8-30-2001

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Recommended Citation

McCort, Maurine E., "A Hermeneutical Study: The Personal Meaning of the Dying Experience of Individuals with a Terminal Illness" (2001). *Theses and Graduate Projects*. 277.
https://idun.augsburg.edu/etd/277

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MASTERS IN SOCIAL WORK THESIS

Maurine E. McCort

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The Personal Meaning of the Dying Experience of Individuals with a Terminal Illness

2001

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The Personal Meaning of the Dying Experience of Individuals with a Terminal Illness

Maurine E. McCort

Submitted in partial fulfillment of
the requirement for the degree of
Master of Social Work

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

2001

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

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CERTIFICATE OF APPROVAL

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Date of Presentation: August 30, 2001

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Acknowledgements

The culmination of these two years of study is a mountain whose height I did not, and could not, climb alone. My gratefulness extends in many directions.

First, I want to recognize the unending support and patience of my thesis advisor, Clarice Staff. It was through her guidance that my mind relaxed enough to allow for the circularity of the thesis process to move at its own pace. This process woke me to the importance of *being while learning,* in addition to *learning through doing.*

I wish to thank Laura Boisen and Sheila O'Reilly who agreed to read my thesis and sit on the thesis committee. Laura's door was always open and I am grateful to her for her support through some difficult and trying times. I am grateful to Sheila for her excitement in looking at this project and her valuable feedback.

I must acknowledge the powerful connection our class felt towards each other. It was through this connection that we helped each other grow emotionally, a necessary element in professional development. As my classmates go forward into their careers it is evident that the world will be a better place with these kind and skilled souls working in the service of others. I am fortunate to have had the opportunity to be with them for two years.

My thankfulness extends to the hospice social worker that aided me in finding the two participants for this study. It is with humbleness that I recognize the powerfully moving work of caring for the dying (and their families/friends) that Ms. West and all hospice social workers have dedicated themselves to.

I am grateful for my dear family and friends who helped me make it to shore. They sustained me with their love, encouragement, laughter, food, clean laundry and an occasional push. My heart beats with theirs.

There are particular individuals that I must acknowledge. I have spent the past 15 years (including undergraduate studies) in school while working and being a mother. My two children, Uriel and Elizabeth, have stood by me, cheering me on and rarely complaining. Being a mother to these two intelligent and loving individuals is the best part of my life.

I am grateful to my father for instilling in me a fondness for learning. He was curious about the endless possibilities of the life around him and I caught that wonder from him. He had a strong belief in me that I could be and do anything I wanted to, and he supported me in questioning the world and looking for answers. Through my relationship with my mother, I learned self-sufficiency and ingenuity. The ultimate lesson I learned was forgiveness.

Many dear friends buoyed me, even when I didn't know I was in deep water. With deep regard and affection, I thank Kim Schanilec and Renee Bergeron. Their clear minds, meditative countenance and their knack for comic relief kept me from running aground. I must thank the two Lees for giving me a port in the storm by building me a sturdy deck and taking me night golfing. To all those at work that took on extra work so I could have time and energy to finish school, you were my life jacket. And to Terry, thank you for the clean laundry, warm meals and companionship that helped me sail through rough seas.

Lastly, and certainly not in the least it is with a grateful heart that I thank the two participants in this study for sharing their stories of living while dying.

As I was in the middle of this thesis, I came upon the writings of Rainer Maria Rilke, a poet who expressed his uniqueness through words. The following words convey my cumulative experience of the past two years in graduate school including the work on this thesis.

> ...have patience with everything that remains unsolved in your heart. Try to love the *questions themselves*...Do not look for the answers. They cannot now be given to you because you could not live them. It is a question of experiencing everything. At present, you need to *live* the question. Perhaps you will gradually, without noticing it, find yourself experiencing the answer some distant day. Perhaps you are indeed carrying within yourself the potential to visualize, to design, and to create for yourself an utterly satisfying, joyful...lifestyle.

