THE LIVED EXPERIENCE OF FACING THE END OF LIFE IN AN INPATIENT HOSPICE ENVIRONMENT

by

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Abstract

This study used a phenomenological approach to explore the experience of facing the end of life in a hospice environment. Findings revealed that central elements of this experience include: (a) caring about relationships with others, (b) caring about knowing and being oneself, (c) a greater awareness of one's relationship to time, (d) needing to think and feel positive, and (e) caring about one's spiritual faith and experience. The results provide support for previous research and have both theoretical and practice implications. Future research could help to build on the small number of phenomenological studies that have looked at the experience of facing the end of life—especially in hospice environments.
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Introduction

The belief that the dying experience is a valuable and sacred part of life is a theme that runs throughout human history and culture (Bradshaw, 1996). Although our Western culture of the past couple of centuries has tended to view the human being in segmented and materialistic terms, there has been a resurgence of a more holistic world view during the last few decades. The hospice movement springs from this holistic world view and is a small but significant vehicle for fostering and illustrating this world view in action.

The first hospices were monastic centers that offered pilgrims care based on spiritual beliefs and holistic understandings of health (Stoddard, 1978). In the late 1800s, religious orders opened hospices based on this medieval philosophy of care that were specifically for the dying (Perron & Schonwetter, 2001).

The modern day hospice movement was modeled after these centers and originated in the 1960s in response to a felt sense of inadequacies in the existing medical system (Merriman, 1999). These inadequacies were viewed as a lack of palliation, pain control and person-centered care (Byock, 1999; Perron & Schonwetter, 2001). Hospice care aims to reinstate a humane, democratic and holistic alternative in response to the reductionistic, technologized, bureaucratized and biomedical care of the dying (McGrath, 1998; Perron & Schonwetter, 2001).

Research into the experience of the end of life and hospice care is a relatively new field of study but is essential for protecting the uniqueness of hospice ideology and care in the century to come (McGrath, 1998). As the population ages in all western industrialized countries, there will be added pressure to find alternative end of life care and increased demand for hospice accountability (See Appendix A for Canadian
demographics) (Kovacs, 1998; 2000; Merriman, 1999). This means there will be a need for both richer qualitative data and larger sample populations for quantitative data. However, research will have to grapple with the illusive nature of hospice constructs such as “a good death”, “holistic care” and “spiritual and existential needs” (Merriman, 1999).

A lack of understanding of hospice is evident amongst the general public (Perron & Schonwetter, 2001) and a lack of coherent ideology is evident amongst hospice caregivers (Rinaldi & Kearl, 1990). Studies suggest that medical practitioners, families and patients have varying conceptions of holistic care, what a “good death” constitutes, and the relative importance of “spiritual needs” (Field, Douglas, Jagger, & Dand, 1995; Steinhauser, Christakis, Clipp, McNeilly, & McIntyre, 2000).

For instance, some studies appear to show that patients regard spiritual and existential needs as of high importance for their end of life experience (Herman, 2001; Kausar, & Akram, 1998; Steinhauser, Christakis, et al., 2000; Thomson, 2000). However, professional (Steinhauser, Clipp, McNeilly, Christakis, & McIntyre, 2000) and lay caregivers rank these needs as relatively less important (Fins, Schwager Guest, & Acres, 2000).

A literature review revealed that the majority of studies in the hospice field have gathered information on professional caregiver and family perception. These studies do not provide a complete picture of patient experience variables (Nolen-Hoeksema, Larson, & Bishop, 2000). Intervening variables (Bretscher et al., 1999; Nolen-Hoeksema et al., 2000) and misconceptions of patient needs (Field et al., 1995; Wilkinson et al., 1999) may interfere with these assessments. As a result, it is important to complement these studies with information obtained directly from the patients (Fakhoury, 1999; Jarrett,
Payne, & Wiles, 1999). Qualitative methods offer a useful means of investigating patient perceptions (Abu-Saad, 2000; Merriman, 1999). To assess the lived experience of patients, a phenomenological perspective is particularly valuable (van Manen, 1990).

A literature review found only one study performed in a hospice inpatient unit that used a phenomenological approach (McKinlay, 2001). She (2001) organized various themes in participant responses into a framework entitled “Circle of Care.” While the study is limited in scope (testing only six individuals), its findings offer a useful framework for conceptualizing the patients holistic experience. In addition, only one study was found that used a phenomenological approach to look at the experience of ‘facing the end of life’ (Kuhl, 1999). While Kuhl’s (1999) research was not performed in a hospice inpatient environment, its findings offer new insight into end of life experience—which is the central focus of this current study.

Purpose of the Study

The general purpose of this study was to understand how individuals face the end of life and how hospice care affects this experience. Cicely Saunders (1999), the founder of the first modern day hospice program, stated that the modern hospice movement “...owes its inception and development to listening to patients and families.” However, much of the literature on death and dying has been derived largely from ‘etic’ or ‘second-hand accounts’ (Corr, Doka, & Kastenbaum, 1999). More ‘emic’ or ‘first-hand accounts’ would enhance our understanding of this part of life (Corr et al., 1999) and would be consistent with the hospice vision of listening and responding to client needs. In an attempt to build on the death and dying literature, this study aims to build on ‘emic’, or subjective accounts.
Choice of Method for the Study

This study utilized an existential-phenomenological mode of inquiry (Valle, 1998) to explore the participant's sense of meaning in facing the end of life and of hospice care. Existential phenomenology aims to be person-centered in its approach and concerns itself with questions related to thanatology and individual's sense of meaning in life (Valle, 1998).

Literature Review

The study of the experience of dying is a relatively new field of research emerging along side of the development of the hospice movement (Perron & Schonwetter, 2001). This research began as participant-observer research in the late 1960's, moving towards quasi-experimental designs in the 1980's, and more recently to patient self-assessment designed to track individuals subjective experiences (Perron & Schonwetter, 2001). This study aims to contribute to this body of subjective research by collecting first hand accounts of individuals’ lived experience of facing the end of life in an inpatient hospice care.

Sociological and Historical Overview

The foundation of the philosophy and mode of hospice care is not new. In fact, holistic treatment was the dominant model of care throughout medical history (Firth, 1998). For instance, Greek, Chinese and Indian philosophy all conceived of holistic care as integral to healing (Firth, 1999; Salmon, 1984). In addition, the spiritual basis of care is notable in the Middle East in the early centuries, in hospitals during the Byzantine period, in monastic care of the middle ages, and in nursing orders in the 17th century (Bradshaw, 1996). Thomson (2000) cites that prior to the Age of Enlightenment, medical
and spiritual care were practiced in conjunction with one another (p.14). In this context, the goal of the physician was “comfort care,” since curative care was rare and death was accepted as a natural process (Perron & Schonwetter, 2001). Centers offering this sort of holistic comfort care existed as far back as Roman times.

In Medieval times, hospices were “...monastic places where the sick, dying, needy, travelers, women in labor and lepers could go and be cherished, protected and refreshed” (Stoddard, 1978, p.16). They were founded on the belief that “…dying persons were seen as prophetic souls, voyagers and pilgrims valuable to the community in a number of ways, not least in the opportunity they provide those around them for service and spiritual growth” (Stoddard, 1978, p.16).

In the late 1800s, the Sisters of Charity formed hospices (Dublin in 1879, and London in 1905) that were modeled on medieval philosophy and beliefs of care (Perron & Schonwetter, 2001). These hospices differed from the medieval centers in that they were specifically for the dying. As in medieval hospices, care included custodial, physical, emotional, and spiritual care. As well, these early hospices saw death as a meaningful part of life’s journey and caring for the dying also held great meaning (Perron & Schonwetter, 2001).

As societal values and world-view shifted in the 20th century, so did society’s model of caring for the sick. For example, societal attitudes towards death was one major force that affected the care of the dying. Fulton and Owen (as cited in Hayslip & Leon, 1992) note that American culture’s portrayal of death was different before and after the advent of the atomic bomb. For instance, they note that there was a shift from viewing death as immediate, visible and personal, to viewing death as distant, invisible, and
impersonal. In addition, they point out that there were changes that affected how death was experienced including: death at home to death in institutions, integration of family to the disintegration of the family, and values being viewed as absolute to values being viewed as relative, etc. (p.8). See Appendix B for a charted comparison.

Western culture’s view of dying has also been influenced by several other factors. The first factor is a high regard for productivity and materialism resulting in fear of loss and pain. Western man “...measures his own worth in terms of what he has produced, not what he is”(Kraft, 1974, p. 131). The second factor is the concept of dualism which sets our consciousness at odds with our bodies. This in turn, negates any conception that physical pain can offer a positive growth in human development. The third factor includes reductive and atomistic thinking, and mechanistic assumptions (Salmon, 1984, p.271). The fourth factor is a lack of rites of passage/or rituals—particularly surrounding the dying process. The anthropologist, Gerald Arbuckle notes that in traditional cultures, the chaotic transitional stages in an individual’s life are not something faced alone, (lecture at the Executive Inn, Burnaby, Oct. 23, 1997). Instead, they are embraced by the community in supportive meaningful rituals—which are lacking in the West. The fifth factor is the self-sufficiency of individualism which is ultimately existentially negating (Becker, 1973). In this context, the dying individual can feel insignificant, unsupported and his/her journey can feel meaningless.

Stoddard (1978) states that it is no great surprise that society would treat death “...as something to avoid, something shameful, unnatural or wrong” (p.10). Petit du Mange (1998) adds that death was viewed as an “enemy” and was a sign of practitioner’s failure. In this context, the medical model of care varied from the hospice model in that
it aimed to...“diagnose and cure disease” (Perron & Schonwetter, 2001). Byock (1999) notes that it was also “problem based” as opposed to person-based, and did not focus on palliation or pain control.

In the 1950’s, the death taboo was fading (Rinaldi & Kearl, 1990) and there was a growing sense of dissatisfaction with the medical model of care. Many causes for discontent are highlighted in hospice literature. Murphy (Firth, 1998), a Canadian psychiatrist, views the medical model as often providing inappropriate care. He argues that “every hospital should be a sacred place with ‘whatever happens, all will be well’ written above the door instead of ‘driving death underground’ ” (as cited in Firth, 1998, p.83). Perron (2001) expresses the view that the medical model of care was an aggressive, expensive mode of treatment that resulted in physical, emotional and spiritual suffering in the patient. Byock (1999) states that the problem-based medical care focuses solely on illness or injury and neglects other key components of palliative care. Poor pain management practice, inhumane and insufficient treatment prevailed (Weissman, 1997; 2000). McGrath (1998) adds that care of the dying has become highly medicalized, technologized and bureaucratized.

The other problems in this model of care are discussed by Byock (1999). She points out that the failure to thrive syndrome in babies who lack attention and touch, is endemic in terminal patients in many medical care establishments. “Residents may be left to sit or lie for long periods of time, untouched; receiving care only when they are wet or it is time for them to be fed...Nutrition, hygiene, and “medical care” may all be adequate, while the persons who reside there languish” (Byock, 1999, p.90).

The National Conference of Social Welfare (1978) notes three characteristics of
modern medical treatment (in hospitals and nursing homes) that lower the quality of care given to the patients (p.43):

1. Hospital care is focused on life saving and life-extending rather than putting the quality of life first.

2. Hospital and nursing care is task-oriented and the individual is under the control of the medical staff.

3. Hospital staff is hierarchical which creates more restrictive role delineations among disciplines and less of a community atmosphere.

A search for new values and methods of care began to emerge as a response to these felt inadequacies in the medical model. This search resulted in a rediscovery of the ancient values, beliefs and philosophy of care. For instance, in 1958 a holistic healing center was built in the U.S. and was modeled after an ancient Greco-Roman healing center called the Asclepion (Firth, 1999). As well, the hospice philosophy emerged in an identifiable form in 1967. Hospice aimed to provide a vehicle where community values, interdependence, a respect for all of life and a holistic view of humans could be reintegrated into culture. The hospice movement also aimed to decrease denial around death and reintegrate values that society had come to ignore. It aimed to be a source of valuing of life and individuals—a place where holistic awareness of the human’s needs could be met.

St. Christopher’s was built in 1967 in the UK (Saunders, 1999). Subsequently, Kubler-Ross popularized the concept of care in North American culture and Hospice Inc.—the first American hospice came into existence in 1974 (Mor, 1987). Perron and Schonwetter (2001) note that these modern hospices were modeled after the Sisters of
Charity Hospices. Their philosophy of care and understanding of death was the same. Once again, the focus was on custodial, physical, emotional and spiritual care. The modern hospice model aims to be a responsive, person-centered, holistic, and loving form of care and is based on the belief that death is a meaningful and sacred part of life’s journey (Perron & Schonwetter, 2001) and caring for the dying person is also meaningful and sacred.

A current hospice standards guide states that the mission of hospice care is to affect skilled and compassionate physical, emotional and spiritual care to enhance the quality of life of persons facing death and bereavement (Victoria Hospice Society, 1990). Perrons and Schonwetter (2001) argue that the only difference between the early hospices and modern hospices is that symptom control has greatly improved.

The spiritual foundation of hospice care is visible in Stoddard’s (1978) description of the hospice:

(beam here) pertains to those exchanges between people, living and dying who value one another as vessels of a purer and more lasting force—who look beyond present turmoil and incapacity, to the realization that our entire planet has now become one village seeking to be healed. With the spread of the hospice concept in our culture, many of us may discover that we are learning from the sick how to be well again and from the dying, how to live...The hospice acts out and embodies the provocative assumption that we are all one family responsible to one another (p.48).

Hospice is a melding of the soul and science. “Not only is (the hospice idea) novel to the high technological big-business system of medical care we have (American), but it
embodies a rather rare combination of spirituality and hard medicine” (Holden as cited in Stoddard, 1978, p. 91).

The modern hospice movement has now been in existence for over 30 years. It has impacted day to day practice, the health care industry, societal attitudes about death and dying and care for the dying, as well as public policy and the national health care budget (Merriman, 1999). It is attempting to maintain integrity and influence in the face of growth and change. The National Hospice and Palliative Care Organization (as cited in Perron & Schonwetter) estimates that in 1998, hospices served approximately 540,000 patients, and in 1999, at least 700,000 patients or 29% of all patients who died that year. Perron and Schonwetter (2001) argue that the demand for hospice care will continue to rise with the aging population.

McGrath (1998) states that protecting and preserving the uniqueness of the hospice ideology including the democratic, holistic and human care of the dying, will be a challenge in this new century. For instance, as the hospice movement gets more routinized, institutionalized, bureaucratized and incorporated into the medical establishment and health care industry, it is questioned whether or not its values will become diluted or compromised (Beresford, 1997; McGrath, 1998; McNamara, Waddel, & Colvin, 1994). McGrath (1998) notes that so far, hospice changes have included:

...formalized and sophisticated management structures brought about by funding arrangements; nursing staff being required to document their services, administrative staff playing an increasingly important role, and the board of the hospice diversifying to include more managerial than community representations (p. 3).
Rinaldi and Kearl (1990) note:

...an interaction between two differing belief systems may cause changes in each, if the stronger does not completely overwhelm the weaker. Conversely, if those in the medical establishment adopt hospice ideas as representing the highest values of that establishment, the ability of hospice to influence modern medicine may remain viable, because the hospice will not be viewed as an interloper but as an ideal (p.298).

In this process, the foundations of care as a sacred endeavor and the view of death as a sacred journey are being called into question. This is creating a growing concern that through this process, hospice care risks losing its integrity and as a result, its healing potential. The Western Christian religious tradition supplied hospice care with an ethical foundation and a set of core beliefs integral to its functioning (Daaleman, & Vandecreek, 2000, p. 2516). Bradshaw (1996) notes that it was based on “the way of love”(p. 412). Beresford (1997) points out that the classic image of “...small, volunteer, spiritually inspired caring communities helping highly motivated individuals on their ultimate journey of self-discovery (is)...receding even farther from the routines of today’s hospices, while some front-line hospice professionals even question whether such an image is still relevant to the needs of terminally ill patients”(p.86). In this original context, the relationships and care were not based on psychosocial skills and techniques but rather, real love (Bradshaw, 1996, p. 413). There is a growing fear that “.... the so-called Hospice Movement might end up merely as yet another technique to be added on to present-day high technology mainstream medicine—a technique behind which professionals could hide and through which they could soullessly exercise power”
Bradshaw (1996) argues that secularization is the cause of the loss of this original hospice ethos. She offers the example of the Nightingale nursing model beginning as a lay movement with a spiritual basis that lost its “spiritual force” through secularization (p.409). Using the words of Max Weber, Bradshaw warns of becoming: “Specialists without spirit, sensualists without heart; this nullity imagines that it has attained a level of civilization never before achieved” (Weber as cited in Bradshaw, 1996).

Accountability Issues

As hospice service become more prevalent, it is experiencing pressure to prove itself as a valid and viable mode of care to its modern day context. The result is a greater demand for more outcome measures and accountability (Kovacs, 2000; Merriman, 1999). Abu-Saad (2000) notes that “the sector’s emotional appeal and anecdotal success” requires justification as its service grows (p.21). Zimmerman (1986) reiterates this, noting that

Up to this point, our efforts to promote the development of hospice care have been hinged largely on our description and anecdotes. Those we are trying to convince will soon rightfully be demanding more from us. They will want some data; we should be ready to provide them. It is only in this way that growth of hospice care can be unfettered” (p.294).

Thus, there is a need for both quantitative studies yielding larger samples as well as qualitative studies yielding richer data. This research aims to provide some of these data.

Providing such research has its difficulties. Not only are hospice constructs easily misinterpreted and misunderstood in the modern Western belief structure, hospice
constructs are also generally illusive and difficult to quantify (Merriman, 1999). Bertman (1998) states that there are "...obscure, repressed, and multiple meanings that logical, theoretical arguments and statistics filter out" (Bertman, 1998, p.6). She argues that qualitative measures such as visual and poetic arts may be more suited to allowing patient voices to be heard, leading to deeper and greater understanding of the experience but more difficult to interpret.

In order to provide accountability and at the same time preserve the meaning of the experience of dying, the research method must be sensitive to this fine balance. Previous research included both interviews and surveys. However, there is still a limited amount of research on the first hand accounts of individuals facing death. Research that offers a glimpse into the lived experience of hospice patients would be valuable for building our understanding of their experience.

Finding ways to research this area would provide an opportunity for a hospice to (a) translate itself in meaningful terms into its current cultural context, (b) maintain its responsive philosophy by using these concrete terms to assess and evaluate its current functioning (from its inception, hospice has incorporated research as a key part of its movement) (Kovacs, 2000), (c) set standards of care (Merriman, 1999), (d) grow in its understanding of the dying process and the needs of the dying (e.g., better pain and symptom control) and thus, in its tradition of responsive care (Beresford, 1997) and, (e) continue its social activist movement of teaching society about death and dying to meet societal needs on a whole.

The Experience of Dying

Many theorists conceptualize the experience of dying in terms of stages of
emotional response. While models are useful in deepening our understanding of human experience, it is important to consider the possible range of individual responses to dying. Elizabeth Kubler-Ross notes five “stages of dying” which she has recognized in her work with terminally ill adults and children (Kubler-Ross, 1975). In her later work, she adapted this model into “emotional tasks” which do not consist of a fixed sequence or pace (Kubler-Ross, 1975) and where some tasks might be skipped altogether (Bee, 1996). Current theory and research appears to support this variability.

The universality of such “emotional tasks” is supported by other cultures’ conception of the dying process. For instance, the progression towards acceptance is outlined in Eastern tradition as well. The Tibetan Book of the Dead is a Buddhist guide to confronting mortality (Fremantle & Trungpa, 1987). While it is believed that the individual experiences this progression after death, and that each task is brought by deities for the individual to overcome, the stage-like journey towards acceptance parallels Kubler-Ross’ model. See Appendix C for a charted comparison.

Four theorists are notable for their conceptualization of the adjustment processes associated with loss: Reigel, Erikson, Jung and Elizabeth Kubler-Ross. They conceive of loss in a paradoxical way—stating that loss can become the impetus for human development. Reigel (1973) theorized that only when the human organism experiences difficult or conflicting interactions between two or more dimensions of life (i.e., physiological, psychological, social, or cultural) will growth occur.

Erikson (1982) theorized that the act of life-analysis and facing one's own finitude offers an opportunity to address the meaning of existence. It is at this point that life is reconstructed in terms of time left to live rather than time since birth. With loss in full
view, meaning making leads to integrity and a failure to find meaning leads to a sense of despair. He conceived that the resolution of this final and most important stage brings wisdom. Wisdom, as such, refers to an expert level of performance in the fundamental pragmatics of life's domain.

Jung (1983) saw the movement through life as leading to more existential concerns. With age, the individual experiences a shift in focus from the 'creation of the self' to the 'finding of the self' which can result in intuitive awareness.

What Erikson termed an attainment of wisdom and Jung referred to as an intuitive awareness, Kubler-Ross refers to as a peaceful awareness. Kubler-Ross' (1975) research focusing on the growth-producing opportunities associated with the dying process. She states that the act of facing one's own finitude produces suffering. Suffering can lead to 'peace' through the resolution of three existential concerns: (a) Who am I?, (b) What should I be committed to?, and (c) In what way will I live my life? Resolution is viewed as bringing peace through a sense of self-identity, a commitment of ourselves to others (and receiving their commitment to us) and a coherent directional style of living.

