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A Hermeneutics Study: The Spirituality of Adults with a Terminal Illness in a Hospice Program

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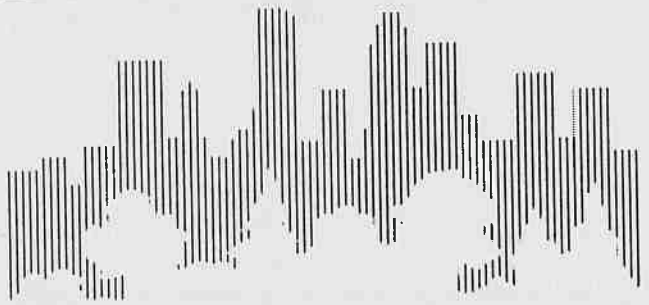

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MASTERS IN SOCIAL WORK THESIS

Ginny K. Backman

A Hermeneutics Study: The Spirituality of Adults with a Terminal Illness in a Hospice Program

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A HERMENEUTICS STUDY:

THE SPIRITUALITY OF ADULTS WITH A TERMINAL ILLNESS IN A HOSPICE PROGRAM

Ginny K. Backman

Submitted in partial fulfillment of
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DEDICATION

This thesis is dedicated to the 3 passionate individuals who fervently took the time and energy to be my co-researchers. I an in debt to your openness and honesty that allowed me to peek through the window of your heart and soul. I felt your presence as I struggled to be true to your narratives. May you rest and joy in the Presence of our God. See you in the mighty forever!

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ABSTRACT

A Hermeneutic Study:
The Spirituality of Adults with a Terminal Illness
in a Hospice Program

Hermeneutic Interpretive Research of the Experience of Spirituality
for Adults with a Terminal Illness

Ginny Backman
January 20, 2001

Despite the increasing literature on the significance of spirituality to individuals with a terminal illness, specific research focused on the spirituality of individuals in hospice is limited to several quantitative studies, only one with a qualitative component. This qualitative study expands understanding or experience through hermeneutic analysis of in-depth interviews with three individuals with a terminal illness. The individual's narratives revealed "believing" as the way they found meaning in the present moment. "Always believing" and "adamantly believing" in a Supreme Being gave their daily lives meaning and direction. They were steadfast in leaving all to God for this life and life after death. Implications for social work practice and policy are discussed.

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CHAPTER 1: INTRODUCTION

This chapter will introduce the background and statement of the problem, establish the purpose and significance of the research study, pose the research question, and explain the researcher's interest in the subject.

Background of the Problem

In London, England, in 1967, Cicely Saunders founded hospice on Christian principles. However, when hospice moved to the United States, although recognized as important, the spiritual component weakened. Hospices themselves and the Commission on Accreditation of Healthcare Organizations (JCAHO) reported spiritual care as a weak element of hospice care that least met required standards. This may be inadvertently due to the natural evolution of differences that happen between founding organizations and subsequent ones, the ambiguous definition of the terms spiritual and religious, the stress on religion rather than spirituality, the strict division of medicine and religion, and the lack and problems of research. Also, to fulfill their mission to serve the entire community and to accommodate staff with less orientation to religion, hospice joined the movement in America to be more individual and inclusive, concentrating on spirituality rather than religion. The complete multi-disciplinarian team can serve all patients. However, the question remained: In the myriad needs of hospice patients, was spirituality being addressed? (Amenta, 1998; Chandler, 1999; Mauritzen, 1988; Millison and Dudley, 1992; McGrath, 1997, O'Connor, 1986; Wald, 1986; Walter, 1996).

Presently, there is a flood of literature acknowledging the importance of spirituality in the everyday lives of the terminally ill. There is less material related specifically to hospice, but even that has increased. However, there are few *research*

studies focused on these issues. Current questions include how much spirituality is encouraged by the whole team rather than being the sole province of religious leaders (chaplains, pastors, ministers, priests, and rabbis) and to what extent spiritual issues are recognized and promptly addressed at the moment they need consideration.

Statement of the Problem

Discovering meaning day-to-day is an ongoing challenge for individuals diagnosed with a terminal illness. They are faced with their mortality and changing, often declining, physical condition. How they defined themselves in the past no longer works. They have to rely on others more and more for care. Self-esteem and worth are questioned.

This research study addresses the spiritual experience of adults living with a terminal illness in a hospice program. The focus is on how spirituality and specific spiritual experiences stood out for the individual and how they impacted meaning in their everyday living.

Spirituality can be understood in many ways. This contributes to the problem of researching the subject, as conceptualizing terms is of primary importance. However, the hermeneutics approach allowed individuals the freedom to define what spirituality meant for them. "Believing" is identified as a more expansive and essential theme to the experience of living with a terminal illness.

The researcher attempted to draw individuals further into their experience to understand and clarify their view of spirituality and believing and their thoughts, feelings, perceptions, and stories related to discovering meaning. The individuals could share anything *they* felt or thought was important. A richer, more complex individualistic

interpretation was sought.

Purpose and Significance of the Problem

Attention to the significant role spirituality plays for the individual with a terminal illness is encouraging. Through the numerous personal examples and case illustrations used throughout the literature, there is no question that spirituality provides meaning for those facing the imminent ending of their earthly lives (Callanan & Kelley, 1992; Derrickson, 1996; Millison, 1995; Steeves & Kahn, 1987). Research, too, has supported the importance of spirituality (Coward, 1989; Ita, 1995; Reed, 1987). However, further qualitative research done in hermeneutical style could add depth and richness to the existing literature.

Also, hospice professionals, caregivers and volunteers could use the main question and prompts from the interview as they talk with hospice patients. The specific model would not have to be replicated, but the open-ended conversational style could lend credence to the issue of spirituality and meaning being available and accessible to anyone who takes the time to listen and ask questions. Method and expertise are far less important than a willingness to be open to the individual at the moment issues surface. Who we are as a participant can be an important part of this discovery process. Awareness of our personal biases and style, rather than eliminating them, is the goal.

Furthermore, the interplay of meaning in life and spirituality may have significance for individuals at many stages in their lives. This research study may lend method and direction to social workers and other professionals or lay people who encounter individuals struggling for healing, purpose, or growth in their lives.

The Research Question

The research question was, *"How does the experience of spirituality impact the everyday lives of individuals living with a terminal illness in a hospice program?"* Then, the first question asked of each participant in the interview was, "Tell me about your experience of spirituality as you live with a terminal illness." The researcher used a list of prompts or probes to clarify details, to move them further into their story, and to investigate the deeper meaning behind their words (Benner, 1994). The list included, "Tell me about a time that comes to mind to illustrate that?" "Tell me more about that." "Help me understand this. Give me a for instance." "What did that mean for you?" Can you clarify that?" What did that help you realize?" "What stands out for you?" "Describe that experience." "What were your thoughts, feelings and perceptions?"

The Researcher's Background

This qualitative research study will utilize the ancient discipline of interpretation called hermeneutics (Benner, 1994). Hussel introduced the idea of "lived experience," that is, knowing through seeing. However, researchers must "bracket" their own opinions and judgments. Heidegger, Hussel's student, refuted bracketing. Separation from one's own views is impossible. Instead, focus is on the recognition of the *process* of understanding. Gadamer, Heidegger's pupil, cited the history and prior understanding of the researcher as giving meaning to the exchange between researcher and participant (Koch, 1995). Therefore, background on the researcher related to spirituality, death and terminal illness is necessary to this study.

This researcher is a white, middle class, middle aged woman who has had little direct experience with death and no experience with terminal illness before my

internship. At the age of 14, I nearly died in a motorcycle accident. I learned death could happen instantaneously without pain. My grandparents died in older age after having full lives. Six years ago, a spiritual mentor died suddenly in the prime of his life. For the first time, the questions of death moved closer.

Spirituality has been an integral part of my entire life. Raised and still grounded in the Lutheran religion, Christianity has provided the framework for my life and how I perceive my own death. However, my spirituality continues to broaden through openness and many eclectic experiences.

Studying for my Masters of social work at Augsburg College in Minneapolis, Minnesota, and my Masters of Arts in Leadership for Mission at Luther Seminary in St. Paul, Minnesota, brought me to my internship at Rice Hospice at Rice Memorial Hospital in Willmar, Minnesota. Interest in the spiritual experience of individuals with a terminal illness naturally followed from my lifetime spiritual journey and current professional schools' teachings.

Summary

This chapter reviewed the background of spirituality in hospice, stated the problem and research question, and established the purpose and significance of this research study and the researcher's background. Chapter 2 discusses the literature significant to the spirituality of terminally ill individuals in hospice. Chapter 3 presents the theoretical framework undergirding this research study. Chapter 4 describes the methodology employed. Chapter 5 reveals the findings of this study. Chapter 6 concludes with the strengths and limitations of this study, as well as the implications for social work practice, policy and further research.

CHAPTER 2: LITERATURE REVIEW

This chapter defines the relevant terms of this study: spirituality, terminal illness, and hospice. The historical background traces (a) the concept of hospice from Biblical times to the present, (b) the essential involvement of religion to the concept and growth of the hospice movement, and (c) the broader, contemporary contribution and debate of the practical efficacy of the spiritual perspective in everyday hospice care. Spirituality, as the experience of finding meaning, will be enriched from the perspectives of relationships, life review, the arts and ritual, transcendence, nearing death, and religion. Finally, gaps in the literature will be identified.

Definition of Terms

Spirituality

Spirituality has many meanings (Burton, 1998). Agreement is not likely, necessary or even valuable as individuals have their own interpretations. In fact, pursuing information with an open mind, without set preconceptions, can prove more helpful (B. Crute, personal communication, May 16, 2000). However, for the purpose of this study, common perceptions in the hospice literature and professional discourse will be identified, especially the relationship between spirituality and religion.

Informal hospice work throughout the ages has been associated with the church and therefore, specific religions. However, openness to individuals of all faiths was the norm. When Cicely Saunders began the first formal hospice, "spiritual needs" were identified. Although based in the Catholic tradition and practice, proselytizing was taboo. The emphasis was on the whole person and showing one's beliefs through

compassion in all actions, believing the final responsibility rests with the Ultimate One (Bradshaw, 1996).

The connection and distinction between spiritual and religious became a topic of discussion when hospice came to America and the whole person was being divided and dealt with as parts. Although the spiritual dimension was always an integral part of hospice, suspicion began of how much validity this had in practice. The terms are often used synonymously, but while religious is spiritual, spiritual is broader and may or may not include specific religious care (Amenta, 1988; O'Connor, 1988). Saunders (1998), who specified spiritual pain as being the last of five types of pain, got into the discussion, reiterating the broader application of spiritual vs. religious.

The literature consistently makes this distinction. Spirituality, which can be "with or without a structured belief system" (Pellebon & Anderson, 1999, p. 229), relates to the love of nature and people, social action, one's experience of well-being, compassion, meditation and passion, the soul, center, essence, life force, holy, mysterious or "who I am." Religiosity, which is two or more people following identified beliefs, is defined by the culture. Activities may consist of attending services and other functions to carry out identified purposes. Both are concerned with the ability to transcend self and one's own concerns in order to connect with a bigger entity outside of one's self. Meaning and purpose in life are fostered through relationships with people, the environment and for some, a higher power and a belief in life after death. These values help individuals determine concrete decisions and actions (Amenta, 1988; Burton, 1998; Canda, 1988; Cascio, 1998; Chandler, 1999; Corless, 1986; Cornett, 1992; Foster, 1986; Fryback & Reinert, 1999; Pellebon & Anderson, 1999; Smith, 1995; Thomas, 2000).

Terminal Illness

All study participants will be enrolled in a hospice program. Therefore, terminal illness will be defined according to Medicare certified hospice criteria that requires "physicians to certify that a patient's prognosis is expected to be six months or less of life should the disease take its usual course" (Keay & Schonwetter, 1998, p. 491). This is easier to determine in cancer patients once they begin "to lose function and weight" (Keay & Schonwetter, 1998, p. 492), but guidelines for all patients "generally combine disease-specific information with functional and nutritional measures" (Keay & Schonwetter, p. 492).

Hospice

Hospice is "a way of caring for terminally ill patients and their families" (Rice Hospice [Program], 2000, p. 1). Hospice provides compassionate and dignified physical, spiritual, psychological, and social care across settings to the patient and family as a unit. Staff focuses on palliative measures of pain management, relief of symptoms of the disease and dying, care consultation, and bereavement assistance for the family and other caregivers. Care is available 24 hours a day (Keay & Schonwetter, 1998; Kovacs & Bronstein, 1999; Rhymes, 1990; Rice Hospice [Brief], 2000).

Death is viewed as a natural process. Hospice affirms and enhances the quality of life rather than exploring cures, extending life or hastening death. The interdisciplinary team consists of the Hospice Coordinator, Nurse Clinician, Home Care Nurse, Social Worker, Chaplain, Medical Advisor, Volunteer Coordinator, and Volunteers. The primary physician, family members, friends, clergy or other health professionals can make referrals (Rice Hospice [Program], 2000).