ABSTRACT

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Most research in the study of dying has focused on the attitudes towards death, anxiety surrounding the dying experience, and bereavement. There is scant research done in examining the personal meaning of the dying process of persons with a terminal illness. This study employed the methodology of hermeneutics, a qualitative research design in the study of phenomenology using text. This study used the interpretation of the text from two 60-90 minute in-depth interviews with individuals with a terminal illness to create a deeper understanding of the personal meaning of dying. The findings indicate that the phenomena of dying are an emotional, relational and spiritual process as well as a physical process. In addition, the study demonstrates that the lived experience of the dying process of those with a terminal illness has the potential to be a transcendent experience, lending personal meaning and purpose to one's living. This study adds to the literature of the dying process and indicates the need to educate end of life caregivers, including social workers, to the holistic needs of those with a terminal illness.

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Chapter One: Introduction

The introduction to this study of the personal meaning of dying includes the background of the problem, statement of the problem, an explanation of the purpose and significance of the research, and the research question.

Background of Problem

Dying is a natural stage of a human's life story and is often identified with the pathology of the disease process that is causing the physical decline in the dying (Fahnestock, 1999; McCue, 1995). There are many stages of development that humans pass through in their life and most of them have been studied in detail, and yet the study of the personal meaning of dying has been virtually ignored (Mor et al., 1988; Pattison, 1997; Steinfels & Veatch, 1975). Most studies on dying have explored death attitudes, death awareness, death anxiety, aging and dying, traumatic loss, and bereavement. Studies on the subjective lived experience of the process of dying are few (Holcomb, Neimeyer & Moore, 1993; Widera-Wysoczanska, 1999).

The majority of American culture admires youth and life while denying the processes of aging and dying. According to the Hastings Center (a research group on death and dying), American society is shielded from images of death and the direct experience of dying, as physicians and funeral directors have replaced the family and the church in the handling of the dying and dead (Steinfels & Veatch, 1975). Pattison (1997) and Martocchio (1982) point out that the dying person is not seen as living, and thus, have no role in daily life. The dying individual is often hidden away in institutions such as hospitals and nursing homes. While in these institutions medical staff often ignored the existence of the terminally ill patient on their ward (Kubler-Ross, 1969). As a result, a vital connection from youth through middle age to the ending of physical presence has been lost (Irish, Lundquist & Nelson, 1993).

The advances of medicine have reinforced the cultural avoidance of the mortality of being human and consequentially, the context of dying has changed (Walter, 1996). Currently in the U. S., approximately 80% of the dying pass away in institutions (with a mere 7% of these individuals involved with hospice care) (Cassel & Omenn, 1995; Walter, 1996). Less than 50% of the dying died in institutions fifty years ago and nearly none died in institutions at the beginning of the 20th Century (McCue, 1995).

As a result, most people now do not die in their home where they would have control over their dying process, while surrounded and supported by their family and loved ones. Instead, most people die among machines and strangers (Martocchio, 1982), often deprived of the ability to live their death in a self-determined manner (Steinfels & Veatch, 1975).

In the past few decades, two contrasting forces have emerged to define dying. On one end, the meaning of dying has been defined narrowly and pathologically, in medical and physiological terms (Holcomb, Neimeyer & Moore, 1993). These monocular perspectives overlook the spectrum of the vast complexities of the dying experience causing a loss of dignity and choice for the dying person (Pozatek, 1994). In response to this institutionalization of dying, broad and humanizing definitions of the process of dying are found in the literature of hospice philosophy, nursing, psychology, and psychiatry. Some of these qualitative studies include interviews with the dying person (Benzein, Norberg & Saveman, 2001; Feifel, 1977; Kubler-Ross, 1969; Martocchio, 1982) and/or their families and/or professional end of life caregivers (Knox, 1989; Martocchio, 1982).

Statement of Problem

A narrow definition of dying does not allow for the deeper meaning of the individual experience of dying and is no longer adequate. Humans are more than their biological make-up. Therefore, the care of the dying entails more than the medical care of the physical body. This is particularly significant for those with a prolonged, terminal illness when most of the focus is on the dying patient's medical needs rather than the individual person's dying process (Pattison, 1997).