Research appears to confirm that (a) meaning making leads to coping (Adair & Mowsessian, 1993; Depaola, 1995); and (b) there is a shift to more existential awareness with age (Lapierre, Bouffard, & Bastin, 1992).

While these theoretical frameworks are valuable and have been substantiated in research, Corr et al. (1999) point out that they offer only part of the picture and require more first hand accounts or 'emic' accounts to fill in the gaps in our understanding of the experience of dying.

Hospice Constructs
There are a few central concepts of the hospice model of care that require further clarification and understanding. These concepts include “quality of life,” “a good death,” “quality of care,” “holistic care,” and “spiritual and existential needs.”

The term quality of life has been defined “a composite of those aspects of life and human functioning that are considered essential for living a full life” (McMillan & Mahon as cited in Thomson, 2000, p. 15). It is defined holistically as the physical, psychological, social, and spiritual domains of health that are influenced by a person’s experiences, beliefs, expectations, and perceptions (Rummans, Bostwick, & Clark, 2000; Thomson, 2000). Byock (1999) reiterates that the term ‘quality of life’ is a “entirely subjective construct; it is what the person says it is” (p. 91). Others note that this subjective well being is mediated through religious and spiritual beliefs. Daaleman and Vandecreek (2000, p. 2515) point out four ways in which such beliefs could mediate well-being: (a) by promoting a salubrious personal lifestyle that is congruent with religious, or personal faith traditions, (b) by providing systems of meaning and existential coherence, (c) by establishing personal relationships with a divine other, and (d) by ensuring social support and integration within a community.

Kellehear (as cited in McNamara et al., 1994) speaks of a ‘Good Death’ as “...the extent to which the interactants accept the impending death, receive mutual emotional care and support, mitigate the dying person’s discomfort and isolation and complete all ‘unfinished business.’ The important impact of meaning making on one’s ability to cope is evident in the research on life review and coping (Boylin, Gordon, & Nehrke, 1976; Kiernat, 1979; Tabourne, 1995) as well as in the research on religiosity and coping (Courtenay, Poon, Martin, Clayton, & Johnson, 1992; Nye, 1992; Thomas, 1991).
Another central construct in the hospice model of care is "quality of care."

Rummans et al. (2000) note that quality care utilizes a full range of interventions including physical, psychological, social, and spiritual to meet the holistic needs of the person. Dalleman (2000) cites the 'support' study which concluded that good care should include attention to physical, social, psychological, spiritual and/or religious needs (p. 2514). In particular, this study "supports a rapprochement among religion, spirituality, medicine, and health care" (Dalleman, 2000, p. 2514).

Spirituality has been defined as a journey that "...involve(s) us in the mystery of experiencing the holy, the mysterious" (Chandler, 1999, p.64). This is an experiential definition that current theorists refer to as "sensory spirituality" (Chandler, 1999). It is in contrast with religious beliefs or beliefs in general. However, much of the current literature is increasingly equating the terms spiritual with existential (Kellehear, 2000). Daaleman and Vandecreek (2000) note that constructs of meaning or a sense of life's purpose often refer to spirituality. This sort of definition focuses on the acquisition of meaning or beliefs. For instance, Thomson (2000) defines spirituality as "...the quality of curiosity in persons that seek to find meaning" (p.15). He states that spiritual care interventions can include (a) attending to the patients own spirituality, and (b) helping the person find meaning through activities such as prayer, presence (with no obvious "spiritual talk"), empathetic listening, sacraments, rituals, life review and pastoral counseling (p.15).

Kellehear (2000) attempted to build a cohesive model of spiritual needs that includes situational, moral, biographical, and religious needs.
Spirituality is often defined in conjunction with the concept of hope. Hope is defined as “an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being...and an intangible experience” (Benzein, Norberg, & Britt-Inger Saveman, 2001, p. 117). Benzein et al. (2001) offer a multidimensional model of the variables that impact a person’s sense of hope when facing the end of life including (p.118):

(a) A sense of personal spirit or personal experience of meaning

(b) Facing risk and uncertainty and

(c) Authentic caring creating comfort.

Models of Palliative Care

Hospice constructs remain relatively unexplored and there is a lack of a cohesive and comprehensive theory regarding the factors that impact the quality of life of a dying person. However, a few theorists are starting to delve into this unchartered area of research. Stewart, Teno, Patrick and Lynn (1999) have created a conceptual framework integrating quality of life and quality of health care indicators. It is based on the
American Geriatrics Society's model of care and a review of the literature in the area (Stewart et al., 1999). It consists of three main categories (a) patient and family factors affecting health care and its outcomes, (b) the structure and process of care (from which to glean quality of care information), and (c) patient and family outcomes of care including satisfaction with care and quality and length of life (Stewart et al., 1999, p.94). While this is a useful framework for understanding the variables influencing quality of life and health care indicators, it offers a general understanding only and does not describe quality of life factors and issues.

Mendyka's (2000) framework for conceptualizing 'quality of care' and 'quality of life' considers some of these factors and issues. He notes that while a holistic perspective is central to quality palliative care, it runs the risk of being misunderstood and misinterpreted by health care workers when it is viewed in an 'essentialist' manner.

Essentialism is "an ideology that emphasizes the meaning of human 'parts' over the meaning of the 'whole' " (Mendyka, 2000, p. 34). In other words, when care providers base their work on a theoretical construct such as the components of holistic care (physical, psychological, social, and spiritual), there is a tendency to lose sight of "the forest for the trees" and view problems/issues from one or another of these perspectives instead of from the overriding holistic perspective. Mendyka (2000) argues that it is the "mix" of and the link amongst these aspects of care that produces the desired outcomes in palliative care. Fundamentally, Mendyka (2000) is arguing that the whole is greater than the sum of the parts. This gestalt perspective has implications for practice as well as for framing interview questions. The prevalent "mind-body-spirit axiom is often exploited in this way (Mendyka, 2000).
Mendyka states that an understanding of holism in these terms is too narrow and does not address the aspect of holism that unites all aspects of it and cites Watson's Model of Human Care as essential to providing truly holistic care. In this model, the patient is seen as "...person, as cultural being, and as a member of a larger phenomenological system (e.g., the family or community) and therefore reemphasize the meaning of the whole over human parts" (Mendyka, 2000, p.34). Watson argues that any ambiguity and confusion surrounding holistic care can be resolved by understanding an individual as a "phenomenal field". "A phenomenal field is a person's frame of reference or subjective reality, composed of the totality of human experience" (Watson as cited in Mendyka, 2000, p.35). Mendyka states that "this definition includes a respect for a person's culture (world views), cultural meanings, and an appreciation of human beings as individuals who experience life" (p.35). When an interpersonal caring relationship is formed, the patients as well as the caregiver's phenomenal fields meet and transpersonal caring can occur. Transpersonal caring symbolizes a growing and spiritual awareness of the 'therapeutic use of self in the context of the illness experience of others' (p. 35).

Mendyka's framework allows for a more cohesive understanding of the meaning of quality of care and life variables and how they interrelate. It also lends support for qualitative research that utilizes face-to-face interviews and phenomenological methodology.

Research Studies

Research on Quality of Life, the Experience of Dying, and Hospice Care. Perron and Schonwetter (2001) note that a National Hospice and Palliative Care Organization survey found that the majority of society remains relatively uneducated about hospice
They found that 80% of respondents from the general public did not know the meaning of “hospice” (National Hospice and Palliative Care Organization as cited in Perron & Schonwetter, 2001, p. 437). An inadequate knowledge and comprehension of hospice care is also visible in physicians and allied health care providers and this has led to a lack of referrals (Perron & Schonwetter, 2001). Rinaldi and Kearl’s study (1990) found that even amongst hospice experts, there is a lack of coherent linking ideology. Naomi Naierman, the executive director of The American Hospice Foundation, states that “...hospice must be better understood if it is to reach all who need it (as cited in Kastenbaum, 1998, p.188).

This confusion around hospice care exists then not only amongst the public and health care professionals, but also amongst those who lead the hospice movement itself. A number of factors may be causing this confusion. First, the dominant cultural worldview, and the existing health care philosophical foundation and bureaucracy may be incongruent with and in opposition of hospice philosophy and values (Beresford, 1997; McGrath, 1998; Merriman, 1999). Second, the relative infancy of the thanatology and hospice field of research may not yet offer enough clarity. Fakhoury (1999) cites that there is considerably less research on the field of patient satisfaction with palliative care than for patient satisfaction with medical care. Third, relatively few attempts have been made to get first hand accounts of the lived experience of the dying and their hospice experience (Teno, 1999; Stewart et al., 1999).

A search of relevant databases located a total of 79 articles of which only 43 were original research studies (See Appendix D). Seventy-nine percent of the research studies were published in the past 4 years. Few of the studies (7 or 16.28%) were conducted in
an inpatient hospice setting. In addition, only 12 or 27.91% focused solely on patient perspectives. Most of the studies gathered information from one type of informant (i.e., professional caregivers only, patients only, families/lay carers only, or volunteers only). The remaining studies gathered information from more than one type of informant. There were also a wide variety of data collection methods the most common of which were interviews or written questionnaires. Many studies used a combination of methods. Only 8 studies involved using a direct face-to-face interview methodology with patients receiving inpatient or outpatient palliative care or hospice services. Only 3 of these studies focused on residents of in-patient hospice services, and only one of these three used an open-ended interview methodology.

Ury, Reznich and Weber (2000) aimed to increase awareness regarding palliative care by assessing the educational needs assessment of medical practitioners. The assessment include (a) an anonymous survey of 51 interns, (b) focus groups of housestaff and nurses (5-20 individuals), and (c) individual interviews with patients (n=11), families (n=9), nurses, attending physicians (n=7), interns and residents (n=14), and the medical residency director and housestaff (n=4). The survey reported little training in palliative care topics in medical school (2000, p.411). While patient views were solicited alongside of the professionals, this study focused on educational needs and not on patient needs or experience.

Pearson-Scott and Caldwell (1997) also solicited the opinion of hospice workers. All hospices in the State of Texas were invited to participate and 156 individuals responded. The volunteer coordinators of each hospice were asked to identify the most “dependable” and “effective” volunteers. They surveyed hospice volunteers to determine
the characteristics of a ‘highly effective’ hospice volunteer. This understanding was considered important for future recruitment, training and support to volunteers—a key component of hospice care. The study used a statewide survey to poll hospice volunteers that were considered “highly effective” in hospice care. Volunteer roles ranged from indirect to direct care and involved both professional and non-professional services.

These volunteers reported a need for greater support and training. They also found that 78.8% of respondents noted some religious involvement. This is congruent with Fischer, Mueller and Cooper’s study (1991) that found that volunteers are disproportionately actively religious people. Pearson-Scott and Caldwell’s (1997) findings also indicated 70% of the volunteers found the experience of volunteering in hospice to be growth enhancing.

Practitioner conception of quality of care was also explored in the literature. Luker, Austin, Caress and Hallett (2000) interviewed 62 community nurses using a critical incident framework to understand quality palliative care. Participants were asked to speak of two cases: one in which they felt they were able to offer quality care to a patient, and one in which they felt that they did not. Thematic analysis revealed aspects of the care considered essential included enabling a home death if desired by the patient, and ‘getting to know’ the patient and family. ‘Getting to know’ the patient and family entailed (a) early access to care which in turn, built a more solid relationship, (b) the importance of determining what the patient and family’s awareness and understanding is around the illness, and (c) the use of the professional relationship to engage in meaningful contact with the patient and family. This ‘meaningful contact’ included talking with the patients and relatives, and preparing the patient and family for the time of
great change. This study points out the importance of a person-centered and humanistic approach to palliative care.

While this study notes that nurses perceive a good death as facilitated by person-centered care and by the person's sense of meaning. However, it does not discuss their perceptions of what constitutes a 'good death' in any more detail. McNamara et al. (1994) attempted to access such perceptions by interviewing twenty-two nurses from both in-patient and outpatient hospice centers. The interviews focused on perceptions of 'a good death' as well as case examples of what a 'good death' looks like. Findings showed that both inpatient and outpatient nurses had many of the same concerns and conceptions. A good death was seen as (a) holistic care and comfort to both the patient and the family, (b) peace and dignity in the dying experience, (c) nurse involvement in the patient’s dying trajectory, (d) involvement of all concerned in the process, and (f) something idealistic yet always worked towards. Nurses also felt that it was inappropriate to label a 'good death' for risk of imposing caregiver values on the patient and family. This study offers a general understanding of nurse perceptions. However, they do not define or offer examples of what it means to have a ‘good death.’ This study offers support for open-ended interviews of hospice patients.

Rinalidi and Kearl (1990) polled a national sample of hospice 'experts' to survey their conception of what constitutes a 'good death'. The 48 respondents generally agreed that hospice care was influenced by Kulber-Ross, offers a radically different way of dying, and is a reaction to the death-denying culture. However, there was a lack of ideological consensus about hospice origins, issues of pain control and suitability of hospice care for older individuals. These studies suggest that there is disagreement
regarding what hospice care is and what it should entail, as well uncertainty surrounding
the needs of the dying. Therefore, more direct feedback from patients would be helpful
in clarifying what forms of hospice care are most effective and valuable.

Some studies have used the objective accounts of medical practitioners to assess
the care and experience of dying persons. Fins et al. (2000) attempted to gain insight into
the care and experience of dying patients in hospitals through the accounts of medical
professionals. They did so by analyzing the medical records of 200 adult deaths in a
hospital (which was not a palliative care unit). Through the use of narrative analysis,
themes were derived from the records. These themes included: documentation of care,
relationships between patients, families, and clinicians, as well as the influence of time,
uncertainty, ambiguity, resource allocation, and spirituality on the course of care (p.400).

Since these records were made by health care professionals, they may not reflect
the experience of the dying person but rather an interpretation of their needs and
experience. In addition, the use of retrospective analysis cannot offer a complete sense
of the care or experience of the dying individuals. These accounts are questionable for
three reasons. First, they were originally recorded for different purposes. Second, they
were not interpreted or confirmed by those that recorded the information or by the
patients themselves. Third, the patients never confirmed the accounts when they were
recorded.

In addition, the medical record did not include chaplain notes since chaplains were
not permitted to write in them. This calls into question whether spiritual needs are
captured in these records. Face-to-face interviews may have offered important aspects of
the patient’s subjective experience that this study cannot comment upon. These studies
offer a greater understanding of the key components of care. However, they are based solely on practitioner perceptions and do not access the opinions of the key stakeholder in hospice care—the patient.

Tierney, Horton, Hannan, and Tierney (1998) used The McGill Quality of Life Questionnaire, The Edmonton symptom assessment system, and an adapted form of the Picker-Commonwealth Inpatient Satisfaction Scale to measure the relationship between various subjective measures of care including patient satisfaction, physical and psychological symptoms, and quality of life. All the tests utilized a Likert format. They interviewed 26 patients in a large hospice. Findings showed that satisfaction with hospice care was associated with quality of life more than symptoms, although symptoms became more important as time progressed. Specifically, dissatisfaction with hospice care was associated more with a worsening of quality of life ($r = -0.51$, $p = 0.01$) than a worsening of symptoms ($r = -0.41$, $p = 0.05$). High correlations were especially found for support and existential scores. Implications pointed out in the study were that “...efforts to improve satisfaction with hospice care (especially shortly after admission) should focus more on quality of life issues rather than physical and psychological symptoms” (p. 342).

Tierney et al. (1998) point out that this does not mean symptoms are not essential for understanding the patient, it just means that quality of life indicators are not given enough attention. They also point out that physical and psychological symptoms may have been given more attention since physicians are more comfortable with the assessment and treatment of symptoms. Therefore, “...further improvements in hospice care will require focusing on the quality of terminal patients’ lives, especially existential and support concerns” (p. 342). This study shows support for the notion that patients can assess their
own needs and care.

One study used interviews and record reviews to provide some useful information regarding pain management. McCarthy et al. (2000) examined 1163 cancer patients participating in a larger project [The Study to Understand Patient Prognoses and Preferences for Outcomes and Risks of Treatments Project (SUPPORT)]. The sample consisted of patients 18 years or older who had either colon cancer metastatic to the liver or lung cancer and who all were in the last six months of life. Findings showed that severe pain and confusion were characteristic of many patients' final months of life. This study calls for better pain and symptom control as well as patient centered treatment whereby patients are at the center of the decision-making process. It also stresses the importance of asking patients directly about their needs. In addition, it calls into question the validity of feedback from patients who are experiencing pain and confusion. For instance, hospice research could maximize validity in these circumstances by getting staff opinion of who is able to participate in research, and by researchers gaining written and verbal consent from participants.

Jarrett, Payne, Turner and Hillier (1999) surveyed the expectations and perceptions of 18 patients with advanced cancer as well as 11 of their relatives. They found a need for pain control and social support. Patient perspective might be masked in this study since it used joint interviews with patients and caregivers. Patient responses may have been inhibited or influenced by the presence of the caregiver.

Jarrett, Wiles, et al. (1999) used face-to-face semi-structured interviews to explore terminally ill patients' and lay-carers' perceptions and experiences of community-based services. Respondents spoke of their perceptions of the providers of care, economic and
practical problems or needs, and continuity of care and communication. A central finding of this study was the conception that the care was disorganized. However, it is important to note that since this study looked at community home-care teams, its findings may not be transferable to hospice care. For example, many of their comments related to scheduling and organizational problems (such as ‘out of hours’ events, roles of community nurses, medical deliveries, etc.) associated specifically with the hospice care delivery system.

Mcdonald (1998) performed in-depth interviews with patients, family members, and hospice staff over a one and a half-year period. Through a thematic analysis, she found that deeper meanings of intimate relationships formed during the dying process. This study suggests that strong personal relationships and support systems made the transition towards death more meaningful. This study also indicates that each death and social support situation is unique and that each patient and family should be treated as unique.

While it is evident that the most valid account of experience and needs would come from the patient, the research literature listed above is only beginning to access their feedback. However, a few studies have focused completely on the experience of patients and have provided alternate insights into the quality of life of patients.

McCord, Mackey and Sparling (2000) interviewed (single-case study) three elderly women with cancer. These women were receiving home hospice care. The aim of the research was to provide the physical therapy field with insight into quality of life issues in palliative home care. The patients had been diagnosed for 3 or more months and had been receiving hospice home care for 3 or more months. They lived in a large
rural county in North Carolina. In-depth, unstructured interviews were used and informants were interviewed twice. Twenty to thirty minutes were allocated to rapport building prior to the interviews. The interviews lasted between 20 to 80 minutes depending on patient preference.

Participants were asked the question: “Please tell me about your illness” (p. 462). Grounded theory analysis organized and extracted key themes in their responses. Religion and religious belief were coded under “faith” and “helping others.” “Faith” was listed under “personal values”, and “spirituality” was the unifying code for religion and personal values (p. 462). Four themes emerged in the analysis: social relationships, spirituality, response to personal mortality, and meaningful physical activity. “Spirituality was expressed in two ways: (1) lifelong religion-based faithfulness to God or (2) internally based beliefs in “self” and personal values used to guide everyday living...informants spoke of their spirituality as preserving continuity with the past, shaping reflections in life, guiding present thoughts and actions, and providing an active strategy for getting through difficult times”(p.463).

This study offered a valuable in-depth look at the experience of dying individuals. However, it left out key information regarding the women’s religious backgrounds. These findings regarding spirituality and religion may not be true for other sample populations. This study is also limited in that it only looked at the experiences of women.

Patient perspectives on quality end-of-life care was also explored by Singer, Martin and Kelner (1999). They note that quality end of life care has not been examined from the perspective of patients. The study purported to attain an appropriate measure and taxonomy of “quality end-of-life care” by asking “those most affected: patients”
Researchers used in-depth, open-ended, face-to-face interviews with 126 participants from 3 patient groups including: 48 dialysis patients, 40 people infected with HIV, and 38 residents of a long-term care facility.

Content analysis of the responses given in three previous studies was used in order to measure “quality of life.” The first of these previous studies sampled dialysis patients to determine their feelings about filling out a generic versus dialysis-specific advance directive form (AD). The second study looked at HIV patients’ preference for filling out an HIV specific or generic AD form. The third study sampled long-term care residents about issues related to “control” at the end of life. The findings showed five thematic beliefs regarding quality end-of-life care including (a) receiving adequate pain and symptom management, (b) avoiding inappropriate prolongation of dying, (c) achieving a sense of control, (d) relieving burden, and (e) strengthening relationships with loved ones.

The most credible element of this research is its attention to detail. The study was performed in such a way that many issues surrounding ethics and data analysis were considered and discussed. The article also offers extensive descriptive detail about the sample population (such as inclusion criteria and drop out rates), the statistical occurrence of themes within the populations, as well as an extensive list of its limitations.

However, the sample populations may not have been a valid resource for determining what quality end of life care means. These populations were not palliative care patients but chronic pain sufferers who may have been a long ways off from the end of life. As a result, their opinions are based on an anticipation of end of life needs—not a first hand, immediate account of their needs.
Finally, and perhaps most importantly, this study’s outcomes are presupposed by its measures. In other words, analyzing the content of studies that concerned issues of medical planning or physical control does not provide adequate resources for determining all quality end-of-life needs. For instance, spiritual and existential needs, economic concerns, and various emotional needs are not addressed. Since this study attempts to provide the basis for a new taxonomy of what “quality of life” means at the end of life, its findings should be viewed with caution.

