ... you don't go ahead and do it."

All the participants had made arrangements or were in the process of dealing with their wills, funerals, and giving away their belongings. One person commented generally, "I've done what I need to do." Others were more specific. For example, one person said, "We decided where we were going to get buried and what we were

going to do with our ashes and who gets what and my husband has been after me to put down some personal things to give to people. I will get through it." Another participant had set herself the goal of having the legal and funeral arrangements completed prior to her death, so her children would not have to deal with them. She stated,

> What I'm doing at the moment, I'm spending all the time I've got at the moment transferring everything around so that it's equal shares with both my girls and myself so that when I go they haven't got a great big bill to pay with the death duties and things like that. So that's keeping me busy, transferring all that stuff over and tying up all the loose ends for that. My husband did it for me so I thought I'd do it for them. And so I do have (pause) I have an aim in life at the moment, which is to make it as easy as possible for them.

All participants indicated that they consciously choose not to dwell on death. For example, as one explained, "But as far as the dying part goes I don't think too much about it. I mean what is the point, we are all dying." Another said, "There's no point in focusing on the bad stuff because it's gonna happen when it's gonna happen. It's just that I've more of an idea that it might happen a little bit sooner than somebody else might think about." A third suggested that even unrealistic hope was preferable to dwelling on dying.

> R: And when you're thinking, are you focused on living or do you ever think about dying?
> P: Hmmm, No. I'm thinking maybe I'm gonna be better.

All participants acknowledged that they had an incurable disease, and either directly or indirectly, acknowledged that they would die soon. This knowledge led participants to discuss or complete some or all of the legal and practical aspects of dying. They only focused on these requirements for short periods of time, then

consciously put thoughts of dying aside. Regardless of their coping strategies, and their approach of reflecting or avoiding reflection on the situation, all participants consciously chose not to dwell on dying.

Accepting the reality of the situation

All the participants, faced with incurable illness and a poor prognosis, were very matter-of-fact about having to handle their situation as best they could because they "had no choice." They expressed their acceptance of this fact very directly. For example, one man said, "You deal with it the same as you deal with everything else! You learn to live with it. ...You know you just, you do what you have to do ... I just do them [sic]." Some participants elaborated upon the fact that the situation could not be changed and described the attitude they had adopted to deal with this fact. For example, one man described how he carried on with his life, despite the drastic changes. He said, "'Cause this year should have been the highlight of many, many years for me and it's turned out to be something quite totally different. But again, you, you just live with what you know, comme ci, comme ca. Whatever it is, you do it." Another person described how she not only accepted what could not be changed, but consciously changed her attitude to deal with things differently, saying,

> This is the hand God dealt you, now play it. Not much good sitting there wishing things could be different because they aren't and they can't be. You can't wave a magic wand and change it. So, the thing that has to change is your attitude toward whatever it is that happens.

She then elaborated on her reasons for changing her attitude. She stated, "This is the way it is. You have no choice and if you've no options, you've no choices. You

can't curl up into a little ball and ignore everything. I mean, you get so tired of yourself with that attitude."

The participants in this study spoke about this attitude or stance towards an unchangeable situation, as if it were the only option available to them. They made very general statements about how they handled this undesirable situation. One person said, "But other than that ... life goes on. You're doing the best you can with what you've got." Another thoughtfully stated, "I think it's an experience that I, I, I have to go through." One individual commented on just getting through each day. He said, "I do the things I need to do." Another participant consciously maximized each day with her attitude, "I just make the best of every day that comes along."

All the participants displayed this matter-of-fact stance towards accepting the reality of their situation. Then, in their own unique way, they faced the situation that could not be worked around or changed.

Maintaining hope

The existence of hope was clearly important to all participants. Having hope, whether realistic or unrealistic, enabled them to get through each day. All participants except one viewed themselves more as living than dying. All these participants made several hopeful statements. The one participant who viewed himself "more as dying than living" said, "I felt pretty healthy before ..... all this came about ..... a couple of years ago ..... I thought they got it beat ..... so when it came back ..... it sort of ..... dashed ..... any real hopes." However, he also made statements about hoping to be able to drive or go fishing in the future.

<u>Open to positive outcomes.</u>

Despite their knowledge about the reality of the situation, all participants remained open to the possibility of positive outcomes that at present did not seem possible. They described positive outcomes such as generally feeling better in the future, being able to do more than they currently were able, or living longer than predicted. One man, who had been well for a month following his radiation treatment, had recently undergone chemotherapy due to further progression of the same tumor. Despite further growth of the tumor since chemotherapy was completed, he hoped for a miracle, "Well, after the radiation ... [cure was] really possible. It was a miracle ... Maybe there's one in the future. Who knows ... Got to be so big [*sic*]." Another participant turned the detailed and dismal news about the extent and progression of her cancer into a possibility for improvement :

> But before I had one to three lesser centimeter lesions. And the last time I had two to three centimeter lesions. Now my husband, he figures that the ones have grown into twos. But you see me, ever optimistic, thinks that the ones are gone and just have the twos and threes to get rid of now. That's what I'm thinking. Because I have two larger tumors and they look different and the doctor says it's different because the cancer grows so fast that the inside of one didn't get the chance to finish growing because it grew so fast.

Faced with incurable illness, individuals still hoped that at some point in the future, they would feel better than they do now or would be able to do more than they can now. For example, one person commented:

> P: I have a basic hope. I don't know what else, how else to put it. Because that covers the end all and everything.
> R: It would be to have a little bit of the life that you had before?
> P: Yeah.

One man's words continued to convey a sense of optimism. "I went ..... just on a trip[*sic*] ..... with ..... my buddies ..... four or five days ..... last fall ..... but just as a ..... passenger ..... and I haven't done any fishing ..... since ..... last fall ..... (longer pause) Hopefully ..... I'll catch another fish." Although he had recently sold all his outdoor recreation equipment he pointed out, "but I haven't ..... sold my car yet ..... I move it ..... around ..... in the driveway ..... sometimes ..... when I'm ..... feeling clear."

Although all participants acknowledged the terminal nature of their illness, most made seemingly unrealistic comments regarding cure or restoration of lost abilities. For example, one person said, "of course my, my, my biggest goal is to beat this completely, but it's in such a precarious spot. It's too close to the heart . The most important thing is getting better. Get rid of this damn thing in here."

One person focused a great deal on his past life and abilities. He wanted it all back. He responded to my questions as follows:

R: So when you think about the future what do you hope for?
P: To have my life back even if I don't go out for all day because you lose all of the hope. But as long as I get my life back (pause) Yep.
R: Do you have a smaller hope than having it all back?
P: Well (pause) I think every minute of that to be back like I used to .

However, this person also made comments about smaller goals and hopes such as being able to walk further or generally feel better.

All participants, except one, also made statements that they may live longer than the doctor expected. For example, "Now chances are I won't live to be 97, but... " Another person commented,

> So that [trip] is the only thing we've done because of the cancer. Like extra, 'cause I think, I mean I would like to have gone a bit later but I think they were all worried I would not make it later. So maybe we will do it again in a couple of years if I'm still around.

Participants often made contradictory comments within the conversation, indicating the understanding of their short prognosis, yet allowing for the possibility that they may live longer. One participant shared her surprise that she was going to be the first sibling to die:

> I always figured I would be the last one to live. Because my sisters are fifteen years older than me, which you know, just how things go. They should die before me. So I always figured I would be the last one alive and kicking. And maybe I will. Who knows?

Even when acknowledging the short prognosis and getting affairs in order, individuals would include qualifying statements that provided some hope of escaping the inevitable. For example, one man said:

> Well, I sort of had to shorten my time frame, to get things done, mind you, when you think you've got twenty years left and suddenly you're told, uh, it takes a bit of adjusting to. So, but basically I've just got to think in terms of how I'm going to get things set up so they're, so they'll be the way I want them to go when I'm not here. But really I don't think I've come to accept that yet, that I'm not going to be here. It's not part of my thought process yet ... I still figure I got another twenty years left.

Participants had realistic and unrealistic hopes. Some comments would lead the listener to believe these individuals were denying the reality of their poor prognosis and inevitable death, but these comments were balanced at other points in the discussion, with comments acknowledging the extent of their disease and the absence of treatment for cure. Being open to the possibility that they may escape

their expected fate provided these individuals with strength and energy to endure the life they had.

Using treatments that may make them feel better.

All the participants except one were using treatments that might enable them to feel better or to get better. One person described the reason he tried the treatment, "You feel a little bit better and, and you stay [live] for - I don't know how long." The purpose of these treatments went beyond managing symptoms. The focus for these individuals was on gaining back some of their physical losses, such as the ability to walk further or to drive again. For the man reliant on tube feeding, the goal for treatment was to be able to take some small amount of food or drink orally. He said, "Well, wouldn't mind if this ..... chemo .....would just kick in ....a little bit ....so I can even eat..... a little bit..... get a taste of something."

Most of the participants were currently receiving one or more treatments. One person had just completed palliative radiotherapy, two individuals were receiving palliative chemotherapy, and one person was waiting for a nerve block. Three individuals also used complementary therapies such as herbal remedies and nutritional supplements, and holistic practitioners such as a naturopathic physician and a practitioner of biokinesiology. One person was not receiving any treatment.

For half of the participants, using complementary therapies and alternative practitioners contributed to the hope for a longer life or better physical condition than existed in the present. The power of hope generated by the use of alternative remedies helped individuals get through the present circumstances: "'Cause they

give me lots of vitamin [sic] and they say they give this [sic], and they give me little bit of that too. I believe it. I keep going." Another individual said, "I see a naturopath. That is who I was talking to on the phone from the States. He's helped me a lot with my diet and to tell you the truth I think that is the reason why I'm still here."

Although the participants hoped the conventional palliative treatments would make a difference, some individuals mentioned that their treatment did not seem to be helping:

> 'After I get through this, this radiation. I hope it's [cancer] all gone because it, it's just like a, like a ton of bricks you're dragging around. And this, this um, um, tamoxifen and, of course, the worry if it's, if it's gone or not ... But it's ... like the proverbial ball and chain. You can't get rid of it, can't get rid of it.

Another person commented on his hopes for one therapy, which turned out not to work, then made hopeful comments about another possibility:

> I know that people say that chemo is full of bad but (pause) I never believe it! I never believe it. I say well, I'll try. (pause) You know, but really. But now I am begin [sic] - I might as well continue. He say give more, it's okay .... Maybe the second medicine help a little bit. I don't know (pause) I get them as long as it works [sic]. I get some result. But so far I got no result. And now one of the doctors said the chemo does nothing we stop. So then we say we can try from medicine from out of country .... Keep you a little better. They don't take the tumor out, eh. Yeah, maybe I put to sleep [stop the tumor from growing for awhile].

Yet another person hoped that the morphine was the cause of his inability to concentrate. He focused his attention on lowering the dose of morphine in hopes that he could read and drive again:

> And that's the other thing with this morphine, it throws the eyesight and the mind out enough that's it's difficult to read. Whereas I used to read books (pause) quite quickly and thoroughly enjoyed them and now I find it difficult to concentrate .... So, it's ... (pause) pretty hard to change and try and cope with. And we're still trying to work with some way of changing this pain so I can get off of morphine.

Individuals were able to maintain hope for improved functioning or possible cure by being open to improbable possibilities and by engaging in conventional and alternative treatments. All the participants had "realistic" goals and hopes as well as, seemingly "unrealistic" hopes that helped them endure their present circumstances.

In summary, each participant made sense of the situation on some level by accepting the reality of the incurable illness and nearness of death, while not dwelling on death. Hope provided a possibility that things could go better than it currently seemed they would. Participants all found meaning in doing what must be done to get through a bad situation, while never letting go of the possibility or hope that the situation could improve.

Surviving within the perimeter

The participants in this study were all living a life that was different than they had known before or would have chosen. Life was restricted in many ways and focused on the basics of physical existence. In this context they discussed: surviving, staying alive, working around fatigue, attempting physical accomplishments, and narrowing of the perimeter.

Surviving

Four of the six participants used the word "surviving" when describing their lives. One participant said, "Actually it's kind of getting up in the morning and putting one foot in front of the other until it's time to go to bed at night. Surviving." Another commented, "You do what you have to survive." They seemed to be referring to the

preponderance of time spent on the most basic activities of daily living and the effort required to "get through" the day with very limited energy.