There is some recent literature showing that the emotional, psychological, social and spiritual needs of humans are as present in dying as they are in living (Benzein, 2001; Feifel, 1977; Knox, 1989; Kubler-Ross, 1969; Martocchio, 1982; Neimeyer, 2001). There have been only a few qualitative studies on the personal meaning of dying.

Purpose and Significance of the Research

The purpose of this study is to enrich the body of knowledge about the process and personal meaning of dying through the stories as told by two persons, each with terminal cancer. There have been some qualitative studies of the dying process, however, there are few studies of the personal accounts of the dying process for those with a terminal illness.

The hospice movement has improved the quality of life for the dying through palliative care and emotional support of the patient and their family (Mor et al., 1988; Saunders, 1996), yet, outside of hospice care, there is little understood of the subjective phenomena of living while dying. For some, dying is a relief from suffering, and for others it is an unwelcome experience. According to Pattison's (1997) qualitative study of the phases of dying, to look at only one way that humans die is to ignore the many ways in which people choose to live their dying. The findings of this study will add to the knowledge of the personal meaning of the dying process.

The Research Question

The main research question of this study is, what is the personal experience of the dying process for persons with a terminal illness?

Chapter Two: Literature Review

Overview

Over the past three decades, since the publication "On Death and Dying" (1969), Elizabeth Kubler-Ross' seminal study of over 200 dying individuals and how they want to be cared for, interest in the aspects of the process of dying has increased in the United States. The increased interest in the study of the dying process has been fueled by the increasing population of those over 65 years of age, the increasing numbers of those dying in institutions, the increasing costs of health care and the controversies posed by the technology of life-prolonging and life-sustaining care. Literature on clinical interpretations and insights on the topic of dying has come from various areas of study including death studies, nursing, hospice care, psychology and psychiatry. Few studies are found in the social work literature.

This literature review will explore the processes of dying, the effects of hospice philosophy on the care of the dying, and responses of social work practice to the care of the dying. The chapter will end by noting the gaps in the literature.

Process of Dying

Eventually all humans will experience the process of dying. For some it will be sudden or catastrophic. For others it may be painless and natural. For those with a terminal illness, it is often prolonged. For all humans it can be an overwhelming and very stressful experience, impacting the person on all levels of their being (Lattanzi-Licht, Mahoney & Miller, 1998; Pattison, 1997). The existential struggle of the dying experience has the potential of a person finding meaning and a purpose to living their dying (Kubler-Ross, 1969; Neimeyer, 2001; Walter, 1996).

Physical and Psychological Aspects of Dying

Death itself is an event, a moment in time, and is usually defined in physical terms such as absence of brain activity, breathing and pulse. On the other hand, dying is a process that is as individual and complex as each of the human beings who experience it (Benzein, 2001; Kubler-Ross, 1969; Parkes, 1998; Pattison, 1997; Saunders, 1996). To describe the complexity of the process of dying, the physical, emotional, psychological, social, and spiritual aspects of a person need to be included (Kubler-Ross, 1969; Munley, 1983; Saunders, 1996; Smith, 1995).

In terms of time, the dying process of those with a terminal illness may last from several months to a few hours prior to the moment of death depending on the circumstances. As the end nears, there is a state of decline in the overall physical and emotional health of those facing their death. The dying person will begin to withdraw from interaction to conserve their energy. A few weeks prior to the moment of death, there will be a decrease in food and fluid intake and in cognitive functioning. According to Pattison (1997) in a qualitative study of aging and death, a few weeks before the moment of death there will be signs of emotional disorganization with an increase of "depressive involution" and a decrease in anxiety (p. 56). Within the forty-eight hours before the last breath, the physical and psychological signs usually show an increase in pain, need for air, restlessness, delirium, and disorientation.