Historical Perspective

The basis and foundation of hospice comes from the New Testament mandate in Mathew 25:35 & 40 (NRSV, 1997), "I was hungry and you gave me food, I was thirsty and you gave me something to drink, I was a stranger and you welcomed me, I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me... just as you did it to one of the least of these who are members of my family, you did it to me." The orientation to "be there" without focusing on treatment or "doing" could be connected to Christ's request to His disciples in the Garden of Gethsemane, "Sit here while I pray" Mark 14:32 (NRSV, 1997).

The specific concept of hospice traces back to the 4th century when the Roman Empire made Christianity the official religion. "Hospes" meaning "host" gradually changed to mean strangers or guests. A hospice was established in Rome, considered to be pagan, for Christian pilgrims traveling from Africa. Often connected to religious orders, hospices not only provided a haven for pilgrims and travelers, but cared for the sick and dying. The focus was on hospitality, safety, refreshment, cherishing and fellowship rather than a cure. Although they evolved into hospitals, 'hospitium' like modern day hospices, referred not only to a place, but also to the nature of the relationship and a concept of care. But after 1000 years, hospitals reigned and the word hospice appeared less and less (Bradshaw, 1996; Ley, 1993; Smyth, 1983; Stoddard, 1978; Wald, 1986).

In spite of this, several hospice concepts were evident. Philippe Aries (1974) presents the perception of a "tamed death," knowing death is close and preparing for it simply and ceremoniously (also a hospice concept), as beginning with the knights. They

faced their deaths without trying to flee it, incorporating rituals and customs. However, terrible deaths such as those from the plague, were not talked about. Aries cites a monk at Saint Martin de Tours in the 10th century, after 4 years of seclusion, "felt that he was soon going to leave this world" (Aries, 1974, p. 4). This knowing came through natural signs or an inner conviction. Even children had this premonition. In the 15th century, the story is told of a very young girl who recognized her approaching death. In the 17th century, Don Quixote, though recognized as mad and spending much of his life escaping into daydreams, recognized his death was near, "'Niece,' he said very calmly. I feel that death is near'"(Aries, 1974, p.5).

The importance of attitude at the time of death connected to life meaning emerged during the 12th and 13th centuries. "Death became the occasion when man was most able to reach an awareness of himself" (Aries, 1974, p. 46). Wills became the way individuals expressed their deepest personal thoughts, religious convictions, and final wishes about disposal of possessions (Aries, 1974).

In the 17th century, Descartes encouraged the separation of mind, soul, and body. "The Church assumed responsibility for the mind (and soul) and science (or medicine) for the body" (Ley, 1993, p. 172). This separation contributed to the intrusiveness of medicine in dying. Individuals were more comfortable dying in the presence of family, neighbors, friends, and even children (Aries, 1974).

The fear of dying alone emerged in the literature in the 18th century when Saint-Simon told of the extreme measures taken by Madame de Montespan to have others around her. However, children soon began to disappear from scenes of dying. Doctors concerned with hygiene complained of overcrowded deathbeds (Aries, 1974).

Many different religions of the 1800s revitalized hospice for care of individuals dying from cancer or tuberculosis. Yet their doors remained open to all. The Roman Catholic Irish Sisters of Charity founded Our Lady's hospice in Dublin in 1846. In conjunction with this movement was the emerging attitude of protecting dying patients and not telling them of their terminal nature. This led to a shift from denial for the good of the patient to avoiding the truth for the sake of those close to the dying patient and society. The perception of death changed to that of death being ugly and interrupting a happy life (Aries, 1974).

By the end of the 18th century, romanticism influenced the concept of death from that of a solemn, common event to one of fascination mixed with emotion and lots of outward, spontaneous expression of sorrow at being separated from the individual. Although the individual still remained the central figure orchestrating his own death, concern for one's own death changed to concern for the death of the other. More trust was given to those around the dying person. Wills became the legal document they are today, disposing of possessions, rather than orations of convictions (Aries, 1974).

The Sisters of Charity expanded to establish St. Joseph's hospice in London, England, in 1905, after coming to work with the sick in their homes. The Methodist foundation spawned St. Luke's to care for the dying in their homes. Yet, dying in the hospital, rather than at home, with the doctors and hospital staff presiding over a technical event, separated from everyday life was the norm (Aries, 1974; Walter, 1996). The stage for hospice to swing the pendulum back was set.

Cicely Saunders, a physician with a deep Christian faith, gave voice to her vision of a home for the dying homeless to a young Jewish man dying of cancer in 1948. Her

first paper, "Dying of cancer," discussing the exploration of the value of spiritual care, was published in 1958. Saunders opened St. Christopher's, in London, England, in 1967, modeling it after St. Joseph's and St. Luke's. St. Christopher's was committed to a strong Christian foundation to deal with patients' medical, social, emotional, and spiritual needs with their families. With technology extending life, but failing to cure the disease, Hospice introduced "palliative care" rather than terminal care. Once the goal shifted from curing the illness to learning how to live with dying, more attention was given to care of the whole person, including spiritual care (Bradshaw, 1996; Clarke, 1998; Smyth, 1983; Walter, 1996).

During the 1960s in America, para-medical literature was increasing on the solitary nature of death in hospitals, the inhibiting reactions of medical staff, and family and the voluntary decision to end life. Therefore, improved healthcare, not a calling from spiritual experience, motivated hospice in America. The first hospice opened in New Haven, Connecticut, in 1974. Individual programs were left to deal individually with spirituality. On paper, it was always listed as part of the service, but by 1980, Cicely Saunders and Florence Wald clearly saw the lack of spiritual development in America (Bradshaw, 1996; Millison, 1995; Munley, O'Connor, 1986; Wald, 1986).

Discussion and literature increased during this decade. Two journals appeared highlighting spiritual care: *The Hospice Journal - Physical, Psychosocial and Pastoral Care of the Dying* and *The American Journal of Hospice Care.* The Yale University School of Nursing held colloquiums focusing on spiritual care in 1985 and 1986. The later year's conference, *In Quest of the Spiritual Component of Care for the Terminally Ill*, was purposely scheduled to precede the International Work Group on Death and

Dying in June and the World Congress on Care of the Terminally Ill in September, 1986. They addressed a wide variety of topics relating to spirituality including the definition, role of the interdisciplinary team, the arts as a spiritual avenue, and the humanistic, Christian, compassionate and social action perspective. Decisions were not made, but awareness heightened and further questions raised (Bradshaw, 1996; Millison, 1995; O'Connor, 1986; Spiritual Care Work Group, 1990).

The Spiritual Care Work Group (1990) from the International Work Group on Death and Dying compiled "Assumptions and Principals of Spiritual Care" of general attitudes, plus specifics related to individuals and families, caregivers, the community, education, and research. They were eclectic and spiritually based, rather than specific and religious (Spiritual Care Work Group, 1990).

Conferences continued and literature increased and broadened (Millison, 1995). The definition of spirituality expanded. The importance of the spiritual component in hospice and the need for all members of the interdisciplinary team to address spiritual issues was established (Ley & Corless, 1988; Millison, 1995; Millison & Dudley, 1992; O'Connor, 1988).

The everyday use of spirituality in Hospice settings to assist patients in their search for meaning continued to be one of debate. Who provided spiritual care, how did this happen, and what was effective? Literature was mixed on the involvement of helping professionals with spirituality. Fichter (1981) found that although healthcare professionals are reluctant to get involved in religious activities, they felt competent to discuss religion with patients (Millison & Dudley, 1992). Although hospice professionals hesitate to share their spirituality, "almost all of them indicated they did

such sharing at least some of the time. More specifically, they indicated that they were comfortable praying with patients and participating with them in 'God talk'" (Millison & Dudley, 1990, p. 76). Similar to this was, "While some professional caregivers choose to leave spiritual matters to clergy, the findings reveal that many non-clergy hospice professionals are assisting patients with spiritual concerns" (Millison & Dudley, 1992, p. 49). Hospice workers surveyed by O'Connor & Kaplan agreed that "they usually understood the importance of spiritual care" (O'Connor, 1988, p. 36), spirituality is too critical to be left to clergy alone, providing spiritual care "became easier and more rewarding," and "patients were their best teachers" (O'Connor, 1988, p. 37). However, most recently, Babler (1997) concluded, "Hospice professionals may be missing opportunities to provide spiritual care" (Babler, 1997, p. 25). How do social workers compare to other hospice professionals in their care of spiritual needs?

Social Worker's Participation with Spirituality in Hospice

Social workers, with a history of concern for all aspects of the person in the environment, have a vested interest in spirituality by virtue of their professional values (Cornett, 1992). Early on, pastors were encouraged to get involved in hospice as "social workers were largely fulfilling the pastoral counseling role" (Millison, 1995). As chaplains became a more integral part of the team, did they take over the role of providing spiritual care?

Continued evaluation of social worker's specific involvement with spirituality has been difficult due to the lack of inclusion of spirituality as a social work task (Kulys & Davis, 1986; Rusnack, Schaefer, & Moxley, 1988) and the majority of research on hospice and spirituality focusing on hospice professionals (Millison & Dudley, 1992).

Nurses, chaplains, and social workers are considered as one conglomerate.

Only one study could be found evaluating the difference of the addressing of spirituality among social workers, nurses, and spiritual care professionals. Social workers ranked lowest in provision of spiritual care and were deemed to "have few tools with which to provide spiritual support and often struggle professionally as to what extent their role allows provision of spiritual care" (Babler, 1997, p. 24). Although nurses ranked in the middle and have had a greater, longer emphasis on spirituality, many were still found to be uncomfortable providing spiritual care. Spiritual care professionals were ranked the highest. Babler (1997) questioned how often *all* professionals took advantage of the opportunity to offer spiritual care.

As social workers have searched for an overall identity in Hospice (Kulys & Davis, 1986; MacDonald, 1991), so they have fluctuated in their involvement with spirituality. Is it an opportune time to increase the consideration given to spirituality?

Spirituality: The Experience of Finding Meaning

Finding meaning in the increasing incapacitation, suffering, pain, and closeness of death is the main theme in much of the literature (Clark, 1999; Herth, 1990; Mauritzen, 1988; O'Connor, 1988). Spirituality and having hope were synonymous with this search for meaning for many individuals, the essence being to help them find their own truth. Saunders adds that "spiritual pain" is the essence of meaninglessness (Clark, 1999; Herth, 1990; Mauritzen, 1988; O'Connor, 1988; Saunders, 1988; Walter, 1996).

Different models were used to organize the themes found in the literature. Derrickson (1996) described this process as remembering, reassessing, reconciliation, and reunion. Callanan and Kelley (1992) used Elizabeth Kubler Ross's (1969) 5 fluid

stages of dying: denial, anger, bargaining, depression, and acceptance. Paton (1996) used Mathew Fox's sacred circle, recognizing the negative, positive, creative and transformative stages.

Despite the differences, several themes emerged. Meaning, to include hope and living in the moment, was experienced through relationships, life review, the arts and rituals, transcendence, nearing death, and religion. Although interconnected, each of these will be examined closer for their contribution to meaning.

Relationships

The New Testament embodies the ultimate concern of hospice, "Remember, I am with you always, to the end of the age," Matthew 28:20 (NRSV, 1997). The environment created with another's presence, compassion, and willingness to go where it hurts is more important than what is done or said. Holding a hand until the end gives hope, peace, and meaning (Callahan & Kelley, 1992; Cousins, 1990; O'Connor, 1986 & 1988).

In hospice, the amount of time with each client is unknown. The more timely a working relationship is established with the individual, the more attention can be turned to quality and meaning of life. The hospice model is based on belief in human compassion rather than a specific assessment tool or great amounts of technique. The relationship, rather than the role or tools of the careprovider, can facilitate this process (Millison & Dudley, 1992).

"Turning toward death together" (McQuellon & Cowan, 2000, p. 312) is a way to define the relationship between an individual with a terminal illness and important others. "Willingness to engage in authentic conversation" (McQuellon & Cowan, 2000, p. 316) is crucial for encouraging individuals' searching for meaning. Using empathy to

understand both the content and feelings of the other and responding with compassion, love, and honesty undergird our suffering with another. Yet, silence and attentive presence can be as powerful as the spoken word (McQuellon & Cowan, 2000).

In Herth's (1990) research on hope, relationships were defined as "interpersonal connectedness" and were one measure of hope. Abandonment and isolation were identified as hindering hope. While a meaningful presence was most important, presence coupled with emotional withdrawal was worse than absence (Herth, 1990).

Corr (1992) suggests that using a task-based approach to coping with dying, promotes not only understanding of the process, but lends more inclusion and direction to caregivers. As individuals identify their most important tasks, caregivers can focus on how they can assist in completing the tasks. This does not preclude the caregiver's option to decline assistance if harm is perceived.

Life Review

Narratives, influenced by life cycle, family structure, and cultural factors, are one way people make meaning of their life and illness. Looking at the accomplishments and disappointments of the past can help one discover how life has been worthwhile and where there is unfinished business. Reviewing one's past competencies and relationships can help the individual feel power and control by transcending the dependency and isolation often felt. One's own personal history, containing life's meaning and the roles played, gives direction to coming to terms with the prospect of death. Price (1995) demonstrated these recurring themes with four hospice patients engaged in narrating their life stories. Burton (1998) cited one case to illustrate the same. Another case illustration showed how reviewing the life strategy helped direct opportunities for a more fulfilling

present (Bissell, 1992; Burton 1998; Callanan & Kelley, 1992; McQuellon & Cowan, 2000; Price, 1995).