Participants described how their lives had changed. For example, one person stated, "We work [*sic*] so hard. We had a good life here. We got good family [*sic*]. All of a sudden, (sighs) no more." Participants also commented on what they had lost. One man said, "So that's a big chunk of my life I've had to give up" and "That's the biggest thing, is the not being able to participate." This participant described the effort of day to day living as "mostly just the coping with the day-to-day and struggling to get through it." He could not see any positive aspects of the experience.

The sense of "surviving" included a considerable amount of time spent thinking about or physically engaging in eating to maintain weight and strength and thus stay alive. The second focal point of attention was attempting physical activity and accomplishments. Physical activity was severely hampered by extreme fatigue, including lack of energy and lack of strength. The increasing physical limitations experienced by individuals due to the progression of cancer resulted in less travel beyond home, termination of work contacts, and fewer social contacts. The participants lived a simple existence within the narrowing boundaries of their lives.

Staying Alive

Individuals discussed concerns about their lack of appetite and nausea, difficulties eating and strategies they used to ensure maximum caloric intake. A primary physical goal of all the participants was eating to maintain weight and gain

strength. One person stated, "It's like an automobile running out of gasoline. It can't go anywhere." Individuals discussed, at length, their continual struggle to eat adequate amounts. All stated that they could only eat small amounts due to lack of appetite. One person said, "I don't want to eat." Another stated, "I eat so little at supper time that it seems hardly worth cooking anything." In addition to lack of appetite, some participants had frequent nausea. Maximizing the benefits of food intake required additional precautions. One person said, "They [my family] are not supposed to make me eat because if I eat and I don't want to eat, then I throw up and it's all wasted. So I eat a little bit. I eat about every two hours."

All participants viewed eating as a responsibility. For example, one person said:

> Sometimes you do have to push yourself to eat .... That's the biggest thing. Probably the desire to eat more. I mean I eat primarily because it's time to eat not because there's any enjoyment in eating. The meals are there because it's a duty you have to do to eat [sic], rather than any enjoyment out of meals.

Another stated, "The other priority is, is how am I going to, to psyche myself into eating better?" One individual was unable to eat due to obstruction of his esophagus so had a self-managed tube feeding. His schedule each day, revolved around the time required for preparing, running through the fluid and cleaning up after each tube feeding. Another person, who lived alone, had difficulty finding the energy and ambition to cook:

> I have food here but I don't want to cook it. 'Cause I've lost all interest in cooking and my cooking is rotten, and then when I do cook, I look at it and I think, oh, gee it looks terrible! I used to be able to cook, you know, a big family and everything. But when you're sick, you just don't want to do it. And when I do it, I have to really psyche myself into doing it.

Participants all worked out strategies to maintain or increase their food intake. One person focused on eating high fat, high calorie foods in small amounts every two hours. Another person planned six small meals a day. It was still difficult to eat enough:

> I'm not eating like I used to and I've found that I'm better if I've six little meals than breakfast, lunch and dinner. But the only problem about doing that is ... if you have breakfast, then you have a snack, you don't really want lunch because you have not got enough room for it. So I'm just cutting what I used to eat. I'm just kind of cutting it in half.

> Some of the participants enjoyed eating out at a restaurant occasionally. However, eating out was difficult with the small appetite. For example, one individual stated, "You know, you go out and what do you order. You can't finish eating what you order." Another person had found a way to deal with this problem by sharing with friends or family. She had a routine worked out with family and friends, where they shared a meal "because I maybe have five bites or something. It's hardly worth ordering something myself."

> Participants explained the importance of eating in terms of maintaining weight and/or gaining strength. One person described the importance of maintaining weight:

> I can't afford to lose weight .... Every time I go away I lose weight and I think I'm going to be able to gain that two pounds back. But usually when I lose it, like if it's five pounds or something I never get it back .... I can lose weight like nobody's business. If I don't pay attention I can drop pounds like nothing.

The participants believed that if they could eat more, they would become stronger and be able to do more things. For example, one individual commented, "The main thing is my appetite. If I could get my appetite back ... could get a little stronger."

Another person said, "If I could eat a little more, you know you can start to move more. Maybe the energy come back." A third person decided the morphine and pain were causing his lack of appetite, but thought that once the pain was controlled by some other means he would be able to eat more, and he would become stronger. He said:

> Well, right now, I gotta get some strength back before I can do anything. I can't go work in the garden or hammer and saw and nail without energy. Especially when you're having trouble breathing ... Actually I was hoping to get rid of this pain and get rid of the morphine so I can get back to a proper eating pattern.

> For these participants, the meaning of eating adequate amounts was

connected to physical existence. One woman explained this vividly:

> That is my biggest thing, is trying to keep my weight on. I might be 110 now. I went down to 108 and I think I might get back up to 110, but I wanted to be 125 and then I wanted to be 120 and then I wanted to be 115. You know, I've been holding 110 for more than a month now so that is a very good sign. So what happens is apparently I will lose a whole pile of weight and I will become anorexic and then I will die. That is how it goes.

Another person commented, "If it was not her [his wife] I was dead already. Because I don't have appetite and nobody push me and that's it. But she push me and she help me lots."

In summary, eating was a major focus of thought and energy for this group of individuals. Eating had become a responsibility rather than a pleasure but the participants continued to push themselves to eat. They believed that eating more would help them regain their lost strength and would enable them maintain their weight and therefore their physical existence.

Working around fatigue

The second physical focus of life for these participants was physical activity. They all spent much time struggling with fatigue. The extreme nature of the fatigue was summed up well in one person's comment, "You get tired and sometime I can't lift anything, even a little straw. (pause) I have to do nothing." Another participant said, "It's very difficult. It's like climbing a mountain to do something. If you can see the top of the mountain then it gives you something to grab for. But in my case it's got to be something worth while. Like you coming today ... was a big goal."

Fatigue or lack of energy was the most significant factor causing a negative impact on the quality of life of the participants in this study. Fatigue produced major limitations on individuals' abilities to work, play, interact with others, prepare food, walk, and perform personal care. It contributed to an inability to engage in activities of their choice. For example, one person said, "So she wanted to come and spend time with me. It was really, really nice, but so tiring!" Another individual stated, "Well, I can do all things myself, like shave myself ... But as soon I do something I, uh, I get tired." A third person said, "I have no energy. My place is a mess. I'm supposed to be getting ready for a yard sale and I just have no energy." One participant described it this way:

> I read a bit..... this part of the day ..... goes ..... rather quickly ..... 'cause I'm ..... doing the and [sic] ..... trach ..... feeding ..... read the paper..... but by this time of the day ..... from then on ..... I have to try to find ..... something to do. I have lots of ..... hobbies ..... but I can't ..... get going at them ..... don't have the stamina .

Yet another individual described the impact of fatigue like this:

When you're, when you're in a situation like this you just can't do it. It's too hard to get there [the store]. I went a couple days ago, started at nine I guess, and didn't home 'til five. That's how long it took me. I was just exhausted, bringing my, my shopping cart home.

Good and bad days were determined by energy levels. A bad day was often described in terms of this lack of energy, for example, "I'm overly tired." One woman explained,

Then I would have three or four good days like that and then I would have a day for no particular or apparent reason I couldn't beat my way out of a wet paper bag. I would think, oh what the heck, I'm not in any more pain than I was before and yet I'm absolutely drained.

A third person could not distinguish between a good and bad day. He said, "My day[s] now, they're all the same .... There are a few day now I feel a little bit better. But, energy still, still very, very, very weak."

All participants planned appointments and other activities around their personal energy restrictions and need for rest. They scheduled a limited number of activities each day. All participants attended doctor appointments outside the home. Three individuals were attending appointments for palliative chemotherapy, one person had just completed a series of palliative radiation treatments and one person was receiving monthly blood transfusions. Another person had a nerve block scheduled. Three individuals were also receiving alternative therapies. As these appointments had to be scheduled in advance, all other activities were scheduled around these appointments. These appointments seemed to provide structure to the participants' lives. Getting to these appointments provided a goal that pushed them to leave the house. Although I did not ask questions about the meaning of these

appointments to individuals, attending appointments seemed to be important in relation to maintaining hope.

All participants scheduled interviews with me on days when no other appointments outside or within the home were planned. They did not have the energy to deal with more than one person during the day, even if one was a helper such as the home support worker or the home care nurse.

All participants spoke about adapting, day by day or moment by moment, to their energy level. Their comments reflected this "step by step" approach to life. One man stated, "I gotta take it day by day. I can't jump to another day eh? 'Cause I can't. My life is not normal anymore, like it used to be. So, now I gotta take it step by step." Another person said, "I can't plan to do anything because I have to be back in an hour to do feeding or whatever." Another comment was, "You get up in the morning and you put one foot in front of the other and carry on until it's time to go to bed." A fourth participant also provided reasons for this outlook. He noted that in his situation, it was difficult to anticipate how he would be feeling or what might happen at any point in the future. He said, "So as I say for the future you sort of, you learn to take it day by day or step by step as it comes rather than try and plan it out ... So as I say as soon as you plan it out somebody comes along and changes the ground rules." Although participants did admit to making tentative plans, individuals would have to adjust, according to how they felt that day or that minute. As one person explained, "So, if I was going to do anything nice I might take the baby this weekend. Maybe I will, maybe I won't. I will see what I feel like."

Extreme fatigue, including lack of energy and lack of strength, had a major impact on what these individuals were able to do during a day. All participants were committed to attending appointments that were necessary for assessment and treatment of their cancer, so took the rest of their day "step by step", adjusting their activities to their energy level at the moment.

Attempting physical accomplishments

A critical aspect of life for this group of individuals was the desire to participate in life by accomplishing physical activities. The main barrier to doing this was fatigue, but other symptoms also interfered with activities.

Each person had a variety of physical symptoms caused by the cancer, the medications and often the treatment(s). These symptoms were significant in that they affected what participants were physically and mentally able to do. Symptoms other than fatigue that interfered with activities included: pain, cough, dizziness, lightheadedness, shortness of breath, sweating profusely, difficulty sleeping, rotten taste in the mouth, nausea, and constipation. The severity of these symptoms also affected these individuals' quality of life.

Pain and constipation were the most troubling of these symptoms. Pain was managed, to varying degrees, by taking medications, which in turn produced constipation and interfered with activities. One person explained the dilemma and his solution:

> But it's a pain that we can't seem to get under control yet. I mean, we've got it under a certain amount of control but it's taking morphine which brings other complications in. Because of the morphine you're got to (pause) your bowels and everything else gets upset which you've got to take more pills so the

focus of mine right now is to try and find some way of coping with this pain to eliminate the problems brought about by morphine.

Another person acknowledged the need for medication to counteract the side effects of the opioids used for pain relief but explained how it interfered with her daily activities:

> Making sure your bowels are moving. Everything you have taken for granted all of a sudden become a major problem in your life .... Your bowels. You can't (pause) you're even scared to eat too much or something in case you get (pause) in case you get taken short like that again. Don't go very far away from home! .... But you can't, well I won't take a Dulcocet tablet today or right now, because I *might* be going out this afternoon.

The same individual summed up the overwhelming influence of symptoms this way:

> I shouldn't say life's no fun, but it's, it's resentment I guess is mostly what you feel. What has worked so well for so many years doesn't, doesn't do it anymore. You know. It's not a case of why me or anything like that, it's just that you've accepted all of these things as granted that they're all going to work and then suddenly all stop working. And, you know, another thing I've got to get used to.

Despite the difficulties with energy level, pain and other discomforts, people's descriptions of a good day were measured by the physical tasks accomplished during the day. For example, one person said, "A good day is if I have enough energy to walk down to the mall and have a bite to eat down there." Another participant stated, "A good day would be a thankful day that I open my eyes and I'm still here and I must be here 'cause I have something to do." Other descriptions of good days included accomplishment of a meaningful activity that the person was still capable of performing. One man stated, "To accomplish something on the computer I guess, whether it'd be a letter off to somebody or a form filled out or

balance the cheque book or something but that seems to be the biggest

accomplishments I can get today." Another person commented,

> A good day is today. I got up. I ate breakfast. I had a shower, washed my hair. Vacuumed the house, dusted it because you were coming. Made my bread. A good day is I would have put my hat and coat on and I would go and I would take myself to the mall and see if there was anything I could spend my money on. My daughter would phone up and we'd have a long chat. The other one would drop around and say, "Do you want to go shopping?" Or my girlfriend would phone and say, "Let's do lunch." And you know, that would be a good day.