Fears and Needs

The dying experience induces fear, anxiety and a feeling of powerlessness in the individual, as well as in their loved ones, especially if the needs of the dying are not met (Garvin & Chapman, 1995; Munley, 1983; Parkes, 1998; Pattison, 1997). In a prolonged, terminal illness, these fears and resulting anxieties, are pronounced (Pattison, 1997). The most common of these fears are: severe and persistent physical pain; inability to control body functions; suffering (psychological, and spiritual); being a burden to friends and family; loss of relationships; an undermined quality of life; and loss of identity (Kubler-Ross, 1969; Lattanzi-Licht, et al., 1998; Mahoney and Miller, 1998; Ho, 1999; Munley, 1983; Pattison, 1996).

Fears of the dying experience are described in terms of needs. In a qualitative study of interviews with hospice workers, Knox (1989) found that the most important needs of those near death was pain control, retaining dignity, control in decision-making (self-determination), desire for truth, opportunity to review the past, receiving affection, and presence of, and relationship with, significant others. These needs appear in nearly all of the literature.

Pain control was the primary concern of the dying. Besides affecting the physical body, pain affects the emotional, psychological, social and spiritual tasks of the dying and needs to be under control enough for the dying person (Lattanzi-Licht et al., 1998; Pattison, 1997; Saunders, 1996).

Social and Relationship Needs

To be able to cope with the enormous amounts of stress and loss inherent in the dying process, individuals need to be able to communicate their existential questions in the context of the experience of dying. According to Steinfels & Veatch (1975), death and dying cannot be discussed with the dying person without the other having a deep understanding of the feelings and behaviors that are unique to the dying process. Throughout the literature, dying is seen as a relational process. Maintaining intimate and meaningful relationships is the social task of the dying (Lattanzi-Licht et al., 1998; Martocchio, 1982; Neimeyer, 2001; Pattison, 1997).

The task of separating from these close relationships and one's existence in life, can evoke strong emotions of fear, anger, sadness, resentment and regrets. These emotions are difficult for most people to listen to, even professionals, especially when coupled with a conversation about terminal illness and dying. However, most individuals with a terminal illness want to and need to speak about their experience of dying, retell portions of their life, and find a means to say goodbye to their loved ones. The person with a terminal illness needs honest and compassionate relationships with their caregivers in order to guide the dying person through these tasks (Kubler-Ross, 1969; Pattison, 1997).

Feifel (1977), another of the first investigators who interviewed the dying, confirmed the existence of this need to have someone listen and understand, and found that by having a conversation about their dying they were able to adjust better to the process. Those with fewer meaningful relationships had a more difficult time with the dying process (Kubler-Ross, 1969).

Denial

Denial is a natural human reaction to sudden and shocking stress (Kubler-Ross, 1969; Neimeyer, 2001). In Martocchio's (1982) report of a social-psychological study on dying persons in a hospital, it is noted that denial is an interpersonal phenomena, as well as an intrapersonal phenomena, and may be observed as avoidant or ambivalent behaviors. Lattanzi-Licht et al., (1998) argues that sometimes ambivalence is not a behavior of denial but rather a person's struggle to understand themselves as both living and dying.

During a terminal illness, a person's level of energy will wax and wane and so will their use of denial. Denial is not seen as inherently good or bad, but rather as a mechanism that allows the person facing their physical mortality time to slowly absorb the fatal news of a terminal illness and to continue functioning (Lattanzi-Licht et al., 1998). In order to have the energy to function both physically and emotionally, denial is used as needed during the dying process to maintain a sense of equilibrium (Kubler-Ross, 1969; Pattison, 1997). When denial becomes an overused defense mechanism, it can become an obstacle to the development and use of other coping mechanisms (Lattanzi-Licht, et al., 1998).

Hope

Imbedded in the fear of the loss of self-identity is the fear of loss of hope. Loss of hope is described in the literature as an inability to tolerate the situation, a loss of self-identity, and a sense of helplessness. In a hermeneutic study of individuals with terminal cancer, Benzein, Norberg & Saveman (2001) found that the patients were able to find meaning in their living and their dying through the hope of being able to live as normally as possible while they were dying.

Persons with a terminal, incurable illness also need hope in order to believe in a future, whether it is for a painless, peaceful death, an existence after death or to simply gain an understanding of the meaning of their life and now their dying (Benzein, et al., 2001; Lauhkauf & Werner, 1998). Daaleman & VandeCreek (2000) state that hope is needed to maximize the psychological adjustments necessary in the process of dying. Kubler-Ross (1969) maintains that those who are dying have some form of hope to the last moment.