Furthermore, telling life stories can facilitate the process of making a will and living will. The reflection on the meaning of possessions and relationships can clarify who is to be named as administrator and beneficiaries or have the power-of-attorney. More connections with loved ones in the present can be made (Johnson, 1990).

Life review, in varying form, provides affirmation of a life lived and a recognition of values and wisdom. The opportunity for closure and resolution can result in the ability to live more firmly in the present. Herth (1990) specified this happens through uplifting memories, to include reminiscing about happy memories and picture albums and reliving positive activities (Singh, 1998).

However, a word of caution is appropriate. Life review is most effective when emphasis is placed on the individual's unique story (including the right not to narrate) and standardization is minimized (Price, 1995)

The Arts and Ritual

Hospice has enhanced the role of the arts in supporting and soothing patients and families, improving their environment, and building bridges to those of diverse backgrounds. Creativity, symbols, and rituals (specifically religious or not) provide an avenue for people to feel alive, relieve pain and anxiety, and instill hope. Creating order and stimulating and enlivening the body, mind, emotions, and spirit help clients feel like whole people rather than completely defined by their terminal illness. They can give to others and be remembered through their art. Joy and humor can be recovered (Bailey, 1997; Chandler, 1999).

Looking at what's been helpful in the past can give clues to meaning for the present. Dancing, reading or writing (poetry, journals, etc), sculpting, painting, listening to or playing music, and pictures, candles, sunsets, incense, the sacrament of communion, blessings of the sick, meditation, and guided imagery can touch one's inner being and provide peace (Burton, 1998; Chandler, 1999; Mauritzen, 1988; O'Connor, 1988). An example of this is, Beyond the Horizon, a book of prose and poetry edited by Cicely Saunders (1990) to help her face suffering and loss and give hope to others.

Prayer, especially, is a common religious and spiritual ritual. Prayer can be a cry for help for you or someone we love, petition through formal readings or prayers, or a more informal talking with God. Prayer can also be silence, listening, meditation, worship or praise, directed toward God or not. A progression is often seen in hospice from hoping for a cure to hope for remission, more time, fewer symptoms, experiencing a special event, living life till death, to hope for life after death. Anxiety is often reduced as acceptance increases (Brown-Saltzman, 1997; Lattaizi-Licht, et al., 1998).

Guided imagery, though less common, has been used to increase an individual's sense of control, reduce or arrest side effects, and promote relaxation. Imagery promotes problem solving by helping reframe the experience and create new ways of seeing the situation (Brown-Saltzman, 1997).

Sensitivity to the individual's belief system is essential when exploring either prayer or guided imagery. However, one cannot assume lack of interest by one professing no faith in God. Experience has shown otherwise (Brown-Saltzman, 1997).

Transcendence

Transcendence, "levels of awareness, of being, of Spirit, that transcend the

personal consciousness" (Singh, 1998, p.1), has been described as a profound, extraordinary, spiritual transformation that brings grace to living and dying. Transcendence includes asking, "Who am I?" (Singh, 1998, p. 160) and surrendering again and again as the answers change. Contrary to giving up, which embodies despair and inaction, surrender acknowledges, "I am dying," and then moves on to actively participate and live until one dies. Suffering is seen as an opportunity for transcendence. Through suffering, we grow, mature, and become fully free (Kramer, 1988; Singh, 1998).

Studying women with advanced breast cancer, Coward (1989) found self-transcendence to be the ability to look beyond oneself to help others, to allow others to help them, to experience pleasure from the immediate environment or to simply accept what cannot be changed. More specifically, Dershimer (1991) uses personal examples to point to those moments when one is "connected not only to another person but to something beyond the immediate relationship and situation" (Dershimer, 1991, p. 35). This could be God, a life force, or a sense of having done well in one's life. "When time is no more" (Mauritzen, 1988, p. 111) was Maurtizen's description of these moments he experienced in 15 years of chaplaincy.

Individuals who had dealt with their suffering or dying to some extent were found to be more likely to experience extraordinary meaning through everyday incidents. Events such as walking the dog or listening to music gave a sense of comfort, peace, and content beyond the usual significance of diversionary activities or pain relief (Steeves & Kahn, 1987).

The world of individuals with a terminal illness narrows. The focus of everyday living is on the ordinary, repetitive, and often difficult tasks. Moments of transcendence

come from a concentration on one's inner life or those we love, in the midst of the pain and suffering. Our worth in former identities and what we have accomplished passes away. As one moves closer to death, silence and listening to that inner voice and finally, to one's breath alone, increases. Clinging and resistance may end in clarity and integration, as well as peace and joy, as we enter the mystery of death (Kramer, 1988; Singh, 1998).

Nearing Death

The experience of nearing death needs to be delineated from the near-death experience, which is the experience of being medically pronounced dead, but then returning to physical life on earth. The experience of nearing death appears to be the universal process of the body dissolving, the self separating, and the spirit leaving with no return to physical life on earth. Yet, what can be seen as a moment of tragedy may also be transformed to a moment of depth and grace (Singh, 1998).

When life is waning, Herth (1990) found relationships, spiritual connections, peacefulness, and serenity to still hold significance for producing hope. Also, the individual may be perceived as having the qualities of withdrawal (not to be confused with the state of depression, but purposeful separating), relaxation, radiance, interiority, silence, sacredness, transcendence, knowing, intensity, and experienced perfection. These may be changing, subtle, and unexplainable. This can occur from weeks to minutes before the death or at the moment of death itself (Singh, 1998).

Patients near death can be found rambling, not making sense, and appearing to hallucinate or react to drugs when in fact they are working out one last thing that may hold meaning for them or those left behind (Callanan & Kelley, 1992). They may:

a) need healing and reconciliation with others, themselves or a supreme being, b) feel something is missing or unfinished, c) have symbolic dreams, d) be in the presence of one who has died (loved ones or saints), e) have a glimpse of another world (through angels, bright lights, a glowing city, beautiful places), f) speak of traveling, going home or looking for a map, g) know when they are about to die or h) choose when they die. Affirming such experiences and including the family in deciphering them can be helpful (Callanan & Kelley, 1992; Phlaum & Kelley, 1986).

Regardless of the life lived and the state of the physical body, death, in and of itself, becomes profoundly significant and growth producing. With no place else to go, we finally have to "be" here. The intensity of being acutely attuned to the present, to the body, and to every twitch culminates in death. The finite me is finally displaced and merges into a larger infinity (Singh, 1998).

Religion

"Many hospices have been founded by believing Christians, often evangelicals or Catholics" (Walters, 1996). Consequently, established religions have had a huge impact on spirituality in hospice. Traditional membership in faith communities, religious icons, visits from spiritual leaders, and prayer prove helpful for patients. The religious, not only listen to the message deep within, but experience the speaker, God, the Ultimate Being, in the most intimate of discourse. They feel responsibility, not only for fulfilling their life tasks, but also *to* their Supreme Being (Daaleman & VandeCreek, 2000; Frankl, 1955).

Yet, to meet the needs of staff and clients outside of this regime, the spiritual, as discovering meaning, has emerged. Everyone has spiritual needs, which can be tended to

by the entire disciplinarian team. Still, chaplains provide the religious piece to those of varying beliefs if a relevant religious leader isn't available (Walter, 1996).

Major religions view death in a variety of ways. "Death has been understood as everything, from defeat and punishment to release and opportunity" (Bowker, 1991, p.209). Within the same tradition, opposites can be maintained, reinforcing the experience as both/and rather than either/or. Together with science, religions affirm the important value of death. Life comes from death. Death comes from life (Bowker, 1991).

World religions see death as a "sacred art, the final ritual, the last opportunity we have to discover life's ultimate meaning and purpose" (Kramer, 1988, p.1). Each tradition has its own set of myths or stories that explain the significance of death, but the overall focus is on transforming "old patterns, habits, roles, identities" (Kramer, 1998, p.12) to the birth of a new person now. Self-sacrifice, surrender, and spiritual death preclude physical dying, as a way to overcome the fear and face death with a changed attitude. Eastern religions and people (Hindu, Buddhist, Chinese, Tibetan, and Japanese) call this self-awakening, while western thought (Egyptian, Mesopotamian, Jewish, Christianity, and Islamic) calls this salvation. The outcome is a greater sense of well-being and personal wholeness. This religious transcendence poses the possibility of higher levels of connection through relationships and love. Christians call this "the communion of saints and the Triune Life of God" (Bowker, 1991, p. 228; Kramer, 1988).

Gaps in the Literature

By far, there is more literature of dialogue than research on the subject of spirituality and hospice, especially focused on lay or professional caregivers, primarily

chaplains, pastors or other spiritual leaders, and nurses. Only one study compared the spiritual caregiving of nurses, social workers, and professional spiritual careproviders. Professional caregivers as a group (other than spiritual leaders) were encouraged to "find new ways to actively support, sustain, or facilitate spiritual thinking...help patients find meaning in suffering,...(and to) transform suffering into an opportunity for growth" (Charleton, 1992; Kirschling and Pittman, 1989; Mauritzen, 1988; Millison, 1995; Millison & Dudley, 1992, p. 51; O'Connor & Kaplan, 1986). Research is very limited when the focus is on the individual with the terminal illness.

The application of spiritual concepts and ideas to hospice individuals is most often made through experience or case illustration, using from 1-19 individuals, the average being 3 (Bell, 1995; Bissel, 1992; Burton, 1998; Charleton, 1992; Derrickson, 1996; Kazanjian, 1997; O'Connor, 1986; Phlaum & Kelley, 1986; Steeves & Kahn, 1987). Only 3 articles were found that touted research focused on the spirituality of the hospice individual with the terminal illness (Herth, 1990; Ita, 1995; Reed, 1987). Ita (1995) and Reed (1987) utilized quantitative studies to look at the designated issues of acceptance of death and well being, respectively. They are well done studies, but are limited in the scope of in-depth information by method and definition of topic. Herth (1990) employed a combination of qualitative (interviewing) and quantitative (the Herth Hope Index and Background Data Form) methods. Although she added a longitudinal dimension by interviewing 10 of the 30 participants 3 times rather than once, Herth did not use tape recording and limited the scope by defining the topic as "fostering hope." Coward's (1989) study, describing experiences of women who lived with Stage IV breast cancer for 2-7 years, was included because of the similarities of subjects to hospice

clients and the phenomenological research design. Again, this study limited the scope to one subject, transcendence. Additionally, 4 of the 5 participants wrote their responses while 1 was recorded.

Part of the problem is the indefinite nature of spirituality. This does not lend itself to methodical, quantitative research. The nature of operationalizing spirituality limits the scope and usefulness of any study. Ita (1995) limited her focus to acceptance of death. Reed (1987) looked at well being. Case illustrations and personal experience have given the most eclectic information about spiritual concerns of individuals with a terminal illness. But this leaves room for selective inclusion of stories. What is the common experience, if the individual is given a free reign to discuss the impact of spirituality on their everyday lives? How is the experience different when conducted exclusively by oral means? How willing are individuals to discuss their spirituality? These are the gaps in which these questions will be explored and analyzed with the hermeneutics approach.

Summary

This chapter defined the terms of this study and traced the historical background of spirituality in hospice. Spirituality as meaning was delineated from the viewpoints of transcendence, relationships, life review, the arts and rituals, nearing death, and religion. The gaps in the literature were identified. In the next chapter, the existential and narrative theories and the model of logotherapy are described and applied to this study.

CHAPTER THREE: THEORETICAL FRAMEWORK

Existentialism and the Narrative theory, the frameworks supporting this research, will be explored in this chapter. The model of logotherapy will be discussed for its contribution to this study

Existential Theory

According to the dictionary (Webster, 1976), existential is concerned with the experience of being or living. Concentration is on "how we exist." The length of time is not important, rather the quality and richness of the life lived. Our finiteness and temporality makes using every moment to the fullest essential (Frankl, 1955).

An attempt to answer the question of the meaning of death begins with the question of the meaning of life. The uniqueness of the individual together with the singularity of the situation speaks to the responsibility of the person. "Being different" is what gives one's life value. Being free to choose one's destiny is what sets man apart. Although destiny includes the biological "disposition" and the "situation" of the environment, "position" or attitude in life can still be freely chosen. Doing one's best takes the starting point into account (Frankl, 1955).

The individual takes direction from personal needs and the needs of the whole. Personal transcendence comes from pursuing personal values (art, nature, and the inner life) or one's contribution to the mosaic of the community (interpersonal intimacy, work, and activities). Even after the flame has been extinguished, the burning of the candle and the ensuing light hold meaning (Frankl, 1955).