Contrasts of good and bad days focused on the number of physical activities that

were accomplished rather than the amount of pain, nausea or other symptoms. For

example, one person responded to the question, "What would a bad day be like?"

with the statement, "When I'm just sitting here doing nothing, accomplished nothing.

All I've done is sat and watched the TV all day and accomplished nothing."

> The ability to accomplish some physical activity was connected to purpose

or meaning in living. For example, one person stated,

> What am I gonna do today? If I haven't got the physical ability, I'm too tired or too fatigued or whatever. I still want a little bit of energy to get even part of it done ... I can't do the whole thing but give me some strength to, to even start it or get it prepared. Then I know, then my day wasn't in vain.

> Finding the strength and energy to get something accomplished was a real

struggle for most of the participants. One person described this vividly:

> I just say, well maybe I'll have the strength to do it tomorrow. Please give me the strength and the knowledge what it has, what I should do and even if I can't do the whole job, let me even do a part of it and then tomorrow, because I've done a little bit today. I'll have the, the momentum has started and it will give me something to, to work on. Well, I did a little bit yesterday. Now that I've started I bet ya I can get more done today. And I do a little bit more today. Then I say, gee it's almost done! And then before you know it, it's almost done. That gives you something to go on. That to me is very important.

The one person who considered himself "more dying than living" was maintaining his weight with a tube feeding but was unable to participate in activities he valued due to fatigue and lack of stamina. He said, "I can't do the things I did before .... my life is gone." He was very clear that staying alive without the ability to physically participate in life, to him, was not really living.

The ability to accomplish physical tasks was the difference for these individuals, between being alive (maintaining a physical existence) and living (participating in life). The most happy and positive responses were descriptions of things they might do or did do. Regardless of whether the individual was a person who reflected upon the illness experience or did not, the ability to physically accomplish something was important and meaningful.

Narrowing of the perimeter

The third theme, " surviving within the perimeter" reflects a direct quote of one of the participants. Her comment seemed to sum up the whole of life at this point in time. She said,

> You gradually build up a little life inside this perimeter you have and it's maybe not the most exciting, but it's the life you have and you make the best of what you can, best you can with it. .... You survive, is what you do. You know where your perimeter [is] and you survive inside it.

All participants described how their lives had changed in terms of the size of their "world." The extent of their abilities to do things and to reach out in terms of contacts or distance, had decreased. Individuals described their typical day within this limited "perimeter" as follows. One woman said, "I do a little house work. I go a little

shopping and I phone my friends and people come for lunch, people come for

dinner. I cook, we go out." Another person had a more restricted life. He stated:

> I read a bit..... this part of the day..... goes ..... rather quickly ..... 'cause I'm
> ..... doing the and ..... trach ..... feeding ..... read the paper ..... but by this
> time of the day ..... from then on ..... I have to try to find ..... something to do.
> I have lots of ..... hobbies ..... but I can't ..... get going at them ..... don't have
> the stamina.

A third participant also reflected on a very restricted typical day:

> Basically sitting in my chair watching TV and doing a little bit of stuff on the
> computer when I can. But even working on the computer sometimes starts to
> hurt after a while, just the different posture.

> The scope of the individual's life shrinks as the individual is less able to go

out and participate in activities outside his or her home. One person stated, "And to

try and break the mold, it is almost impossible because you're, you're house bound."

Outside activities were generally reduced to medical appointments, shopping and

short walks outside. Individuals had given up jobs, volunteer activities, driving, and

much of their previous socializing and recreational activities. The following

comments of participants reveal the individuality within the restrictions in their lives.

> Well it certainly restricted my activities and my abilities to do things. That's
> the biggest change. Because I can no longer just nip in the (pause) go do
> this or go do that on moment's notice. Then I can't help other people either.
> Like with the volunteer driver - sometimes somebody'd be sick and I'd get
> called in on five minutes notice to help out. Well, I can't do this anymore.

> --

> I don't know how long ..... I can carry on ..... but it's no way of life. I've got .....
> rifles ..... guns ..... shotguns ..... I did a lot of ..... fishing ..... and hunting .....
> camping. I don't have that anymore.

> --

> I used to walk five or ten miles a day. I love walking. That is another thing I
> miss, is I don't walk anymore. But I like, I can walk to the mall. But I'm so I

> kind of like to have somebody with me. Never used to be like that .... I walk so slow it's pathetic .... I've always been go, go, go, and now I just sort of sit on my butt.

> With the pain and with the oxygen, of course, I can't get out and attend the meetings and activities that I want to do. This was supposed to have been a very active year for me and I was supposed have been out two or three nights a week at various meetings and having to be on oxygen and in pain, especially being in the hospital for six weeks, has shot all that down.

All three men commented spontaneously about not being able to drive. For example, one man said, "I think I'm old in the future. I do this, I do that, I did a lot of things. Now I can't. I can't even drive now." Another man related, "Most of the time..... I'm feeling tired ..... and weak ..... and ..... not driving ..... sort of spoils ..... my way of life ..... having to depend on people ..... a little more than I want to." The third male participant stated, "Well right now it's [life] uh, it's more restricted than I want because of the constant pain and having to be on morphine means I can't drive the car which restricts my freedom or independence." For these men, not being able to drive was a significant restriction that negatively impacted the quality of their lives.

Some participants described the suffering in their lives. For example, one person had always worked in his flower garden. He considered it his "friend." Not being able to plan, organize and work in his garden so that it was as he liked, was a great loss to him. He said, "And maybe another person will do it their way and I don't like that. I like flower my way on my property and my house (pause) And now, I really suffer for that." Another person's suffering related to the terminal diagnosis she had to live with every day. She commented:

Because this thing that is happening is there everyday. Everyday,.everyday I think oh, gee another day. I got so many things to do. Everyday (pause) I don't think it's gonna go away, I think it's gonna go away. You don't know. The doctors don't know. It's just like ... a ghost following you all over. Even in a bright day it's there.

The sense of putting in time surfaced in the comments of several participants. For example, one individual stated, "And you still got 24 hours in a day or (pause) 168 hours in a week, you know (pause) to go through." Other participants related this slowed sense of time in relation to getting through the day as follows:

Then you sort of, sort of wait for the eleven o'clock news. That's sort of the highlight. Well, eleven o'clock news and I have to go to bed which is a far cry from what we need. There is 24 hours in the day and I'd say half of those hours are just waiting and wondering what am I gonna do?

Sit in the house ..... and wait..... until it's ..... time to clean my trach ..... or have another feed ..... (pause) its really boring ..... and monotonous. ..... I go for chemo ..... once a week ..... that takes half a day ..... of sitting around ..... and waiting around ..... which is dull ..... and boring.

And I think having things set up, you know, like with these medications that, having to take medications at 8 a.m., noon, 5 p.m. and 8 p.m. sort of sets a flag post or guide post for the day that you know. Certain markers that you got to get to and through.

The scheduled appointments to physicians and alternative health care practitioners seemed to provide some structure to their days.

For all participants, except one, the smaller perimeter of life included fewer social contacts. One participant had frequent visits from extended family and friends. Participants who had spouses were content with having their spouse as their main social contact. The two people living by themselves talked about isolation

and loneliness. One said, "The day is long, very, very long when you're by yourself." She added,

> The only, the only thing that cares for me is my little kitty cat. I'm very, I'm very fortunate that the animals really like me. Cats and dogs, no matter what it is. If it's on four legs, they, they like me 'cause they must feel that I really love them. That's the only ones I can really feel happy with now and that is wonderful but it's not enough, it's not enough.

> You go into the store everything is sold business like. You're standing in line and you're hoping somebody'll say hello. Nobody really does or they don't want to or they're in too much of a hurry.

The second person who lived alone had more contact with family and friends.

However, she also looked for opportunities to be with people:

> You know, I mean it sounds thrilling to go for a walk through the mall but you'd be surprised the number of people you can find to talk to and right now the only thing you've got to talk to is your cat and it can't answer. It's nice to get out even if you only say hello or smile at somebody at the mall. You've mingled with people.

> The essence of life for these people, living near the end of a terminal illness, was physical existence and physical activity. Participants viewed eating as a means to staying alive. Physical accomplishment provided the sense of being a living being. Lack of energy and a variety of symptoms limited the individual's ability to participate fully in life. They worked around the fatigue, as best they could and lived through the days. Each person survived within their shrinking perimeter of life.

Summary

While individuals with end-stage cancer are difficult to study due to their frail conditions and vulnerability, qualitative research is well-suited to this population. The participants were pleased to tell their stories and be heard. The interview

approach enabled them to provide information with limited physical and mental effort. The participants discussed aspects of both living and dying, when describing their experience of living. While the living aspects of the experience could often be described separately from the dying aspects, living and dying could not be separated. This was summed up well by one woman, who was asked, "Do you think you can separate living and dying?" She replied, "No, it's you. All there is you."

Within the first theme, coping with terminal illness, each participant used a unique combination of coping strategies, as one might expect. The most interesting finding was that the sample was evenly divided in relation to the general coping style used. One half of the participants reflected upon the illness experience and the other half consciously chose to avoid reflecting on both psychological and spiritual aspects of the illness experience. Whether or not they reflected was a continuation of how the individual coped with difficult situations or problems in the past. In this study, the individuals who reflected were women and those that did not were men. This was a small sample so this may not always be the case. The individuals in this study who reflected upon the experience were able to find purpose and meaning in their present circumstances. The individuals who chose to avoid reflecting on the experience dwelled more on physical losses, and did not articulate any positive aspects or sense of purpose in living within their current circumstances although they did find meaning in getting through each day.

Making sense of the situation included very clear commonalities for all participants in relation to their acceptance and attitude towards their terminal

condition. All participants acknowledged that they had an incurable disease and limited duration of life but all chose not to focus on dying. All participants had a matter-of-fact acceptance of the reality of their situation. They all viewed it as a forced-choice with no other options than to go through the experience. Despite this apparent acceptance of their incurable illness and inevitable death, all participants made unrealistic hopeful statements during the interviews, sometimes within the same sentence. Taken in isolation, these statements could be interpreted as the individual being in denial of death but taken within the context of the entire discussion, they were not. Both realistic and unrealistic hopes seemed useful as they provided these individuals with strength to endure their current circumstances.

All the participants concentrated their attention on day to day physical existence. They all focused attention and energy on eating to maintain weight. The ability to maintain weight was linked to staying alive. Due to the meaning that was attached to maintaining weight, eating became a duty or responsibility rather than a pleasure. Attempting physical activities was a key aspect of their lives. Accomplishing an activity, no matter how small, was the main factor that made a good day. In fact, it seemed to be what distinguished *being alive* (maintaining a physical existence) from *living* (participating in life). This meaning related to accomplishing physical activities was important regardless of whether the individual also reflected on their illness experience or did not. Lack of energy and strength were the main factors that interfered with the participants' abilities to carry out

activities. This fatigue was much more important than pain or other symptoms, which could be controlled to some degree by medications.

The participants had a shrinking scope of life, due to their physical limitations and symptoms. Their infrequent outings were mainly for doctor appointments or shopping. Contacts with individuals beyond their immediate caregivers was limited. They focused mainly on the basics of living. All the participants viewed themselves as surviving within a smaller perimeter of life than they had known before their illness.

The participants in this study found meaning in staying alive, accomplishing physical activities, and doing what must be done in a bad situation, while never letting go of the possibility or hope that the situation could improve. In addition, the participants who reflected on the experience also found meaning and purpose on psychological and spiritual levels.

Chapter 5   Discussion of Findings

This study provides a preliminary investigation of how end-stage cancer patients experience life. The results, based on exploration of living rather than dying, reveal different themes and areas of importance than previous research, which focused on dying. Individuals did not describe a journey, or discuss fears and losses related to death and dying. They clearly did not put all their energy into preparing for death or dealing with the knowledge that they were dying. Instead these individuals focused much of their attention and effort on maintaining some normalcy within a restricted life. In addition, individuals spent more time and energy on physical aspects of existence, than existential aspects. While confirming a focus on living, the results also strengthen the assumption that the tension between living and dying continues to near death.

Davies et al. (1995) conducted the only other study found in the literature that describes the experience of individuals in the palliative phase of cancer. Although their study focused on the transition from living to dying, rather than living, as did the current study, several similar findings are evident. Individuals in both studies made the best of their situation, focused on the present, got through the day as best they could and tried to maintain as normal a life as possible. They all struggled with the tension between living and dying. In both studies, individuals worked through changes in roles and responsibilities as their abilities became more limited. Participants in both studies made some preparations for death.