The Need to Find Purpose in Life and Create Meaning

The need to find a meaning and a purpose in one's life while dying is described throughout the literature (Balk, 1999; Saunders, 1996). The task of ascribing meaning to one's dying is more important than the specific ways in which this task is accomplished (Balk, 1999; Neimeyer, 2001; Saunders, 1996; Walter, 1999).

The ability to ascribe meaning to dying is aided by the establishment of a coherent understanding of the many losses facing the dying person and is necessary for the process of grief and personal growth (Balk, 1999; Neimeyer, 2001). In an article on spirituality in end-of-life care by Daaleman & VandeCreek (2000) it was reported that in the lived experience of women with breast cancer, the ability to maintain a meaning in their life was necessary for spiritual well-being. In a review of studies on the experience of loss, Neimeyer (2001) notes that there is a "powerful need for meaning" for a person who has experienced a traumatic loss such as those losses brought on by a terminal illness (p. 139).

The ability to have meaning and purpose in one's life incorporates the beliefs individuals have about themselves. Self-identity, the uniqueness of each individual, is affected by loss. Pattison (1997) states that until a person can affirm that their life has been unique for them, death will be an intrusion. Subjective studies of the dying support the concept that each dying is as unique as each life that was lived before it (Kubler-Ross, 1969; Martocchio, 1982).

The Existential Struggle

The struggle to understand and make meaning of living within the context of dramatic physical, emotional, psychological and spiritual changes is described in most of the literature on the dying process. This struggle has been depicted in two ways within the literature. One is described as stages and phases of dying. The second way is in terms of a dynamic experience between two seemingly opposing forces.

This existential struggle has been explained in terms of stages of dying since Kubler-Ross' study in 1969. The well-known five stages of dying include denial/isolation, anger/rage, depression, bargaining, and acceptance. Although these five stages have been often misinterpreted as a linear process, Kubler-Ross (1969) saw them as a dynamic and continuous process with the dying person moving in and out of the stages, sometimes staying in one stage longer than in another, sometimes experiencing more than one stage at a time, and sometimes experiencing one stage more acutely than another.

In a qualitative study of aging and dying, Pattison (1997) described three phases, rather than stages, of dying: acute, chronic, and terminal. Several other pieces of literature present aspects of these stages and phases as adaptive patterns of behaviors that were established in life and appear to persist through the dying process for the dying person as well as the family (Martocchio. 1982; Munley, 1983; Saunders, 1996).

Parkes (1998) hypothesizes that the stages and phases model of dying with terminal cancer does not correspond to the particular nature and course of cancer, and sees the need for a model that will correspond better to that disease process. Neimeyer (2001) in his review of literature on traumatic loss seems to be in agreement with Parkes and adds that there is a need for a comprehensive and holistic model of the process of dying, particularly with a constructivist framework.

In addition to the literature supporting stages and/or phases of dying, literature during the past two decades, describes this process as a dynamic experience of opposing forces. In 1983, Munley saw this struggle as dialectic and described it as a struggle alternating between hope and disappointment, hope and fear, hanging on and letting go, and hope and resignation. Lattanzi-Licht, et al., (1998) illustrate this struggle as a natural ambivalence when one is under great stress and that responses vary in intensity and length of time. Benzein, et al., (2001) found that there is an experience of tension between the *hope for something* and *living in hope* (reconciliation/comfort with both living and dying). Neimeyer (2001) hypothesizes that the struggle to make meaning of the experience of loss is a cognitive, oscillating process between loss-oriented meaning and restoration-oriented meaning.

Whether this dynamic experience, or struggle, is perceived as a stage, phase or experience of opposing forces, the result is that humans will arrange their lives into stories from past and recent experiences to give their living a sense of meaning (Turner, 1996). These stories or cognitive structures are methods in which a person copes and adapts to the duress of dying.