Campbell's (1968) transfer of this analogy to a hero on a journey can be a helpful interpretation for terminal illness. Life as known is left behind. Trials and

learning follow. Then, being transformed, one reenters life with a new way of being. This can be in individual transformation or one of a leader who then goes on to model behavior for others. The eclectic nature of the hero can span cultures and religions and be manifested as Jesus, Moses, Mohammed, Buddha, the Aztec Tezcatlipoca or the old men of the Australian tribes (Chandler, 1999).

Narrative Theory

Another theory contributing to this study is the Narrative Theory. Narrative in the simplest form is a *story,* told in everyday language and describing events over time. "Stories not only exist but they have powerful effects on human behavior. They tell us not only who we are but who we have been and who we can be" (Rappaport, 1995, p.1). Stories common to a group of people form a *community narrative.* Neighborhoods, organizations or cultures have narratives describing the history and future of their members. *Dominant culture narratives* influence individual and community narratives. These commonly known narratives sometimes include stereotypes difficult to escape (Rappaport, 1995).

The central focus of the narrative theory is on the fluid meanings attributed to life experience. How meaning is constructed from the experience is emphasized over the actual behavior and events. There can be many valid understandings and interpretations that change over time. The stories we tell "organize our experiences and shape our behavior" (Nichols & Schwartz, 1998, p. 398). Stories are encouraged and questions are asked to understand the impact of the problem on the client (individual, family or community). Changes can be made as the expanding awareness triggers one to consider and create different ways of looking at the situation. However, to maintain their

individual narratives, clients need the support of community narratives, especially when they are being newly formed. People with similar views or an emotional connection can provide social and emotional support. Support groups, peers, and families are examples of this (Nichols & Schwartz, 1998; Rappaport, 1995).

The stance of the facilitator is also important. To listen, collaborate, ask questions, and look for strengths of the unique story is the goal. Stories are used as resources to empower individuals. With terminal illness taking away many choices of the hospice client, narrative theory provides a framework for developing autonomy and self-esteem (Price, 1995; Rappaport, 1995).

Logotherapy model

Logotherapy, derived from the Greek word, "Logos," that denotes "meaning," embodies the essence of this study. Frankl (1959) believed the primary motivation in one's life is to search for the meaning of one's existence in this very moment, relative to the present circumstances. From his experience of surviving the Nazi concentration camps by focusing on the image of his wife and the brief moments of peace (seeing a sunset through barred windows, a prayer in the darkness of a locked cattle truck), Frankl quotes Nietzsche, "He who has a why to live can bear with almost any how" (Frankl, 1959, p. 9). Although one cannot change the circumstances, they can choose their attitude. One can turn from despair "to living as meaningful a life as possible with the time and the ability that the individual retains" (Hutzell, 1986). When one rises above one's self, meaning remains to the end. Love transcends time or space. Worth is measured in terms of dignity, not usefulness (Frankl, 1959).

Logotherapy seeks to bring individuals to more consciousness of that still small

inner voice; that is, to more awareness of the spiritual realm so they can act more responsibly. Discovering specific tasks related to one's own unique person and life situation is the objective. Frankl (1955) suggests that this process includes, "clear recognition of goals, honest resolution, and a certain degree of training in making decisions" (Frankl, 1955, p.86). No one else can make the identical decision or fill the same niche. We can choose how to exist in this moment. The past does not have to be unfortunate, regrettable mistakes, but fodder for learning to make better choices today. We can even choose not to be in this moment. We are like a sculptor with a masterpiece to finish, with limited knowledge of the actual deadline (Frankl, 1955).

Application of Theory and Model

As an existentialist, Heidegger (1927) related the authentic existence of individuals to the interpretation of their experience in the world. Paul Tillich (1952) used the existential approach to broaden the concept of Christianity to spirituality and the common experience of humanity and meaning. Spirituality, then, becomes the creative participation in meaning. The "ultimate concern" (Tillich, 1952, p. 47) is that which "gives meaning to all meanings" (Tillich, 1952, p. 47). Creatively accepting loss and having faith in a power of being, greater than the power of oneself or the power of the world, as a way to find meaning mimics hospice (Burton, 1998; Tillich, 1952).

Existential theory connects spirituality and the experience of dying in a hospice environment. Like existentialists, hospice looks at all people as unique, free individuals who can still control their present. The diagnosis of a terminal illness changes ones perspective of life. This often includes some aspect of disillusionment or regret, as the adjustment is made to knowing death is closer. However, acceptance comes when the

emphasis is on how individuals can find fulfillment, meaning and self-transcendence in the immediate moment in the midst of their dying experience (Corr & Corr, 1983; Frankl, 1955; McGrath, 1997; Nichols & Schwartz, 1998).

Narrative theory adds an additional facet to the aspect of meaning. Hospice is a place where clients tell life stories to help them transcend their illness, illustrate spiritual beliefs, understand their lives more honestly and resolve old issues. The perspective that meanings can change is central to assisting an individual to deal with a terminal illness. As they move towards dying, old meaning can be replaced with the creation of new meaning. Reviewing their lives assists them to bring together their old life of activity, productiveness and roles with this new position of simply "being." Telling stories brings about an integration of who they have been throughout their life and now are becoming (Price, 1995; Singh, 1998).

Following from existential theory, the model of logotherapy centers on meaning. Hospice clients cannot change their terminal illness. However, they can choose their attitude, maintain their dignity, and exist in love until the end. Meaning is found in spite of and because of their terminal illness (Singh, 1998).

Finding meaning in suffering permeates the literature on spirituality and individuals with a terminal illness (Burton, 1998; Clark, 1999; Mauritzen, 1988; Steeves and Kahn, 1987). The existential and narrative theories plus the logotherapy model have their central focus on meaning. This makes them well suited to this study on terminal illness and spirituality. Thus, these theories serve to guide and inform the research question under study.

Summary

This chapter described the existential and narrative theories, along with the Logotherapy model. The relevance of these theories and this model was applied to the study of the spirituality of individuals with a terminal illness in hospice. In the next chapter, the methodology is outlined.

CHAPTER FOUR: METHODOLOGY

The purpose of this qualitative research study was to explore the impact of spirituality on the everyday lives of individuals living with a terminal illness in a hospice program. The interpretative method of hermeneutics utilizes a circular process to uncover multiple layers of meaning and hidden relationships (Van Manen, 1990). The explanation of the research methodology includes restatement of the research question, the philosophical background of hermeneutic research, the research design, a description of the participants, the criteria for quality in interpretive research, the processes of data analysis, and the protection of human participants.

The Research Question

The research question was, "How does the experience of spirituality impact the everyday lives of individuals living with a terminal illness in a hospice program?" This question was explored with the questions and prompts listed in Appendix B to reveal the common experiences of the research participants.

Philosophical Background of Hermeneutic Interpretive Research

The traditional concept of hermeneutics grounds it in the reliability of time. The word hermeneutics is formed from the Greek word, which means "interpreting" (Heidegger, 1999, p. 6), that is, "'to announce and to make known'" (Heidegger, 1999, p. 111). The original meaning can be traced from Greek mythology (2000 B.C.-700 B.C.) where the god Hermes communicated messages from the gods to mortals. Aristotle (384 B.C.-322 B.C.) expanded on Plato's (428 B.C.-347 B.C.) use of regular dialogue, by utilizing "methods rooted in observation and experience" (Brumbaugh, 2000). Augustine (354-430) first applied hermeneutics to the translation of scripture. Schleiermacher

(1768-1834) helped change the view of hermeneutics from interpretation to the broader concept of a doctrine or technique of understanding. He saw it as a "disciplined strategy" (Van Ness, 1996, p.133) to decipher differences and commonalities of the subject under scrutiny while considering the subjectivity of the involved individuals and groups (Heidegger, 1999; Van Manen, 1990; Van Ness, 1996).

The contemporary understanding of hermeneutic interpretive research derives from the phenomenological perspective of Husserl (1859-1938) (MacLeod, 1996). He advocated seeking knowledge through direct, lived experience. By bracketing one's subjective experience, phenomena can be approached objectively. From Husserl's phenomenology, Dilthey (1813-1911) developed the hermeneutics of research. Understanding comes from looking at the expression of the lived experience of individuals. A deeper level of comprehension was sought by capturing meaning through the point of view of the individual involved in the experience (Heidegger, 1999; MacLeod, 1996; Van Manen, 1990).

Husserl's student and German philosopher, Martin Heidegger (1889-1976), deviated from the phenomenological perspective. Rather than looking at the experience of the individual and how the phenomenon appears, Heidegger emphasized the process of understanding. What the observers see is related to their history and experience in the world. There can be no detached viewpoint. One simply attempts to "'...clarify the conditions in which understanding takes place' (Gadamer, 1976)" (Koch, 1995, p. 830). Methodology is replaced with an ongoing conversation (Koch, 1995).

Four of Heidegger's related ideas help explain his position. They are pre-understanding, background, co-constitution and interpretation.

Pre-understanding describes the structure of our existence in the world. The words and ways of our culture give meaning and organization to our lives before we understand them. Out of this preconceived stance comes human beings' *background,* which takes into account their individual history and culture. Although influencing their understanding of the world from birth, this can never be made completely explicit (Koch, 1995).

Co-constitution depicts the interaction of people and their world. At the same time, the person constructs the world while being impacted on by that same world. Therefore, *interpretation* must take into account the person's background, understanding, and interface with the world. Hermeneutics interprets both the conscious and unconscious self-interpretation of familiar everyday activity which leads the researcher and participant to better evaluate their options for 'being' and acting in the world (Koch, 1995; MacLeod, 1996; Plager, 1994).

This research study is situated in the second of Heidegger's three ways to explore everyday life. The first, also a focus of hermeneutics, concentrates on smooth functioning. The third, the focus of natural science inquiry, ceases natural activity to isolate measurable characteristics. The second, focusing on situations which interrupt everyday activity, captures the nature of this study and the clients in hospice with a terminal illness and life expectancy of less than 6 months (Plager, 1994).

Research Design

The contribution of spirituality to the meaning of terminal illness has been discovered through individuals telling and retelling stories (Callanan & Kelley, 1992; Derrickson, 1996; Reed, 1987). Literature turned from dialogue about spirituality to the

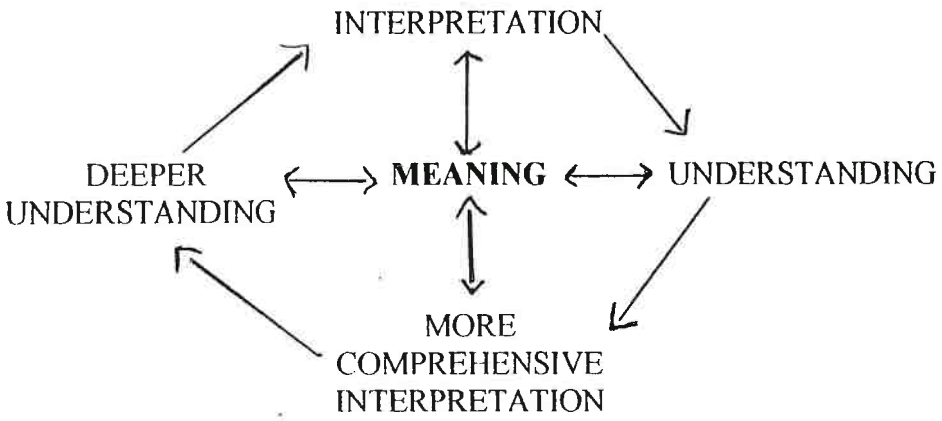
description of spirituality in specific individual lives (Herth, 1990; Phlaum & Kelley, 1986; Spiritual Work Group of the International Work Group on Death, Dying and Bereavement, 1990; Wald, 1986). Now, the individual is given the complete freedom to describe *their* spirituality. Therefore, the hermeneutics model of interpretative phenomenology lends method to this study.

The complex hermeneutics circle of inquiry deviates from the linear process of quantitative research (See Figure 4.1). The hermeneutic circle was employed to move between the parts and the whole. The analysis of the parts moves towards a more complete understanding of the whole. The overall picture enriches the interpretation of the parts. Yet, hermeneutics captures that which is beyond the parts and the whole (McCleod, 1996; Van Ness, 1996).

In the hermeneutic method of interpretation, meaning is found through a continual process of interpretation and understanding (See Figure 4.1). Strength is found in the availability of a greater depth of understanding. The on-going process involved with the here-and-now lends flexibility and a chance to modify according to circumstances. The focus is on what *is* rather than on deficits. Use of structure, technique and specific examples lends to the openness and credibility of the interpretation. Lastly, qualitative research can be relatively inexpensive (Macleod, 1996; Rubin & Babbie, 1997).

Emphasis on context and individual stance, an integral part of hermeneutic interpretation, can be seen as a weakness of the design. Generalizations, though not the concern of hermeneutics, are difficult. Also, replicability and biased sampling can be a problem (Macleod, 1996; Rubin & Babbie, 1997).

Figure 4.1 The circular interpretive process of hermeneutic research (Nelson, 2000).



Note: This figure is replicated from Nelson, 2000.

Participants

The three study participants were chosen from the caseload of Rice Hospice, administered from the main office at Rice Memorial Hospital in Willmar, Minnesota, but servicing 11 counties in rural west central Minnesota through 7 satellite programs. One of 70 hospices in Minnesota, the first patients were accepted into Rice hospice in August 1982. In 2000, 25 paid staff and 210 volunteers served 441 clients.