In contrast to Davies et al's (1995) study, some of the participants in the current study ignored rather than reflected upon, the illness experience. Davies et al (1995) found that the individuals in their study tried to "put their experience into context and endure the turmoil" (p. 43). They reflected on spiritual aspects of life. In the current study only half the participants did this. However, both those that reflected and those that did not seemed to find meaning in staying alive, accomplishing physical activities, and doing what must be done to get through a bad situation, while never letting go of the hope that the situation might improve.

The current study is significant in that it provides a systematic analysis of the experience of living *from the patient's viewpoint,* in contrast to many studies investigating this population from the perspective of staff and family members. The findings are important because, in addition to validating the above study, they challenge some commonly accepted professional beliefs and practices in relation to caring for cancer patients at the end of life. Discussion of this living perspective will be limited to the three most challenging and clinically significant findings: (1) physical accomplishments and quality of life (2) non-reflection as a valid coping style, and (3) the relationship between hope and unrealistic appraisal, in contributing to hope at the end of life.

Accomplishing physical activities within the narrowing perimeter

An interesting finding of the study is the key importance to individuals of participating in life by accomplishing physical activities as the perimeter of life narrows. This was an important part of living for both individuals who reflected and

found meaning in other aspects of their illness and those who did not. Physical accomplishments were connected to purpose and meaning in living. For all participants, a good day was measured by physical accomplishments more so than the amount of pain or other symptoms or interactions with others. It seemed to be an indication that they were still able to participate in life; that they were *living* rather than *existing*. Verwoerdt (1966) supports this viewpoint, "The sense of feeling alive is based on movement, change and activity related to one's environment and the idea of moving forward through time toward a future containing purposes and goals" (p. 3).

In the literature related to dying, researchers and clinical experts emphasize the importance of the dying individual adapting to the series of losses that occur as one approaches death (Canine, 1996; Pattison, 1978; Rando, 1984; Sourkes, 1987). These losses include decreasing physical abilities, control, independence and productivity (Rando, 1984). From this dying perspective, the inevitability that these losses will occur and people will have to adjust them is taken for granted. Although authors encourage professional caregivers to facilitate patients' independence for as long as possible, the emphasis of care is placed more on existential issues as physical abilities decline. From the living perspective identified in this study, physical accomplishments were a part of life that individuals struggled to maintain. Participants were able to adapt to their increasing limitations by adjusting their goals for accomplishments, but they continued to expect to accomplish physical activities.

All the individuals in the current study focused their attention mainly on rudiments of living: food, rest, and activity. Perhaps this is because physical needs must be addressed before higher level needs can be addressed (Maslow, 1962). For these terminally ill cancer patients, meeting physical needs took most of their time and energy. The essence of life was physical existence and physical activity. Participants viewed eating, not as a pleasure, but as a means to stay alive and perhaps gain some strength. Physical accomplishments provided the sense of participating in life. However, physical accomplishments and activities were limited by lack of energy or fatigue.

A review of the literature reveals an initial awareness and understanding of cancer-related fatigue. Cancer-related fatigue is different than the fatigue healthy people experience in that it does not usually improve with rest or sleep and may increase, unrelated to activity or effort (Mings, 1998). It is "persistent, emotionally overwhelming, and can result in tiredness, lack of energy, lack of concentration, weakness, exhaustion and depression (Mings, 1998, p. 6). Graydon, Sidani, Irvine, Vincent, Bubela, & Harrison (1997) define fatigue as follows: "a subjective feeling of tiredness and reduced capacity for physical and mental activity that varies in intensity, frequency and duration" (p. 5). Fatigue is multidimensional and affects all aspects of quality of life, physical, psychological, social and spiritual (Ferrell, Grant, Dean, Funk, & Ly, 1996). Ferrell (1996) found that individuals were particularly concerned about physical well-being: energy, functional ability and strength. Although participants in studies on fatigue have most often been cancer survivors

(Ferrell et al., 1996) or individuals undergoing active cancer treatment (Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Messias, Yeager, Dibble, & Dodd, 1997; Mings, 1998), my study of end-stage cancer patients also supports similar conclusions.

My study found that fatigue was a more prevalent and disruptive problem than pain or other symptoms. This coincides with recent research on fatigue in cancer patients (Ashbury, 1995/96; Ferrell et al., 1996; Winningham et al., 1994). The importance of fatigue as a significant problem may have been due to the fact that it was more constant and had more far-reaching effects that could not be remedied by medication, as other symptoms could. Other symptoms could be remedied if one made the choice to endure the side-effects. The participants' descriptions of fatigue included lack of energy, strength, and stamina . The individual's level of fatigue was unpredictable. These results emphasize the significance of fatigue in relation to the quality of life of cancer patients. Much more research is needed regarding mechanisms, correlates, assessment and interventions for fatigue.

The data gained by focusing on living provided some interesting findings related to quality of life. In order to accurately assess an individual's quality of life, it is important to know which domains are most meaningful to a particular person. All areas do not hold the same importance for everyone. Quality of life tools provide caregivers with some general areas of importance to explore with patients, but usually provide no indication of which aspects of living are most significant to that

person. My study indicates that individuals focus much time and energy on eating and physical activity. Quality of life instruments often do not assess this. Most tools do not identify accomplishing physical activities as a key aspect of quality of life.

Are quality of life tools missing important aspects of living? Using the McGill Quality of Life Questionnaire (MQOL) (Cohen et al., 1996), physical well-being is determined by measuring generally how the person is physically

(for example, well.. terrible)

and asking the individual to rate the severity of their three most significant symptoms. Axelsson and Sjoden, (1998) include six physical items: hours recumbent during the day, need for help with hygiene and dressing, physical strength, pain, nausea, and defecation problems. Neither of these tools adequately reflects meaningful physical aspects of life. According to the data in my study, a question related to the individual's ability to accomplish meaningful activities and the individual's satisfaction with those accomplishments would provide a more accurate measure of quality of life.

In McMillan's (1996) Quality of Life questionnaire, the physical/functional category includes the following questions: "How much enjoyable activity do you have? How much of your usual work are you able to do? How tired do you feel? How well do you eat?" (p. 1224). These questions fit well with the key components of physical well-being found in the current study.

Axelsson and Sjoden (1998) reported that the lowest quality of life ratings for patients during the final six weeks of life were: ability to do what one wants, physical

strength, global quality of life, and meaningfulness. When McMillan (1996) evaluated the quality of life of hospice cancer patients, she found that patients were least satisfied with physical/functional aspects of quality of life. The lowest score related to the amount of usual work that the person was able to perform (McMillan, 1996). My study supports these findings, with participants directly relating quality of life to the ability to perform activities.

In summary, accomplishing physical activities remains critical to a sense of participating in life even as individuals adjust to losses of physical ability and independence. Although current instruments used to measure quality of life do reflect some physical aspects of quality of life, they do not adequately reflect the importance of physical accomplishments. It is important that these tools include questions that reflect this aspect of living. As well, on-going research related to fatigue, particularly in palliative care, is required to develop a better understanding of fatigue and interventions to mitigate its interference with physical accomplishment and quality of life for cancer patients.

Non-reflective coping style

This study revealed two common coping styles of terminally ill patients. Half the participants reflected on the experience and half the participants chose to avoid reflecting upon the existential aspects of the experience. The choice of coping style reflected a continuation of how the individual had coped with difficult situations or problems in the past.

Research related to coping styles

Although my study sample is small, the significant representation of non-reflectors in this sample suggests that non-reflection may be a common coping style. However, a search of the coping literature offers no direct reference to reflecting or non-reflecting coping styles. In Chapter 2 a general review of the coping literature established cancer as a stressful experience (Ferrell, 1993) mediated by appraisal of the personal meaning of the situation (Lazarus & Folkman, 1984). This process of appraisal and choice of coping strategies is useful to explore in relation to the findings of my study. I will review two bodies of research initiated by Miller and Lazarus & Folkman, specifically in relation to coping styles used in response to negative, unchangeable situations.

Miller's (1987; 1990; 1988) research provides some interesting parallels and differences to the current study. Miller (1990) believes that the process of coping involves both individual styles and situational circumstances. She proposes that individuals are predisposed to a particular style or combination of styles which reflect cognitive strategies to prolong or eliminate psychological awareness of the threat. Miller (1987; 1990) has identified two main coping styles that reflect differences in information-seeking behavior preferences of individuals in uncontrollable threatening situations: monitoring and blunting. The first dimension "is the extent to which they seek out and *monitor* for information about threat, and the second is the extent to which they can cognitively distract from and psychologically *blunt* threat-relevant information" (Miller et al., 1988, p. 142). Miller

(1987) has developed the Miller Behavioral Style Scale (MBSS) to identify those who seek threat-relevant information (high monitors), those who do not seek or avoid threat-relevant information (low monitors), those who distract themselves from threatening information (high blunters) and those who do not distract themselves from threatening information (low blunters). The validity of this scale to measure these coping styles has been tested in a variety of situations, with a variety of problems and outcome measures.

Miller's research is pertinent to this discussion because of her finding that the "coping style interacted with and moderated the impact of threat-relevant information" (Miller, 1990, p. 111). The blunters (low monitor/ high blunter) benefited more from distraction and the monitors (high monitor/low blunter) benefited more from obtaining information. This indicates that the amount of information given to individuals should be varied according to their coping style, in order to reduce anxiety and increase satisfaction. The results of a series of studies suggests that, in uncontrollable situations, low monitoring and high blunting are most effective in reducing stress, anxiety and frustration (Miller, 1990). This finding lends credibility to distraction and avoiding information as appropriate coping strategies in dealing with unchangeable threatening situations. However, in my study there is no evidence that the non-reflectors were avoiding information about their illness or that less information would be beneficial. When questioned, they were able to provide details of their cancer and treatment.

The distribution of blunters and monitors in study samples reveals a common existence of both styles within the population. Miller (1987) reported approximately equal numbers of individuals exhibiting high blunting/ low monitoring or high monitoring/low blunting coping styles. Miller, Brody, & Summerton (1988) reported approximately equal numbers of individuals who were high or low monitors. Their sample included 45% high monitors and 55% low monitors. Women were equally divided between the two coping styles; men were more likely to be low monitors (68%).

Miller's work supports the existence of pre-determined personality-based coping styles for moderating the effect of threatening information. Miller's coping styles reflect personality differences in seeking or avoiding information. The two coping styles identified in my research could reflect personality differences in reflecting upon the illness experience or avoiding reflection. This process of analyzing, self-awareness and introspection, however, moves beyond seeking or avoiding information to seeking or avoiding introspective processing of information, emotions, psychological and spiritual factors. Despite these differences, Miller's (1990) research lends credibility to the claim that a person's usual personality-based coping style is likely to determine the way the individual copes with an unchangeable stressful situation, such as living with end-stage cancer. This coping style should be recognized and supported accordingly.

Lazarus & Folkman (1984) also support the use of different coping styles or strategies in relation to unchangeable situations. According to Lazarus & Folkman's

(1984) theory of coping, once an event is appraised as stressful, the individual then determines what can be done to overcome or prevent harm or improve the possibility of benefit. Coping options are then evaluated and employed. Coping includes process (what the person thinks and does), context (situational variables plus personality) and value (the effort to manage demands is evaluated rather than the outcomes of efforts). Coping has two main purposes: to regulate stressful emotions and to alter the environment causing the stress. Problem-solving strategies are used more frequently when the situation is changeable, and emotion-focused strategies are used more often when the situation is appraised as unchangeable (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The individuals in this study were dealing with the unchangeable situation of incurable cancer. Therefore, emotion-focused strategies are most useful. These strategies include: distancing, escape-avoidance, self-control and positive reappraisal. Folkman et al. (1986) found that individuals used distancing and escape-avoidance to avoid focusing on the distressing situation. A self-control strategy was sometimes used to delay responding until more information was available. Sometimes this strategy was useful for problem-solving later and sometimes it led to use of the escape-avoidance strategy. Positive reappraisal, a strategy that involves reflection and change, was used by some and resulted in positive outcomes (Folkman et al., 1986). In my study, the non-reflective individuals used combinations of the first three strategies, while the reflective individuals relied more heavily on positive reappraisal.