Engle, Fox-Hill and Graney (1998) looked at the experiences, needs, priorities, and concerns of nursing home residents during the living-dying interval (the time between the awareness of one’s impeding death and death itself). This qualitative study was part of a larger ethnographic project examining differences between Caucasian and African-American individuals. Therefore, in addition to studying the phenomenon of dying in a nursing home, they were trying to establish whether there were differences among black and white populations. This sample included 11 married individuals and 2 single individuals. All of the participants were religious and affiliated themselves with the Protestants tradition. Thirteen participants were asked open-ended questions including: “How have things been for you?”, “What would make things better for you?”, “What would make you more comfortable?”, “What does dying mean to you?”, “What are the most important things for nurses and nursing assistants to know?”, “...Describe a typical day”, and “Do you ever think of passing on?” (p.1092). Thematic analysis identified six core needs related to day-to-day living, inadequate pain relief, difficulty chewing and swallowing, importance of religious activities, giving care to others, and appreciation of respectful and prompt care. This study was successful in allowing for
patient subjectivity through open-ended accounts. It presented some interesting findings such as the need to care for others. It also extracted religious core beliefs such as: a trusting, positive, loving God, a definite sense of right and wrong, the Golden Rule, the importance of attending church, and having little or no fear of death.

However, the framing of some of these interview questions may be considered insensitive. For instance, “What does dying mean to you?”, and “Do you ever think of passing on?” are both fairly blunt questions to ask without establishing a rapport with the participants. However, it is difficult to assess the appropriateness of these questions without knowing more about the context in which these questions were asked.

Nonetheless, it does point out that qualitative research with dying individuals requires sensitivity in question formation, and the timing of questioning. In addition, it points out the value of having trained interviewers perform this form of research.

The studies listed above indicate three things. First, there is a lack of ideological consensus surrounding hospice constructs amongst practitioners and some constructs (such as a “good death”) are inadequately defined and measured. Second, there is a value in and need for research that attains direct feedback from patient. Finally, hospice research should verify that patients are mentally and physically capable (and willing) to participate and that they are empowered (e.g., through a clear description of confidentiality) to participate.

Research on Spiritual and Existential Issues. Some studies appear to show that patients list spiritual or existential aspects of their experience as being of high importance (Herman, 2001; Kausar & Akram, 1998; Steinhauser, Christakis, et al., 2000; Thomson, 2000). However, professional and lay caregivers do not always understand the inner life
of the dying person or know how to meet them in their experience or needs. Highfield and Canson (1983) attempted to assess nurse caregivers' awareness surrounding patient spiritual needs and concerns. The study aimed to assess whether nurses (a) recognize signs of spiritual health, (b) recognize signs of spiritual problems, and (c) are aware that patients can experience spiritual problems. Clinebell's framework of "religious-existential" needs were used to identify and define spiritual needs. These needs included the need for meaning and purpose in life, the need to give love, the need to receive love, and the need for hope and creativity. See Appendix E for a description of behaviours or observable conditions assumed to correspond to these four spiritual needs.

One hundred questionnaires were sent to nurses practicing on surgical floors in a 1,200 patient private hospital in a large southwestern medical center. Thirty-five nurses responded (of whom 80% were registered nurses, the remaining 20% were licensed vocational nurses). Twenty-five were Protestant, seven were Catholic, one was Jewish and one did not specify a religious affiliation.

The survey asked nurses to assess the nature of various needs and problems (as either psycho-social or spiritual in nature), the importance of these needs and problems, and the frequency their patients exhibited each behaviour or condition (on a scale of 1-5).

One-half of the respondents studied mentioned spiritual care and were comfortable with such care, and 31% felt there was a need for more education in this area. Almost all considered physical and psychosocial care as areas where they needed more training and they tended to focus more on physical and psychosocial care and less on spiritual care. This study concluded that spiritual needs were underestimated, misunderstood and possibly unmet. For instance, only items with direct reference to
“God” or to religious beliefs were considered associated with spiritual health. In addition, 43% of respondents considered the spiritual health indicator “lives in accordance with his value system at present” (p. 189) and forty-six percent of respondents considered “values his inner self more than his physical self” (p. 189) as a psychosocial indicator. While the phrasing of these indicators may have confused respondents and may have been misinterpreted (e.g., some may considered the physical self as equally representative of the spiritual dimension), the responses do suggest some confusion amongst nurses as to how to define certain conditions and this confusion could affect the delivery of care.

When signs of spiritual health were grouped into four main categories (see above), only fulfillment of the need to receive love was considered a spiritual dimension. The need to give love and the need for hope and creativity were considered psychosocial in nature. The need for meaning and purpose was considered psychosocial by 42% of respondents and spiritual by 44% of respondents. The need for patients to give love was not considered a problem at all.

The needs and signs of spiritual health in this study could have been poorly phrased or more representative of psychosocial issues. It is also possible that the spiritual needs are still met even if they were considered more psychosocial. However, it is also possible that their method of care has a predominant psychosocial orientation that does not have an adequate focus on spirituality. Misdiagnosis of spiritual problems and needs may result in inappropriate or insufficient interventions. For instance, nurse caregivers might overlook a need for patients to not only receive love but give it as well. Since nurses are often in greatest contact with patients and are the first to diagnose and
treat many problems, their awareness and understanding of certain needs are crucial. This study also suggests that while staff might consider themselves religious or spiritual, there may still be a need to educate regarding spiritual needs and care, most importantly by listening to the unique needs of each patient.

Kausar and Akram (1998) compared terminal and non-terminal patients and found that patients with terminal illnesses used more emotional-focused coping strategies, and sought more social support vs. the patients with non-terminal diseases. They also tend to cite ‘spiritual well being’ as an important and unacknowledged contributor to overall quality of life.

Thomson (2000) notes that spirituality is a predominant coping strategy and has not been adequately studied due to the fact that it is difficult to reproduce it objectively and to quantify it. Thomson attempted to assess the meaning of spirituality by administering the Functional Assessment of Cancer Therapy Scale (FACT-G) on multiple occasions over the course of 16 patients’ use of outpatient services. All but one listed a religious affiliation. This scale has 46 questions and has six subscales including physical well-being, social/family well being, relationship with doctor, emotional well-being, functional well-being, and spiritual well-being.

Thomson (2000) defined spirituality in an existential sense stating that it is “...that quality of curiosity in persons that seeks to find meaning” (p.14). Spiritual care interventions includes helping “...a person grapple with questions...(and) may include prayer, the ministry of presence (with no obvious ‘spiritual talk’), empathetic listening, sacraments, rituals, life review, and pastoral counseling”(p.15). The patient’s average spiritual well-being score ranked higher than their overall QOL score meaning that
"...spiritual well-being serves to pull up a hospice patient's general quality of life." (p.20). While these findings suggest that spirituality benefits a person's quality of life, they cannot be generalized to populations other than religious populations similar to the one tested here.

Carla Hermann's (2001) research had two main aims. First, to define and assess spiritual needs. Second, to substantiate the claim that spiritual care is a professional responsibility of the nursing profession. The mean age of participants was 72 years of age (males n=9, females n=10). Its method of inquiry was a qualitative, semi-structured interview used to explore the phenomenological experience of 19 patients from a large outpatient hospice.

The study utilized two open-ended questions: "What does the word spiritual mean to you personally?", and "What needs can you identify related to your spirituality as you described it?" (Hermann, 2001, p68). The data were analyzed through thematic extraction and grouped into six topical categories including (a) the need for involvement and control, (b) the need for companionship, (c) the need to finish business, (d) the need for religion, (e) the need to experience nature, and (f) the need for positive outlook (Hermann, 2001, p.69). Implication of these outcomes were discussed and concrete nursing applications were offered. This study is an interesting attempt to build knowledge in a relatively unchartered research area. It also provides a practical discussion of specific ways in which these needs can be addressed in the nursing practice.

However, as a research project, it is questionable for a number of reasons. First, the definition of spirituality may be tainted by the fact that the question is posed as "What needs can you identify related to your spirituality?" This question presupposes that
spirituality is a major concern in the person’s life or that they are ‘spiritually minded’.
As well, the question, “What does spirituality mean to you?” may reflect what the person
thinks the construct should represent and not his/her lived experience. A more valid
assessment would have allowed the topic of spirituality to arise more naturally through an
open-ended discussion of all of their needs, or by using a more open-ended question such
as “What is important to you now in your life?”, or by questioning one’s sense of identity
as a result of their experience. Second, the study does not provide adequate information
about its sample selection. Although the article states “the desire for a heterogeneous
sample was emphasized (p.68), it does not say how it attempted to attain it.

Third, vital data are excluded from the article. For instance, the reader is not told
how common (in general or specific terms) each “need” was. Therefore, it is not clear if
a theme was felt by most of the patients or arose solely as a side note in one patient’s
response.

Fourth, the rigor of this study may be weak. The article argues that Lincoln and
Guba’s criteria for rigor were met (Hermann, 2001, p. 69). However, the extent to which
they were met is questionable. For instance, the article states that ‘trustworthiness’ was
enhanced by careful construction of the interview questions, but it does not describe this
process.

The studies focusing on quality of life, quality of care, and spirituality suggest
four things. First, they point out that aspects of the dying experience could be better
understood by professionals or caregivers. Polling patients directly could help to
augment understanding and address any misconceptions surrounding their experience and
needs. Second, it may be more valid to get the accounts of individuals who are facing the
imminent loss of life rather than facing the future loss of life. Third, it would be useful to study individuals from diverse backgrounds including non-religious individuals. This would help clarify the importance of spirituality and existential awareness in holistic care. Fourth, these studies show the importance of framing interview questions in qualitative research in a non-leading fashion if they are to access a more accurate description of a person’s lived experience.

Research on Hope and Dying. Related studies have noted the importance of ‘hope’ in the experience of dying patients. Benzein et al. (2001) interviewed 11 patients in outpatient palliative home care. They were interested in looking at patient narratives regarding hope. The patients were asked specifically about their lived experience of hope and to provide concrete examples of their experiences. Findings showed patients felt that hope was related to a will to live for a while longer. The patients also expressed that they lived in great uncertainty, experienced a lack of control, and that uncertainty in their lives gave rise to their thoughts on spirituality. Four central themes regarding hope were: “...a hope of being cured, a hope of living as normally as possible, a presence of confirmative relationships and reconciliation with life and death.” (p. 120). The study notes that there appears to be a tension between various aspects of hope. To hope for life (hope for something) but to also to have reconciliation with and comfort with life and death (living in hope). “The experience of belonging to both life and death is a disunion and a puzzling situation. This dialectic experience of belonging to “two worlds simultaneously—the world of the sick and the world of the healthy” (p. 123). The philosopher Marcel speaks of this not as a contradiction but as the ‘ontological mystery’ i.e. to ‘hope against all hope’.
Marcel believes that the understanding lies in viewing hope as a mystery, i.e. 'I cannot place myself outside it or before it... I am inside it'. This can be accomplished only in a state of recollection, by joining 'being' and 'acting' or, in other words, transcending the dualism between the two. Recollection means to 'recollect' myself as a unity, which also includes relaxation and abandonment. Within recollection, I become capable of taking up my position – in regard to my life; I withdraw from it in a certain way...it is an inward hold, an inward reflection. (The ontological mystery)...is a mysterious principle that one person’s will is also the will of other people (i.e., feeling connected) and that being doomed to death does not mean giving up, being a useless creature, but entering into the state of encountering oneself beyond all judgments of life ((Marcel as quoted in Benzein et al., 2001, p.123).

Paradoxically, this research suggests that hope is even of value when facing ultimate loss of life. This implies that hope is an essential spiritual need and that supporting hope (but not a false sense of hope) is relevant in end of life care.

Research on Family Satisfaction. Several studies inquired about the level of family satisfaction with hospice care (Grbich, 2001; Greer & Mor, 1986; Kane, Wales, Bernstein, Leibowitz, & Kaplan, 1984; McGrath, 2001; Nolen-Hoeksema et al., 2000; Seale, 1991). McGrath’s (2001) notes that the relationship between client satisfaction and quality of life measures is not clearly understood. In an attempt to gain a better understanding of the elusive outcomes of hospice care, McGrath (2001) looked at family satisfaction in a Buddhist-based Australian hospice outpatient service. This research aimed to gain a better understanding of family needs in order to create a family
satisfaction survey. Families spoke of "...compassion and genuine caring, respect for choice, joy in living whilst dying, the holistic care, continuity of follow-up, anticipation of needs, the importance of the private space at home, and spirituality..." as central tenets of care (p.84). The focus groups regarded the hospice experience as being a spiritual journey whereby the hospice staff was instrumental in creating a space for this journey. Another important finding of this study was that times of great joy and meaningful contact were conceived as being central to the family's experience. While family needs and experience of care is central to hospice concern, future researchers may also wish to focus on patient experience and satisfaction with care.

Grbich (2001) found similar findings in her study of caregiver's strategies for coping with caring for the dying family member and coping with loss. The study explored family members' emotional experiences and coping strategies while utilizing home-based hospice care. A stratified random sample was attained from referrals to a community hospice program within an approximately one-year time period. Twenty family carers were interviewed. The first interview looked at the family perception of the initial diagnosis experience. The second interview addressed the experience of care. The final interview looked at the post bereavement experience. Broad, open-ended questions were used to get the family perspective. All seventeen of the live-in caregivers reported "...extreme physical and mental exhaustion, noting that they were too tired to cook or eat properly, and had no time to just sit and relax. They also experienced endlessly disturbed sleep" (p33). Coping strategies included: "...tai chi, woodwork, dancing, going to football, going out to eat or drink with friends, going shopping, or going for a walk" When the caregiver was continuously needed by their loved one, strategies included:
"...guitar playing, walking into another room, talking to oneself, talking to family, friends, or a priest, using the research interview as a therapeutic outlet (self-reflection; organizing life around the patient, functioning on automatic, and being flexible and adaptable)" (p. 34).

In regards to post-bereavement, coping became more difficult for the participants after death. Participants expressed feeling physically and emotionally worn out, overwhelmed, disoriented, with a sense of inertia and lack of direction and organization in life. The caregivers spoke of family, friends, religious networks, and other community resources as being their main support during this phase.

On the other hand, fifteen of the participants expressed "...considerable pleasure that death was a lengthy process as it allowed them to explore things which they wouldn't have had the opportunity to do had it been a sudden event" (p.33). These participants noted that their “burden” of care, was also accompanied by strong positive emotions related to the opportunity of experiencing precious moments of loving communication and contact with their loved one. Again, this study points out the importance of transpersonal, meaningful contact. It also points out that the grief experience can coincide with personal growth. This current study aims to explore this possibility of growth when facing the end of life.

Other studies have also found that bereaved families feel personally supported by the hospice service. Nolen-Hoeksema et al. (2000) performed a long-term study of families served by 11 outpatient hospices in the San Francisco Bay area in order to test the correlates of family member satisfaction with hospice care. Satisfaction with care was measured by general satisfaction ratings measured by Lickert scales and 'yes' and
‘no’ responses. If participants expanded their answers, their responses were coded and themes were extracted from the data. This methodology was valuable in getting at general sentiments. However, it ran the risk of getting only superficial data that does not explore subjective satisfaction at a more descriptive, depthful level.

Ninety-five percent of those surveyed stated that hospice care had been helpful. Dissatisfaction with services was correlated with caregiver characteristics such as gender, history of depression, perception of support from others in the family and friends, and perceptions regarding the amount of care needed by the patient. This study suggests that intervening variables exist that may interfere with accurate caregiver assessments of patient experience and needs. Future studies could also get direct feedback from patients to supplement family feedback.

Some research indicates that the surviving family members believe that hospice helps to alleviate the pain of patients (The National Hospice Organization as cited in Merriman, 1999). However, many studies have found that caregiver’s perceptions of care and quality of life are different from the patient’s perspective. Intervening variables such as characteristics of the caregivers were correlated with certain responses of satisfaction (Nolen-Hoeksema et al., 2000) and there is a tendency for primary caregivers to rate patient quality of life lower than the patient rates their own quality of life (Bretscher et al., 1999) and misconceive of certain aspects of patient experience such as psychological symptoms or degree of distress caused by symptoms (Field et al., 1995). Wilkinson et al.’s (1999) literature review examined 831 research documents and noted that this is especially the case in retrospective assessments whereby intervening variables such as the process of grief over time may skew satisfaction and view of patient needs.
For instance, the family member’s own sense of loss and resulting depressive symptoms might cloud their memory of the care and experience of the patient. Direct assessments of patient experience is a valuable source of input.


**Research on Patients.** Some studies have aimed to correct the lack of direct patient input in research by interviewing patients alongside of other stakeholders in various palliative care settings. Steinhauser, Clipp, et al. (2000) used focus groups and in-depth interviews with patients, families and health care providers to gain a better understanding of what constitutes a ‘good death’. Major components of a good death were process-oriented and had biomedical, psychological, social and spiritual components. They included: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Since the findings were process-oriented, they fall in line with the view that the experience of dying can be understood through a developmental perspective. This study also found variations amongst group opinions whereby physicians held biomedical aspects as most important whereas patients and families held psychosocial and spiritual issues as equally important as physiological concerns.

Steinhauser, Christakis, et al. (2000) also performed a cross-sectional, stratified random national survey of 340 seriously ill patients, 332 recently bereaved family members, 361 physicians and 429 other care providers (such as nurses, social workers,
chaplains, and hospice volunteers).

Patients and families were randomly selected from the national Veterans Affairs (VA) Patient Treatment File database and caregivers were selected from membership lists of national professional associations. The average age of respondents was 57 years. Fifty-one percent of the respondents were men, 82% were white, and all but 10% noted some religious affiliation whereby patients and family members had slightly higher levels of religious affiliations. Finally, 44.2 to 48.3% of patients and family members had a high school level of education.

A written questionnaire included ratings of the importance of 44 attributes of end of life experience. The survey was based on the findings of the previous study listed above which conducted 12 focus groups and in-depth interviews with patients, family members, physicians and other care providers to assess their conception of a ‘good death’. Twenty-six items were consistently rated important by at least 70% of the respondents. These included pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a “whole person.”

There was also variation amongst the beliefs of each group in regards to what a ‘good death’ constitutes. For instance, 8 items were considered very important by patients but significantly less important by physicians. These included: being mentally aware, having funeral arrangements planned, feeling that one’s life was complete, not being a burden to family or society, being able to help others, coming to peace with God, and praying. The greatest variation in ranking between patients and physicians was in regard to being able to help others (88% of patients agreed that it was very important at
the end of life while 44% of physicians believed this not to be the case). The study notes multivariate analyses controlling for sex, race/ethnicity, socioeconomic status, household composition, religion, and religiosity showed that patient differences still persisted. Intra-group and inter-group variation was seen on ten items including: decisions about life-sustaining treatments, dying at home, and talking about the meaning of death.

Patients were significantly more likely than all types of caregivers to stress the importance of using all available treatments irrespective of the chance of recovery. This finding is congruent with Benzein et al.’s study (2001) on the importance of patient’s sense of hope for recovery. In this study, participants who saw faith or spirituality as unimportant were significantly more likely to view the control of time and place of death as important. These researchers also found that the other form of hope essential to living through dying is “living in hope” which includes reconciliation with life and death.

Steinhauser, Christakis, et al. (2000) also found that care providers and family members were more likely to agree that talking about the meaning of death was important. Patients who felt faith or spirituality was important or patients and family members who were women were more likely to agree that talking about the meaning of death was important.

The 44 attributes were grouped into nine categories including (a) freedom from pain, (b) being at peace with God, (c) the presence of family, (d) being mentally aware, (e) treatment choices, (f) having finances in order, (g) feeling life was meaningful, (h) resolving conflicts, and (i) dying at home. According to these categories, patients noted the importance of spirituality and both family and patients ranked coming to peace with God as utmost importance whereas physicians and other care providers rank these
attributes as less important (p. 2481). The researchers suggest that for some patients, "...issues of faith that are resolved with oneself are more important than social or interpersonal expressions of spirituality" (p2482). Finally, patients ranked pain control only slightly higher than mental awareness (with a mean rank difference of 1.51) whereas physicians ranked pain control much higher than mental awareness (with a mean rank difference of 3.76). This suggests that lucidity may be more highly valued than analgesia by patients than by physicians. Variation in opinion was believed to be moderated by individual values, knowledge, and preferences for care (p.2481).

This study aimed to access the meaning of the dying experience directly from patients. It also provided a useful empirical information regarding the views of various individuals in a variety of settings with a broad range in age, education and socioeconomic status. Finally, it points out some possible differences in patient and caregiver perspectives.

However, it does have some limitations. First, most of the participants had religious affiliations and the findings may not be transferable to non-religious individuals. Second, while it utilized focus group research to boost validity and reliability to its question set, it did not include open-ended questions to allow for freedom in response. Future researchers could utilize in-depth interviews to compare these findings to the focus group and survey responses.