In addition, each person who is experiencing dying needs the freedom to choose new coping and adapting mechanisms. As competency in the use of these skills builds, hope is renewed (Benner & Wrubel, 1989; Lattanzi-Licht et al., 1998; Martocchio, 1982) and the person's narrative of their dying moves towards synthesis resulting in a transcendent experience. This process of change persists throughout the dying experience (Munley, 1983).

Transcendent/Spiritual Experience

The experience of living with a terminal illness confronts humans with their mortality and in turn sends them on a search for the meaning and worth of their life. According to Munley (1983), to include spiritual care into the care of those at the end of life enhances the ability of the dying to move towards synthesis of the experiences of dying into the very essence of their being and everyday living.

The main spiritual tasks of dying, as identified in the literature, are to find meaning and a purpose in one's dying that is able to sustain the dying person through the dying process. This includes the ability of the dying individual to give and receive love, to find and experience hope and to die as one chooses (Balk, 1999; Benzein, Norberg & Saveman, 2001; Saunders, 1996).

The experience of human mortality is often experienced within the structures of religious organizations and/or in terms of spirituality. Religion is often defined as a relationship with a particular set of formalized beliefs, whereas spirituality is defined as a search for the core of one's existence and to establish a personal meaning in life (Daaleman & VandeCreek, 2000). Either or both can be, and have been, used to reconcile the struggle of living in the two worlds of living and dying.

For the purpose of this study, the broader sensibilities of spirituality will be used as the standard in describing one's existential experiences. In support of this, it is offered that hospice philosophy has been a forerunner of spiritual care of the dying using the religious philosophy of western-based Christianity. However, through the years hospice philosophy has broadened the definition of this relationship with God to be more inclusive of other beliefs redefining the end-of-life experience as a "...personal and psychological search for meaning" (Daaleman & VandeCreek, 2000).

Recent literature out of psychology and death and religious studies suggest that there is a positive relationship among spiritual orientation, personal well-being and an increase in the quality of life for those dying (Balk, 1999, Daaleman & VandeCreek, 2000; Neimeyer, 2001; Saunders, 1996; Walter, 1999). This literature implies that a transcendent or spiritual experience occurs through the acquisition of coping and adapting abilities learned while experiencing the distress and suffering in the dying process. These acquired abilities to cope lend support to those facing their mortality to discuss their spirituality as well as their physical issues (Balk, 1999; Neimeyer, 2001; Smith, 1995).

Three principal spiritual tasks have been identified. First, there is a need to find meaning in life. Second, the dying need to have the ability to choose their dying in a manner that is congruent with their own values. Third, there is a need to transcend death, which is achieved through new spiritual insights, and in that act leave something of themselves for future generations.

Palliative Care

Palliative care is used when there is no hope for a cure and it is certain that the individual is in the process of dying. This type of care focuses on the comfort of the person at the end of their life and includes the use of adequate pain management, medications, food and fluids as requested, a comfortable setting and the monitoring of vital signs and the person's mental health. Palliative care allows the process of dying to take a more natural course with less focus on medical intervention and more focus on the care of the dying person and their family and loved ones.

Being able to choose how one dies is an important element in palliative care. Besides choosing to have palliative care, those with a terminal illness may also choose to not prolong their lives through the refusal of foods and fluids; the termination or refusal of medical treatment; and the use of the advance directive (living will), which may or may not include Do-Not-Intubate (DNI) and/or Do-Not-Resuscitate (DNR) orders if a person goes into respiratory arrest.

Hospice Philosophy and Care of the Dying

The hospice movement has played an important part in developing the concept of quality end of life health care for those with a terminal illness and for their family through palliative care (comfort care) since its inception in England more than 25 years ago (Mor, et al., 1988; Munley, 1983).

One of the main beliefs of hospice care is that the full meaning of dying cannot be experienced until the pain is under control. Cicely Saunders, a psychiatrist in England, is credited with developing the founding philosophy of hospice based on the concept of "total pain". This philosophy acknowledged the many dimensions of intractable pain (physical) and suffering (emotional, psychological, social, and spiritual) in those with a terminal illness, and thus recognized the importance of a holistic approach to the care of the dying (Cassel & Omenn, 1995; Kubler-Ross, 1969; Lattanzi-Licht et al., 1998). In Benzein, et al. (2001), adequate pain and symptom management was a necessary element in order for those with incurable cancer to continue hoping and thus living fully and normally as possible.