In the palliative care literature, there is much emphasis on assisting individuals to find meaning and purpose in their illness. The exploration of emotional, psychological and spiritual aspects of one's self in relation to suffering and illness is considered to be important, therapeutic, and necessary for transcendence (Cassell, 1982; Frankl, 1959). There is also value placed on self-awareness, self-exploration, learning and self-growth by segments of society. As nurses, these values and beliefs are firmly entrenched in our professional education. In the general population, there are people who naturally reflect on their circumstances and difficulties, to make sense of their lives. These people like to analyze and discuss their feelings and thoughts. Caring for these individuals, who match the coping style typically used by nurses, is rewarding and satisfying. However, there are also many people in the general population who are not reflectors. They do not verbally reflect on their experiences and cannot be readily engaged in the process by others. They do not see value in reflection and choose to put their energy into other activity instead. It may be that men are more likely to be among this group than women (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1982). Nurses often feel concerned or frustrated with non-reflective patients and often feel inadequate that they were not able to help individuals work through this experience in a more "healthy" way. Although nurses may be sensitive to the fact that they cannot push patients to discuss or reflect upon existential aspects of the experience, there is often a sense that these individuals are not

using the time they have in a productive manner. Therefore, a bias towards self-reflection may exist amongst palliative care staff.

In general, people reflect on their lives to differing degrees. O'Connor et al. (1997) conducted an ethnographic study on spirituality in palliative care in which both patients and staff were interviewed. Spirituality was understood as meaning-making; each person makes sense of his or her life by interpreting events and experiences. Three of the findings are applicable to this discussion. First, patients viewed their spirituality as private, personal and connected to their family. Second, spirituality for these patients involved an emphasis on making the most of life now. Third, patients showed varying degrees of reflection in making sense of their lives. These findings resonate with my study. Those participants who chose to avoid reflecting upon the situation were individuals who chose not to reflect verbally about their illness experience. They showed no indication that they had found meaning or purpose in their current circumstances. These individuals had always lived life without reflection about difficult situations.

In my study, the sample was equally divided between non-reflectors and reflectors. This even distribution suggests that non-reflection may be a common strategy and may be appropriate rather than detrimental. The approach of ignoring what could not be changed had enabled these individuals to do what they needed to do to get through difficult times in the past. They were satisfied with how they had managed to get through those circumstances. Is it reasonable to expect individuals who have, over their lifetime, focused on physical action, rather than inner

awareness and exploration, to change their coping strategy during what is likely the most stressful experience of their lifetime?

At present, it is not well understood whether there are detrimental effects related to the avoidant coping style. In this study, these individuals did appear to be more depressed and unable to pull themselves out of this "feeling down". They appeared to be more focused on the physical losses and limitations. Due to their severe physical limitations at present, they did not articulate positive aspects or meaning in their current circumstances. Many questions remain unanswered. Does activity as a coping strategy create predictable limitations once physical energy is threatened? Are there some individuals who, faced with such a life altering crisis, change their preferred coping styles?

Redefining and self-integrity

Walford (1991) states that dying persons must grieve their losses and integrate their disease into their life. This is ongoing because there are a series of losses that continue until death. According to Walford (1991) "Acceptance means integrating the "who you are" of the past and future into the present so that existence once again has meaning" (p. 14). By accepting life as it is, with its new limitations, the person chooses to be who he or she is -- a person who is dying. Only one person in the current study had redefined himself as a dying person.

Davies, et al (1995), identified "redefining" as a part of the process of "fading away." Individuals with terminal cancer must redefine themselves in terms of their identity, as their abilities become more limited. They must "let go of their view of

who they used to be and develop a new view of themselves and others" (Davies et al., 1995, p. 8). This is a gradual process that takes place over time. In their study, Davies et al. (1995) found that individuals who successfully redefined themselves were able to maintain a sense of who they are as people, while finding ways to deal with the world differently so that they are reasonably content. Those who were unable to redefine themselves "experienced a sense of anger, worthlessness and frustration with the altered situation" (Davies et al., 1995, p. 8).

In the current study, the individuals who reflected upon their experience seemed able to redefine themselves in terms of being less physically able to do some things, but were also able to carry on with such roles as mother, grandmother and helper, despite their illness. They seemed to find a way to continue giving to others. This reflects Bayer's (1993) study of women approaching death. He discovered that the women valued caring for others and that continuing to do so enabled them to live fully until close to death. The women in the present study seemed to more easily carry forward some of their former roles as these roles did not depend entirely upon physical abilities.

Individuals who did not reflect on the illness experience were unable to continue with previous activities, such as driving and participating in work or recreational physical activities, which had defined them as individuals. Society defines individual value in terms of usefulness related to achievement (Frankl, 1959). Differences found in my study could be related to traditional male and female

roles that may have affected the men's view of themselves and therefore, redefinition of themselves.

In my study, differences may also be related to the physical limitations of the individuals interviewed. It is difficult to determine whether the men were more physically dependent than the women. However, the three women were still able to walk several blocks with rest periods, while two of the three men were limited to walking about two blocks at any given time. One of the men was limited by the use of continuous oxygen, and another had a tracheotomy and tube feeding. None of the women required these. One woman and one man had recent radiation treatment, while one man had recent chemotherapy. These differences may have influenced how individuals coped.

All the non-reflectors were in the process of redefining themselves. Although they did have difficulty accepting their increasing physical limitations, they all adjusted by adapting their activities according to their fatigue and level of strength. This involved giving up activities and asking for help, when required. However, they seemed to dwell more on what they could not do, rather than what they could do. It was difficult to determine how well they were able to internally integrate their new identity. However, inability to follow through with one's usual coping style, such as engaging in activity rather than reflection, may make it more difficult for these individuals to cope successfully with their terminal illness.

Cassell (1982) states that suffering exists when the integrity of a person is threatened and that suffering exists until the person is made whole again. "The

personal meaning of an illness may be largely invisible" (Howell, 1998, p. 14).

Verbal communication may be insufficient for shared understanding of meaning.

Patients may communicate meaning instead by using stories, symbolic language or

metaphors (Howell, 1998; Moore, 1991). I have indicated that all the individuals in

my study found meaning on some level. Meaning often related to physical

accomplishments or attitudes displayed by individuals. This finding corresponds to

Frankl's (1959) work. He cites three ways to find meaning in life: (1) creating or

accomplishing something, (2) experiencing something related to nature or culture,

or loving someone, or (3) by adopting an accepting attitude towards a situation that

cannot be changed and involves unavoidable suffering. This attitudinal stance may

be a result of finding purpose in the suffering or "accepting the challenge to suffer

bravely" (Frankl, 1959, p. 118), and may in itself, provide meaning. All the

individuals in this study found meaning in the present by continuing to accomplish

physical activities and by making the best of the bad situation while being open to

the possibility of improvement. In addition, the reflectors articulated meaning and

purpose for their suffering on existential levels. Perhaps the non-reflectors found

meaning in getting through the experience in a dignified, courageous manner.

Perhaps their meaning relates to maintaining honor and self-respect. Considering

meaning from this perspective may provide some guidance for helping these

individuals.

Gender influences

Gender differences may also provide a partial explanation of the differences between reflectors and non-reflectors. Staudacher (1991) discusses men and grief in relation to societal expectations and how these expectations interfere with men experiencing a "complete grieving process" (p. 143). She claims that in Western culture, where men are expected to be strong and not show emotion, men are prevented from "working through" their grief in a constructive way. This results in five coping styles where grief does not show: remaining silent, engaging in solitary mourning, taking physical or legal action (in relation to unexpected death), becoming immersed in activity, or exhibiting addictive behavior. She recognizes that men tend to be less communicative about loss and tend to accept support in one to one relationships. Staudacher (1991) believes men are not allowed opportunities to express feelings. They keep busy so they don't have to think about it or experience the emotions of the experience and so they don't work through it as they should. "Working through .... involves confronting, enduring and working through a wide range of grief responses" (p. 5). She comments on the difference between talking about the facts and talking about the emotional impact of these facts. "At first, men will say they don't want to 'dwell' on it.... It's interesting that women talk about it, analyze it, discuss it, get it out, and that this same process is viewed by some men as *"dwelling on it"* (p. 155). The accepted way of dealing with grieving is to help all individuals talk about it, release their emotions and cry (Rando, 1984; Staudacher, 1991). This may be imposing a female model on men.

Some men are not able to adapt to health care professionals' expectations in relation to grief behavior. The men in the current study had opportunities to express thoughts and feelings during the interviews. They did describe feelings but did not elaborate. In addition, they seemed at a loss about what to say when asked questions that required introspection and analysis of existential aspects of the experience.

Can grieving losses related to an incurable illness, loss of abilities, and loss of life be compared to loss of a loved one? There exist gender differences in how men and women communicate, view and deal with life when they are well (Gray, 1992). This seems to be less acceptable when men are ill. It is commonly accepted than men and women express pain and emotions in different ways. Once they enter the health care system, there is often the expectation that men should be more open and verbal about their situations.

"Researchers have long surmised that the genders differ in their approach to life, values, and life roles" (Dibble, Padilla, Dodd, & Miaskowski, 1998). Dibble et al. (1998) investigated gender similarities and differences in relation to quality of life. They conducted a secondary analysis of data from two studies done on a total of 657 oncology outpatients. The participants of one study were receiving treatment for cancer. In the second study, participants were receiving mucositis-producing chemotherapy. All participants completed quality of life questionnaires. Findings revealed that some questions were understood differently by men and women, therefore those questions combined into different groupings for each gender. The

questions clustered under psychosocial well being and physical competence for

women, while they clustered under vitality and personal resources for men. The

findings suggested that antecedents of quality of life and essentials dimensions of

quality of life should be separated. Findings also suggest that doing this reveals

different dimensions of quality of life for each gender. This is a new finding that

requires further investigation. However it lends credence to the importance of

identifying possible gender differences.

Further Interpretations

Due to my personal beliefs about the importance of self-awareness and

reflection for self-growth, I have worked diligently to be objective. I have had to

continually refer back to my raw data to confirm the viewpoints of the participants. I

initially found myself using judgmental language as I attempted to explain the non-

reflective style. By ensuring I have been true to the data, I have been profoundly

affected by these individuals, who patiently shared their perspectives with me.

These non-reflective men chose to participate and continue interacting with me

even though they could not answer all my questions. They were committed to

having their story heard.

In this study it became evident that choosing to avoid reflection on the

psychological and spiritual aspects of the illness experience and not dwelling on the

poor prognosis or inevitable death reflected the coping style and strategies of the

individual, and not the existence of denial. This is clear because the non-reflectors

recognized the realities of the situation and continued to cope satisfactorily with day

to day life, family members and treatment of their illness. How often are individuals with an avoidant or non-reflective coping style erroneously labeled as being in denial? Is this why there is no literature that describes a non-reflective coping style?

In the current social climate, it is in vogue to search for meaning and face up to the realities of death and dying. Facing up and dealing with the realities in a visible and productive kind of way is valued more than ignoring or avoiding the issues. Literature abounds on the importance of seeking the meaning of illness, pain, and cancer. The role and responsibilities of nurses and other health care professionals to journey along side individuals as they work through existential and spiritual issues related to life, death and dying, is a worthy goal. I believe that, for those who are readily engaged in this journey of self-reflection, we need to continue to participate in this process. This is important work and one of the most satisfying aspects of working with palliative care patients.

On the other hand, the individuals who demonstrate a non-reflective coping style also have the right to be supported in their way of being. I wonder what harm nurses might do by expecting these individuals to be more reflective. I suspect that, unconsciously, we transmit our concern and frustration or sadness in our language, our affect, and our actions. Do we contribute to these people feeling like failures, because they are not doing it the prescribed way? Do we prevent them from finding their own way to come to terms with their life and death? Are we missing cues, openings, or understandings because we, as reflectors ourselves, fail to recognize the significance of a different approach? Will different questions provide us with

better answers? How can we understand these individuals better so that we can ensure that their wishes are enacted? Nurses need to become aware of their biases against a particular coping style. I believe that nurses, just as we strive to protect the rights of ethnic and religious minorities, must be watchful to protect the rights of those who want to cope in a manner that is different than the popular trend.

Although no studies could be found to directly support the existence of reflective and non-reflective coping styles, it became evident in this study that non-reflection is likely an important and relevant coping style. The findings of this study, related to reflection and non-reflection, suggest that we should question our current conceptualizations and practice. Further research in this area is necessary, to confirm these findings and explore the non-reflecting or avoiding coping style in more detail. Although this is only a small, preliminary study, the results should sensitize nurses to the validity of non-reflection as a relevant coping style to be accepted, rather than changed. Acceptance of this perspective will enable investigation of more appropriate interventions to assist these individuals live fully and prepare for death.