Bretscher et al. (1999) state that "relatively scant objective data are available about the lived experience of dying from the point of view of the patient" (p.309) although quality of life is subjective in nature. They point out that while soliciting patient views may not always be possible, they should be viewed as the primary resource of
patient needs and experience. Their study used self-administered QOL scale questionnaires to test the views of 22 patients, as well as their primary caregivers and hospice nurses. Findings indicated that the dying person does not always perceive his/her state as negatively as their caregivers, and that not all dying patient have a progressive decline in quality of life. The authors state that an important implication of these findings is that hospice caregivers need to listen to patients more often. This also implies that future research would benefit from a similar approach of collecting direct feedback from patients.

Field et al. (1995) studied 28 terminally ill patients and their lay caregivers in home care prior to admittance into inpatient hospice care. They asked questions regarding support needs in daily living, patient symptoms, patient knowledge of their illness, and the care they received from doctors and nurses in the hospice and in the community. Reports did not differ significantly in regards to specific activities of daily living. However, there was discrepancy between patient and caregiver reports on psychological symptoms such as anxiety, depression and change of mood. Caregivers reported that these symptoms were present more often than patients’ reports.

This is an important finding because it underscores that there are certain aspects of quality of life that are not as visible to caregivers and may be misunderstood due to the caregiver’s own characteristics. It is possible that the patients had a means of coping that was not communicated to these caregivers. Another possibility is that patients wanted to appear on best behavior upon entry into the inpatient center. Whatever the case, the focus of this study was fairly narrow and it did not contribute significantly to our understanding of the lived experience of dying. The questions focused primarily on
physical, and general mental symptoms (such as confusion, depression and anxiety). There was nothing asked about general quality of life or various aspects of holistic health. It is possible, for instance, that there is a discrepancy between patient spiritual experience or needs and caregiver’s conception of this experience or these needs.

The studies listed above suggest that there is a discrepancy between patient and caregiver’s conception of patient experience and needs. Therefore, it is would be useful for research to access more of the patient ‘voice’. This is especially the case since hospice care promotes itself as being a responsive, client-centered service. These studies also suggest that accessing the patient voice may require research that is indepth and qualitative in nature.

Research Measures. Some studies have attempted to survey patients regarding their experience and needs through the use of assessment tools. While direct information from patients is central to understanding their needs and experience, there are limitations to using such tools. Eischens, Elliott, and Elliott (1998) polled nurse (n=8) opinion regarding the value of various quality of life assessment tools. The study notes that assessment tools have evolved from focusing on physical functioning to self-report formatting. It argues that such a format is more valid and reliable since it allows for the patient’s view to come through. Eischens et al. (1998) state that in the last five years, QOL forms for palliative care use have been created that use “...relevant content, simple directions, and ease of administration”(p.144). The surveys studied here included the Revised Version of the Hospice Quality of Life Index (HQOL) and the McGill quality of life survey (MQOL). The researchers selected these inventories because of “...their relevant content, simple directions, and ease of administration” (p.144). Both are Lickert
scales that measure aspects of holistic care.

Findings showed that nurses (n=8) felt that the HQOL scale was inadequate for their patient population because it was confusing (e.g., could be confused with scales used already to assess pain), too long, and contained a category (on sexual activity) that was inappropriate. However, the nurses reported that the rest of the aspects of quality of life tested were relevant and that questions in the test were appropriately phrased.

The nurses reported that the MQOL contained scales that were confusing to patients. For instance, "...the questions used scales that reversed from question to question (‘1’ meaning ‘most’ in one question and ‘least’ in another)” (p.146). However nurses did feel that the MQOL was helpful in assessing various aspects of holistic care, and that it was an appropriate length and easy to administer. Overall, the nurses preferred the MQOL scale to the HQOL scale and noted that their daily care plans improved through its use.

While nurse opinion is valuable in assessment, this study fails to ask the patient’s view of the tools. In addition, it polled home hospice care nurses and its findings may not be easily generalizable to inpatient hospice nurses. Difference in their perspective may occur because inpatient hospice nurses can be involved more fully in their patient’s care, and therefore, have more time and sense of the patient needs.

Another limitation of the Lickert inventories listed above is that they do not specifically measure spiritual experience (Cohen & Mount, 2000). Current research has suggested that spiritual experience in essential to understanding the holistic experience of individuals nearing the end of life (Herman, 2001; Kausar & Akram, 1998; Steinhauser, Christakis, et al., 2000; Thomson, 2000).
Guo, Fine, Mendoza and Cleeland (2001) also assessed the validity of the Brief Hospice Inventory. They note that there are very few valid and reliable outcome assessment tools for hospice care. Five assessment tools commonly used in this context are discussed including: the Missoula-Vitas tool, The Hospice Quality of Life Index, The McGill Quality of Life Questionnaire, The McMaster Quality of Life Scale, and The Brief Hospice Inventory (BHI). They note that the Missoula-Vitas assesses general symptoms and does not address specific symptoms. They also argue that the Hospice Quality of Life Index does not deal with the complete range of symptomatological variables such as shortness of breath. Finally, they state that the McMaster Quality of Life Scale is a cumbersome tool for some seriously ill patients. As an alternate measure, they looked at the Brief Hospice Inventory which covers both physical and psychological symptoms.

Guo et al. (2001) used the BHI to access 145 home-based hospice patients and their professional caregiver's perspective of their patient's symptoms and quality of life. They found that the BHI was useful in assessing symptom severity and quality of life over time. However, this tool is limited in scope, is not-open ended, and does not address all of the basic aspects of holistic quality of life such as spirituality or symptomatology resulting from spiritual or social needs.

Novak, Kolcaba, Steiner and Dowd (2001) also tested several formats of end-of-life comfort for patients. They tested 38 patient-caregiver dyads in both in- and outpatient settings. They administered the General Comfort Questionnaire, as well as visual analog scales to access aspects of comfort. Results showed strong reliability and beginning validity for the questionnaires. However, the study does not specify the content of the
questionnaires and so it is impossible to judge the validity of its questions.

Many surveys of professional palliative care workers attempt to assess the needs and experience of patients through other indirect means. They provide only a limited sense of the patient’s voice. This study will aim to give voice to patients by using a qualitative, face-to-face interview methodology.

Abu-Saad (2000, p.20) notes that there are no “gold standard” measures in palliative care research and that there is a need for further psychometric testing before instruments are used with patients. Fakhoury (1998) states no comprehensive research has identified the relevant dimensions of palliative care. The studies listed above suggest that different tools serve different purposes and each comes with their own set of values and drawbacks. As a result, the research question posed should determine the optimal method of inquiry.

Abu-Saad (2000) states that qualitative methods may be a particularly well suited methodology for palliative care research since they can reflect the complexity of the palliative care “encounter” and study the phenomenological experience of individuals in hospice (Beresford, 1996). Both Beresford (1996) and Merriman (1999) argue that hospice research ultimately tests an inherently subjective experience that is difficult to quantify. For this reason, Merriman (1999) points out that large scale research in the area is challenging.

Hospice research ultimately tests an inherently subjective experience that is difficult to quantify with the current measures of study. The benefit to using a phenomenological approach is that it allows for a person-centered, flexible, and intimate form of data collection. Teno (1999) states that quality of care can only be heightened by
“listening and responding to the patient’s voice” (p.168).

McKinlay’s Circle of Care. As noted earlier, there are a limited number of studies using interview methods with patient informants and only a couple that used an open-ended phenomenological approach. McKinlay (2001) used such a methodology in order to gain a better understanding of patient experience within an inpatient hospice center.

She states that, “There is a mystery about the journey of dying, which situates it in the realm of the only-partially understood. There will always be a conflict between the known and the unknown, what should be investigated and what should be hidden. Lived experience conveyed through story expands this understanding” (p.22). McKinlay attempted to fill the gap that other researchers have not addressed by focused on the unquantifiable aspects of the dying person’s experience. She used the hermeneutic-philosophic approach developed by van Manen (1990). The phenomenological method is based on the belief that “…multiple truths and beliefs exist, even within a very defined group” (p.24).

She interviewed six New Zealand patients in a hospice inpatient center. Three were men and three were women and all were between 58-79 years of age. The interdisciplinary staff identified individuals who were “least vulnerable” in all aspects of health. The term “least vulnerable” meant “potential participants were judged by the staff to be able to sustain the research process of meeting the researcher, being asked questions, and having to reflect emotionally and verbally on their illness and care” (p.24).

Two questions (as well as several prompts designed to meet various responses) were asked including (McKinlay, 2001, p.25):
(a) What services have you been involved with at the hospice since you first started to go there?, and

(b) I’d like to go on to talk about your experience of care at the hospice. It may be difficult for you to talk about that directly; you may find it easier to tell me a story or to describe a situation which remains in your mind about your care at the hospice. It may have been good or not so good.

The themes that emerged from the interviews were conceptualized as interconnected experiences of palliative care forming the ‘Circle of Care’. This circle is composed of 11 themes and are described through descriptive accounts (through anecdotes given by the participants) as well as interpretive accounts (thematic summaries of elements in patient representations).

The first and most central of the themes is ‘Identity’. Eight themes—five of which were patient actions—included keeping control, chosen isolation, being safe, relinquishment and relaxation, and mortality awareness. Three other themes related to interpretations of staff actions including being watched, caring qualities and humour. Another theme in the patient’s accounts was the experience of ‘the philosophy of care’. The last theme evident in the stories pertained to the ‘environment’ which comprised of both aesthetic and spiritual dimensions.

McKinlay summed up that “only people who are living with all that it means to be dying—the symptoms of the illness, the threat to mortality, the anticipated grief and losses, the look in their loved ones eyes, the inevitable fatigue and mental clouding—can state what is of value to them” (p.27). She notes that patient accounts emphasize process (rather than outcomes) of “…acknowledging identity, of being watched, of relinquishment
and relaxation, of being safe, of keeping control, and of chosen isolation” (p.28). She states that this study is small and there is much room for further research in this area of patient experience of any and all of these themes in the Circle of Care.

Kuhl’s Exploration of What it Means to have a Terminal Illness. Another study that utilized a phenomenological approach was Kuhl’s (1999) work entitled: “Exploring Spiritual and Psychological Issues at the End of Life.” He focused on what it means to have a terminal illness. He completed a 10-year study which used in-depth interviews to ask 21 individuals what it meant to have a terminal illness. Some of the individuals were interviewed one time, and others were interviewed numerous times over the course of 2-11 months. The interviews were predominantly in home settings, with a few being in a hospital palliative care unit. Kuhl (2000) found that individuals spoke of facing both spiritual and psychological issues including (a) changing perceptions of time, what it meant, and how to spend it, (b) the suffering they experienced when receiving their initial diagnosis and their need to communicate effectively with health care professionals, (c) the physical pain and its affect on who they were, (d) the natural process of reviewing one’s life as a result of understanding that they were going to die, (e) speaking and hearing the truth, (f) longing to belong, in regards to past relationships and present relationships, (g) asking the question—Who am I?—to know who they were in the present, free of the expectations with others, and (h) experiencing transcendence through meaning, value, God, spirituality, a higher being greater than oneself. In addition, he found that participants wished that what they shared would make a positive impact on society, and in the suffering of others facing a similar situation. It is possible that these findings would vary in alternate settings.
Both McKinlay (2001) and Kuhl (1999) studies provided insight into the end of life experience. McKinlay (2001) provided a useful framework for conceptualizing the patient’s holistic experience of in-patient hospice care. Kuhl’s (1999) study did not take place in an inpatient hospice and was not focused on care but on facing the end of life.

This current study built on the work of both authors using a similar open-ended phenomenological approach to data collection. It aimed to lend further understanding to the concept of “self” or identity, within the dynamic interplay of the experience of dying and hospice care.

Method

This chapter will discuss the existential phenomenological methodology utilized in this study as well as the question of rigor. It will also describe the participants, ethical issues related to on-site hospice research, the investigation procedure, and the data analysis.

The Research Question

What is the lived experience of facing the end of life in an inpatient hospice environment?

The Phenomenological Method

This study utilized an existential phenomenological approach (Valle, 1998). This approach is congruent with the hospice philosophy—which aims to be person centered and respectful of the unique perspectives and needs of all it serves.

The aim of phenomenological inquiry is to reveal the lived experience of the individual through an exploration of that individual’s subjective values, beliefs and sense of meaning. “The phenomenologist affirms the life-world experience and proceeds by
critically examining it, in order to describe its essence, structure and character” (Karlsson, 1993, p.43).

The researcher attempts to represent an individual’s experience in its pure form. “...The aim is to understand a phenomenon by allowing the data to speak for themselves, and by attempting to put aside one’s preconceptions” (Osborne, 1990, p.81). In addition, existential-phenomenological research is interested in questions that relate to the meaning of life and an examination of death is central to this investigation (Valle, 1998).

Van Manen (1990) states that the aim of data collection is to describe the deep meaning structures. To do so, Kvale (1983) outlines the following aspects of phenomenological interviewing: “(a) it is centered on the person’s life world, (b) it aims to grasp the meaning of phenomenon of this life world, (c) it is qualitative, (d) it is descriptive, (e) it is specific, (f) it is presuppositionless, (g) it focuses on certain themes, (h) it is open to ambiguities and changes, (i) it depends on the sensitivity of the interviewer, (j) takes place in an interpersonal interaction, and (k) it can be a positive experience” (p.174).

The overlap of various individuals’ lived experiences offers a clearer sense of the core nature of common human experiences. In other words, the goal is to describe lived experience shared by various respondents (shared meaning) and thus shed light on essential structures of a phenomenon (van Manen, 1990). In this research study, the intent was to explore the shared sense of how people face the end of life and how they experience hospice care.

Rigor

Rigor is an important consideration in phenomenological inquiry. McKinlay
(2001) points out that the trustworthiness of the data is dependent on “...the detail given to the reader about how the interpretation was made, and the audit trail of the overall research process” (McKinlay, 2001, p.24). The audit trail can be tested by “...reflection in conversation and writing with clinical and academic colleagues, with the academic examiners assessing this work” (McKinlay, 2001, p. 24). Lincoln and Guba (1985) also point out the importance of factors such as credibility, dependability, and confirmability for enhancing the trustworthiness of findings in phenomenological studies. This study includes the following information that should assist the reader in assessing the trustworthiness of the data: (a) a description of the interview process including an explicit description of the prompts, (b) a description of the data analysis process which included several examinations of data by my academic supervisors, (c) an audit trail consisting of the typed and coded transcripts (on file in the U.B.C. Department of Educational and Counselling Psychology and Special Education) and data analysis notes (available from the researcher).

Another aspect of rigor in phenomenological inquiry is the premise that because each individual experiences life through their own unique subjective perspective, it is essential for a researcher to be cognizant of their own personal subjectivity that could interfere with the data collection and analysis. Before beginning this study, I went through the process of bracketing my personal perspectives, biases and preconceptions. For instance, I recognized that I believe that spiritual and existential awareness are basic dimensions of human experience and, as such, are important in understanding human beings and in the practice of counselling. I also recognized that I believe that facing the end of life could bring growth in spiritual and existential awareness. As a result of this
bracketing exercise, I was always aware in my interactions with the interviewees and my analysis of the data, to let the data 'speak for itself'.

Participants

Individuals living at two Vancouver hospices—May's Place and Cottage Hospice (both operated by the St. James Community Services Society)—were recruited for this study. Recruitment was done on a strictly volunteer basis and those selected included individuals who could give informed consent (based on the clinical assessment of the head nurse). This maximized the number of individuals in the study while not discriminating between participants.

Eight hospice residents, age 50 to 92, volunteered to be interviewed about their experience of living in the face of death and all of the participants were dying of various forms of cancer. All of the participants had lived at the hospice for at least two weeks before being interviewed. Three of the participants were women and five of them were men. Six participants were Caucasian, one was Native, and one was African. The socioeconomic status of participants ranged from lower to middle-class. Four participants had been married—three were widowed and one was divorced. Three of the participants had adult children. Two participants identified themselves on the hospice intake form as spiritual and/or religious—one practiced as a Muslim, the other, as a Jehovah Witness.

Ethical Issues

Due to the vulnerable nature of this population, it is important for qualitative studies to be especially sensitive and respectful of participants’ rights (Raudonis, 1992). Clinical judgment of hospice nurses was respected as to which residents were capable of
giving informed consent. Verbal and written consent was attained directly from these residents after they had a chance to read an advertisement for the research study. Participants were told that their participation would not affect their hospice care in any way and that they could choose not to participate at any stage of the research.

I aimed to carry out the research in a way that was compatible with the operating philosophy of the hospice including respect for teamwork and community, respect for the patient and family’s quality of life and self-determination, and valuing and respect for the person’s well-being. I endeavored to be aware of my relationship with the hospice staff and the impact of my presence on the day-to-day functioning of the hospice. I also endeavored to be flexible and to blend into the day to day functions at the hospice, trying not to interfere with client needs or with staff roles. In addition, I kept the Coordinator of the hospice informed about the general progress of the research—without breaching confidentiality of the participants.

The participants were empowered to choose the level, extent, and quality of their participation in the interview process. The interviewing schedule was flexible to allow for participant preference in regards to length of the interview and whether they needed to take a break during the interview. Since the topic of the interviews entailed the discussion of emotional issues, participants could have experienced emotional distress. This required that I was sensitive to the possible impact on participants and that I conducted the study in a manner that placed the person’s well-being before all other considerations.

Procedure

The two hospice settings had a total number of 16 bedrooms and therefore, had a
capacity to house 16 people. There are approximately 2 or 3 new residents per month. I assumed therefore, that approximately 25 people would reside at the hospice for some period of time during the 4 month data-gathering phase. I understood from my planning discussions with hospice staff that some of the residents would not be psychologically able to participate and to give informed consent. It was also clear that some would only reside at the hospice for a short time before they died and that it would not be logistically possible to schedule interviews with those people. It was also evident that some people would not want to volunteer for the study. I assumed therefore, that the maximum number of participants would be approximately 10 individuals. I ended up interviewing 8 individuals. My assessment, in consultation with my supervisor, was that rich, common, and coherent themes had emerged in the 8 participant responses and that further interviews were unnecessary.

The selection process was as follows:

(a) A letter was sent to the organization outlining the purpose and general format of the study and inviting their residents to participate.

(b) The head nurse discussed my request with each of the residents that they assessed as psychologically well enough to participate and to give informed consent. The discussion took place with all eligible residents who were living at the hospice at the point at which my letter was received as well as with any new eligible residents who moved into the hospice during the four month data gathering phase of my project.

(c) The head nurse would telephone me with the names of the individuals who volunteered to participate and I would set up a time to go to the hospice to meet with them.
The interviewing process was conducted in a manner consistent with the earlier discussion on ethics and hospice philosophy. For example, I always put the comfort of the participants ahead of the task at hand and would often assist them to get more physically comfortable, get them something to drink, or give them time to take a break.

After I introduced myself to a volunteer, I explained the purpose of the research, the research process, the ethical guidelines, and their rights as volunteer participants. I also re-verified whether they wished to participate. This proved to be an important step since one individual who had initially indicated to the head nurse that she wanted to participate, told me when I asked her, that she was really not keen on participating, so I did not interview her. All 8 volunteers preferred to do the whole interview in one sitting when we met. Therefore, once the participants had signed the consent form, the interview ensued. The interviews lasted 40 to 90 minutes. All of the interviews were audio-taped for subsequent transcription and data-analysis. The interview question was:

1. Can you tell me about your experience, and what life has been like for you, from the time you first heard about your illness?

In addition, certain prompts were used to explore (a) relationships, (b) values, (c) self-concept, and (d) sense of time—if the participants did not already address these areas in the initial response. These prompts included:

(a) Has your relationship with family and friends changed, or been affected, since you learned about your illness?

(b) Has your views about life...i.e. your beliefs and values changed, or been affected, since you learned about your illness?

(c) Has your views about yourself...i.e. how you see yourself and feel about
yourself changed, or been affected, since you learned about your illness?

(d) Has your sense of time changed, or been affected, since learned about your illness?

The participants were also prompted about their hospice experience in the following questions:

(e) Can you tell me about your experience here at the hospice?

(f) Is there any way that hospice services here could be improved?

I originally intended to have an entirely open-ended inquiry. However, as part of my planning process, I conducted a pilot interview with someone who would not be included in the study population. This “practice run” as well as discussions with hospice staff, and my review of the literature, convinced me that the process would be facilitated by the use of some prompts. Therefore, I prepared prompting questions in the case that they should become necessary.

These prompts proved to be essential to the research process since the participants responded better to a conversational style of dialogue with some concrete questions rather than an entirely open-ended inquiry. This preference could be related to physical aspects of their experience (e.g., their health and energy level) and/or to psychological aspects of their experience (e.g., values).

In order to provide a sense of closure to the interview for the participant as well as to obtain feedback regarding the experience of participation, the client was asked:

2. How was it for you to participate in this research?

Raudonis (1992) suggests that a greater understanding of ethics in qualitative hospice research, as well as the meaning derived from such research, could be attained by asking
patients at the end of the interview what the experience of participating was for them. Therefore, this research includes an analysis of participant responses about their experience of the interview process.

The participants were given a thank you card soon after the interview.

Data Analysis

The raw data were transcribed and coded to keep the identity of participants protected. The analysis and write-up of the findings required translating the qualitative comments into summary form. I used content analysis to extract common themes from the responses. Patton (2002) notes that this process includes several readings of the data, labeling the data, and establishing a data index for clustering and analysis. While the questions are open-ended, they were structured to address separate topics for thematic clustering.