Dying is considered a spiritual experience and spiritual journey within hospice philosophy. Munley states that the experience of dying is the “salient theme of the hospice patient” (1983, p.109). Once the physical issues are addressed, the magnitude of suffering (fears, anxiety, and depression) is addressed and reduced allowing for an increase in energy and the psychological room needed to find meaning and purpose in each individual’s living through the dying process.

The holistic approach of hospice is based on the belief that each person is a unique physical and spiritual being. Inherent in this uniqueness is the right of the dying to die as they choose. Through the support of the hospice worker, the right to choose one’s own dying process as well as the individual’s and the family member’s sense of autonomy and individuality is preserved. This support is necessary for an individual to adapt to their situation and is an integral part of hospice care (Saunders, 1996).

Dying is seen as relational in hospice philosophy and supportive relationships are seen as important at the end of one’s life as they are during a person’s life. Kubler-Ross (1969) noted that the dying who had fewer open and honest relationships had more difficulty with the dying process. According to Saunders (1996), a compassionate relationship between the hospice worker and the dying person assists in the process of identifying the problems, needs and tasks (physical, emotional, psychological, social and spiritual) of that individual. The necessary energy and psychological room needed to find meaning and purpose in the person’s life then becomes available. When there is a sufficient level of trust in significant, supportive relationships the person who is facing their own mortality gains self-awareness and is able to transcend suffering to find inner peace (Wesley, 1996).

Social Work and Care of the Dying

A central concept in the end-of-life debates is the right to choose how one wishes to die (Wesley 1996). In the Code of Ethics of the National Association of Social Workers (NASW), this right of self-determination, to be able to live within one's defined values and goals, is prized and respected by the profession of social work. In support of this right of self-determination, the NASW Delegate Assembly in 1993 recognized that the terminally ill have the right to choose their manner of dying (Miller, 2000). This position supports the right of an individual to access the full, available spectrum of medical end of life options from the most aggressive medical treatment, to physician-assisted suicides (PAS), to palliative care (Wesley, 1996). In support of the emotional needs of the dying, a social worker may attend a PAS, but is not to dispense the medications (Miller, 2000). In addition, this assembly noted various ways in which social work advocates for client self-determination for those in the dying process by supporting palliative and hospice care, and promoting a holistic model of human needs that includes a spiritual dimension.

Social work practice recognizes that purely autonomous decision-making is an anomaly and that family, culture and community are significant factors in how a person chooses their way of living and dying. Feifel (1977) noted that two of the three most important conditions for an individual to die as they wish are open communication and warm personal relationships. A core concept of social work practice is the establishment of a warm, honest, supportive and meaningful relationship between the social worker and the individual (Turner, 1996). It is within the therapeutic relationship between the social worker and the individual that the interventions used empower and strengthen the individual and their support system to develop the necessary skills and support needed through the dying process.

Gaps in the Literature

Although there is a growing body of literature of clinical interpretations and insights about the process of dying, there is little research into the personal, subjective meaning of dying (Holcomb, Neimeyer & Moore, 1993). Most of the literature found was in studies of thantology, nursing, hospice care, medicine, psychology and psychiatry. There was no social work literature found regarding the personal meaning of dying. The four articles found in the social work literature on the subject of death and dying included, social work and end-of-life care (Wesley, 1996), psychospiritual distress of death (Smith, 1995), physician-assisted suicide policy in Oregon (Miller, 2000) and social work in the postmodern era (Pozatek, 1994). Three of these addressed the need for improved care of those with a terminal illness. None of these were qualitative studies, interviews with those who were dying regarding the meaning of living their dying.