Of the 6 individuals who responded to the initial inquiry, 4 were male and 2 female. The 3 research participants lived within a 20-mile radius in Southwestern Minnesota and were clients of the same hospice satellite. The 1 female and 2 males were ages 95, 87 and 47, respectively. Two lived in the nursing home and 1 at home, although the latter was interviewed both times in the hospital. Two were Caucasian and one part Native American. Two were members of the Lutheran church, describing a lifetime Christian affiliation, although 1 grew up in the Baptist church. One belonged to the Assembly of God church for less than 2 years. Two had cancer. One was diagnosed 2 years ago, on hospice 9 months and expecting to die shortly. While the other participant with cancer was on hospice 13 months, had no symptoms and believed the cancer could be gone. The third, only on hospice 1 month, could not state the diagnosis, commenting, "Am I terminal?" but complained of pain in the front, back, and bottom. All had 4 children.

Criteria for Quality in Interpretive Research

Quality for interpretive research or hermeneutics is in the process of being defined. According to Lincoln (1995), scholars are not willing to take a back seat to conventional scientific inquiry, but are embracing three new commitments. First, they

identify the importance of the relationship between the researcher and participant. Second, they are looking at the use of research. Can it be an avenue towards action? Finally, can it enable and promote "justice, community, diversity, civic discourse, and caring?" (Lincoln, 1995, p. 277-278).

For the purpose of this research, seven of Lincoln's (1995) emerging criteria for evaluating the quality of interpretive research will be used. Standards for judging quality in the inquiry community will not be considered as it applies to research geared towards publication, which this research quest is not. The criteria move from the more formal to the more personal: a) positionality, b) community as arbiter of quality, c) voice, d) critical, transformative subjectivity, e) reciprocity, f) sacredness, and g) sharing the advantages of privilege.

Positionality recognizes the context and culture of the research and stance of the author. General truths cannot be reached (Lincoln, 1995). This researcher's background and experience with spirituality, death and hospice were explored in chapter one. The context of the research and the demographics of the three individuals interviewed were discussed earlier in this chapter. The spirituality of any given individual in hospice may or may not be similar to these three individuals.

Community as arbiter of quality emphasizes that research is conducted in the confines of a particular community. Research exists as much for the purpose of the community as for the educational value (Lincoln, 1995). Telling one's story is important for hospice recipients to rediscover and maintain meaning. This hermeneutics project is an extension of that intent.

Voice speaks to the attentiveness of the researcher to those who cannot speak for

themselves or who may have been silenced. Listening for and making known the alternative voices and interpretations of the text conveys quality. Going back to the one living participant to clarify her experience was part of the rigor of this research. Allowing her to read and comment on the final draft gave her continued input, power and a chance to be heard.

Critical, transformative subjectivity is the ability of the researcher to be acutely aware of one's own reactions before, during and after the interview in order to discriminate between the subtle differences in the meaning of the interviews which may lead to personal or social transformation (Lincoln, 1995). Keeping a journal of my personal state and the process before and after the interview gave insight to the ongoing interpretive process.

Reciprocity pays attention to the relationship between researcher and participant. Mutual sharing, trust and caring characterize high-quality research (Lincoln, 1995). The care with which this researcher chose participants was the first step in this process as well as giving time and credence to staff concerns and having an initial contact to commence this process. Rewarding participants with a stipend recognized my appreciation of the time, thought and life experience they contributed to my research efforts.

Sacredness highlights the essence of the human spirit embodied in human dignity, justice, mutual respect, and shared power. Addressing the subject of spirituality eclectically, with openness to the experience of the participant was one attempt to convey this researcher's feelings of "walking on holy ground."

Sharing the advantages of privilege connects the outcome of the research to both

the researcher and the participant. Often, the researcher gains dignity, respect, prestige, and economic power from the participants contributions (Lincoln, 1995). In part, this is true of this researcher. This research project will assist me in completing my Masters of Social Work and Masters of Arts in Leadership for Mission. Yet, dealing with a terminal illness, "one day at a time," lies in the ability to ascribe meaning to the here and now moment of today. Participation in the interview appeared to be significant for the 3 individuals. May the gift of the tape to their families and the completion of the study, help their stories live on.

Data Collection Methods

The three participants used for this research study were chosen by the following method. Due to my involvement with the Willmar hospice as an intern, no clients from the Willmar office were considered. Letters (Appendix C) explaining the research project and inquiring about interest in participation, were mailed by hospice staff to 21 of 40 possible clients in the satellite hospice programs, who were not deemed unable to deal with such a request by their social workers due to diagnosis (i.e.. Alzheimers), physical condition, emotional fragility or closeness to death. The researcher did not have access to these names and addresses. The recipients were asked to return an addressed, stamped postcard within a week, designating if they did or did not have interest in the project. If they were interested in participating in the study and checked yes on the postcard, a space was provided for their telephone number and name.

Twelve postcards were returned, with 6 designating Yes and 6 No. The researcher followed up with a telephone call (Appendix D) to the individuals in the order in which they were received. Again, the individual was given the opportunity to decline

participation at that time. If interest was expressed, more information was given and questions answered.

The first three individuals who consented to participate in this study and met the specified qualifications were used as the research participants. They were viewed as co-investigators of this study and their ongoing interest was encouraged (Van Manen, 1990).

A brief introductory visit was conducted to sign the written consents (Appendices E&F) agreeing to the terms of the interview and indicating their wishes for disposal of the tapes. Conversation suggestions (Appendix G), the interview question and prompts (Appendix B), and arranging an interview time and location convenient and comfortable to the participant was also addressed in this visit. The introductory visit screened out the second respondent who was taken off Hospice due to an improvement in her condition. Therefore, she no longer fit the criteria of this study. To maintain the integrity of this study and acknowledge her willingness and excitement about being interviewed, I offered to proceed in spite of the fact it could not be used for my study. Nonetheless, she declined.

The first interviewee thought it was too laborious to have two interviews and suggested I just come once. Therefore, I gave her the main interview question on the phone and stopped in briefly before lunch to meet her, sign releases, and reiterate the main interview question. The taped interview took place 1 hour later.

An in-depth interview from 30 to 60 minutes was employed to gather information, but the health and interest of the individual determined the length of the interview. After a short period of establishing rapport, the individual was asked this question, "Tell me about your experience of spirituality as you live with your terminal illness." Prompts

(Appendix B) followed to search for varying and deeper understandings. The researcher wanted to "illicit vivid descriptions concerning (a)feelings, thoughts, actions, and life events related to" (Widera-Wysoczanska, 1999, p. 76) their spiritual experience and the impact of those experiences on the person's life.

The dialogue followed the 3 stages described by Widera-Wysoczanska (1999). The individual could share anything they thought important (spontaneous stage). Prompts were used to clarify and broaden the information (conceptualization stage). Then, after completing all 3 interviews and analyzing the information, I returned to the one living individual for the purpose of clarifying my understanding (verification stage).

This researcher was open to the ever-changing experiences of the individuals with a terminal illness as they moved closer to death. The person's story was tended to for the expressed meanings and the meanings behind the scenes. The purpose was to gain understanding and insight into the common meaning of spirituality in the lives of these 3 individuals living with a terminal illness. The process was given as much importance as the content. The individual was trusted for their life interpretation (Nichols & Schwartz, 1999; Van Manen, 1999; Young, personal communication, September 29, 2000).

The style of the researcher was one of collaboration, listening, and participation. The personal history and style of the researcher was seen as strengths to the purpose of uncovering spiritual significance for each individual. However, this was minimized to allow the participant freer reign to explore their experience. The goal was to lead them further into *their* story, not along preconceived ideas, by keeping the participant and the researcher oriented towards the phenomena of spirituality (Nichols & Schwartz, 1999; Van Manen, 1999).

Processes of Data Analysis

For the purpose of this hermeneutic interpretation, the transcripts and field notes were treated as text. The hermeneutic circle was employed to seek, not the 3 individuals' interpretation or the researcher's interpretation, but the interpretation compiled through the interaction of each in this time and place (Macleod, 1996). The researcher used the systematic process utilized by Widera-Wysoczanska (1999) in her study of everyday death awareness in adults.

Step 1: *Open-minded reading of the script.* The researcher read and reread the texts a number of times. She wanted to put herself into the perspective of the participants to learn as much as possible about their understanding of spirituality in their lives.

Step 2: *Searching for themes.* While reading and rereading the text, possible important themes and ideas about their meanings were noted. Asking two questions from Van Manen's (1990) reading stances approached this.

1. Holistic: What phrase may express the overall meaning of this text?
2. Detailed: After segmenting sentences, what does each reveal about the nature of spirituality?

Step 3. *Discovering key ideas.* Words or phrases that stood out as significant to this experience were highlighted. This was not necessarily related to their frequency of use.

Step 4. *Looking for unity of meanings.* Key words and phrases were compared and analyzed in detail. Discrepancies were discussed and related back to the text for specific examples of support.

Step 5. *Creation of "poles of meaning."* Segments of text with similar meanings were placed together in the order they appeared in the transcript. Similarities and differences were noted, especially relating to exclusive words or phrases as "never" or "everybody knows."

Step 6. *Formation of a personal picture of the spirituality of individuals with a terminal illness.* Incidental themes were eliminated leaving the common experience. A question was entertained, "If this commonality is deleted, is the experience still the same?" (Van Manen, 1990).

Step 7. *Formation of a personal model of the experience.* All the information was integrated into a model of their experience.

The text was read and reread. Each rereading contained and contains the possibility of new meanings. Interpretations were written and rewritten. One main theme is recognized as a simplification of the experience and will always be incomplete. However, this lends structure to the experiences and leads to the common experience and meaning. The researcher was acutely aware that this circular process separated her from and yet united her to a deeper understanding of the spirituality of the individual with a terminal illness (Gadamer, 1999; Van Manen, 1990).

Protection of Human Participants

To protect the participants in this study, the hospice team was consulted about potential risks and safety precautions. Acting director of Rice Hospice, Leslie Erickson, gave approval for the research study (Appendix H). Plans and procedures were developed in coordination with Brenda Wiese, Social Work Supervisor. The researcher received approval from the Rice Memorial Hospital Institutional Approval Board

(Appendix A) and the Augsburg College Institutional Review Board, IRB approval #2001-2-1 (Appendix I).

Every effort was made to facilitate each individual's free choice to participate or not to participate in the study. After an explanation of the purpose and method of the research and the potential risks and benefits, participation in this research project was completely voluntary. The consent to participate could be revoked at any time without any negative consequences.

Possible risks identified were an invasion of their privacy and the potential for thoughts and memories evoking an emotional reaction. However, participants were encouraged to bring their concerns to David Rivers at the Grief Center at Rice Memorial Hospital, free of charge, or to Woodland Centers for private pay or insurance. Benefits included a $20 honorarium given before the interview began. Possible indirect personal gains were enhanced well being from further understanding of the spiritual process in their own life, being able to share their experience with others, and the option of preserving the tape for family members.

Each participant, before interviewing began, signed an informed consent. These included consents for audiotaping, use of direct quotations to promote accuracy of the individual's story, use of a private transcriptionist, bound under the confines of confidentiality, and designation of their wishes for destruction or possession of the tape. The consent could be withdrawn at any time.

All names and identifying information from the interview were changed to protect the participants and their families. However, participants were told in the consent form that the study does not guarantee anonymity, but only confidentiality. The researcher

explained that due to the small sample size, someone could or might recognize their stories. The data will not be part of the individual's chart or other permanent records.

The records of this study will be kept private. The tapes and text were stored in a locked box at the researcher's home. The tapes will be disposed of, before December 31, 2001, according to the participant's wishes.

Summary

This chapter presented the research methodology used in this study. The various components of the methods were discussed. The next chapter will report the findings, followed by discussion of relevance to existing literature.

CHAPTER 5: FINDINGS AND DISCUSSION

The narratives of these 3 adults revealed how *believing* in a Supreme Being was the most significant part of their spirituality as they live with a terminal illness. In spite of the different stages of their terminal illnesses and the different ways believing evolved in their lives, believing was intricately woven into many aspects of these individuals' lives and now sustained them.

Believing will be explored from each of their unique perspectives including believing in spirituality and religion, believing in not judging, and believing in whom. Then, believing will be explicated through 3 common facets: Leaving the unknown to God, believing throughout life, and believing as meaning in daily life.

Believing

Unlike spirituality and religiosity, which are difficult to define and therefore defined at great length in the literature (Amenta, 1988; Burton, 1998; Canda, 1988; Cascio, 1998; Chandler, 1999; Corless, 1986; Cornett, 1992; Foster, 1986; Fryback & Reinert, 1999; O'Connor, 1988; Pellebon & Anderson, 1999; Smith, 1995; Thomas, 2000), believing for these 3 individuals can be confined to a simple, dictionary definition. Believing, according to Webster, is "1. a. to have a firm religious faith b. to accept trustfully and on faith 2. to have a firm conviction as to the reality or goodness of something" (G. & C. Merriam Co., 1976). This accurately describes the strong spiritual conviction of each participant. All three individuals were clear and adamant about what they defined as the essence of believing.