The thematic analysis outlined by van Manen (1990) was used to understand the meaning participants attribute to their lived experiences. Themes were extracted using two approaches including the wholistic or sententious approach (making a core summary of the transcript in 4-5 lines), and the detailed or line-by-line approach (doing a line by line analysis and then creating a larger summary).

The study of the themes was guided in part by previous thanatology literature, any prompts or questions that were asked (e.g., on relationships), and by an existential framework including: lived space (spaciality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality).

After each transcript was read wholistically, core summaries were made to get a general sense of the themes that emerged. With a general sense of the themes, the
transcripts were read through line-by-line and themes were recorded in the margins of the
transcripts. At this stage, any and all possible themes were recorded and when a theme
overlapped with another, it was recorded under both categories.

The themes were charted on a conceptual map with all the possible themes and
corresponding quotes listed. I consulted the data several times, re-read the thanatology
literature, and consulted with colleagues and my academic supervisor during the
conceptualization process. When the themes became more refined, I consulted with my
academic supervisor and together, we assessed the general patterns in the data and the
quality and quantity of quotes under each theme. We eliminated quotes that were vague
and kept only the comments that were clear examples of certain themes. Based on the
collection of quotes that remained, we reassessed the patterns in the data. Some themes
were placed more logically as sub-themes under more general themes. Some themes
were much less pronounced and could be integrated more logically in other categories.
Then the themes were shown to another academic supervisor and the titles of the themes
were refined to better represent the data in phenomenological terms.

Findings

This study asked ‘What is the experience of facing the end of life in an inpatient
hospice environment?’ Findings revealed that this experience can be defined by caring
about one’s relationships with others, caring about one’s relationship to oneself, a greater
awareness of one’s relationship to time, needing to think and feel positive, and caring
about one’s spiritual faith and experience. When one faces death in a hospice
environment, the experience of hospice is valued for how it impacts all of these
experiences.
Caring About One's Relationships with Others

When facing the end of life, relationships to family, friends and people in general can become very important. A general orientation to relationships is noticeable in one's caring about relationships, greater intimacy with others, an aim to facilitate one's relationships, and a focus on giving and receiving. Many participants in this study spoke of connections with others as of paramount importance in life. For example, one man expressed the importance of feeling connected with his deceased wife: "I go to my room (in the hospice), and it doesn't matter where I look—I'm going to see her picture." One woman spoke of the importance of her relationship with her daughters. When asked what is most meaningful to her currently in her life, she said:

My daughters. I have two girls and they visit practically every day whenever they can possibly come, they come, in the morning or afternoon, and their husbands come too—that means the most to me.

Another man shared that for him, family was of highest importance: "Oh, just family...that's about it—just my family." One woman said she felt lucky, and when I asked her why, she responded: "Having so many friends. Friends make your life. I like people. I've been with people all my life, worked with them—I like people. So, that saved me you know." When asked what is valuable and strength enhancing in his life, one man: "Well, most of it is the close friendships."

All of the participants spoke of the importance of their new relationships at the hospice. For instance, one man commented: "Ahh, the care you get here is excellent...and the staff—they tend to be more personal than in the hospital." Another person expressed how his experience of hospice relationships helped him feel less alone:
If it wouldn’t be for this (hospice), I would be more isolated. When I was in the
Marble Arch Hotel, I was just in a place on my own so I had to do everything
myself...

This individual also spoke of his need to connect with others after feeling depressed from
his diagnosis:

Well. I went down into the dumps.... Well, I imagine everyone felt the same way.
I’m not alone in this world. I’m not alone—no well, that’s why they’ve got a
hospice—it’s what it’s for.

One woman also shared that in her loneliness, she craved to connect with others:

I get lonely. No reason that I should because there are people all around me all
the time...but all my old friends are gone...the last one lives in Australia...and
I’ve made a lot of new ones and some of them—those people—come out—those
who have a car—come out to visit me. Yup, I couldn’t expect more you know,
really...But then again, not everyone is as lucky as I am.

Others spoke generally about the importance of connections and love. For instance, one
woman expressed a need for human contact:

A few people say “I have my three girls—I don’t need anybody else”—You do
need somebody else—and don’t let anybody tell you that you don’t. You need
other people to talk to—even if its not important—just somebody just to sit and
shoot the breeze.

In reference to the value of love, she stated:

...There isn’t enough love in the world...you know there wouldn’t be the
wars...you know, I think that if women ran the world there really wouldn’t really
be wars. You know women wouldn’t want to bear children and carry them for nine months and then turn around and shoot them.

**Greater Intimacy with Others.** When facing the end of life, there can be a change to how relationships are viewed, as well as how they are experienced. Most individuals in this study spoke about how their view of relationships and in fact, the nature of some of their relationships had changed by becoming more intimate as a result of the onset of their illness. Some individuals spoke of experiencing deeper connections with others. For example, one woman commented: “The bond has always been strong, but it seems to have strengthened since we knew...” Another man responded:

It was quite a shock. Before I went into the hospital, he’d keep telling me that ‘if you need any help, just call me because I’m available’... Ya, it made me look at it (the relationship) in a different way...you know because, here’s somebody who is supposedly ruff, tough longshoreman and all of a sudden, he—voluntarily just—you know, one of the first things he did was remove my socks and shoes and my feet were all peeling so he was rubbing my feet—with hand lotion you know! And joking with me saying “Don’t be telling anybody at the waterfront that I was rubbing your feet!” You know, and it went from there to helping me get dressed and undressed—if we’re going out in the chair or something, he’ll help me get my sweat pants on and he actually did the shopping for the sweat pants.

He also spoke of having a deeper knowledge of his friend: “It just made me see him in a different light. You know, I’d never seen that side of him before.” Another man also experienced greater intimacy since the onset of his illness:
I think it (relationships) got better...the people I know—the people I travel with—they seem to understand that there's a change. They could see it—even before they knew what it was—they knew there was something different about me.... Some how, they got to know what it was—and we were like that (showing a strong bond gesture with his hands).

This man also recalled an earlier experience when a friend of his had got cancer and it had brought them closer together: “I knew when he got the cancer and, I don’t know...it got me closer to him too...” Another person spoke of valuing other people more at this time in his life:

    Well, when I got these (tattoos), if you looked me the wrong way—I’d punch you out....ohh people didn’t mean anything to me then.... I’ve got more respect for people now...People mean more to me now than they did...you know? They’re not these goofy people anymore...they’re adults. You know?

A couple of participants spoke of the pain of not being able to connect with family or friends. For instance, one man commented:

    There’s only one thing I’d like to do one more time...I would like to see my kids one more time.... to say a final good-bye...ahh...I don’t want him to care...I don’t want him to feel hurt...and I want him to look after his woman—they’re young you know---and their children....Ya, just look after his family and that...You know...make sure everybody is ok.

**Aiming to Facilitate Relationships with Others.** Not only does one appreciate relationships, but one may also recognize what facilitates relationships, and take action to facilitate relationships with others. Most individuals interviewed spoke of their ability to
connect with others as facilitated by openness, honesty, and authenticity. One person used the interview process to illustrate her views on openness: “Look, we are both talking and we are trying to open up to each other. If you don’t open up...that means you won’t be able to know yourself and other people too.” When asked what it means to ‘open up’, she responded: “To open up is...that you don’t have to be ‘miser’ (Interviewer: Cheap?)...cheap, cheap, cheap.... Be open...available to anybody.” The same participant spoke of the value of “opening up”, the importance of giving oneself a “chance” to open up, and the natural shifts in capacity to open up:

Ya...well...you give yourself a chance to open up...There will be a time that you open up very little...and will be a time when you can open more....you see?....It depends on the time...and your thinking whether you have the opportunity of opening this much...you’ll know in your heart.

Another participant spoke of being authentic regardless of whether or not it is the social norm:

I remember the relatives of my daughter’s mother-in-law...she had one son...she was very “up to herself”—Everything was very proper and she was different in her outlook at the time...and when her son married my daughter, she saw a difference in the way people lived I guess...and you know, I would grab her and kiss her hello whether she liked it or not! I mean, just being...I mean she’d come in the door and I’d greet her just like everybody else.

One person experienced that her self-knowledge and knowledge of others were dependent on her degree of ‘openness’: “If you don’t open up to each other...if you don’t open up...that means...you won’t be able to know yourself and other people
too…Got it?!” One participant spoke of the strength she derived from more honest contact:

…They (friends and family) give me strength too because, I think I’m honest with them. If I am not honest with them, that means they cannot be open with me you know?

Finally, one person spoke of appreciating honesty from health care professionals:

…If I want to ask about some job, well, I want the blood truth about it…And I said, what’s wrong with me—tell me right out. And he says “you’ve got incurable cancer and it’s asbestos cancer of you boilers that you’ve worked on since you were 21.” That’s the biggest thing—to be told that—well in my opinion…some people might not like it—but as a professional engineer—that’s the best thing that could have happened to me—to be told straight out. They respect you in telling you and I respect them for telling me.

Focusing on Giving and Receiving. Caring exchanges with others may become of central importance to the dying individual. There is an appreciation of the care received, an experience of adapting to receive more care, and a desire to not just to receive, but to give to others as well. Most respondents spoke of appreciating care and of receiving more care from others. Many also spoke of caring as difficult to describe but of paramount importance in life. When asked about whether or not relationships have changed, one person expressed: “Oh no…no, no…. unless you could say for the better…. it could be for the better because they look after me, they watch me constantly and phone.” Another spoke of feeling care from staff: “They are so…how can I say it—they
are more dedicated if there's such a word—and I don't know what it is but they are really really dedicated...and you can feel it.” Then, in reference to a nurses' care, he shared:

...Basically, you know...going above her duty. I mean, she can only do so much but she does beyond that—she’s trying to help in any way that she can to try to make me feel better—and I can feel that...(Interviewer: Is it a ‘caring’ that you feel?) Ya, ya. I can feel that. It passes between two people. I can feel that. It’s not only her...Absolutely great. Great...really feels great because I know that the staff is on your side.

When asked if anything has given him strength or encouragement to live fully, some spoke of an increase of caring and noted that reciprocation was occurring at this time in life:

You know, as I went through life, I just treat people the way that I want them to treat me...and it has come back in just the people that come to see me...I must have dealt with them in a good way because it is all coming back now—they come to visit me and bring me home baked goods....

Another shared:

I think there’s a more caring attitude...from both sides. Like the couple that was here—she’s been almost like a daughter. I mean, her daughter is now 18—just graduated—I’ve known her—I’ve been looking after her and what not since she’s been 3.... So now it’s their turn to do for me.

Some respondents spoke of being a ‘receiver’ at this time in their lives. Some found it difficult to become a ‘receiver’, to learn how to receive, and to face a role reversal. One person shared: “Um, it was quite a shock. Before I went into the hospital, he’d keep
telling me that 'if you need any help, just call me because I'm available'.” One man spoke of having the experience of accepting more help:

...They do everything so that you don’t feel pain and if you say you're feeling pain—as they say, 'there’s no heroes in the hospital’...(Interviewer: you don’t have to endure excess suffering) No, no, no, no. That’s the first thing that that they try to tell you...because you’re used to putting up with it (the pain).

Another man shared that it was a difficult transition to receive care from others:

I’ve always been a very independent person—I’ve been a bachelor most of my life. I’ve always fended for myself and it was a challenge having to accept people wanting to help my—you know not just from the health care professionals but buddies from work that I’ve known for years.

All participants also spoke of their need and desire to give to others. One participant spoke of feeling a role reversal from being a giver to finding herself in the position of becoming a receiver. She commented that this was a difficult adjustment for her to make:

Well, I think I get a little frustrated, because I’ve always been on the other end—I’ve always been the caregiver and not the care-getter and so it’s definitely a new experience and it’s definitely frustrating....I want to be the one that’s giving the help.

As a result of this role reversal, she felt a heightened need to find ways to continue giving. When asked how she is able to give, she spoke of training staff:

Well...OK, we’ve got a new LPN on today—brand new. First day. And she came to give me a shower but she didn’t know how because I have a very special
method... So, I explained to her what we did and how we managed. So in that way, even though I'm not giving the care to somebody else, I'm making it easier for the next person who gets a shower from that particular LPN. So, it's give and take, but it's not quite the same.

She also spoke of how her independence needed to be supported in order for her to be able to give:

Ya because they give me my independence...I'm doing the things that I'm capable of doing.... (Interviewer: Do you still feel like a giver here in hospice?)

To a point. I won't say all the way—because it's not. But it is one of those things that they let me give as much as I can.

One man spoke of his desire to help in any way in response to the care from staff: “I know that the staff is on your side (his side) and if there is anything that I can do to help to make it easier, I do...any way I can. But they are great.... they are great.” Another spoke of his desire to help future residents by participating in this research:

I'm agreeable to something like this (the research). If it helps someone else. Ya, I imagine it will over a period of time. They know what my situation is, and if I've got any problems, I explain what my problem is, they write it down, if it comes up again for someone else. I've found out things there that has helped me through some of the staff.

One woman noted that she was appreciated for her sense of humor:

I think that if you don’t have a sense of humor, you’re lost. And the girls here are all the same.....and they appreciate that in me too because, you know...it’s half the battle.
Another person spoke of the reciprocity of care and love at the hospice, whereby she pointed out that she was an integral part of this exchange: “Well, the people are extremely kind—they are very loving...and I'm that way myself, so that fits in.” She also responded: “We’re a loving bunch...and we kid each other a lot, and I think that keeps you going...They are, they are (loving) they really are...and I return it...”

Caring about Knowing and Being Oneself

When facing the end of life, knowing and being oneself can become a central focus. Knowing and being oneself entails feeling a level of freedom in living, have a deepened, or stronger connection to oneself, feeling a sense of life purpose, and feeling the preservation of one’s identity through life and especially through one’s current experience.

Freedom to Live. Caring about knowing and being oneself at the end of life can entail valuing one’s freedom in life. When I asked the question “Have your views about yourself—how you see yourself and feel about yourself—changed or been affected?”, most spoke about their continued need for freedom and self-determination, their deepened connection with themselves, and their sense of life purpose. The participants who spoke about freedom were clear that their illness placed constraints on both their range of choices and the type of activity in which they could participate. However, they stressed the importance of maintaining a sense of self-determination. One woman reflected:

...because I’m really independent, they give me as much independence as I can cope with...which means that I can get out of bed and go to the bathroom, I can wander around the room, I can put my shoes on and housecoat on and go out and
have a smoke...and you know, if I need a little bit of help getting back to bed—I just ring the bell. So my independence is kept for me. It's not like when you're institutionalized—you're on a regime and you go by that regime not what you want. Um, I can get up at 6:30 in the morning or I can get up at 9 in the morning—and I can still get breakfast.

When asked about desire to give, she stated that her ability to give was dependent on how much her independence was supported at the hospice:

...they give me my independence...I can get up and I can go where I want. Like on my end, I can put my clothes on. They put them on the table there—and I put them away....I'm doing the things I'm capable of doing.

Another spoke of the relationship between his experience of having had no choice in coming to the hospice, and his need for having his self-determination supported once he arrived: “They’ve asked me if I consider myself capable of doing the things like this little walk that I’ve done today. I say ‘ya—I’ll only do it in stages’.” He also shared an alternate way he felt his self-determination was supported: “If I need anything extra—It’s just a case of asking. They’ll ask me if it’s necessary and if I think it’s necessary—they do. So they make a note of it.” The experience of appreciating independence is reiterated in the following person’s experience of hospice care: “And ha...I just....I like these people—they’re great, you know. They let you do anything you want.” Another person spoke of the need to feel the freedom of movement, and appreciating being supported in this freedom:
I try to be open with them... Uh huh... only the thing is... at least I can be a little mobile, you know... if they pull me up... then I'm high up on there... and then I can sit there and talk to them...

Some spoke of freedom in terms of facing death and illness in their own, self-directed way:

So they tell me ‘You do yourself’ and I say ‘I’m trying my best—I’ll do what I can.’... they want me to assert more strength... Well sometimes I have to do what they feel like... that is hard yes...

The following quote also reflects the need for self-determination: “They’ve done the best they can... They’re just helping me ease into it... you know... they’re not trying to make me give up.” Others also spoke of receiving enabling support at the hospice:

Well, by gaining (support), I don’t have to depend on my family to take me in... or... depend on them to take me to a doctor or... to get things done. I’m independent. But I’m not independent—it’s like I say—I’d like to be able to go out to lunch.

One person quoted a song to express his need for self-determination, when asked how he feels about himself in this part of his life: “And now I face the final curtain—Paul Anka.... Well Paul Anka said it just right in that eh—‘I did it my way’.”

Deepened Connection with Oneself. Caring about knowing and being oneself can establish a deepened connection to oneself. Sometimes this deepened connection occurs as a surprise to the dying person. Other times, it occurs as a result of a conscious choice. Either way, it helps one to cope with and grow from the proximity of death. Many respondents spoke of having experienced a deepened connection with
themselves. When one participant was asked if his views about himself had changed or been affected since becoming terminal, he shared:

...it makes me realize that, you know, maybe I was a pretty good person...I feel like I’ve succeeded in living my life in a way that has made a positive impact on the people that I’ve dealt with.”

Others talked about essential aspects of this deepened connection. One commented on the importance of accepting the range of feeling he was experiencing sharing how he coped: “Oh, a little bit of laughter...a little bit of tear.” This person also communicated the importance of being realistic and honest with oneself about life: “I’d say, get used to it—cause it’s coming.” Another shared that honesty with himself was essential in accepting his death: “You have to face it (death). Either you do or you don’t. And I’ve come to the point that I’ve accepted it as it is.”

Sense of Life Purpose. Caring about knowing and being oneself can mean focusing on one’s sense of life purpose. Most participants spoke of their sense of life purpose as fundamental to how they saw themselves and felt about themselves. Several people spoke about their vocational life as an important component of purpose with the focus generally being on their sense of accomplishment and the impact of their work on others. For example, one person commented:

Like I said, I don’t have kids I’ve left behind and had to teach them from a teacher’s role. But as a union man, I’ve impacted my union brothers and sisters. And hopefully, a few of them have changed the way they go about things because of what I’ve said to them.

Another person spoke of her sense of purpose:
Well, people who run themselves down, they need confidence don’t they. I’ve always strived to look my best, and not to hurt anybody...So when I got into selling clothes, it was the joy of my life because I like to help other people—people who have no sense of dress...Like I heard someone one day “I don’t have to look at myself—I don’t care” but I said “other people have to look at you” you know.

A third person shared:

See, my brother is a doctor—he’s a younger brother and um...he was one of the pioneers in perfecting the cochlea ear implant—he was a pioneer in that...so he has left a mark. I haven’t in that sense. He has, so he’ll be remembered a long time after I’m gone, after he’s gone probably. See, I haven’t done that. Making people happy—that was the nature of the job and I was happy doing it—I was lucky to have it, I was lucky because not everybody has that or has that chance. (Interviewer: What does making people happy give you?) I’ve had times when I’ve made 2,800 kids in a theater happy—and that’s a great fulfillment for me. It made the kids happy and it gave me great joy and fulfillment in knowing that I’ve done something for the little kids. That’s my part in it—that’s my end of it.

Others spoke of additional components of life purpose such as happiness: “The first thing your gonna find happiness in life—you’ve got to find happiness.” Some people commented on living with integrity which they usually defined as being true to their life purpose and to their values and beliefs. For example, one man stated:

I see myself as I see myself. I’m not in the least interested in what others say I am. You must stay within society thinks, if you don’t—that means that you’re an
outcast. But that doesn’t mean that you have to go ‘puppy dog’ all your life... You live for your own values as long as you stay within your own society. He also said:

...If you do not challenge the rules of life, you’re a follower and you’ll never be nothing you’re whole life....It’s (life’s) worth challenging for—you have to challenge for it.

Many of the participants spoke of staying true to their values in experiences such as: relationships, faith, or coping with life’s challenges.

For most participants, their sense of purpose provided a sense of continuity of their identity, and a basis for life review and a sense of life completion. A couple individuals spoke of the importance of reviewing one’s life. For example, in response to my question about what gives him strength, one man spoke of the importance of reviewing his life and concluding that his life was complete:

Oh, it’s thinking about things...you know...its thinking about my family....thinking about living...thinking about dying.....I just think about it...and finally realize that it’s time.

Others did not talk explicitly about completing a formal life review. However, they indicated that they had a sense of completion, acceptance, and contentment when they thought about their life. For instance, when asked what life had been like for him since he got a terminal illness, one man responded: “Ohh, it shook me up at first...but then, I figured, well, I had a good life...so no use complaining about it.” Another shared: “You’ve got to have (a sense of humor)....Ya with that shit...what’s the use of feelings
bad for yourself. I’ve had an excellent life.” A sense of contentment and completion is also evident in the following woman’s response:

I’m ninety-two, ninety….I can’t remember now! (chuckling). Ya, I’ve lasted a while…I’ve had a fun life—a happy life—and two loving daughters—they are very close.

Another person shared:

I think been very lucky…Honestly, I think I’ve been very lucky…Lucky. I’ve had my whole life, my whole engineering life—and everything—and thoroughly enjoyed myself.