Hope at end the of life

Participants in the present study spoke about aspects of both living and dying. This reflects the fact that living and dying cannot be separated. We are all both living and dying (Hall, 1990; Walford, 1991). The tension between fighting to live and letting go appears to involve a swinging back and forth between focusing one's attention on living aspects of the experience and focusing one's attention on

preparing for death. Downing et al. (1993) have described this phenomenon as a lateral tension between life promotion and death acceptance (Figure 1). Life promotion is described as the "natural or instinctual 'drive to survive'" which may be conscious or subconscious (Downing et al., 1993, p. 28). Downing et al. (1993) state,

> Life promotion is evident whenever someone promotes the value of continuing to live, the hope of cure or positive response to treatment ....These two lateral processes are normal for everyone. They exist as a dynamic tension, swinging back and forth over time. It is often misrepresented as ambivalence and vacillation" (p. 28).
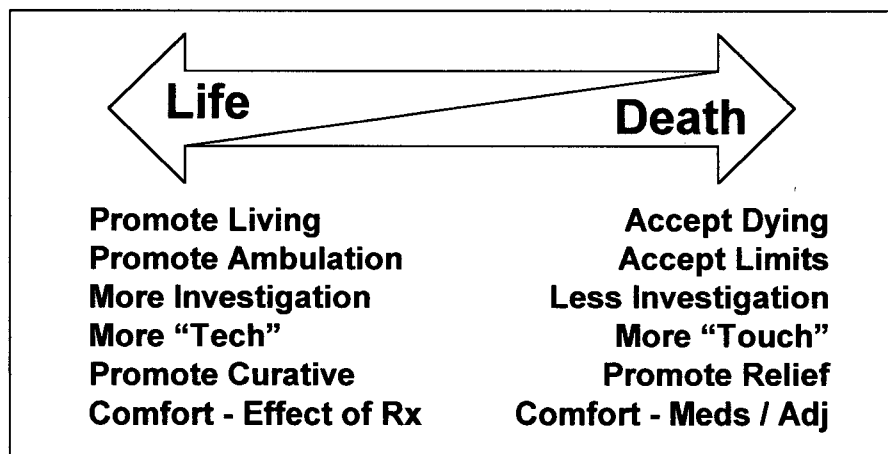

Life	Death
Promote Living	Accept Dying
Promote Ambulation	Accept Limits
More Investigation	Less Investigation
More "Tech"	More "Touch"
Promote Curative	Promote Relief
Comfort - Effect of Rx	Comfort - Meds / Adj

Figure 1   Living -- Dying Tension

Note. From "Victoria BGY palliative care model: A new model for the 1990s" by G. M. Downing, D. L. Braithwaite, and J. M. Wilde, 1993, *Journal of Palliative Care, 9*(4), p. 32b. Adapted with permission.

This model accurately reflects the findings of the current study. Participants placed emphasis on living and hope while still acknowledging and preparing for death when necessary. I obtained more detail on living than dying, due to the focus of my questions. Downing et al.'s (1993) lateral tension arrow shows that living and dying cannot be separated; they are a part of a whole. Yet, the living aspects are greater

on the left side of the arrow and the dying aspects are a greater part of the whole on the right side of the arrow. This correlates well with the focus of patients when their physical and mental abilities decrease as death approaches. The concept of living-dying tension fits closely with the findings in my study, in contrast to stage and phase theories of death and dying, which focus on acceptance of death (Kubler-Ross, 1969; Pattison, 1977). For participants in the current study, life had changed, but individuals still valued and found meaning in being alive. All the participants in the current study, except one, viewed themselves, as living, rather than dying.

Davies et al. (1995) describe this tension between fighting to live and letting go as "struggling with the paradox". They found that patients often hope for a miracle even when they acknowledge their poor prognosis. They also found that patients put the disease out of their minds, used distraction, focused on good days and what they could do in order to put the paradox or dilemma aside temporarily. This enabled individuals to focus on more enjoyable aspects of their lives (Davies et al., 1995, p. 29). These findings correspond to the findings in the current study.

The participants in the current study chose to focus most of their attention on living rather than preparation for dying. They all employed strategies to make sense of their situation in a way that enabled them to keep this focus on living. Their matter of fact acceptance of a situation that could not be changed and acknowledgment of their poor prognosis established a base in reality. They consciously chose not to dwell on the fact that they were dying so set this awareness aside much of the time. This allowed them the opportunity to spend their

limited time focused on living. This strategy seems appropriate and useful. However, when individuals use this strategy and also make comments about seemingly unrealistic expectations regarding future activities and cure, they are likely to be inaccurately labeled by nurses as "being in denial". Hall (1990), also found evidence to question the interpretation of this kind of hope as denial in her study of eleven seropositive men.

My research suggests a need to re-examine the relationship between denial and hope, and the criteria used for labeling someone as being in denial. Denial is generally viewed as a subconscious defense mechanism, or a legitimate coping strategy used to protect the individual from emotional stress and allow them time to develop other coping skills (Burgess, 1994). Denial maintains the integrity of the person (Rando, 1984; Verwoerdt, 1966). Therefore, many agree that denial should be supported as a coping strategy (Burgess, 1994; Rando, 1984; Scanlon, 1989; Smith, 1993; Walford, 1991). However, use of denial continues to be viewed negatively as it is seen a protective mechanism that assists the individual to get through the situation when he or she is unable to cope in other more acceptable ways. When offering hope to patients, nurses sometimes worry about encouraging denial. Hall (1990) found that when professional caregivers label hope as unrealistic or denial, they negatively affect the quality of life of the individual and force the person to turn elsewhere (such as the alternative health care system) for help.

I believe that the term denial is often used inappropriately due to insufficient information within the context of the patient's life. This is evident in the current

study. Although most of the participants in the present study made seemingly unrealistic remarks regarding cure or regaining abilities, the contradictions in their comments indicated that they understood the reality of the situation on some level. They did not exhibit total denial of their poor prognoses or death. Individuals participated in doctor appointments, tests and sometimes palliative treatments to manage their disease. They adjusted to their increasing physical limitations by adjusting roles and expectations, goals and relationships with others. They continued to deal with their illness appropriately and function satisfactorily in their lives.

This position is supported by Kelehear and Fook (1989) who argue three alternative explanations to the existence of denial. First, they claim that being positive may demonstrate denial of the dying role rather than denial of death. It may be an attempt to preserve relationships and show ability to cope. Participants in the current study support this focus on being a living person rather than a dying person. They did not discuss their relationships with others. Second, patient hopes that may seem unrealistic to professionals may be realistic according to the person's subjective sense of the experience, including how they feel and how individuals react to them. In my study there was no clear indication of these differences. In addition, my clinical experience leads me to suspect that some of the comments of patients may be a way to test the reality of their perceptions by watching the reactions of nurses or family members. Third, Kelehear & Fook (1989) state that although the individual may seem to be denying death, there might actually have

been some miscommunication. In my study, miscommunication or misinterpretation of comments could lead health care professionals to erroneous conclusions. For example, it would be easy to take patient comments regarding cure out of context and assume the person is in denial. However, discussion with participants who made these kinds of comments confirmed acknowledgment of their nearness to death, at another time or on another level, either through direct or indirect statements made and understood in the context of the whole of their lives. The key to determining that the individuals were not in denial but instead were appropriately using hope as a coping strategy, is that these individuals were still coping adequately with life. They were engaged in life, following through with appointments and medical care for their cancer.

The term unrealistic hope also provides a negative view of certain hopeful thoughts. Debate regarding unrealistic hopes revolves around differing assumptions made about reality. Ersek (1992) outlines three viewpoints of reality: "(1) reality is objective, (2) reality is determined by normative values; and (3) reality is defined by the individual" (p. 20). The first two views enable nurses to make a judgment about what is realistic and what is not. The individual's perception of reality is judged by others. In fact, this is what most frequently occurs. The third view of reality allows the patient to determine what is realistic but does not deal with the perceptions of nurses, based on knowledge and experience. Dufault and Martocchio (1985) support the third view that "hope is reality-based from the perspective of the hoping person" (p. 384). Yates (1993) notes that nurses' beliefs and expectations influence

patients' hopes and questions whether or not they can distinguish realistic from unrealistic hopes. I agree that nurses may not always be able to distinguish realistic from unrealistic hope, but the term "unrealistic" sets an artificial judgment on the hope of the individual and negates its value. However, I continue using the term for the following discussion, to provide clarity in relation to other literature.

Ersek (1992) warns of the possible negative outcomes of denial, illusions or unrealistic hopes. Included in such negative outcomes are: increasing anxiety, increased isolation from others, inability to cope with additional threatening information, engagement in risk behaviors, delay in seeking appropriate health care, interference with the rights of others, unreasonable persistence at difficult or impossible tasks, psychosomatic disorders (p. 23). I would argue that these concerns are unfounded in situations where terminally ill individuals have a mixture of realistic and unrealistic hopes. The participants in this study all had specific, realistic goals and hopes, in addition to those that could be viewed by nurses as unrealistic. Hope seemed to provide them with energy to get through each day. The unrealistic hopes seemed to help them endure their otherwise unchangeable situation.

Search of the literature revealed no studies or theoretical papers that included acknowledgment or discussion of the fact that both realistic and unrealistic hopes may exist simultaneously for a given individual. Perhaps this is because hope has not often been considered or studied within the context of an individual's life

(Yates, 1993). The current study provides some preliminary findings from this perspective.

It is generally agreed that maintaining hope is essential for survival (Frankl, 1959; Hall, 1990; Rando, 1984; Verwoerdt, 1966) Hope is necessary for a will to live on, and to deal with the remainder of life constructively (Rando, 1984; Verwoerdt, 1966). Although hope is generally associated with positive outcomes, it is unclear whether unrealistic hope results in positive or negative outcomes. No studies have been found that have investigated outcomes in relation to realistic or unrealistic hopefulness. In my study, the combination of realistic and unrealistic hopes did not seem to be detrimental to the individuals interviewed.

It seems that the increased certainty of death during the palliative phase of illness does not eliminate the hope that cure may still occur. In the current study, participants held hopes for cure or major improvement in their condition, despite their poor prognosis. Other researchers also maintain that hope of cure, even close to death, is normal (Davies et al., 1995; Hall, 1990; Kubler-Ross, 1975). Hall (1990) states:

> My experience and those of my informants have brought me to the conclusion that hope is something all people need until they take their last breath. I have seen very little evidence that most people accept death. Rather, they accept life. If they accept life well, then they die well (p. 178).

Hope changes as the person moves closer towards death (Dufault & Martocchio, 1985; Morse & Doberneck, 1995; Scanlon, 1989). This is confirmed in this study by the changes in specific, short-term goals and hopes that patients

described. However, all patients coincidentally remained open to the possibility of extended longevity or cure.

It may be that these hopes for longevity or cure continue because the individual does not fully accept the certainty of death. Ignoring some of the facts enables individuals to maintain uncertainty of survival rather than certain death (Kelehear & Fook, 1989; Mishel, 1998). Mishel (1998) proposes that uncertainty may be appraised as either danger or opportunity and, therefore, coping strategies may be employed to reduce or maintain uncertainty, depending on the positive or negative meaning of the situation to the individual. When coping strategies are effective, adaptation occurs. Difficulty with adaptation indicates difficulty manipulating uncertainty in the desired direction. Adaptation is defined by Mishel (1998) as, "biopsychosocial behavior occurring within persons' individually defined range of usual behavior .... it allows goal-directed behavior to continue" (p. 231). "Uncertainty can be seen as an opportunity when the alternative is negative certainty" (p. 231). An example of negative certainty would be a person with a terminal illness and downward trajectory. In such cases, uncertainty allows the opportunity for construction of illusion, which allows the person to perceive a positive outcome. Uncertainty is necessary for hope to exist (Ersek, 1992; Mishel, 1998; Nekolaichuk & Bruera, 1998). Uncertainty is maintained, using illusion. Input that may alter the view of uncertainty is blocked using various strategies such as avoidance, selective ignoring, reordering priorities and neutralizing (Mishel, 1998, p. 231). These strategies help ease fears about the future. It may be that individuals

who face certain death in the near future unconsciously choose to maintain uncertainty. This would also help them maintain a future orientation, which is an important aspect of hope.