Out of Irene's frustration with the church being too focused on "doings," came her description of what she thought was more "necessary" (Italics are mine.).

"The *main thing* is the Bible and God...and the help you get out of it.....you don't have to know and do an awful lot if you know John 3:16, "For God so loves the world that he gave his only begotten son that whosoever believes in Him should not perish but have everlasting life"...*all you need* is to have the good Lord to depend on.....believe in...*Always* the good Lord first.....it is meant to be so simple that anyone can understand it. I think that is why he said John 3:16...they (the words) are the *best for you* because they are *the real thing.*

The words Irene chose to describe the "main thing" of believing show her passionate belief. According to Irene, John 3:16 is central, that is, believing the "whole thing...in your heart."

The concept of "the real thing" was significant for Paul, too. He explored the meaning of church in his life to uncover the "real meaning" of spirituality. In the past, he avoided churches because of his desire not to be hypocritical. "We didn't go to church for several years...I didn't want to be somebody who went to church on Sunday and the rest of the week was out in the bars chasing women and drinking." The realness of the members was what finally attracted him to his present church. "There was nothing fake about any of these people at all...that...was something that I had been looking for all my life, to get rid of the phoniness of people." Yet, Paul stressed the essence of believing in contrast to the prominence of church.

I probably put too much emphasis on going to church because going to church doesn't mean anything really. The *only thing* it (spirituality) *really means* is how you personally have Jesus in your heart...and life."

As much as Paul appreciated his "church home," the most vital to Paul was personally

knowing Jesus both on your inside, in your heart, and having Jesus on the outside, in your life. Without believing, church had no meaning.

Harvey used the word "faith" 24 times in his narrative to describe what believing meant to him.

> If you have faith, *you have everything*.....I know I have faith in my heart and that is *all I have to worry about.*

What brought him through the accidents of his younger years was not luck, but faith. When at the VA hospital for his last operation and he was close to death, "Because I have my faith...it was so peaceful. I had no fears." Faith is the reason "nobody in this world...has been given more." Faith is the reason all his children "come out good." Harvey was confident that everything in this world related back to his faith. Believing for Harvey was not worrying, but having a firm faith.

Believing was the most important aspect of each individual's spirituality. Believing helped make sense of or gave meaning to their entire life. Believing was central to their lived experience of their terminal illness.

Believing in spirituality *and* religion.

The experiences of these individuals show that believing goes beyond the surface to their hearts. However, the "church" and the "outer life" remained significant. Making a distinction between the inner and the outer and between spirituality and religion was an additional way to refine their concept of believing.

Irene used her parents as an example. "Both my parents were very good Christians, not just for the outside, but on the inside and all over." Irene believes Christianity makes a difference in both the inner and outer life. Paul agrees.

> To me that is a lot of the difference between...spirituality or Christianity and religion, because (in) religion, you never find that deep-in love. Jesus says in the Bible that you will know they are Christians by their love, and that is so true. I mean, if you don't have love for somebody else...you can't possibly have love for Jesus, because if you love Jesus, then you know what love is, and he has told us, "Love one another as I have loved you."

Paul begins to be dogmatic and exclusive about the deep love of spirituality *never* being part of religion. As he goes on, he recognizes that spirituality and religion are intertwined. Paul believes religion can be devoid of love, but if one truly has Jesus' love on the inside, you will naturally love others. Paul does not see how one can love others without the love of Jesus inside, so they are dependent on each other.

Harvey differentiated between religion and spirituality, but also described how they fit together.

> Religion is whether you are Catholic or...spirituality is your faith. You had to go to church to get the faith.....Part of the bargain, to take you down the right side...read your Bible...(go) to Sunday School...(get) confirmed.

Church, Sunday School, and the Bible (the outer or religious) and faith (the inner or spiritual) depended on each other for Harvey.

Similarly, the literature distinguishes between inner and outer, spirituality and religion. In Herth's (1990) study, 38 of the 40 hospice participants distinguished between spiritual beliefs and spiritual practices. They believed "in God or a 'higher being'" (Herth, 1990, p. 1254), prayer, and listening to spiritual music which could be separate from a specific religion. However, they also maintained customs, activities, and

relationships associated with their spiritual community (Herth, 1990).

O'Connor (1988) observed spirituality and religion are often used synonymously, but while the religious is spiritual, spiritual is broader and may or may not include specific religious care. Canda (1988) studied the differences and common themes between 5 religious perspectives in the literature. He found they all "value commitment to compassionate and moral relationships...the connectedness of biopsychosocial and spiritual needs of clients...(and) enabl(ed) the client to overcome suffering and alienation by supplying both subsistence and fulfillment needs" (Canda, 1988, p. 241). After interviewing social workers of varying religions about their inclusion of spirituality in their practice, he discovered agreement that the purpose of helping clients was to "discover meaning in life" (Canda, 1988, p. 243). Therefore, Canda broadens spirituality to include,

> moral decision making, searching for a sense of meaning and purpose in life, and striving for mutually fulfilling relationships among individuals, society, and the ultimate reality, however conceptualized. In that these aspects of human activity are common to all people, they are necessarily relevant to all areas of social work practice (Canda, 1988, p. 238).

Regardless if spirituality and religion start with a definition, the experience of individuals, or with the experience of social workers, they can lead to meaning in life. Could believing be a more useful concept, encompassing both the general and the specific? Could believing step outside the stereotype of both spirituality and religion, becoming more relevant in the practice of social work and more applicable to healing and wholeness?

Believing in Not Judging.

As adamant as participants were about their own beliefs, they left room for another's viewpoint and cautioned not to judge. In the midst of describing her resolute faith, Irene fosters openness.

> You have *to* call on God *in your own way* to tell him you are ready to consent to be one of his children...you have *to* be willing to accept him in your heart and then close it tight. Uh-huh. Then you have *to* keep on believing.

Although this is her fervent belief, she leaves room for differences with, "in your own way." Irene recalled being nonjudgmental in the midst of frustration with churches being too focused on food.

> Sometimes I read the bulletins and I don't see much more in them than something to eat.....There is one lady that says she has gone to 6 lutefisk suppers. Well, I don't think that is really necessary...but she maybe gets more out of that than I would get out of anything because she is kind of alone now.

Irene does not hesitate to express her reservations, but attempts to be understanding of diversity. Likewise, Harvey advocates, "You can't say somebody has faith unless you know. Then you are judging them. You shouldn't be judging people." Out of Irene and Harvey's experience comes an understanding of holding strongly to one's own beliefs, but not putting them on others. Are they modeling an approach social workers could adapt when talking with clients? Social workers can have our own belief system, as strong as it may be, and clients are allowed to have their own beliefs.

Similarly, the individuals in Canda's (1988) study indicated "a strong commitment to their own beliefs" (Canda, 1988, p. 245) while appreciating diverse

beliefs. When dealing with spirituality, as well as other issues, the focus remains on the client's choices and plans (Canda, 1988). Judging is not the professional's job. Clients are allowed the freedom to talk about *their beliefs* and the meaning they lend to their life or this particular circumstance.

Furthermore, Canda (1988) advocates for *all* social workers to foster spiritual *self*-awareness. Is he suggesting that we can be more open to other's spirituality when we are clearer about our personal views? Does this make it easier to acknowledge other's beliefs without judging them regardless of their difference from our own?

Believing in "Whom?"

All three individuals named "whom" they believed in. The terms were eclectic, including general and specific names.

Irene: Total: 32. God: 10, Lord: 9 (7- The Good Lord), Holy Spirit: 7, He: 3 (2 referring to the Holy Spirit), Somebody: 1, Father: 1, Son: 1.

Paul: Total: 44. God: 25, Jesus: 14, Christ: 3, Lord: 2.

Harvey: Total: 9. Somebody: 4, God: 2, Christ: 2, He: 1.

Naming whom he believed in was most important for Paul. By far, God was his most frequent choice (25 times). Jesus, next in significance, was used 14 times. Christ and Lord comprised the other 5 times of usage. No pattern could be found in how or when Paul named the Ultimate One. Nonetheless, Paul's experience of believing is grounded in the specific images and roles of God and Jesus with Christ and Lord used uncommonly.

Irene used God (10 times) and Lord (9 times, 7 being more descriptive with "the Good Lord") most often. Yet, in the first 30 % of her interview she only used a name

twice, God and Somebody. Irene chose Holy Spirit 7 times. Although, including the 2 times she uses He to obviously pertain to the Holy Spirit, Irene uses it equally as many times as Lord (9 times). However, Irene used Holy Spirit only once before I invited her to "tell me more about the Holy Spirit because you said the Holy Spirit talks to you" in the last part of the interview. Without this prompt, Holy Spirit would have been less significant. Except when I returned to share my findings, Irene emphasized, "God is at the head, but the Holy Spirit tells you what's right or wrong." Other isolated uses of names include He, Father and Son. Irene isn't as concerned as Paul about naming the One she believes in. However, her experience of believing includes God, Lord, and the Holy Spirit.

Harvey refers to a Supreme Being the least, only 9 times. He is less explicit, using Somebody 4 times, all when referring to how he lived through 3 accidents. Harvey specified God when I asked who Somebody would be. God and Christ are used twice, with He used once. Harvey, no less adamant about his faith, does not find it as important to name the One associated with his faith.

God was the only name common to all three individuals. Then again, Irene and Paul employed Lord, but Lord was not as noteworthy for Paul. Both Paul and Harvey used Christ from time to time. Naming the Ultimate One was of varied importance to these 3 individuals. Fervently believing remained the core theme.

The experiences of these individuals show that naming a Supreme Being could or could not be important for clients. Naming the recipient of their faith could or could not be related to the status of their faith. However, paying attention to the names clients use, could give some indication of the direction of their beliefs.

Believing as "Leaving the Unknown to God"

Believing not only meant strongly knowing what they believed, but as importantly, being able to leave the rest to God. Not knowing, questions, and discrepancies were a part of believing for these individuals.

When confronted with the main question at the beginning of the interview, "Tell me about your experience of spirituality as you live with a terminal illness," Harvey began crying and pointed to, " leav(ing) it in God's hands and He will take care of it." Harvey's first response was not to explain or tell about what he believes, but to affirm that he leaves all to God and trusts God's care of him. This was Harvey's theme throughout his narrative. He would not be pinned down to explain specifics. Death "would have been very peaceful...You can't explain it." When asked what heaven will be like, he replied, "Nobody knows." Does he believe in miracles? "Whatever will be, will be." Although he connected his children turning out good to faith, Harvey would not say if you did not have faith, you would not turn out good. He simply responded, "You never know...At least it could go bad." According to Harvey, faith assures him the future will be "better", even "wonderful," but he has no need to explain or doubt because of not knowing.

Individuals commonly questioned if they were dying. They held on to the hope that they could be getting better or healed completely. This question arose for Harvey in the present.

> What they say I have, I don't have any effects of, so I know there is Somebody here taking care of it for me...The cancer in the prostate, you know, it's like it has gone away. I'm getting better instead of worse." (Yet,) "Whichever way I go, it

turns out for the better.....Whatever will be will be.....He can cure you or carry you on.....So if I die tomorrow, it is fine with me.

Because Harvey is not feeling any immediate affects of his illness, he believes he is getting better or is healed, "It is possible. It's a miracle." Harvey firmly believes Somebody can heal him, but accepts either healing or death. He leaves the unknown to God, believing whatever happens will be better.

Searching for healing characterized Paul when he was first diagnosed with a terminal illness. He connected healing with a stronger faith. People told him, "You will never be healed 100% because you just aren't quite strong enough in your belief." Paul describes his initial response, "I will try a little harder," until he was "so mixed up and so confused." Then, Paul elaborated on the way his lived experience brought him peace about healing.

> "If I died right now, *I am going to Heaven* and my Lord is going to give me a brand new body...so I know that at some point, *I am 100% healed* if it is on this earth or if it is when I go to the next...It makes no difference when it is. *I know I have got it* and I am not necessarily pushing right now and saying, 'Well, God, if You can't get me well now, I am not going to believe in You.' Because God makes His own choice, in His own way, in His own time, and who are we to try and tell Him what to do or even guess how He is going to do it."

Paul places his faith in what he does believe, "I am going to Heaven," "I am 100% healed," and "I know I have got it." Like Harvey, he doesn't have to know all the answers, specifically about healing, but comfortably leaves all to God. Although Paul has more recently found strength in God, is younger, and appeared closer to dying when

interviewed than Irene or Harvey, he is still adamant about trusting in "God's way and God's time." Both Harvey and Paul found peace in believing and leaving the unknown to God.

Believing Throughout Life

The undergirding dynamic of spirituality, present in some dimension in their past, contributed to these 3 individuals' present state of steadfast believing. Irene and Harvey had a strong cord of spirituality woven throughout their lives. Paul rediscovered his thread of spirituality when faced with his terminal illness. Regardless of how differently believing developed in their lives, believing was rooted in their childhood for all three individuals. Irene exemplified this in her first response to the interview question,

> Well, spirituality, of course, has been with me since I was a child...Both my parents were very good Christians...At 13 I got to play for church...sing-alongs...Christmas programs.