At other times, participants spoke of being able to meet the end of life with greater ease as a result of recognizing that they had a full or lengthy life: “I’m glad that it happened now than thirty years ago—you understand—or I would have felt cheated.” When one man was asked what life was like knowing that he will die, he spoke of the importance of having a full life: “No problems….I’ve had my share of life….I’ve….how can I say it…I’ve pretty well done everything that I wanted to do in my life, you know?”

Another person joked: “I’ve had my time and that guy (God) keeps on shouting to me “you’ve had your time shmuck!” Another person commented: “Take it as it comes. You have the good and the bad and I’ve had both so you know…I’ve had a great life.”

A couple people commented that they felt positive about themselves when looking back over their lives. For example, one person said: “Um…It hasn’t really affected me I don’t think…but it makes me realize that, you know, maybe I was a pretty good person.” Another replied:
No, because I’ve never hurt anybody in life—that I know of—I have nothing to apologize for...you know...not in far as hurting somebody—maybe I have and not known it...but on the whole—you don’t set out to hurt anybody, do you? I always liked myself.

Another shared: “I feel like I’ve succeeded in living my life in a way that has made a positive impact on the people that I’ve dealt with.”

Life completion was often spoken of in terms of having a wealth of experience, which was growth enhancing. Some individuals spoke of how their past vocational experiences assisted them in dealing with their current challenges. For example, one person spoke of it as creating perspective about his current suffering:

Oh that’s important and the fact that I’ve been around the world about 24 times and seen all the poor places in the world—that’s important to me too...because I know—it doesn’t matter what I get—there’s people a lot worse off than me. Like in Calcutta, Bangkok or even Hong Kong.

He also said:

The same way I’d face engineering. That’s really the only way you can do it....You just went for it...because eh...on board on a powerhouse, I took my A.S. MacKee later on and I was a boiler and vessel inspector for a large insurance company. And you go in and inspect. Well, you’ve got to inspect right on the second and you write a report and you say “we dump this immediately” or else we reinsure it. ...(You face it in) the standard way you’d face anything in life—and in engineering especially. You can’t put your head in a box, and pull the cart leather on top of your head and ignore what is wrong.
One woman also shared: “Because I’ve worked in hospitals so long, I guess I’ve got a realistic view of it and I don’t really panic...it just kind of fell in to place.”

One man felt that his life was not complete because he had unfinished business with his children: “There’s only one thing I’d like to do one more time...I would like to see my kids one more time (begins to cry).”

Preservation of Identity. Caring about knowing and being oneself can mean having a sense that one’s identity is preserved through the experience of facing the end of life. Several people commented on the question of whether their sense of selves and their sense of self worth had changed since the onset of their illness. For example, one woman commented: “I don’t think that’s changed any...I can still make people laugh.” Another respondent spoke of the his ‘happy’ disposition as innate and enduring: “I guess I was just born this way...I must have.” A third person shared: “No, nothings changed. People always tell me that I’ve been—so long as they’ve known me—that I’ve always been positive.”

One person felt that his sense of self worth had been negatively affected by his diminished sense of capacity: “My own values are over. They’re finished...It’s different now because I can’t do what I used to do...Ya. I’m dead. I’m dead—that’s it. So, there is no more value to me.”

A Greater Awareness of One’s Relationship to Time

Findings revealed that the experience of facing the end of life is also defined by a greater awareness of one’s relationship to time. A person’s relationship to time takes on new characteristics. This change can entail letting go of time, feeling a time progression
after diagnosis towards a greater acceptance, an altered sense of time, going with the flow of time, and embracing time left.

**Letting Go.** Facing the end of life may involve the feeling of letting go. All of the participants spoke of time in terms of letting go and most also spoke of embracing the time remaining as a result of facing the end of their lifetime. One person spoke of letting go of worries: “Well, you don’t need to worry about your health (at this time of his life). You know exactly where you stand—at least I do—I know exactly where I stand.” Others spoke of letting go of valued attachments: “Well ya, you have to let your whole past... practically your whole past go by... because it’s all there at one address (her home).”

There was also a major theme of acceptance in the participant’s description of time. For instance, one person stated: “Well, let me put it this way—I know my time is limited—that’s as far as I can go.” Another person said: “I’ve had my time...” Another shared: “I’m allowed so much time and that’s it—I’m 75. I’ve reached this year and I have no qualms about any part of that... I’ve accepted my fate—no problem.” Another shared:

We see guys who abuse their body, and you don’t expect them to live—and it amazes ya that they do live for so long—and myself included—in my earlier years when I abused my body. And then you see the people who look after themselves and eat properly and do all the right things and they die at an early age....you know, like Michael J. Fox says “This is my bag of hammers.”

**Time Line Towards Acceptance.** One may become aware of a progression to a greater acceptance of confronting the end of life. Many individuals expressed sensing a
time line from diagnosis to a greater acceptance: “Well it was devastating at first...to get used to anything...You can’t do anything about it so you have to accept it.” Another communicated: “You just kind of know that it’s there and it takes a few days to kind of—you know—come to grips with it.” Again, this theme is evident in the following response: “Ooh, it shook me up at first... but then I figured well... I had a good life so...no use complaining about it.” Another shared: “I just think about it...and finally realize that it’s time.”

**Altered Sense of Time.** Sometimes, this relationship with time can feel altered. A couple respondents spoke of having the experience of time speeding up. He shared that the fact that it was speeding up helped him cope:

Ya, being in here, weeks just run from one to the next. Time has been going fast for me anyways—I’ve noticed that the older you get the faster time goes by. But since I’ve been in care, you know, I find it hard to believe—gosh I’ve been here 3 months and I move somewhere else and gosh I’ve been here 2 months already and it just seems like I just come a couple weeks ago...The thought of dying, the thought of being dead doesn’t bother me...doesn’t scare me. But the thought of dying—the way you die—that’s scary because you don’t want to die a very painful death or anything like that you know....If the thought of being dead bothered me, then yes, the fact that time flies so fast would bother me because I’d be wanting to hang on to every single minute. Ya but because my attitude towards that, you know, in my case it is a good thing that it goes by so fast—you know, what’s gonna be is gonna be you know.
When asked whether her sense of time had changed, one woman responded that she often felt disoriented about what time it was:

Ya! (laughing) I never know what day it is! I’m looking for a TV program on a certain channel and then I think ‘aw—that doesn’t come on till Thursday—this is only Tuesday...come on!’......Well, it’s the days that confuse me because one day runs into the other. But the time is still the same because I’m still getting up every 2 hours at night to go to the bathroom.

Later, she added:

I’m always saying ‘What day is it? What date is it? ...and then they say to me ‘You know what year it is?’ and I say ‘ya of course I know what year it is—I just don’t know what day and date it is—haven’t got Alzheimer’s yet!’

Going with the Flow of Time. One may also feel a sense of ‘flowing’ with his/her time left. This experience of ‘flowing’ with time was discussed by some participants. When one person was asked if her views about life had changed or been affected by facing death, she responded:

Ya...it (her views) helped me to pressure my—my ...what do you call this (pointing to her head) mind...to continue. Because if I think of the views that I have heard that— you have this/ this has happened to you— so what will you do? And I told them...Look, I’m not going to continue thinking about it at all—I’m just going to continue you know...going forward.

Another shared: “Oh ya...I’d like to live a little bit longer...but, you know, if you can’t you can’t—that’s all there is to it. Go with the flow—that’s it.” When asked about his sense of time, one person responded: “This is that time of year—I accept it. It’s the Fall
of the year—I just take it as it comes. I have no choice over time...I just accept time as it comes.” When asked his views on life, he shared: “Take it as it comes. You have to good and the bad and I’ve had both so you know...I’ve had a great life.”

**Embracing Time Left.** Letting go of time may also be accompanied by a feeling of embracing time. It appears that detachment from life can also bring the embracing of life. This experience of embracing the time remaining in life was described by some of the participants. When one individual was asked about how it affects her to know how much time she has left to live, she shared: “Hey, I’m going to live it to the fullest!” One man spoke of his desire to live in the moment with a sense of will and purpose:

It’s not regrets. I mean just because I forgot to tell you something, I’m not going to live in regret all my life—and neither will you because you’ll be too busy in you own little chili-wagon...(Interviewer: Every moment--)Is precious.

**A Need to Think and Feel Positive**

Dying persons may also have a need to think and feel positive. Since facing the end of life may entail suffering, it appears that good thoughts and feelings become of paramount importance. Engaging in positive thoughts and feelings is not only a need, but also a choice. In addition, it can give meaning and value to one’s current state of being, and be substantially uplifting. All participants spoke about choosing to engage in positive thinking. They also spoke of being engaged and engaging others in positive experiences.

**A Need to Have a Positive Outlook on Living.** When facing the end of life, a person may feel uplifted by engaging in positive thoughts and having a positive outlook. One woman commented about her positive outlook:
Well, then I said, “Look”, (to) the other doctor, I said “Look, I’m going to—I just want to live on. If I will live on...that means...that means....my thinking is all positive.

Later, this individual added the impact of having a will to be positive and continue on with life:

This views...of my life...of, you know, of continuing life with the cancer...it did not, determa...determa...determination? Ya...It helped me to pressure my—my...what do you call this...Ya mm hmm mind...to continue. Because if I think of the views that I have heard that—you have this—this has happened to you, so what will you do—and I told them...Look, I’m not going to continue thinking about it at all. I’m just going to continue you know going forward.

One person spoke of positivity and humor as being necessary for facing this part of his life: “You’ve got to have (a sense of humor)...Ya with that shit...what’ the use of feeling sad for yourself. I’ve had an excellent life.” One woman shared that a positive perspective was the ‘sensible’ strategy for facing the end of life:

Well you would have to be sensible wouldn’t you to be positive? To be sensible you would have to be positive. At least I guess that’s what it is...You have to be sensible about it and be positive about what you think.

Another spoke of choosing to enjoy life: “I’ve enjoyed every fair minute of it...That’ the only thing you can do. I mean there’s no use in standing in the corner crying, is there?”

When asked how one respondent went from his initial depression at facing the onset of his terminal illness, to his current, more positive psychological state, he shared: “Well, um...every time I used to go to the Legion, they never see me without a smile—never.”
When asked about his happy disposition, he replied: “I guess I was just born this way... Ok, and it’s having the right type of people around you.” Others spoke facing the end of life with a positive perspective: “I think been very lucky. Honestly, I think I’ve been very lucky.” One person commented on his body in view of the fact that it was not healthy anymore: “It’s done well though...Just arthritis and gout. Another stated: “I’ve had a fun life—a happy life.” The importance of finding happiness was spoken of as a paramount life goal by this respondent: “The first thing you gonna find happiness in life—you’ve got to find happiness. I’ve found it here (at the hospice).”

A Need to Have Positive Experiences. Not only may positive thoughts be important, but it may also be essential to have positive experiences as well. One needs and sometimes seeks out engaging and being engaged in positive encounters. Laughter, humour, and joyfulness, all are valuable to the dying individual. Most of the participants in this study commented on the importance of sharing experiences of playfulness, liveliness, humor, and laughter with other. They framed these experiences as both a result of engaging others, and/or being engaged by them. One person communicated the value of humor in her life:

I think that if you don’t have a sense of humor, you’re lost. And the girls here (at the hospice) are all the same...and they appreciate that in me too because, you know, it’s half the battle. I think so.

Another participant spoke of valuing the joking at the hospice:

Well, OK, like (staff member), whose out there today always greets me in the morning with ‘Hello Darling!’ She makes the whole day go—there’s always a joke—always a—you know.
Another shared: “We’re (at the hospice) a loving bunch... and we kid each other a lot... and I think that keeps you going.” The value of humor and personal attention was also illustrated in the following response:

...in here, the cook comes down to my room delivers breakfast in the morning and came back to comment because she gave me way more than I asked for. I just commented to one of the care aids and it got back to her and she comes down and she pops her head in and says “what’s this I hear about my breakfast?!”—You know, just joking around like that. In the hospital, no one would have time to do that.

Caring about One’s Spiritual Faith and Experience

Placing value on spiritual faith and experience may be important when facing the end of life. Most of the individuals in this study described this experience in terms of their ‘beliefs’ and ‘faith’ as well as its outcomes of: strength and coping, values clarification, and a sense of life meaning and purpose. Two participants also described their spirituality in terms of an experience of God and feeling close to God—especially in their spiritual practice of spontaneous or ritualized prayer.

Having Faith. One may find strength, comfort and meaning in faith and beliefs.

One respondent shared her experience of faith:

Oh relations with people eh? Ya sometimes... when you start to talk and try to... make them understand... that this is your position with the soul with the God... and they say “But how come you are doing this—how can you go on like that?” You say “No, you cannot say that I cannot go on like that... no!” You know we’ve—you have to close—be tighten from (i.e., Be close to) the faith...
If you don’t have faith that means you will really have to go around this way and then go around that way (showing with her body language a crooked path)...oh the faith you know...its a....ya.

One participant responded to the question: “Anything else that is meaningful to you or has given you strength?” with: “Yes...I’m a Christian...and I believe in doing the right thing by everybody...being nice to everybody.” Another explained:

Anybody who has been at deep sea—there’s no atheists at sea—just like there’s no atheists in a fox hole—there’s no atheists. If you’re leaving Australia and you’re going to Cape Town—and the smallest wave is 40 feet—believe you me, there’s no atheists down there—because the ship is fully out of the water—and that’s big ships that we’re talking about—1,500-2,000 passengers...heh, heh.(Interviewer: Why is that?) The same reason there’s no atheists in fox holes—Why are there no atheists in foxholes in battlefields? Because you’re in constant danger—you’re in constant stress.

Another stated: “Well, I’m a Jehovah Witness and all my strength comes from there. (And how do you get strength from God?) Well, you just have to ask him! Well basically, as Jehovah Witnesses, we live by the Bible and, it covers everything you need to know to make life worth living.

Felt Experience of the Spiritual. Along with beliefs, one may have spiritual experiences which give strength and meaning to one’s current life. Two participants spoke of their felt sense of closeness with God and their deep value of this relationship. One of these participants described this relationship as follows: “It’s like going to my earthly father and talking to him—except that I’m talking to my heavenly father.” When
asked: "On a daily basis, what gives you strength?", she responded: “Prayer...ya, I just turn my face into the pillow and...” The other respondent also reiterated the power of her relationship with God:

It is difficult, you know, to go on with this kind of disease and...ah pain and ha...and then it overpower everything...ya...it did overpower it. So that means, that in the morning...when I wake up...I say my prayers...Ya...I always say my prayers...say my prayers...I have two types of prayers. Ya, one type is saying the prayers with the, you know, saying the names of the Lord. OK, and then, the second I have, another prayer that goes in my hair—in my head—it goes in...and then, you know...I settle down here on the pillow and think about it....and I said—oh God! Please help me! You help me, you know, to better this disease, that to go on...so that, you know...I don’t get head headache or anything, just so that I want it to get away from me...So, God has really helped me (Interviewer: Tell me how?) Well, I said, ‘Oh, oh oh God...please help me...to overcome this, the headache or you know—The pain, ya...to get over it...and I close my eyes and it disappears!

When asked about what prayer gives her, she shared:

It...it gives me the strength. It tells me that you have all the strength and be brave, don’t be weak. Be strong, and that—to live. When you fight this, you will be very strong... It has...made me more strong...more strong.

The Hospice Experience

Dying persons can experience a deep appreciation for being in a hospice and experiencing its care. Although the respondents often found it difficult to communicate
the exact qualities of the care they received at the hospice, they often spoke of it in terms of how it made them feel. For instance, it was described as making them feel valued and cared for, free, safe, at home, understood, connected, and enlivened. Often participants would state their appreciation and valuing of the care in general terms such as in the following: “I like everything about this place” and “They’ve been very nice—you have no idea.” One respondent said: “So far, what I’ve seen here has helped me, oh you might say, 100%.” Another person shared:

I’ve just been lucky to have landed in a place like this! They’re beautiful eh. I commend them all the time—the nurses and the nurses’ aids and whatever…I commend them all the time.

When participants did offer more detailed descriptions of the care, they framed it in terms of valuing the (a) empathy, warmth, responsive, and respectful support, (b) companionship and intimacy, (c) enabling support, (d) vivacity, and (e) homeliness. In addition, a couple of participants spoke of ways that they felt the hospice service could be enhanced.

Valuing Empathetic, Warm, Responsive, and Respectful Support. When facing death in a hospice, empathetic, warm, responsive, and respectful support can be deeply appreciated. The respondents often spoke of the responsive support of staff who attended to their unique needs:

...They are going to put me in that back room with a balcony because I’m claustrophobic. And they said ‘would it make a difference if you had the balcony’ and I said ‘yes, as long as I’ve got one door that I can open and see a way out—I’m fine.’
The following patient’s response also expresses a sense of receiving responsive support:

…it’s very adaptable because you see…everybody here is in a different stage and I think I’m actually one of the better ones at the moment. So they kind of leave me alone unless I call—and if I call they know that something is wrong.

This individual also spoke of feeling heard:

…this place is run—it’s safe. And as for medication, its’ right there when I need it. If I need anything extra, it’s just a case of asking. They’ll ask me if it’s necessary and if I think it’s necessary, they do. So they make a note of it.

The theme of empathic response is also evident in the following: “They’ll do anything for you because…they know the situation that you are in.” Many spoke of appreciating the responsive support that met their physical and psychological needs. Often they spoke of physical care, pain control and quality of good food. For instance, the following respondent spoke of the care provided from a nurse:

…Basically, you know…going above her duty. I mean, she can only do so much but she does beyond that—she’s trying to help in any way she can to try to make me feel better—and I can feel that.

Another shared:

The staff is great…Two doctors—they alternate and they are absolutely—well they’re so dedicated you know—you can feel it….same with the nurses. The two senior nurses—they are absolutely fantastic because they do this everyday. They do my back—they change the things everyday, they drain this…They are so…how can I say it…they are more than dedicated if there’s such a word—and I don’t know what it is but they are really dedicated…and you can feel it!
The appreciation of receiving responsive pain control is reflected in the following:

I’ve had no pain whatsoever. No, because the nurses give me morphine and they give me some of two things—they were giving me Tylenol 3’s but the Tylenol 3’s upset my stomach eh. So they give me codeine and cough medicine mixed. And I just—every two hours. See they can’t afford to let me cough because if I start coughing, my whole system will go out of whack.

The experience of responsive pain control is also expressed in this account: “They do everything so that you don’t feel pain and if you say you’re feeling pain—as they say, ‘there’s no heroes in the hospitals.’ Many also expressed the value of receiving care through physical nourishment: “All I can say is the food is great. They have good cooks...The care is great for anything you need you know.” Another responded: “The care is good...the food is good...and I...I’ve not...I have no complaints at all...I’m happy.”

Most expressed feeling cared for with a special warmth, kindness or lovingness of staff. One person shared: “Well the people are extremely kind—they are very loving...and I’m that way myself, so that fits in.” Another expressed: “The staff is great—they treat you like...a king.” One person was at a loss for words for expressing the kindness of staff: “They’ve been very nice—you have no idea.” Another stated: “Well, they’re just beautiful. They are very dedicated to their job eh.” The experience of valuing hospice care is also visible in this man’s response: “I am very happy here—I wouldn’t change this place for any other place on earth—that’s what I think of this.” One man spoke of feeling that the care helps him face fears of dying:
Well, I’m surrounded with people like this... She’ll (head nurse) look after me totally... Ya. Ya. They’ll care for you. Even though two months ago they hadn’t met me before in their life.

Later, he added how connections at the hospice helped him: “In fact, if it wouldn’t for this (hospice), I would be more isolated.” The sense of feeling valued as a result of the care was described in responses such as the following:

These people are fantastic... you know? They treat you like human beings.... They don’t toss you around like you’re some sort of—what do you call it—guinea pig.

Others framed this valuing in terms of feeling respected in honest communication with staff about their health: “They respect you in telling you and I respect them for telling me.”

Valuing Companionship and Intimacy. Individuals may also have a deep appreciation for the companionship and intimacy received at the hospice. When asked how the care made him feel, one man commented on feeling companionship with the staff:

Great. Absolutely great. Great... really feels great because I know that the staff is on your side and if there is anything that I can do to help make it easier, I do... any way I can. But they are great... they are great.

Another framed the care as personal and intimate:

Ahh, the care you get here is excellent... and the staff—they tend to be more personal than in the hospital... because there’s fewer staff and more patients you know—they’re more rushed and they can’t take the time to stop and chat sort of
thing…. Ya, like just before you came in, you know there was two of us—they call us residents—we’re not patients—we are residents—sitting at the table drinking coffee and eating cake with one of the staff. In the hospital, that just wouldn’t happen. You know, it can’t they’re just so overworked. There isn’t even a common dining place you know—in the hospital—everybody eats at their bed. Here, we got the dining room.

One man reiterated this sense of feeling companionship and connection at the hospice: “I enjoy having a meal with the gang—it’s just one happy family when we get together.”

Finally, one person shared: “The rapport with the doctors is there…Ya you know, the feeling with the two of us, you know…same with the nurses…the two senior nurses.”