Hope is future and goal-oriented (Benzein & Saveman, 1998; Dufault & Martocchio, 1985; Hall, 1990; Verwoerdt, 1966). Hall (1990) argues that it is normal for all people, both well and terminally ill, to hope for a future. In fact, it is necessary to hope for a future, because without a future, there is no meaningful present (Frankl, 1959; Hall, 1990; Walford, 1991). Hall (1990) ascertains that having a future orientation is important right to the end of life so that people can live, rather than be set aside from living (p. 183). Based on her research of the lived experience of terminally ill people, Hall describes hope as a "universal need of humans" which requires an "interconnection between the present and future, and a strong feeling of optimism" (p. 183). This involves: having a future despite the diagnosis, having renewed zest for life, finding a reason for living, and finding a treatment that one believes will contribute to survival. In order to have a future orientation persons must bridge the present, future and past (Dufault & Martocchio, 1985; Nekolaichuk & Bruera, 1998; Walford, 1991). A terminal diagnosis disrupts order and continuity. The past is cut off from the present and the future is uncertain and disconnected. This results in loss of meaning in the present (Walford, 1991). "It is important to be able to dream even if a patient is mortally ill" (Hockley, 1993, p. 84).

The findings of my study suggest that having *unrealistic* hopes is not necessarily detrimental to an individual and that statements of seemingly unrealistic

goals or a focus on life rather than preparing for death does not indicate that a person is in denial. I found that participants were not in denial of their poor prognosis or death, despite their seemingly *unrealistic* hopeful statements. Rather than conceptualize the process in this negative way, I believe these individuals choose to focus on living in order to live until they die rather than dying until they die.

Summary

Discussion has centered on the three most significant findings of the study: physical accomplishments as critical to a sense of participating in life, non-reflection as a valid coping style, and both realistic and unrealistic hope as useful and necessary for individuals with an incurable illness. Physical accomplishments were identified as being extremely important to quality of life for end-stage cancer patients. Data from this study suggests that a non-reflective coping style commonly exists, despite a lack of recognition in the literature. Concerns have been raised about labeling non-reflectors as being in denial, and pushing them to conform to being reflective. A more in-depth review of appraisal and coping styles revealed some support for using familiar and avoidant coping behaviors in negative, unchangeable situations. It is proposed that there is benefit in supporting individuals to use their usual coping style rather than helping them to change. However, many questions need to be answered before we can support individuals in a meaningful and helpful manner. Hope within the context of palliative care is not

well understood. However, there is support in the palliative care literature for the

view that unrealistic hope is normal and appropriate for this population.

Chapter 6   Summary and Implications

<u>Summary of the study</u>

The majority of patients in palliative care settings have cancer and a life expectancy of less than six months. Practitioners in palliative care settings strive to help these individuals *live until they die*. However, most of the research done in relation these patients is focused on aspects of dying and adaptation to losses. In addition, palliative care research often reflects patient perspectives through the eyes of staff or family members, as participation of dying patients in research is difficult. No studies were found that investigate what living means to patients who are near the end of the dying trajectory. Therefore, the purpose of this study was to describe the palliative care patient's experience of living during the end-stage of cancer.

Interpretive description is the qualitative methodology chosen for this study. It was chosen because it promotes in-depth description of the phenomenon and also provides structure for the interpretation of nursing knowledge and practical application of findings.

Six individuals with a diagnosis of terminal cancer and a prognosis of less than six months were interviewed. The home care nurse or a palliative care team member obtained permission for the researcher to contact potential participants. Data were collected during face to face, unstructured interviews in patient's homes. Data collection and data analysis occurred simultaneously. All participants, except

one were interviewed twice. Emerging findings were validated with participants during the second interviews.

Analysis revealed three major themes: coping with terminal illness, making sense of the situation, and surviving within the perimeter. Findings revealed new data by focusing questions on living rather than dying. Participants revealed individual preferences in use of coping style and coping strategies, while simultaneously adopting common attitudes that enabled them to make sense of the situation and endure their circumstances. These attitudes included a matter of fact acceptance of their incurable cancer, a conscious decision not to dwell on death, and use of hope to maintain a future with positive outcomes. The participants viewed themselves as surviving within a shrinking perimeter of life. Much of their time was focused on eating to stay alive, resting and attempting physical accomplishments. Appointments with physicians and other health practitioners were important. Participants had developed strategies to help deal with fatigue, which was the most significant obstacle to living. In addition, half of the participants found meaning and purpose in reflecting upon the psychological and spiritual aspects of their illness.

The conclusions of this small preliminary study reflect the patient's view of life, rather than death during end-stage cancer. Participants were able to distinguish between living and dying aspects of their experience, although they experienced life as a whole. It appears that people may cope with this stage of life in a manner that is characteristic of coping styles developed over a life time. In addition, individuals

seem to utilize a common set of attitudes to help endure their fatal and deteriorating condition. Physical maintenance seemed to become an important focus of attention, including eating to stay alive, and accomplishing physical activities, which provided a sense of living. In addition, half the participants found meaning in exploring psychological and spiritual aspects of the experience. Qualitative methodology enabled collection of comprehensive data and also provided therapeutic benefits to participants. The findings of this study have implications for interdisciplinary clinical practice, education, and research within the context of palliative care.

Limitations of the study

The sample in this study reflects a variety of views of terminally ill patients who felt well enough to participate and agreed to participate in the study. Potential participants were screened by the home care nurses, who were protective of their patients. Those patients who were not asked to participate may have a different perspective than this small sample. Findings are applicable to patients with a prognosis of less than six months, who are able and willing to talk about their experience, and speak English well enough to be understood. The fact that non-reflectors were represented in the sample provides some strength to the variation in the sample. The findings represent a limited cultural and social perspective. The researcher's time and resources did not allow for an unlimited sample size so it was not possible to achieve maximal variation.

The study was limited to individuals with cancer. However, the individual can only be fully understood in the context of his family. In addition, family members are

considered a part of the unit of care in palliative care settings. Therefore future research on the living aspects of dying should include family caregivers in the sample.

The findings of this small study provide only preliminary results. Some of these findings correspond with results of previous studies. However, further research must be done to confirm the conclusions related to the importance of physical accomplishments, existence of reflective and non-reflective coping styles, and positive aspects of having both realistic and unrealistic hopes at the end of life. In addition, this type of study should be repeated with more debilitated patients, with patients who are receiving no anti-tumor treatment, and with younger patients, in order to include other common palliative care patients not represented in this sample.

Implications within the interdisciplinary context of palliative care

A variety of implications for clinical practice, education and research emerge from the findings of this study. It is important to place the findings within the context of the palliative care setting and the philosophy of palliative care. The philosophy of palliative care includes two important premises pertinent to this discussion: (1) the unit of care includes both the terminally ill individual and his or her family members; (2) care is provided by an interdisciplinary team of health care professionals. Therefore, it is important to discuss conclusions not only as they apply to the individual patients in the program and nurses caring for them, but also how these

results influence care of family members and care by other health care professionals in the palliative care setting.

The nursing methodology chosen for this study provided a structure to describe the experience of living and also to delineate practical application of findings. These findings are equally useful to all disciplines involved in providing clinical palliative care, such as: occupational therapists, physiotherapists, dietitians, social workers, physicians, pharmacists, and spiritual care providers. The implications are discussed from a nursing perspective, but also apply to members of other professions on the palliative care team. Suggestions should be modified by each discipline to fit their role and interactions with palliative care patients.

Findings validate the importance of utilizing a team of health care professionals to meet the variety of psychosocial, spiritual and physical needs of palliative care patients. The aspects of life described by participants can be greatly enhanced by drawing upon the expertise of a wide variety of disciplines in the provision of care for end-stage cancer patients.

Implications for clinical practice

I will discuss implications for clinical practice according to the following areas: communication, non-reflective individuals, hope, and physical maintenance.

Communication

Findings highlight several implications related to communication. First, nurses need to be vigilant to ensure they are treating terminally ill cancer patients as living beings rather than dying patients. Do we non-verbally treat them as if they

are dying rather than living? Does our language reflect this in our verbal communication? In what subtle ways do we do this? What are the outcomes in terms of patient communication and behavior? Do we use an approach that dichotomizes life and death? How does this affect our approach to patients, their families, or the situation in general? Patients are more likely to be treated as dying in settings, such as general surgical or medical wards in hospitals, where professional caregivers are geared towards cure and are less familiar with the palliative care philosophy. However, palliative care staff may also slip into this posture in more subtle ways, if not consciously watchful of their own beliefs and values. Their non-verbal behaviors and actions must match their intent to help people live until they die.

Kessler (1997) states, "we owe the dying exactly what we owe the living, for they are fully alive and living right up until the end: honesty, respect and compassion ... we have an obligation to help them live and die with dignity" (p. 151). He states that dignity is maintained when the individual can see his or her self as unique and special beyond their roles. Nurses must help the individual and their family members to see the individual, not in the past tense, as who they used to be or what they used to do, but as he or she is now, a whole person until death. "Being treated with dignity means being fully included in all aspects of life, regardless of the level at which one can participate" (Kessler, 1997, p. 15). One way to treat individuals as living is by focusing on what they *can* do now rather than what they cannot do.

This reinforces the importance of caring, a core component of nursing practice. It reinforces the importance of nurses using basic communication skills to show respect and understanding. The participants in my study described several attributes and actions of nurses that were important to them. They told me that they would like to be listened to and really heard. Some stressed that they would like to be listened to in an interactive way. One woman reinforced this statement by saying she did not want to be listened to as if she was lying on a psychiatrist's couch with the psychiatrist nodding and "uh-huhing". The participants asked to be treated in a non-judgmental manner, with respect for individual beliefs and ways of being or doing things. For one woman, it was important to know her questions would be answered in a compassionate, respectful and knowledgeable way. Another participant stressed the need to have consistent caregivers so that he could feel comfortable with them and not have to re-explain the history of his illness. One participant voiced a need to be able to trust the nurse to be there for her, to make her quiet, calm and comfortable at the end. These direct comments of participants provide clear direction for important aspects of communication.

It is important that the nurse meet each person where they are at psychologically and move with them as they move or stay with them there. This may include a focus on living or dying, the level at which the person wants to deal with his or her illness, and the preference for reflection or non-reflection. Non-verbal communication is sometimes more intimate or deep than stating everything verbally can possibly be. Levine (1986) describes this well:

But this is somebody else's melodrama. You're not there to save them. You're there to be an open space in which they can do whatever they need without your coloring to the least degree their unfolding .... When love touches the pain of another, it is called compassion. Compassion is just space. Whatever that other person is experiencing, you have room for it in your heart .... To have room in your heart for whatever pain arises, not differentiating between "I" and "other", is compassion (p. 168).

Another implication is that nurses must ask questions that address living in order to improve the patient's quality of life. Quality of life research has produced questionnaires to help evaluate outcomes of interventions for the purpose of research, but these tools are not yet useful for assessing an individual's quality of life at a given point in time. A few key questions are useful in providing critical information about quality of life. The questions I found most revealing were, "What is most important to you today?" or "What is the most important thing you'd like to do today?" I think it is important to ask this type of question at least daily, in order to understand the patient's values and priorities, and thereby maximize the quality of life for these individuals.

Non-reflective individuals

The implications discussed in relation to communication apply to all individuals regardless of whether they have reflective or non-reflective coping styles. In addition, there are three major implications specifically directed at interactions with non-reflective individuals.

First, nurses must recognize and acknowledge their biases and beliefs related to working with non-reflective individuals. How do we interact with these individuals? Does our non-verbal behavior send negative messages about our

expectations, frustration, or feelings of inadequacy? It is important to discover where the patient is at psychologically and to let him or her lead the nurse from there. Listening skills are important as always, and the nurse must be truly present and hear the individual's story. Sharing the unspoken word is often a very powerful way of communicating with individuals. It can go beyond what is possible with mere words. Howell (1998) suggests that, in order to explore meaning and suffering, the nurse needs to know the person, have true presence, and the courage to bear witness. I suggest that this is even more important when working with non-reflective individuals. Nurses should continue to provide openings and pay attention to the patient's non-verbal signals. It is necessary that nurses be aware of differences in coping styles, not so that they ignore the existential aspects when caring for these individuals, but so that they are open to other ways to address those issues, maintain comfort, contain anxiety and assist the individual to live through the experience.