Irene's first thought when thinking about her spirituality, was to connect it to her childhood. She went on to affirm (Italics are mine), "I have *always* called on the good Lord." Believing in the good Lord began in childhood and continued throughout her life.

Harvey agreed, "I've *always* had faith." Harvey, who was "just about killed 3 times" as he was growing up, believed "Somebody helped me...Somebody was watching over me." "Somebody" was there for Harvey before. Harvey believes the same about today, "Somebody is taking care of me." Facing mortality early in life, contributed to his faith which gave him the assurance that everything would be "taken care of" throughout his life. Now, this specifically applied to living with a terminal illness.

Paul, too, recognized a long-term belief. He described his experience when he

was first diagnosed and searching for God.

> (I) realized that through my life growing up, I had *always* believed in God and still did feel a strong leaning toward that way, so I was going to search it out quite strongly.....I would have to find this church at least following some of the rules or doctrines that I had seen as a child because obviously that is strongly rooted inside of everyone, what their parents teach them or what they bring them to.

Although Paul did not nurture his spirituality for a time, he still went back to the faith of his growing up years that was still there in some way. As he renewed faith in his present life, he realized the values his parents taught him were still pertinent. These values helped shape his present believing.

All three individuals used the word *always*. As they reflected back on their lives, they understood God had *always* been a part of their living. Did that help them make sense of God being a part of their dying? The existential theory takes that premise. The meaning of death comes from the meaning of life (Frankl, 1955).

Reed (1987) observed that the tendency to avoid childhood beliefs diminished as people moved closer to the inevitability of their death. Did they realize the importance of this element or did it fall away as unimportant as other aspects did? The three participants in this study used their long-term connection to God as further evidence of the sustaining presence and goodness of God right now.

Can social workers use this as an example of how to discuss spirituality with their clients? As clients discuss the status of their faith, social workers could ask about their past experience with believing. How did you experience spirituality, believing or faith as a child or when you were growing up? What parts still make sense? What parts have

changed? As individuals explore the meaning of their past experience of believing, will this lead to more awareness and clarification of their present beliefs? As they explore believing as a part of living, will they find further meaning for their dying?

Believing as Meaning in Daily Life

A deep assurance that believing was their essence and what mattered most encompassed each individual. Believing as giving meaning to their lives wasn't just theoretical, but translated to making a difference in their present moments. Irene, Paul, and Harvey lived out the Logotherapy model by finding meaning in their daily lives (Frankl, 1959).

A connection to others gave meaning to Irene's everyday existence. Irene described her interactions as good for herself and others.

> You need each other.....There are several of them that will come by and then they will say, 'Are you having a nice day today?' I will say, "Yes." And they will say, "The good Lord bless you now the rest of the day." You know, just wishing you a blessing...is something good for you...There is one gal who wants prayer for herself, too...It is kind of a good feeling when you think maybe you are helping a little bit and if you aren't...you are doing good for yourself.

Little connections with others made a big difference in Irene's day. She is "doing well" for herself, both by receiving positive comments from others and giving back to them. Irene is clear that she benefits from the act of giving even if the other person doesn't. In fact, when Irene experienced good care from hospice staff she thought they *had to* be spiritual, too.

> I think they have something in them that are very spiritual. They must have.

They have to have...It would be hard to do what they do otherwise...They come with some little gifts...(and) some extra things for your heart. And at Christmas time, when you are in groups, you are so busy that there isn't time to think about anybody else, but with this there is always time for something with hospice.

Showing kindness, doing good deeds, and taking time illustrated believing for Irene. Again, she emphasizes the outer, taking time and giving gifts, *and* the inner, having things for the heart. Both were important for giving meaning to her daily life.

Dealing with a terminal illness led to a changed outlook on daily life. Paul expressed an appreciation for each day.

> It has just gotten to the point where all I do is I just live every day. I wake up in the morning and say, 'Thank you for another day, Jesus.' And I enjoy that day the best that I possibly can."

Reflecting on his days, Paul calls them a

> blessing, just for the fact that it has made such a turn-around in our family..... I had already wasted a lot of years of my life...I ignored my kids...my kids are now at the point where my youngest is 19 and the other night he sat down with me.....1/2 hour to 45 minutes discussing 2 or 3 little questions that he had, and in years gone by and days gone by, there is no way that any of my kids would either have thought of something like that, let alone sit down and talk to me about it. And what that does is it strengthens all of us. It pulls us together.

Paul realized the importance of his family. Spending more time with them was one way he "lived the best he could." Another aspect of Paul living each day, or "living for Christ" as he called it, is sharing his faith with others.

> What that has done for me is opened me up to a point where I have been in the supermarket...and it doesn't bother me in the least to look at the checkout and ask her or him, "Do you have Jesus in your heart?" Because I have this in my heart and I found what it means to me, so I want to share it with everybody.

Paul's experience led him to believe what has meaning for him can be helpful for others, too. Sharing Jesus with others gives meaning to Paul's daily life. He sums it up by saying, "It's such a happy life."

Harvey, also, takes life "day by day.....When I look at the world...I see things like flowers, other miracles of life...my family." Harvey gets meaning from brief moments of observing the "miracles of life." Irene described her moments. "I imagine many beautiful things. I love beauty. The different things you read about in the Bible - The golden streets...(and) music is my second life." These brief moments of peace are precisely what gave Frankl hope in the Nazi concentration camps (Frankl, 1959). Frankl's logotherapy embodies this choice of attitude (Hutzell, 1986). Harvey cited his faith as the reason for his attitude; he was not a "grumpy old man" like his roommate, who "has a terrible tone on life...He looks at family pictures and cr(ies)." Harvey says, "My (family) pictures make me laugh."

Herth (1990) calls this "lightheartedness" and "uplifting memories," that contribute to hope which is "an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being" (Herth, 1990, p. 1256). Also, like Irene, Paul, and Harvey, Herth's (1990) participants identified spirituality and connecting with other's as creating hope. Similarly, Ita (1995), when looking at the acceptance of death in hospice patients, found spirituality increased social

support.

In addition, Coward (1989), in her phenomenological study with women living with Stage IV breast cancer for 2-7 years, named transcendence, "the capacity to reach out beyond oneself" (Coward, 1989, p. 162), as a way to find meaning. Like Irene, Paul, and Harvey, the women looked beyond their illness to give them a purpose and help connect them to others.

Both in the literature and for the individuals in this study, the give and take of relationships and experiencing moments of beauty and laughter were a part of living each day, transcending their terminal illness, and giving them hope and meaning in their lives. In keeping with the existential theory, each individual found direction uniquely from what was before them in their lives (Frankl, 1955). Operating from this stance, Canda (1988) gives a working mandate to social workers. "As the social worker explores underlying dynamics of the client's suffering, both the client's lack of resources *and* lack of meaning in life must be addressed.....The client can be helped to discover and construct meanings that help transform suffering into an opportunity for growth" (Canda, 1988, p. 245-246).

Summary

This chapter explored the experience of believing as an avenue to find meaning in the lives of 3 individuals living with a terminal illness. Their attitudes of "always believing" and "leaving all to God" revealed additional dimensions of believing. Related literature expanded this discussion.

CHAPTER 6: IMPLICATIONS

The contributions of this study will be indicated in this chapter. Recommendations for social work practice and policy will be made as well as suggestions for continuing research on spirituality.

Contributions of Study

Spirituality and death have been significant elements of life. Subjective factors such as diverse cultures, religions, and historical trends have influenced the dialogue about and understanding of them. Once again, the pendulum of time shifted as society and the medical community moved to put dying back into the hands of the individual. Hospice evolved as a means to integrate the wishes of the individual with their impending death. Spirituality, questioned as the forgotten element of hospice, can be approached with a new perspective in light of this research study.

This hermeneutical study contributed to a deeper and richer understanding of the significance of spirituality in the lives of these 3 individuals with a terminal illness. Careful, conscious study from the individual's perspective, using their own words, rather than talking *about* their experience, revealed spirituality not only adds meaning to a terminally ill individual's life, but *is* the ultimate meaning. Believing and the multitude of ways it is manifested in these 3 individual's lives were explained more clearly.

The concept of believing was not found in the literature. Perhaps this study introduces believing as a way to encompass a broad scope of religious, spiritual, and humankind values and beliefs, giving individuals more latitude to explore meaning in their lives.

The intensity and overwhelming significance of spirituality in the present

existence of these 3 individuals was not anticipated. They were adamant about their beliefs. The participants were far less concerned with process, confidentiality, and anonymity as they were with the importance of "telling their story." They had experienced many losses, but focused on believing and what gave meaning to their life in the present moment. This is difficult to measure quantitatively. This qualitative method allowed individuals the freedom to define and discuss spirituality and believing as they wished, within the parameters of their time, energy, and interaction with the interviewer.

This project may have helped create meaning in their lives. Telling their story helped them transcend their illness for the moment of the interview and enjoy the brief relationship with the interviewer. Further impact is unknown. Yet, narrative theory supports the story as a way to understand experiences and make changes (Nichols & Schwartz, 1998). The possible benefits resulting from the telling of their stories are limitless. Families of the participants have expressed interest in the tapes. This project may enrich the traditions of their families. At the least, the stories contributed to the larger cause of research and learning. Even Irene expressed her hope that this study could "make a difference."

These stories were not only the backbone of my research project, but became a significant spiritual event in my own life story. I was inspired by their stories and felt in the presence of the Ultimate One. Their stories affirmed my story; in the end, the great "I AM" was, is, and ever shall be.

I continue to process how this model can be replicated in the lives of meaningful others in my life. My history and relationship with them would undoubtedly change the content of the interview. This is not a barrier as I first thought, but the beauty of

hermeneutics. The nature of the interview would be *changed*, but no less significant. Being aware of the different dynamics would help me proceed with "careful consciousness."

Implications for Social Work Practice and Policy

> The gift of the hermeneutic method for interpretive research is in the lesson it teaches for the practice of social work. As a practitioner, I cannot perceive what the human beings with whom I work perceive. What I can do is try to understand how others are in their worlds and how they perceive the broader culture to which we both belong (Nelson, 2000).

Even that understanding will always be shrouded. There is no way I can completely comprehend another's experience. The experience of this in-depth interview and subsequent circular interpretation taught me to always leave room for the other's perspective. As a practitioner, when I think I understand my client, I may not. Even when I have had the same experience as my client, I still cannot understand exactly how it has played out in their life experience. They are as a unique as I am. I do my best to understand their point of view, recognizing that full comprehension is not possible.

As I read and re-read the transcripts of the tapes, I gleaned new insights previously hidden. This circular process could continue as long as I took the time to tend to the script. Interaction with the interviewees could shed further enlightenment on the meaning. This I had limited opportunity to do, as 2 individuals died before I completed my interpretation. However, as I have multiple contacts with clients as a practitioner, I would have the opportunity to continually check out my observations. Welcoming new and different information can bring me closer to understanding of clients' life experience

and interpretation of their world.

This study reinforced the importance of paying attention to spirituality for patients in hospice. Babler's (1997) comments on spiritual care remain central.

> Spiritual care in hospice involves allowing the view of spirituality held by the patient, family, and caregiver to be the framework from which spiritual care is provided. Spiritual care in hospice involves all team members concerned or interested in the spiritual needs and realities of the patient, family, and other caregivers, even if their spiritual/religious tradition and beliefs differ from their own...These spiritual needs may be expressed openly by patients and family members or may be 'below the surface' and need to be drawn out by caring questioning. Based on the recognition that spirituality is a process, spiritual care in hospice isn't approached with the idea of 'curing,' but rather with the ideal of presence, support, and spiritual healing (p. 18-19).

Social workers must "seize the moment" and address spiritual needs when they arise in order not to miss opportunities to promote transcendence of the illness and meaning for the remaining time left. They must practice authentic attentiveness and make use of their relationship with the individual when the time is right (Babler, 1997).

Furthermore, they must *make* the time and *initiate* the discussion of spirituality. The relationship does not have to be long term or in-depth. This study shows the willingness, even eagerness, of individuals to discuss their spirituality with a caring individual when the time is made.

At the risk of being simplistic or reducing the discussion of spirituality to a format, I offer some hints, gleaned from the literature and the experience of this

researcher, to assist professionals and lay workers in their attempts to address spirituality.

Get in touch with your own spirituality (Canda, 1988).

"Create an environment where the patient's spiritual orientation can flourish" (Millison, 1995, p. 5).

Believe spiritual care is as important as psychological, physical, social, and financial care.

Be willing to make and take time for "God talk" (Millison & Dudley, 1992, p. 51).

Be truly interested.

Believe you need no special skills but listening, caring, and time.

Open the discussion. Then follow the person's lead.

"Help the person find significance in past experiences and allow him or her to reflect on death and on the meaning of life" (Millison & Dudley, 1992, p. 51).

"Enter into the world of others and respond with feeling" (Millison & Dudley, 1992, p. 51).

Listen to their words. How do they address the Ultimate One?