**Feeling Enabled by the Support.** Residents may desire and appreciate the enabling support given at the hospice. Many respondents had an experience of feeling supported in their autonomy. One man spoke of feeling that he was allowed emotional freedom: “They’re just helping me ease into it…you know, they’re not trying to make me give up.” He also spoke of feeling supported in his autonomy:

And ah…I just…I like these people—they’re great. You know…They let you do anything you want. You need something from the store…or you know, they’ll go get it for you. These people are fantastic.

Another shared that she gained freedom from dependency on others: “Having this (hospice) filled the gap where you might be forced to go live with the children…so it is a wonderful thing to have.” One person spoke of freedom to do as she wished on a daily basis:
...you don’t have to get out of bed if you don’t want to...but because I’m really independent, they give me as much independence as I can cope with...which means that I can get out of bed and go to the bathroom...I can wander around the room; I can put my shoes on and housecoat on and go out and have a smoke, and you know, if I need a little bit of help getting back to bed—I just ring the bell. So my independence is kept for me—its not—like when you’re institutionalized—you’re on a regime—and you go by that regime—not what you want. Um, I can get up at 6:30 in the morning or I can get up at 9 in the morning—and I can still get a breakfast.

Valuing the Vivacity of Staff. Hospice residents can be positively affected by the vivacity of staff. Many of the participants commented on the lively spirit of the staff and viewed this as helpful in coping with the challenges that they faced. One woman framed it as helping to make her day go by:

...they’re caring...like ___(staff member), whose out there today, always greets me in the morning with ‘Hello Darling!’ She makes the whole day go—there’s always a joke—always a—you know...I’ve found that the girls that care the most—have the most fun at work.

Another person noted that they he felt happy about being at the hospice because: “There’s always a laugh somewhere around here—there’s never a dull moment....I wouldn’t give it up now for anything—I wouldn’t. No way...I’m quite happy right where I’m at.”

Feeling ‘At Home’. Residents appreciate feeling ‘at home’ at the hospice. Sometimes, respondents spoke of having a homey room, bringing sentimental items into
their rooms, being made to feel at home by staff, and having visiting family and friends made to feel at home. One woman commented:

...I have a nice room...I brought things—the girls brought things—from home to make it look like what it always has as much as possible....pictures and quilts and you know...just things.

Another spoke of the staff as making him feel at home: “I found out that they’ll make you right at home. They did!” Finally, some spoke of having family and friends welcomed into this environment. One person spoke of her daughters are loving like she is and noted how they come over to the hospice to visit and help out: “(her daughter) comes out, she’s the second youngest of the two, and weeds the garden and picks up all the junk...and cleans up for them and waters it.” One man spoke of the importance of having pictures of his beloved, deceased wife in his room: “I go to my room, and it doesn’t matter where I look—I’m going to see her picture.” The importance of having the freedom to have family visits at the hospice is reiterated in the following: “My family is very very important to me...and my friends of course—I don’t have many left—but I’ve a few...some new ones that come out here to visit me.”

**Sensing How Hospice Care Could be Improved.** Residents can sense ways in which their hospice care could be improved. While all participants spoke positively about the care during their hospice experience, three of the participants noted areas in which they felt the service could be improved. For instance, two individuals mentioned they would like to go on more outings. One shared:

See, we get volunteers here—which is a whole—see the nurses don’t have the time to take you out for a walk because they’re working 12 hours a day already.
But these people volunteer their time 3-4 hours a day different people different days and they take you down for a walk.

Later he remarks that there was a need for more hospice funding: “Even this place is short of nurses....short of nurses, short of staff.” Another woman spoke of wishing her hospice was closer to town so that she could feel more connected to community life to help with feelings of isolation and loneliness:

Well, being in here I’m isolated—I’m not used to that. I think that they should be closer to town so that people can have other advantages as well as their maintenance and you know, the way that its run...I feel lonely at times—and I have a lot of visitors—but it’s not enough for me...Well, to me it means being able to go out and to be amongst people and um, being able to go out for lunch or go out shopping or wandering through the stores...getting your fingernails done or pedicure.

One participant spoke of the care as ‘good’ but also experienced unwanted pressure from staff:

So they tell me “You do yourself” and I say “I’m trying my best—I’ll do what I can”...I just can’t...They want me to assert more strength....well sometimes I have to do what they feel like...That is hard.

Later, she did not want to talk about it anymore for fear that she would be overheard through the walls: “…if I told, they could hear it on the other side.”

Some felt that the length of their stay thus far (at least 2 weeks) may not have been long enough to assess if any improvements could be made. For example, one man commented: “If I was here a lot longer, you know, I could probably find things that could
be improved, but right now, I’ve been here for such a short time that I can’t really comment on that.”

The Interview Experience

Hospice residents who choose to engage in research can feel that participating in qualitative research is a positive experience. All the participants indicated that they found the interview process to be a positive experience. When asked “What was it like for you to participate in this research?”, one person responded: “Lovely...I’ve given some interviews and have been in a few court cases with engineering so...” When thanked for her ‘openness’ in the interview, another person shared: “That’s the only thing you can be at our stage of life.”

Most of the participants also commented that they found the process to be easy: “It was easy sure. You’re a nice girl—you’re easy to talk to—so, nothing difficult about it.” Others felt that the interview was actually therapeutic: “I opened up so much to you—more than I have ever, ever done in my life!” Later, she added: “I really enjoyed it thoroughly because what has happened...because...I have never, ever experienced this kind of thing with anybody. Never.” She also perceived that the interview affected the interviewer positively: “I really shared a good amount of my life with you...God has blessed you...I have not—I have no strength...I don’t have strength...strength is the God Almighty.”

Most of the respondents also indicated that they hoped that their comments were helpful. One person said:
I don't mind—anything I can do to help, I like doing it. I've never done it before—no one has ever asked me for—I mean I've done interviews at work but that's a different thing. But to help the kids, in any way I can. I'm happy to do it.

Another person spoke of helping future residents by participating in the study:

I'm agreeable to something like this if it helps someone else. Ya, I imagine it will over a period of time. They know what my situation is, and if I've got any problems, I explain what my problem is, they write it down, if it comes up again for someone else. I've found out things here that has helped me though some of the staff.

Discussion

Theoretical Implications

The research question in this study was: What is the lived experience of facing the end of life in an inpatient hospice environment? This chapter will discuss the theoretical implications of the findings and will compare them to previous findings in the research literature. Limitations, implications for health and social services, implications for counselling, and implications for future research will then be discussed.

There is always some risk in comparing the findings of a phenomenological study to other research. When doing so, it is important to keep two cautions in mind. First, as researchers move from "the immediacy of the participants worlds" (Benner, 1994, p.99) to the identification of themes there is always some degree of variation in how the perceptions of the participants are grouped and named. Second, although the identification of themes provides a way of identifying core human experiences, something is lost when moving from specific individual perceptions to general themes.
(Kuhl, 1999). It is important to keep in mind that from the viewpoints of the individual participants, their perceptions were part of a gestalt—integrated aspects of their worldview that was not divided into themes, and sub-themes.

Subject to these two cautions, it appears that the findings in this study generally support previous thanatology research. This is particularly the case in relation to what I have identified as the five core elements of the experience of living in the face of death including: caring about relationships with others, caring about one’s relationship to oneself, a greater awareness of one’s relationship to time, a need to think and feel positive, and caring about one’s spiritual faith and experience. There were a few sub-themes in this study (e.g., a deepened connection with oneself) which were not reported in any other study except Kuhl’s (1999) work on the meaning of having a terminal illness.

Core Experiences

Caring about Relationships with Others. As in this study, previous patient survey research has also reflected that relationships can be integral to a dying person’s experience (Benzein et al., 2001; Herman, 2001; McKay & Sparling, 2000; McKinlay, 2001; Tierney et al., 1998; Kuhl, 1999). One survey also reflected professional caregiver awareness of the importance of relationships at the end of life (Fins et al., 2000).

The participants in this study also expressed that the nature of some of their relationships had become more intimate since the onset of their illness. Some experienced having deeper connections with others. One individual also expressed a desire to re-connect with loved ones. Both McKinlay (2001) and Singer et al. (1999) also found that patients desired to strengthen relationships with their loved ones.
There were two relationship experiences in the literature that were not discussed by the respondents in this study. These experiences included a need for physical touch (Kuhl, 1999; Steinhauser, 2000) and chosen isolation (McKinlay, 2001). It is possible that physical touch was not discussed because this research did not ask any questions about physical experience. In addition, chosen isolation may not have been discussed because this sample may have been more interested in social contact (e.g., they chose to be interviewed for this study) than other sample populations.

Many individuals spoke of knowing what facilitates relationships, as well as aiming to facilitate their own relationships. They described having facilitated their relationships through honesty and openness. McKinlay’s (2001) study of hospice inpatients also found that individuals said they were “taking down the barriers” (p.25) in relations with others.

Participants also focused on giving and receiving. They described that they found it difficult to receiving more care from others. Some expressed that this was a difficult adaptation and others expressed that it entailed a role reversal. This finding is compatible with previous research (McKinlay, 2001). It also supports a more recent finding in the thanatology literature—the need of people facing the end of life to give to others (Engle et al., 1998; Herman, 2001; Steinhauser, Clipp, et al., 2000).

Participants spoke of appreciating the exchange of: warmth, caring, values; knowledge, love, and joy. They framed their desire to ‘give’ as a result of a variety of needs including staying active in life, wanting to give to others out of gratitude for living, wanting to make a difference in life, needing to feel valuable and valued by others, and needing to fulfill a sense of life purpose.
Steinhauser, Clipp, et al. (2000) noted that they were surprised by their finding that participants expressed a need to “contribute to others” (p.828). They conceptualize this need in terms of the developmental task of generativity (Steinhauser, Clipp, et al., 2000, p.829). This study lends support to the notion that integral to the dying person's personal growth, is a need to contribute to others in their own unique way.

**Caring about Knowing and Being Oneself.** Knowing and being oneself was discussed by participants as of central importance in the experience of facing the end of life. Knowing and being oneself entailed self-determination or freedom in living, an experience of life purpose, the preservation of identity, and a deepened connection to oneself. Self-concept, a related construct to this phenomenon, has been discussed in previous research as a central part of the dying experience (Kuhl, 1999; McCord et al., 2000; McKinlay, 2001; Steinhauser, Clipp, et al., 2000).

In addition, various aspects of knowing and being oneself have been highlighted in previous research to be central to the end of life experience. For instance, this study found that knowing and being oneself entailed feeling a level of freedom and self-determination. Self-determination has been noted in previous research as important to dying persons (Hermann, 2001; Kuhl, 1999; McKinlay, 2001; Singer et al., 1999).

This study also found that knowing and being oneself entailed feeling a sense of life purpose. Other researchers have also found that a sense of purpose is an essential need (Kuhl, 1999; Thomson, 2000; Tierney et al., 1998). This study found the end of life experience as also having four elements that have only been described in one previous study (Kuhl, 1999). First, a deepened connection to oneself was a core experience. Second, integrity to one's current life purpose was described in this study as of central
importance. Third, one’s sense of self and self-worth was dependent in part on life review assessments and a sense of life completion. Fourth, prior life experience assisted them with their current ability to cope. This study also found that many referred to their vocational experience as helping them cope with their current situation.

Other researchers have outlined that reviewing one’s life and finding a sense of life completion are essential elements in facing the end of life by patients (Benzein et al., 2001; Hermann, 2001; Kuhl, 1999; Steinhauser, Clipp, et al., 2000; Tierney et al., 1998). The respondents in this study spoke of life completion in terms of feeling a fullness in life, success in life purpose, and gratitude for life. An experience of “unfinished business” by one participant reflects that completion may be desired but is not always accomplished. Finally, most felt that their sense of self had not changed—that there was continuity of identity. This impacted whether or not they felt good about themselves. For instance, one person indicated that his sense of himself had changed and his sense of self-worth had diminished.

This study found that knowing and being oneself was also facilitated by feeling a stronger connection to oneself. Individuals in this study, experienced a deepened connection with themselves with the assistance of greater honesty with oneself and an increase in self-awareness. One other study found that a need to know and understand oneself was integral to the dying person (Kuhl, 1999).

There was one quality of the dying experience related to knowing and being oneself that was found in other research that was not present in this research. This was the impact of physical movement on defining one’s sense of self. While this research found
that action in the way of purpose or incapacitation was integral to one’s sense of self, there was no mention of physical activity per se.

**A Greater Awareness of One’s Relationship to Time.** This study found that individuals had a greater awareness of their relationship to time. The experience of time was described in terms of ‘letting go’ of time, acceptance of losing time, embracing time, and an altered sense of time. Most participants also spoke of a time line from the shock of initial diagnosis towards greater acceptance. These findings fit with the conceptual frameworks developed by Kubler-Ross regarding the progression towards acceptance (1975). Previous research has also had similar findings (Benzein et al., 2001; Engle et al., 1998; Kuhl, 1999; Mackey & Sparling, 2000; McKinlay, 2001). For instance, Benzein et al. (2001) found that individuals needed to make a reconciliation with life and death and that it was essential for living in hope (p.122). Respondents spoke of ‘going with the flow of time’ left. Another study found a similar finding whereby individuals spoke of needing “to take one day at a time” (Hermann, 2001, p.69).

**The Need to Think and Feel Positive.** Participants spoke of needing and choosing to engage in positive thinking. They described their positive thinking as provided them with the will and strength to live and to face the challenges of this part of their lives. Hermann’s (2001) study of dying patient’s spiritual needs, found a need for a positive outlook.

Participants also spoke of positive feelings as a fundamental need that kept them alive and engaged in life. This is a finding that has recurred throughout the literature (Engle et al., 1998; Hermann, 2001; McKinlay, 2001; Steinhauser, Christakis, et al., 2000). Engle et al. (1998) found that individuals referred to humour as a means of
coping. This was also found in the current study. Hermann (2001) found that individuals “expressed a need to see the smiles of others” and that for some, this was because it “cheered them up” (p. 71). She also found that individuals spoke of the need to think “happy thoughts” (p. 71). McKinlay’s (2001) study of hospice inpatients found that humour was an essential part of their experience and her interview with them. In addition, a study of patients, families and professional caregivers also stressed the view that maintaining a sense of humour was a core need of dying individuals (Steinhauser, Christakis, et al., 2000).

**Caring About One’s Spiritual Faith and Experience.** It is important to point out that spirituality is defined in multiple ways throughout the literature and varies from general to more specific definitions (Tracy, 2003). In this study, spirituality included both individual experience of “beliefs and faith” and “closeness with God.” Only a couple of individuals referred to themselves as “spiritual,” “religious” or having “spiritual or religious” needs or values in their hospice admittance form. However, most of the respondents spoke of spirituality as a central part of their experience. This is reminiscent of a study by Benzein et al. (2001) which found that while all of the interviewees claimed not to be religious, they had “thoughts about God” and/or “talks with God” (p. 122).

The experience of spirituality was described in terms of their ‘beliefs’ and ‘faith’ as well as its outcomes of strength and coping, values clarification, and a sense of life meaning and purpose. Thanatology research notes that spiritual beliefs and faith are common aspects of the dying experience (Benzein et al., 2001; Engle, et al., 1998; Hermann, 2001; Kuhl, 1999; Mackey & Sparling, 2000). Kuhl (1999) found that individuals described their spirituality in terms of: “Nature, God, a Higher Power, Jesus,
Buddha, and for some meaning, purpose or value”(p.164). Kuhl (1999) found that “In the context of a terminal illness and the experience of physical weakening due to disease progression, the essence of the spiritual dimension became ever greater”(p.81). Thomson (2000) also found that “spiritual well-being” was defined by: meaning, beliefs and values and actually was found to rank higher that patient overall quality of life average. Therefore, spirituality appeared to aid in coping and actually “serves to pull up a hospice patient’s general quality of life” (p.20). This is conducive with this study’s findings where spirituality was often described in terms of a central ‘life-line’. One person explained why he was spiritual in his following remark: “…there’s no atheists in a fox hole.”

In addition, this study found that some individuals had a “felt experience” or “closeness with God” through their spiritual practice. Three other studies have found that individuals expressed having an experiential element to their spirituality in communion with God or nature. (Benzein et al., 2001; Hermann, 2001; Kuhl, 1999).

The Hospice Experience. The participants comments regarding the hospice were intertwined throughout the interview with comments regarding all five of the core elements discussed above—especially in the areas of relationship to others, to oneself, and needing to think and feel positive. The hospice environment was an aspect of the gestalt they described. The gestalt is best expressed as “the lived experience of facing the end of life in an inpatient hospice environment.” It is not possible to know whether their reported experience about facing death would have been different in an alternate environment. However, the hospice and palliative care literature assumes that the hospice experience is instrumental in facilitating “a good death.”
Hospice research to date has found that patients and their families give a positive endorsement to hospice care and express that there are generally few problems with the care given (McGrath, 2001; Nolen-Hoeksema et al., 2000; Tierney et al., 1998). This is in line with Brecher’s (1999) findings that patients perceive that hospice care helps to increase their quality of life (p.40).

Many previous studies have focused on pain control in palliative care studies and found that it was a major element of their experience (Jarrett, Hillier, et al., 1999; Jarrett, Wiles, et al., 1999; McCarthy et al., 2000; Tierney et al., 1998). This research found that although symptom relief was mentioned it was not an over-riding theme in participant responses about hospice care. This does not mean that pain control was of any less importance, but rather, because the interviewees chose to discuss more personal relationship issues.

All of the respondents experienced hospice care as invaluable—essential to their physical and psychological well being. They spoke of an essential quality to this care that affected them deeply. They described their appreciation of the empathetic, warm, responsive, and respectful support. Studies of end of life care have also found that individuals appreciate empathetic, warm, responsive and respectful support from professional caregivers (Jarrett, Hillier, et al., 1999; Jarrett, Wiles, et al., 1999).

Individuals in this study appreciated the companionship and intimacy with caregivers at the hospice. This has been referred to in other studies as dying person’s need for “companionship” (Jarrett, Wiles, et al., 1999) “personal interaction” (Jarrett, Hillier, et al., 1999), “comfort with staff” (McGrath, 2001), and a “warm positive bond” (McGrath, 2001).
Another theme in the experience of hospice care was the appreciation of ‘enabling support’ whereby individuals felt supported in their autonomy and active participation in life. Yeung, French and Leung (1999) also found that inpatient hospice patients valued independence.

The residents also shared that the vivacity of staff impacted them positively. McGrath’s (2001) study of family conception of hospice care also found that ‘focusing on living’ through joyful experiences was important to them and their loved ones. Finally, the members of this study expressed that they valued feeling ‘at home’ at the hospice. McGrath (2001) also noted that families conceived that dying at home was an important part of why they valued outpatient hospice care.

In addition, to appreciating hospice care, some respondents also expressed how they felt the hospice services could be improved. A couple of respondents shared that they wished to have more opportunities to go on outings. Hermann (2001) also found that a need to look outside, and to be outside or have elements of nature inside (such as flowers) was described an important spiritual need of respondents. Remaining connected to life appears to be a need that could be met through minimal resources in care—whether it means more volunteer accompaniment on walks, or bringing parts of nature or the community to the hospice (e.g., artists displaying their work or playing music, visits from pets, etc.).

The Interview Experience. Kvale (1983) states that one of the main values of phenomenological research is to offer a positive experience to those who participate. All the participants indicated that they found the interview process to be a positive experience—and a few felt that it was therapeutic. McKinlay’s (2001) phenomenological
study of hospice patients had the same finding. She found that the research
“conversations were interspersed with laughter, jokes, warmth, and times of sadness, and
tears” (McKinlay, 2001, p.27).

As a researcher, I noticed similar qualities to the interviews. I also noticed that the participants were comfortable and appeared to feel valued and empowered by the experience of taking part in this research study. As a researcher, I too was affected by these intimate encounters with these individuals facing the end of their life. I was humbled and honored by their willingness to share and be open with me. I also noticed that the intimacy between us tended to grow quickly.

Limitations

Since this research is phenomenological in nature, its goal was to illuminate the meaning of facing the end of life and of hospice experience for those who participated. There was no assumption that the findings could be generalized to other sample populations. However, the study does aim to contribute to the on-going body of thanatology and hospice research through experiential accounts.

This study is also limited by the fact that it does not account for those who did not want to volunteer for the study. It is possible that these individuals would communicate other aspects of the experience of facing the end of life and of the hospice experience. Another limitation it that it only polled individuals who were past middle age.

Another possible limitation is the disadvantage of performing on-site research at a hospice. Since the participants were on-site, it may have been possible that some were reluctant to be critical of hospice care while they were dependent on its care. Even if privacy is ensured, participants might have felt the proximity of staff and have been
afraid to compromise the care by speaking of problems with its service. For instance, one respondent feared that during the interview, staff would hear her negative assessment through the wall of her room.

Implication for Health and Social Services for the Terminally Ill

Encouraging and supporting “best practices” is an on-going challenge for organizations serving the terminally ill. The literature identifies five approaches that organizations use to improve practices (a) clear mission statements and operating philosophies (McNamara et al., 1994; Rinaldi & Kearl, 1990; Weissman, Griffie, Muchka, & Matson, 2000), (b) on-going staff training (Miller, Miller, & Single, 1997; Ury, et al., 2000), (c) operating procedures and methods that support operating philosophies (Eischens et al., 1998), (d) effective and adaptive organizational structures (Bennett & Corcoran, 1994), and (e) seeking feedback from consumers (Abma, 2000; Vitetta, Kenner, & Kissane, 2001; Wiles, Payne, & Jarrett, 1999).