The findings of this study did not provide any definitive answers about how best to support these non-reflectors. Findings infer, however, that approaches used with reflectors are not effective for non-reflectors. The first step is to recognize that these individuals cope with stressful situations differently, be sensitive to these differences, and be creative in responding to cues and opportunities. It is important to listen to what these individuals *do not* say. When I interviewed these individuals, I noticed that they were most comfortable with limited eye contact. We sat side by side, rather than facing each other. Perhaps asking different questions or

approaching topics while engaging the individual in an activity would be more supportive and helpful. I think it is important to support their established coping style, while offering opportunities to reframe the experience. Helping the individual get through the experience in a dignified manner may be a significant goal, providing meaning in itself. Supporting non-reflectors by helping them to use their familiar coping style effectively, rather than expecting them to become more reflective, may help them move forward positively in their experience.

The second implication is that use of physical activity may be therapeutic for these individuals at this time. The men in this study dwelled more on physical losses. Physical activity was how they had occupied themselves during difficult times in the past. Now they could engage in few of their previous physical activities. Perhaps there are activities that individuals with limited physical stamina and strength could participate in that would provide meaning and purpose and complement their usual coping style. For example, having a scooter to drive around independently may assist an individual by providing a meaningful way to occupy his time, while also providing increased independence. More research is required in this area.

The third implication is that nurses should be alert to conflict between the patient's coping style and the coping styles of family caregivers. Communication and interventions must address the needs of family members in addition to the needs of the patient.

Hope

This study raised many questions about hope as it relates to individuals with end-stage cancer. When people reach this stage of their illness, it becomes more difficult to maintain hope, partly because maintaining hope requires energy (Morse & Doberneck, 1995) and partly because it becomes more difficult to find a basis for hope. However, "most people are quite attached to life" (Husebo, 1998, p. 43) so they persist in maintaining hope as long as possible.

Results provide four major implications in relation to hope. First, it is important to assess all types of hope that exist for the individual. Do individuals have specific, achievable goals and hopes? What are their generalized hopes? Do these generalized hopes fit with the reality of the professional caregiver? If they do not, are there other ways or times that the patient acknowledges the reality of their disease? Findings suggest that a mixture of realistic and unrealistic hopes is normal for a person with end-stage cancer and is not detrimental to their well-being.

Second, it is reasonable and necessary for nurses to compare their view of what is realistic with the patient's stated hopes. However, this appraisal must then be placed in context of the whole of the patient's understanding of the illness and current experience of life. It is important to assess non-verbal and indirect communication, in addition to verbal communication with the individual. Sometimes, an implicit understanding that the patient "knows" is enough to enable the nurse to support hopes that give the patient a break from the inevitable downhill trajectory of his or her disease. There are no clear answers about how best to balance truth-

telling and supporting hope (Nekolaichuk & Bruera, 1998). However, the above guidelines may help nurses to sensitively assess the patient's awareness of reality so that they are better able to support hope without concern that they are encouraging the patient to deny the reality of the disease process. Individuals who are in total denial of their diagnosis or prognosis would fall outside the suggestions related here.

Third, nurses must support individuals by allowing them to use hope to escape some of the negative facts about their illness, so they can continue to have the energy to endure and maximize their current life. Hope can be supported by encouraging individuals to discover or re-discover what they have and emphasizing what they can do (Verwoerdt, 1966). Nurses can help build meaning and hope by recognizing the life that an individual has lived, and taking an interest in the experiences and values that mean a great deal to the individual (Husebo, 1998). It is important to foster realistic hopes and help individuals redefine hopes over time (Dufault, 1983; Herth, 1990). In addition, nurses must recognize some of these generalized hopes for cure or other seemingly impossible goals exist as dreams.

Finally, nurses must support both living and dying aspects of the illness experience simultaneously. The contradictory comments about reality and hopes seem to reflect the ongoing pull between fighting to live and letting go. Nurses need to follow the lead of the patient by being open to a focus on either living or dying at any point in time. Knowing that it is normal for the terminally ill individual to move back and forth between struggling to live and letting go of life, rather than expecting

a gradual acceptance of death, should enable nurses to normalize this tension for patients. Timing discussion of reality appropriately and using language carefully can make it easier for patients to work through practical arrangements related to dying. For example, in palliative care settings, professional caregivers commonly approach completion of practical legal and family matters by suggesting that the individual "plan for the worst but hope for the best". Individuals are often encouraged to get these things out of the way so that they can focus on living. By helping patients deal with these things in short time frames, then helping re-focus them on living, nurses can help patients to maintain balance in their experience.

Physical maintenance

The findings of this study have implications related to eating, accomplishing physical activities, and managing fatigue. This study reinforces what nurses caring for dying patients have experienced, particularly with family members, when the patient is no longer able to eat. It is important to understand the time and energy that has been put into eating to maintain weight and stay alive, by the individual with cancer and their family members, over a period of months or years. This understanding makes clear the magnitude of the notion that the patient must be fed and explains why it is so difficult for family members to accept the transition to not eating, when it occurs. Nurses must educate and help family members develop other nurturing activities so that they can let go of feeding their loved one without feeling like they are "starving them to death".

Nurses' awareness of the critical importance of accomplishing physical activities should translate into making time to support individuals in doing what is most important to them. A simple question like, "What is most important to you today?" may reveal the thing that will most improve quality of life for that person that day. Bottorff, Steele, Davies, Garossino, Porterfield, & Shaw (1998) found that the ongoing day to day decisions made by palliative care patients involved a process of "striving for balance in the context of terminal illness" (p. 12). This process includes weighing things up, communicating a choice then negotiating with others, and living with one's choices.

> Striving for balance may be one of the means by which patients find a way to live with their illness, find windows of opportunity to turn their attention away from their bodies, and in turn experience moments of optimal balance that enhance their quality of life and therefore comfort (Bottorff et al., 1998, p. 16).

Nurses must make time to help the individual accomplish the physical activity of his or her choice.

Nurses must also pay more attention to the patient's experience of fatigue. It is important to take time to listen to patients, understand their experience and help them communicate to others the impact of fatigue on daily activities. Physiological causes must be identified and treated. Nurses should support and encourage strategies related to daily routine that reduce or work around fatigue. The participants in the current study attempted to work around their fatigue by: planning major activities such as doctor and nurse appointments ahead of time, limiting the number of activities in a day, pacing themselves, allowing rest periods, allowing others to help, prioritizing activities, and taking each day "step by step" according to

how they were feeling. Most events were not planned, but instead, depended on how the individual felt at the time.

Individuals have to adapt to a series of losses as they approach death. Some of these losses are physical. In addition to helping people adjust physically and psychologically to these losses, an understanding of the importance and meaning of being able to accomplish physical activities can help nurses respond in more helpful ways to individuals who struggle to do things themselves rather than ask for help. Nurses need to help patients identify which activities are most important to them and help them conserve energy to use for these activities. Nurses can arrange help or engage family and friends to assist in doing tasks that are necessary but less meaningful or rewarding, such as household chores, making meals, or paying bills. It is important that the nurse does not impose his or her personal beliefs, values or wishes upon the person. The ability of individuals to use their limited energy on accomplishments of their choice will add significantly to their quality of life.

Implications for education

Education about death and dying must go beyond discussion of stage and phase theories of death and dying, losses, fears, and use of defense mechanisms. Education must include discussion of the living-dying tension, transition from living to dying, and the living aspects of dying. These processes and perspectives must include the experience of both the patient and the family members, communication, assessment and intervention, as discussed in relation to clinical practice. Education that encourages collaboration of interdisciplinary team members at a student level

would enhance working relationships and shared skills amongst team members in the work setting.

Implications for research

The findings of this study indicate the need for more research focused on understanding the living aspects of the dying experience. Questions focused on living seem to provide different data than questions focused on dying. Further investigation from the patient and family caregiver viewpoints could enrich nurses' understanding of what it means to "live until we die" and enable nurses to better enhance quality of life for these individuals and their family members. In addition, further research on the living aspects of dying would add to the knowledge of the concept of living-dying tension during end-stage cancer.

Further research is required to confirm the importance of physical accomplishments in relation to quality of life, then include measurement of this criteria in quality of life tools. On-going research on cancer-related fatigue should include investigation of mechanisms, correlates, assessment and interventions.

Further research is required to verify the existence of personality-based reflective and non-reflective coping styles. Exceptions to this coping style may be identified by selectively looking for reflective men, non-reflective women, and younger people. Research is required to gain a better understanding of non-reflectors and determine approaches that would be most suitable to complement their coping style. Investigation of activity as a coping strategy may be beneficial. Several questions remain unanswered. Is use of diversional activity always part of a

non-reflective coping style? Do some individuals change coping styles? If so, what factors influence this change?

Several questions also arose in relation to gender. Were some of the differences between reflectors and non-reflectors related to gender? How does gender affect assessment of quality of life? Do traditional male-female roles affect the individual's redefinition of self as physical abilities decline?

The investigation of hope must be focused on end-stage cancer patients to determine if hope is different at end of life and if so, in what ways. Research must acknowledge the simultaneous existence of combinations of realistic and unrealistic hopes and investigate the effects of combinations in comparison to having all realistic or all unrealistic hopes. What are the outcomes for different kinds of hope? Is it better to have unrealistic hope than no hope at all? More detailed investigations of hope within the context of life may provide new knowledge that is not possible from conceptualizations of hope in isolation. How does hope relate to the living and dying tension experienced by terminally ill individuals? How can nurses best support individuals and their families as they swing back and forth between the living and dying perspectives?

This study has raised many questions. Investigation of communication between patients, family members, nurses and other health care professionals may provide more insight into language and non-verbal behavior that relates to treating the person as a living person or a dying person, and positive or negative outcomes related to approach. Studies using qualitative methodologies, particularly

incorporating participant observation, are required to do this. These types of studies would also provide useful data related to interactions between health care professionals and individuals with reflective and non-reflective coping styles.

Conclusion

This study, in focusing on living aspects of the dying experience near the end of life, has raised new perspectives and questions about understanding and caring for advanced cancer patients. It is my hope that the results will encourage both nurses and other health care professionals in the palliative care setting to question their practice, be open to new viewpoints, and to initiate research that helps answer these important questions.

APPENDIX A

Demographic Data Collection Sheet

1. Patient Identifier _____

2. Age _____

3. Male _____   Female _____

4. Diagnosis _____

5. Income _____

6. Religious preference _____

7. Educational Level _____

8. Marital status _____

9. Occupation _____

10. Ethnic or cultural group _____

11. Family involved in care _____ yes _____ no

12. Time since diagnosis _____

13. Time since admission to palliative care program

APPENDIX B

Sample Trigger Questions for Initial Interview

Although the investigator's intent was to ask few questions and follow the lead of the participant in terms of the direction of the interview, the following sample questions were sometimes used to guide the discussion:

1. Describe your experience of *living* at this point in time.

2. How do you make meaning of this experience?

3. What is important to you now in your life?

4. What kinds of things do you need or want right now?

5. What have you or other people done that has helped you with these?

6. What are your hopes or expectations?

7. What inner resources or spiritual resources do you draw upon?

8. How does this affect your experience?

9. What kinds of things would you like nurses and other team members to understand about your experience of living and dying at this point in your illness?

In addition, by participating in this study I will be contributing to new knowledge about living and dying. Understanding the meaning of this experience from the patient's viewpoint will assist nurses and other health care professionals in providing optimal care for future patients and their family members both in hospital and at home.

Confidentiality:
All patient information related to this study will be kept strictly confidential by the researcher and her faculty advisors. All documents will be identified only by code number. My name and identifying information will not be included on written transcripts of the tapes or excerpts of transcriptions used in the study reports. All interview tapes will be kept in a locked cupboard and will be erased when all written reports are complete. I will be given a copy of the study findings upon completion of the study.

During the interviews, I may share information with the investigator that could be useful for improving my current nursing or medical care. I understand that the investigator will **not** share this information with other members of the palliative care team, the nursing staff or my doctors unless I specifically request this.

I understand that if I have any questions or desire more information about this study, I should contact the investigator, Kathy Bodell at 412-4920 or her thesis advisor, Sally Thorne at 822-7482.

If I have any concerns about my treatment or rights as a research subject, I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598.

Consent

I understand that participation in this study is entirely voluntary and that I may refuse to participate or I may withdraw from the study at any time without any consequences to my continuing medical or nursing care. I have received a copy of this consent form for my own records. I consent to participate in this study.

Patient Signature   Date

Witness Signature   Date

Investigator's Signature   Date

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