Freely refer the individual to their own spiritual leader or the hospice chaplain. Ask if they would like you to make the call.

Discussion openers:

Tell me about your experience of believing.
Tell me about your experience of spirituality.

What do you put your faith in?

How is your spirit today? (O'Connor, 1988)
How is your soul today?

What are your inner concerns? (Ley, 1993)

"What nourishes your spirit?" (O'Connor, 1988, p. 33)

"How have you addressed your spiritual pain before?" (O'Connor, 1988, p. 35)

"What helped to relieve this pain?" (O'Connor, 1988, p. 35)

As we experience the healing power of spirituality, we must dialogue with each other, the public, administrators, and legislators to broaden each other's perspective. Public forums, educational conferences, and classroom discussions could raise awareness and add to the potential benefits of a spiritually sensitive practice. Lobbying for social workers to have the time and occasion to address meaningful, though less task oriented, issues is vital for overall client well being. We have much to learn. The opportunity to join with others in this ongoing learning process is paramount.

Conclusions

Research focused on believing rather than spirituality may lead to increased awareness and a broader understanding of the meaning of life. Further research with larger numbers of participants and a wider diversity of religious and cultural backgrounds may enrich the information gathered. A longitudinal study looking at changes over time may give valuable insight into needed strategies at varying stages of a terminal illness. However, this is difficult, due to individual's fragile and changing status. Research specifically focused on the interaction of social workers and clients about spirituality and believing may be helpful. Adding the rigor of Biblical exegesis as an adjunct to research may explicate the significance of names assigned to the "One of believing."

As spirituality continues to be more integrated into social work practice, the effects of utilization will be in a better position to be measured. Quantitative research may be appropriate to delineate the relationship of age, culture, and religion to spirituality. However, the richness and surprise of qualitative research must not be set aside.

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RICE

Appendix A

December 6, 2000

Virginia (Ginny) Backman
340 55th Avenue NW
Benson, MN 56215

RE: **Research Study - "A Hermeneutic Study of the Spirituality of Adults with a Terminal Illness in a Hospice Program."**

Dear Ms. Backman,

As its meeting on December 4, 2000, the Institutional Review Board reviewed and approved the above study and consent form.

On behalf of the IRB, I wish you success with your research.

Sincerely,

Leslie Erickson, R.N.
IRB Chairperson

RICE MEMORIAL HOSPITAL
301 Becker Avenue SW • Willmar, Minnesota 56201-3395
(320) 235-4543

APPENDIX B

Interview Question and Prompts

Main question:

Tell me about your experience of spirituality as you live with a terminal illness.

Prompts:

Tell me more about that.

Tell me about a time that comes to mind to illustrate that.

Help me understand this further.

Give me a for instance.

What did that mean for you?

Can you clarify that?

What did that help you realize?

What stands out for you?

Describe that experience further.

What were your thoughts, feelings, and perceptions?

Continue to describe the experience until you feel it is fully described.

Augsburg IRB# 2001-2-1

APPENDIX C

Recruitment letter

Dear XXXXX,

Hello, my name is Ginny Backman. Benson is my home and I am a student at Augsburg College in Minneapolis in the Master of social work program and an intern at Rice hospice in Willmar. You are receiving this letter because of your participation in a Rice hospice satellite program.

As part of my program requirements, I am working on a research paper focusing on the experience of spirituality of individuals as they live with a terminal illness. I would like to find out what spiritual experiences stand out for an individual with a terminal illness and how spirituality has impacted their everyday living.

For my research, I will be interviewing three individuals from 30 to 60 minutes. The amount of time we spend together will be determined by how they feel. I would like to audiotape the interviews for accuracy and transcription purposes. I will make every effort to protect the individual, respect their privacy and maintain confidentiality. For example, hospice staff, without my knowledge of your name or address, did this mailing. Also, individuals will be given the choice to destroy or keep the tapes. Participation or lack of participation in this research study would in no way affect the individual's relationship with hospice or Augsburg College.

Would you be interested in hearing more about this research project? Please check yes or no on the enclosed postcard and return it within a week. If yes, include your first name and telephone number. Upon receiving the postcards, I will call those who expressed interest with a 'yes' and explain my project in greater detail and answer questions. Again, you will be given the option to say no. If you remain interested, I will set up a brief introductory meeting to sign consents and arrange an interview time and location convenient to you.

Thank you for considering this project!

Sincerely,

Ginny Backman

Augsburg IRB# 2001-2-1

APPENDIX D

Recruitment Follow-up Phone call

"Hello, this is Ginny Backman from Benson. I am the student at Augsburg and intern at Rice hospice who sent you a letter explaining my research project exploring the spirituality of individuals with a terminal illness. Thank you for expressing interest! I am willing to explain my project further and answer questions or if you've decided you're definitely not interested, that's OK, too. Are you still interested?"

If interest is expressed, I will continue, "Let me explain how I will protect your privacy and maintain confidentiality. Names and all identifying information will be kept confidential and changed by the transcriptionist, but it is impossible to ensure complete anonymity. Because of the small sample size, I cannot guarantee that someone may not recognize your specific story.

Data will be kept in a locked box only to be seen by myself, the confidential transcriptionist, my research team of fellow students, and my thesis advisor. The transcripts and audiotapes will be destroyed when I am through with my thesis, unless you give me written permission that you wish to keep them or have them given to a specified individual. You will be given the opportunity to read through an interpretation of the interview for accuracy and feedback, if you wish.

I want to emphasize that participation is completely voluntary and the consent can be withdrawn at any time. Reminders of this will be given 1 week after taping your interview and again after you have read the draft manuscript.

Possible risks include an invasion of privacy and the potential for thoughts and memories to evoke an emotional reaction. However, support and counseling can be received for concerns, free of charge, from David Rivers at the Grief Center. If private pay or insurance is preferred, Woodland Centers can be contacted. The potential indirect benefits include the opportunity to reflect on and share your experience of spirituality, the improved understanding of the researcher and others about the experience of spirituality, and the opportunity to preserve the experience for family and friends. You will receive a $20 honorarium whether or not the interview is completed.

Do you have any questions?"

If the individual is interested in being a part of the study, I will set up a brief introductory visit to begin establishing rapport, sign consents, present the conversation suggestions, interview question and prompts and arrange an interview time and location convenient to the participant.

Augsburg IRB# 2001-2-1

APPENDIX E

CONSENT FORM

The Spiritual Experience of Adults with a Terminal Illness in a hospice Program

You are invited to participate in a research study designed to look at the spiritual experiences of adults with a terminal illness. We ask that you read this form and ask any questions you may have before agreeing to be involved in this study. Participation is completely voluntary. This research study is being conducted by ***Ginny Backman*** *in partial fulfillment of the Master of social work thesis requirement at* ***Augsburg College.***

What will happen during this study?
This study consists of one audiotaped interview that will last from 30-60 minutes for each participant. I, Ginny Backman, a Master of social work student working on my thesis, will conduct the interview. I will ask you to relate stories about what it has been like to experience spirituality in the midst of your terminal illness. Once I have written an interpretation, I will contact you to review the findings. Changes may be made to the written interpretation to reflect your comments.

Are there any risks?
It is possible that through the discussion and recollection of your story, painful memories or thoughts could occur. David Rivers at the Grief Center, 320-231-4714, will be available for counseling at no charge or if you prefer to use private pay or insurance, you could contact Woodland Centers, 1-800-992-1716.

Are there any benefits?
It is possible that you could experience an enhanced sense of well-being or sense of satisfaction as a result of telling your story. Also, participants will receive a $20 honorarium before the interview begins.

When and where will the interview be done?
The interview will be scheduled at a time and place that are convenient and comfortable for you. Interviews will be done in private and in person.

Who will have access to the interview material?
A transcriptionist bound by confidentiality will transcribe the audiotaped interviews. Any identifying information from the interview, including your name, will be removed in the transcribed text. The text, which will be identified with a numbered code only, will be read by the researcher, research team and thesis advisor for purposes of interpreting and analyzing. All information is confidential and every effort will be made to protect your anonymity, although anonymity cannot be guaranteed due to the small size of the study sample. No names or other identifiers will be used in the study. Raw data will be destroyed by December 31, 2001. Audiotapes will be disposed of in the manner that you designate.

What if you change your mind?
You are free to withdraw from this study, refuse to answer any question, or refuse permission for the use of your interview or transcript at any time. In any case, the $20 honorarium will be yours to keep. Your decision whether or not to participate will not affect any current or future relationship with hospice or Augsburg College.

Contact me with questions or concerns:
Augsburg College: Ginny Backman, MSW student
320-231-4442 (Internship)

Or, my thesis advisor:
Maria Dinis, Ph.D.
(612)-330-1704 (Work)

Before you sign this form, please ask any questions regarding aspects of the study that are unclear. I will attempt to answer questions that you have prior to, during and following the study. If I am unable to answer any of the questions to your satisfaction, you may call my thesis advisor as listed above.

AUTHORIZATION: *I,* _____, *have read this consent form and have chosen to participate in the research project described above. My signature indicates that I give my permission for information that I provide in the interview to be used for a thesis research project. I will receive a copy of this form for my records.*

Signature_____ Date _____

How would you like me to contact you to verify my interpretation of your experience?

_____

_____

In addition: (1) *I consent to be audiotaped.*

_____ Date _____
(Signature)

(2) *I consent to the use of direct quotations.*

_____ Date _____
(Signature)

(3) I *wish to keep the tape.*

_____ Date _____
(Signature)

(4) *In case of my death, I wish for* _____ *to be given the tape.*

_____ Date _____
(Signature)

(5) *I wish for the tape to be destroyed.*

_____ Date _____
(Signature)

Augsburg IRB# 2001-2-1

APPENDIX F

CONSENT FORM

Transcriptionist Confidentiality Form

This research study includes sensitive and confidential information about study participants. This information is shared with you confidentially for the purpose of being transcribed. By signing this form you are agreeing not to reveal names, identifying information or any other content of the interview.

Transcriptionist Name _____

_____ _____
Transcriptionist Signature Date

_____ _____
Participant Signature Date

_____ _____
Participant Signature Date

_____ _____
Participant Signature Date

Augsburg IRB# 2001-2-1

APPENDIX G

Conversation Suggestions
(Van Manen, 1990)

1. "Describe the experience as you lived through it" (p. 64).

2. "Describe the experience from the inside...the feelings, the mood, the emotions, etc."(p.64).

3. Focus on particular examples. Describe specific events, adventures, and happenings.

4. "Try to focus on an example of the experience which stands out for its vividness, or as it was the first time" (p. 65).

5. Attend to how your body felt, how things smelled, sounded, tasted, and looked.

6. How you experienced it and how you say it is just fine. I'm not looking for "fancy phrases or flowery terminology" (p. 65).

Augsburg IRB# 2001-2-1

rice hospice

a division of Rice Memorial Hospital

APPENDIX H

Locations:

Appleton
Appleton Municipal Hospital
30 South Behl
Appleton, MN 56208
(320) 289-2422

Benson
Swift County Benson Hospital
1815 Wisconsin Avenue
Benson, MN 56215
(320) 843-4232

Dawson
Johnson Memorial Health Services
1282 Walnut Street
Dawson, MN 56232
(320) 769-4323

Granite Falls
Granite Falls Municipal Hospital and Manor
345 Tenth Avenue
Granite Falls, MN 56241
(320) 564-3111

Montevideo
Chippewa County-Montevideo Hospital
824 North 11th Street
Montevideo, MN 56265
(320) 269-8877

Ortonville/Graceville
Ortonville Area Health Services
750 Eastvold Avenue
Ortonville, MN 56278
(320) 839-2502

Paynesville
Paynesville Area Health Care Services
200 1st Street West
Paynesville, MN 56362
(320) 243-3767

Willmar
Rice Memorial Hospital
301 Becker Avenue SW
Willmar, MN 56201
(320) 231-4450
Fax: (320) 231-4864

RICE HOSPICE
MEMORANDUM

TO: Virginia Backman

FROM: Leslie Erickson, CHPN
Hospice Program Manager

DATE: December 1, 2000

RE: **RESEARCH PROPOSAL**

I have reviewed your research proposal entitled **"A Hermeneutic Study of the Spirituality of Adults with a Terminal Illness in a Hospice Program"** and find that this is acceptable with our patient population. Findings may provide a heightened awareness of issues and spiritual dimensions of hospice care.

LKE/mfd

AUGSBURG

C•O•L•L•E•G•E

MEMORANDUM

TO: Ginny Backman

FROM: Sharon K. Patten, Ph.D., IRB Co-Chair (612-330-1723) SKP

RE: Your IRB Application

DATE: 17 January, 2001

Thank you for your response to IRB concerns. Your study, "A Hermeneutic Study of the Spirituality of Adults with a Terminal Illness in a Hospice Program," is approved; your IRB approval number is 2001-2-1. Please use this number on all official correspondence and written materials relative to your study.

The IRB wishes you every success.

DEPARTMENT OF SOCIAL WORK

Campus Box #51 • 2211 Riverside Avenue • Minneapolis MN 55454 • Tel. (612)330-1189 • Fax (612)330-1493