The interest in best practice does not just focus on inpatient hospice care, but in all types of services for the terminally ill (such as palliative care; acute hospital; nursing homes; hospice, etc.). It also applies to all the various roles in those organizations (physicians, nurses, counsellors, volunteers, physiotherapists, etc.)

Acute care hospitals and long-term care facilities have different functions and priorities. However, many characteristics of the hospice environment valued by the participants in this study can also be established in these types of facilities. As noted by Rinaldi and Kearl (1990), hospice principles are already being incorporated into the operating philosophies of hospitals and LTC facilities.
Several themes identified in this study, and in previous studies that listen to the patient voice, may deserve increased emphasis from organizations in developing their operating philosophies and practice guidelines as well as in their staff selection and on-going staff training activities.

This study found that residents valued qualities such as warmth, empathy, authenticity, companionship and responsiveness in hospice staff. The ideal of empathetic, responsive and respectful service is not new to the professional literature. There is also widespread recognition in the literature about the importance of “the human dimensions” of the patient-professional caregiver relationship. However, there is often a gap between these ideals of and what happens in practice.

Health and social service organizations committed to these ideals have to work on them on an on-going basis. However, it isn’t enough to just select staff with the “right” attitudes and provide them with on-going training. It is also important for them to recognize that professionals work in the real world—with real time constraints, real resource constraints, and real limitations in their physical environment. Organizations have to recognize that all of their operating policy decisions involve trade-offs. For example, increased demands for record keeping may increase accountability and provide an on-going source of data for program review, but the trade-off may mean less time available for patient-nurse interaction. No matter what decisions organizations make regarding these sorts of trade-offs, professional caregivers will always be busy. The participants in this study were aware that the nurses were busy, but they felt that when they nurses interacted with them, they were focused on them and not thinking ahead to
the next task on their agenda. They felt that they truly “shared the moment”. There is an old saying “There is a difference between being busy and being in a hurry.”

Another important theme was the value patients placed on the vivacity of staff and on the importance of being engaged and engaging others in humorous interactions. This helped to create an environment that was life affirming to the individuals—the participants were facing the end of life—but they also wanted to feel alive while they were here.

Two other themes that may be particularly relevant are “giving and receiving” and “independence and control.” This could mean that flexible roles rather than rigid role differentiation between patients and nurses (e.g., nurses give care and patients receive care, nurses know best when it comes to care questions, and patients don’t care for other patients or for nurses) would benefit the residents. The participants in this study appreciated the nurses as “expert care givers” but they also indicated how important it was to maintain a sense of self-determination in regard to their care plan. They also did not want to define themselves as only “receiving people” and wanted to help themselves as well as give to others to the extent that they were able.

There are four main implications for nursing practice. First, the act of caring should be viewed as an exchange. Openness is required on the part of both parties in this exchange. Second, care should be viewed as enabling support. This is already a theme in professional literature but sometimes in the rush of daily practice, it is easily to do something for someone than to support them in doing it for themselves. Third, contact and care should always be viewed within the context of the person’s need for meaning making. A core element of the needs and experience of the dying person, are encounters
with others. The concept of such "encounters" is central to existential thought. May (1958) explains:

Encounter is, in general, not so much the fortuitous meeting and first acquaintance of two individuals, but rather the decisive inner experience resulting from it for one (sometimes for both) of the two individuals. Something totally new is revealed, new horizons open, one's world view is revised, and sometimes the whole personality is restructured...an encounter can bring a sudden liberation from ignorance or illusion, enlarge the spiritual horizon, and give a new meaning to life (p.119)

Since the hospice patient's last encounters are largely with hospice caregivers, the staff plays an important role in the dying person's sense of life meaning and potentiality.

Fourth, the caregiver should be sensitive to the prevalence and significance of dying person's spiritual experience. While few of the participants in this study acknowledged spiritual or religious affiliation or practices on the hospice intake form, most of the respondents highlighted their spirituality as central to their current experience. This suggests that this spiritual aspect of their experience could be overlooked by staff. In addition, Highfield and Cason (1983) found that nurses had a limited awareness of patients' spiritual concerns and needs and underestimated the frequency of spiritual behavior and conditions. Therefore, it seems important to point out the importance of: being open to, learning about, respecting, facilitating, and even participating in whatever brings spiritual sustenance to the dying individual—according to the person's wishes and the caregiver's openness and comfort in doing so.
Facilitating spiritual experience could include anything from listening to, affirming, or engaging in spiritual moments or thought to connecting the person to their spiritual or religious community; to helping to create a meditative environment or the respect of a sacred space, or to recognizing spiritual struggles. Participating in spiritual experiences could range from recognizing and being present to an “encounter” with the individual to engaging in prayer, meditation, or ritual. Highfield and Cason (1983) note that “Whether or not it is appropriate and effective will depend on the individual nurse’s actions (or lack of action) in response to the presenting patient needs” (p. 192). It is important to recognize that the benefit or result of a dying person’s spirituality are strength, peace, a sense of connection to the divine, feeling loved and a more positive identity, hope, meaning making, and moment to moment coping.

In summary, this study suggests that the professional caregiver should tend to the dying person’s needs through open and honest exchanges that meet the person’s need for human contact, as well as through affirming their sense of self-value, life value and meaning. This offers the professional caregiver the opportunity to “meet” the individual in their place of facing the mystery of life, and acknowledge and witness the “truths” they have found regarding who they are, what they are committed to, and how they choose to live their final days. Here, the practitioner can provide opportunities for the person to feel their purpose and intrinsic value.

One final caution. Becker (1973) points out: We might say that modern man tries to replace vital awe and wonder with a “how to do it” manual...if you clock the mystery of creation in the easy steps human manipulations you banish the terror of death...(p.164). It is important not to view any of this discussion regarding implications
in an essentialist manner or as a prescription. For example, one respondent spoke of feeling unwanted pressure from staff to behave in ways that conformed to the hospice theoretical version of what constitutes a good death.

Implications for Counselling Practice

All of the comments listed above regarding implications for services for the terminally ill also apply to the role of counsellors who are working with the terminally ill (and to some extent, with clients who are facing grief and loss or major life challenges). However, this study also had some implications that are specific to the counselling role.

The first implication is in relation to the theoretical framework that is used by the counsellor. Two frameworks that appear to be particularly useful given the themes in this study are the person-centered approach, and the existential approach. The person-centered approach puts the relationship at the center of the therapeutic process and affirms the unique value and potentiality of each human being. "What is most important here is not logic or technique, but the actual experience of the unique individual human being in facing personal annihilation. "One does not solve the problem of human suffering so much as one enters into it....One must connect empathetically with the sufferer" (Firman, 1997, p. 250).

This study sheds light on the possibility that by this phenomenon's very nature, facing the end of life is a paradoxical experience of communion with life and letting go of it. Therefore, it is useful for the practitioner to approach the dying individual with a level of openness that the dying tend to crave and have. This may require that the practitioner let go of their perceptions of the need to "work through" grief. Klass (1996) explains the problems with this need to "work through" grief:
The modernist approach to life is one that emphasizes goal directedness, efficiency, and rationality. In psychology, modernism has given rise to the machine metaphor of human functionality. When applied to grief, this view suggests that people need to recover from their state of intense emotionality and return to normal functioning and effectiveness as quickly and efficiently as possible. Modernist theories of grief and related therapeutic interventions encourage people who have experienced loss to respond in just this way. Grieving, a debilitating emotional response, is seen as a troublesome interference with daily routines, and should be “worked through”. Such grief work typically consists of a number of tasks that have to be confronted and systematically attended to before normality is reinstated. Reducing attention to the loss is critical, and good adjustment is often viewed as a breaking of (relational) ties. (p.32)

The counselling relationship could benefit from being more of a “human” encounter than a “professional encounter”. “The healer has to keep striving for the space...in which the healer and patient can reach out to each other as travelers sharing the same broken human condition (Nouwen, 1975, p.76). This study suggests that relationships, as well as the act of being open in human relations, are important to the dying individual. As a result, the counselling relationship has the possibility of developing faster and there could be more self-disclosure on both the part of the dying person and the counsellor.

The existential approach focuses on the impact of meaning on wellness and growth. This study supports the notion that counselling practice with the terminally ill should have less of a focus on dysfunction, problem solving and mental illness, and a greater
focus on the healthy journey towards growth, self-discovery and higher awareness. The presence of death is not something to be removed or 'cured' and psychological health is not necessarily dependent on physical health, but also on the individual's meaning structures.

These findings also stress that the experience of facing the end of life can elicit a heightened openness to growth. Minuchin and Barcai (as cited in Visher & Visher, 1988) point out that crisis can offer an opportunity for growth:

Because crisis requires change, at least temporarily, a period of crisis may be an optimum time for establishing the foundation of permanent therapeutically indicated change...(as therapists) we frequently induce and capitalize upon crisis induction (p.59).

Self-awareness as well as openness and honesty with self are also important elements of this experience of facing the end of life. Not only is there a greater openness to change, but this study points towards the possibility that is a natural tendency for individuals to derive meaning from their experience. Therefore,

The objective should not be to redo personality, but to assist them in finding whatever form of appropriate usefulness they can...(their strengths) should be recognized and used in helping them to face the demands of their lives and to make choices about the conditions they face, instead of resolving issues of the past...(when clients) find meaning in life, recognizes responsibility and can make choices about life circumstances, s/he becomes empowered...In this process of empowerment, s/he becomes a more self-actualized individual, spiritually, socially, and psychologically (Brown & Romanchuk, 1994, p.64)
The therapist could best support a dying individual by trusting that he/she could find their own complex meaning woven into their experience, and the therapist would then risk being a ‘non-expert’.

Within this framework, the individual might focus on important elements of their dying experience such as connections with others, sense of self, sense of freedom, a sense of time, positive thoughts and experiences; and their spiritual beliefs and experiences. The counsellor can support the person in experiencing whatever brings courage, personal value, life value, hope and peace. An existential approach to practice would also place a greater emphasis on the present. While the past is valued as a means to understand life-purpose, and the future in order to process the loss, the predominant focus should be on living fully in the immediate moment. In addition, the counsellor might also help the individual in their attempt to ‘go with the flow of time’ and ‘embrace time’ by helping them feel more comfortable in the moment. This could include techniques that help with pain control, as well as experiential techniques such as relaxation techniques, guided imagery, and meditation.

The second implication of the study for counselling practice is in relation to how the counselling role is defined and to the structure of the counselling process. In looking at the counsellor role, it is important to stress that there may not be as much role definition or differentiation (ex. between nurse and counsellor) as in other counselling relationships. There may also be less definition to the formal structure of the counselling process. For example, there may not be sessions, contracts, or work contracts. It is fundamentally a relation and structure that is client directed and may look more like “being with” others in therapeutic “moments” rather than 40 minute sessions. As the
respondents put it, they experienced time in terms of flowing with it, embracing it and experiencing that every moment was “of the essence”. Therefore, the counsellor could aim to be more present to each moment with the dying individual. The time before death is an example of what existential psychologists refer to as ‘kairos’—

....a critical, decisive point...when time suddenly acquires a qualitatively different value...such that an intervention is likely to be fully successful at such times, whereas it would have been premature before and without prospects later” (May, 1958, p.120).

The third implication for counselling practice is in relation to the work to be done. This study’s findings suggest four main tasks that may arise in the counselling relationship including (a) assisting with meaning making, (b) life review facilitation, (c) assisting with the logistics of unfinished business and family work, and (d) spiritual interventions.

A counsellor might assist the dying person to think about the meaning of their life. This could range from an open-ended dialogue to a more structured life-review. A structured life review does not necessarily have to be formal (for example, it doesn’t have to be written or recorded, nor would it have to be comprehensive). The main point is that it would feel natural and beneficial to the person. Another important aspect of the counsellor role in life review, is to act as a witness of the review. Sometimes the family plays the primary role in listening and witnessing and the counsellor is not needed to assist in this aspect of the process. However, if the family is not present, the counsellor may become a “family substitute” in regards to this role. The counsellor can assist the
person to use their sense of meaning and accomplishments to cope with the challenges of their current situation.

In addition, a counsellor can assist with the logistics of helping the person deal with unfinished business. For example, they could help locate and contact family members with whom the person wishes to reconnect. Another aim could be to engage in, or facilitate more interaction with the person’s support system (family and friends) to facilitate other sources of intimacy and meaning for the individual. In addition, the counsellor may also work collaboratively with a team of interdisciplinary professionals to help facilitate a sense of community around the individual.

Finally, these findings suggest that a central goal of therapeutic focus could be on affirming the unique spirituality of the dying person. The counsellor should affirm the agency of the individual in all spiritually-focused interventions (e.g., accessing the person’s creativity through art, music). Depending on the counsellor’s training and/or experience, specific counselling tools could include: meditative and relaxation tools, guided imagery (Zasep Tulku Rinpoche lecture, 2001), and physical touch or therapeutic touch (May, 2001). In addition, the practitioner could respect, facilitate, and even participate in whatever brings spiritual sustenance to the dying person, in turn affirming their needs, experiences, and unique wisdom.

Suggestions for Future Research

Given the limited number of phenomenological studies of terminally ill patients especially those residing in hospice environments, it would be useful for this study to be replicated with other sample populations. Also, some of the suggestions that I have made regarding the implications for practice in health and social services for the terminally ill
could be evaluated. For instance, future research could examine the extent to which the valued staff characteristics identified by the participants in this study is a function of the personal staff characteristics, or the operating environment in which the staff work. It would also be valuable to look at the difference between authentic vivacity of staff vs. inauthentic vivacity as well as the difference between spiritual accompaniment vs. the application of 'soulless' spiritual techniques. In regards to counselling, the whole question of spiritual interventions (such as meditation) would benefit from further exploration. The specific qualities of care that are most life affirming, or validating to their life purpose, could also be explored.
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Appendix A

Canadian Demographics of the Aging Population
The Canadian Population is Aging...

Canadian Population by Age and Sex, 1996

<table>
<thead>
<tr>
<th>Age Groups</th>
<th>Males</th>
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Projected Canadian Population by Age and Sex, 2021

- In the coming decades, seniors will comprise a larger share of the Canadian population, growing from 3.5 million people in 1996 to an estimated 6.9 million by 2021.
- Populations are aging in all western industrialized countries. In Sweden for example, seniors comprise 18 per cent of the population while in Canada they form 12 per cent of the population.
Appendix B

Changes in American Culture’s Portrayal of Death

(Fulton & Owen as cited in Hayslip & Leon, 1992, p.8)
<table>
<thead>
<tr>
<th><strong>Cohort 1</strong> (born prior to the advent of the atomic bomb; persons in their 50’s and 80’s)</th>
<th><strong>Cohort 2</strong> (born after the advent of the atomic bomb; persons in their 20’s and 40’s)</th>
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<td>Death was immediate</td>
<td>Death is distant</td>
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<td>Institutionalized death</td>
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<tr>
<td>Self-reliant, or reliant on others for survival</td>
<td>Reliance on technology for survival</td>
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<tr>
<td>Death was ever present, visible, real</td>
<td>Death is invisible</td>
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<tr>
<td>Judeo-Christian belief system</td>
<td>Less traditional belief system</td>
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<tr>
<td>Reduced life expectancy</td>
<td>Enhanced life expectancy</td>
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<tr>
<td>Education a benefit few enjoyed</td>
<td>Education is accessible to many persons</td>
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<tr>
<td>reduced exposure to and impact of TV</td>
<td>Enhanced influence of TV</td>
</tr>
<tr>
<td>Atom bomb served to end the war</td>
<td>Atom bomb serves to end all life</td>
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<tr>
<td>Clear differences between good versus evil, hero versus villain</td>
<td>Good/evil, hero/ villain can coexist</td>
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<tr>
<td>Values are absolute</td>
<td>Values are relative</td>
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<tr>
<td>No specialization of care</td>
<td>Specialization of care</td>
</tr>
<tr>
<td>Integration of family</td>
<td>Dissolution of family</td>
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<tr>
<td>Personal death</td>
<td>Impersonal, anonymous death</td>
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Appendix C

Cultural Conceptions of Dying
II. Anger

I. Denial (Emotion)

Terminal illness (Significant change)

II. Anger (Emotion)

III. Bargaining

IV. Preparatory Depression

V. Acceptance

Increased self-salience

Stages of Dying

(Kubler-Ross)

(1) Denial

(2) Rage and Anger

(3) Bargaining

(4) Depression

(5) Acceptance

Stages of Dying

(Tibetan Book of the Dead)

(1) Deliberate Ignorance

(2) Aggression and Anger

(3) Greed and Pride

(4a) Attachment and Yearning

(4b) Envy/Ambition/Need to Act

(5) Awakened Consciousness/Surrender
Appendix D

Documentation of The Literature Search Process
My literature review has been guided by a number of key words including: "hospice," "hospice and research," "terminal care," "palliative care," "death—psychological aspects," "action research," "needs of the dying," "hospice care," "patient satisfaction," "outcome assessments," etc. The review has also utilized numerous sources including: the UBC Library on-line database, the Social Science Citation Index, Current Contents, Medline, Eric, PsychInfo, and DISS Dissertation Abstracts Online.
## Articles by Journal

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<td>American geriatrics society</td>
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<tr>
<td>American journal of hospice and palliative care</td>
<td>9</td>
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<tr>
<td>Annals of Internal medicine</td>
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<td>Cancer</td>
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<td>Cancer nursing</td>
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<td>European Journal of Cancer</td>
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<td>Evaluation and program planning</td>
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## Research Studies by Year

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### SETTING

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### INFORMANT

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<tr>
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<td>4.65%</td>
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<td><strong>100%</strong></td>
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Appendix E

Signs of Spiritual Problems and Spiritual Health

(Highfield & Canson, 1983, p. 188-189)
**TABLE I**

<table>
<thead>
<tr>
<th>Need</th>
<th>Behavior or Condition</th>
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<tbody>
<tr>
<td>Need to receive love</td>
<td>Expresses that he has no reason to live after death</td>
</tr>
<tr>
<td>Need for meaning and purpose in life</td>
<td>©es Virginia, 1976 2000 - 2006 by the American Psychological Association. All rights reserved. It is not for commercial use.</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Expresses despair</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Exhibits emotional detachment from self and peers</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Employs humor as a coping mechanism after death</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Expresses feeling lack of self-worth</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Expresses feelings of being dependent</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Does not discuss feelings about dying with significant others</td>
</tr>
<tr>
<td>Need to receive love</td>
<td>Does not call on others for help when he needs it</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses fear of tests and diagnosis</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses feeling lack of supportive others</td>
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<td>Need to receive love</td>
<td>Behaves as he “should” by conforming to the behavior of a “good” patient or person</td>
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<tr>
<td>Need to receive love</td>
<td>Refuses to cooperate with health care regimen</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses guilt feelings</td>
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<tr>
<td>Need to receive love</td>
<td>Confesses thoughts and feelings about which he is ashamed</td>
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<td>Need to receive love</td>
<td>Expresses anger with self/others</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses ambivalent feelings toward God</td>
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<td>Need to receive love</td>
<td>Expresses despondency during illness/hospitalization</td>
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<td>Need to receive love</td>
<td>Expresses resentment toward God</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses anger from God</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses fear of God’s anger</td>
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<td>Need to receive love</td>
<td>Worries about financial status of family during hospitalization/ separation from family</td>
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<tr>
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<td>Worries about separation from others through death</td>
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<tr>
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<td>Expresses fear of loss of control</td>
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<tr>
<td>Need to receive love</td>
<td>Is unable to pursue creative outlets due to high level of physical disability</td>
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<tr>
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<td>Expresses boredom during illness and hospitalization</td>
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<tr>
<td>Need to receive love</td>
<td>Exhibits overly dependent behaviors</td>
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<td>Expresses anxiety about inability to pursue career, marriage, and parenting because of illness</td>
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<tr>
<td>Need to receive love</td>
<td>Expresses fear of therapy</td>
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<tr>
<td>Need to receive love</td>
<td>Denies the reality of his condition</td>
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**TABLE II**

<table>
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<td>Need to give love</td>
<td>Expresses that he has lived in accordance with his value system in the past</td>
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<tr>
<td>Need to give love</td>
<td>Expresses desire to participate in religious rituals</td>
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<tr>
<td>Need to give love</td>
<td>Lives in accordance with his value system at present</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses contentment with his life</td>
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<tr>
<td>Need to give love</td>
<td>Expresses hope in the future</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses hope in life after death</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses confidence in the health care team</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses feelings of being loved by others/God</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses feelings of forgiveness by others/God</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses desire to perform religious rituals leading to salvation</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Trusts others/God with the outcome of a situation in which he feels he has no control</td>
</tr>
<tr>
<td>Need to give love</td>
<td>Expresses love for others through actions</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Seeks the good of others</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Asks for information about his condition realistically</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Talks about his condition realistically</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Sets realistic personal health goals</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Uses time during illness/hospitalization constructively</td>
</tr>
<tr>
<td>Need for hope and creativity</td>
<td>Values his inner self more than his physical self</td>
</tr>
</tbody>
</table>