The first recognized qualitative study of interviews with the dying themselves was published in 1969 by Kubler-Ross and opened the eyes of the professional helping fields. Since 1969, there have been some qualitative studies of interviews with dying persons, but these are few. The qualitative studies used in this study were interviews with dying individuals and were found in three studies: the social-psychological factors and interactions between the dying and those around them (Martocchio, 1982); the attitudes death and dying in those over the age of 60 living in institutional care situations (Pattison, 1997); and the lived experience of hope in the dying (Benzein, Norberg & Saveman, 2001).

The emerging literature from thantology, hospice, psychology and psychiatry is indicative of the need for studies of dying that allows for the individual definition of the needs and tasks in the process of dying, particularly in the area of spirituality. These studies would view humans as actively constructing their own definition of dying and would support a holistic method of adapting and thus, transforming their lives (Lattanzi-Licht et al., 1998; Neimeyer, 2001; Pattison, 1997).

Ashford, LeCroy & Lortie (1997) address the dying process in the chapter on late adulthood. It states that the dying process is due to both natural causes and chronic illness, and is mostly related to the process of aging. It notes that there have been several inquiries into the study death and dying, however, the only ideas presented are Kubler-Ross' five stages of dying. The obvious gap in this text is the absence of information on the intrinsic and holistic meaning of living one's dying.

The institutionalized isolation of the terminally ill has oppressed the ability of those with terminal illness to speak for them and be heard. To meet the needs of the oppressed and promote social change on behalf of clients are primary missions of social work profession (National Association of Social Work Code of Ethics, 1999). The lack of social work literature in the study of the personal meaning of dying impacts the role of social workers and their ability to support the dying, their families and the community that surrounds them. In addition, research from the global perspective that social work offers could add breadth and would build upon the knowledge base of literature from other disciplines.

Summary

In Chapter 2, terms specific to the process of dying were defined that relate to this study: the process of change, palliative care, hospice philosophy and social work care of the dying. In addition, gaps in the literature were illuminated. Chapter 3 will discuss the conceptual framework of postmodern constructivism and existential philosophy and how this framework supports the concepts presented of the process of dying.

Chapter Three: Conceptual Framework

Overview

The human experience of being terminally ill and in the process of dying is complex, requiring conceptual frameworks that are able to support and inform this complexity. This chapter describes how postmodern constructivism and existential philosophy are applied to the human phenomena of dying.

Postmodern Constructivism

The beginnings of constructivism can be found as far back in history as in the writings of an ancient Greek philosopher, Protagorus, who believed in the subjective perception of the world with no one perception being truer than another (Turner, 1996). Contemporary (postmodern) view of constructivist thought adds the dimension of humans inventing their reality by playing an active role in the creation and organization of their subjective reality, meaning that human beings create their own knowledge and truth (Neimeyer, 1999; Pozatek, 1994; Simon, 1992; Turner, 1996).

With this perspective, Neimeyer (2001), a leading researcher in the study of loss and meaning reconstruction, states that writers of postmodern constructivism no longer agree with the modern idea of humans having a core identity. Rather these writers are advancing "...the theory of the self that is multifaceted, dynamic and narrative in nature" (p.216) allowing for a deeper understanding of the many differences in human behavior.

Although constructivist thought is relatively new to the study of social work, it has affected diverse fields including the arts, natural and physical sciences, ontology, epistemology, and psychology (Turner, 1996). Neimeyer (1999) states, "Constructivism has emerged as a viable epistemic perspective in twentieth-century psychological science" (p. 84).

In Turner (1996), many of the principal concepts of constructivism are similar to concepts found in several accepted theories, approaches and perspectives of social work, thus lending validity to the use of constructivist framework in this social work study of the personal process of the dying. The recognition of the value of uniqueness in each person is also found within the constructs of feminist theory and existential philosophy. The view of client as the authority, knower and expert in their own life, is shared with cognitive theory, feminist theory, empowerment approach, and client-centered approach. The belief that a person has the right of self-determination is shared with feminist theory and humanist approach and is a tenet of social work practice.

Postmodern constructivism emphasizes that humans are beings that make meaning of their lived experiences. Interpreting an individual's story is key to understanding these meanings. This theme is shared with client-centered theory, narrative therapy and the methodology of hermeneutical inquiry. The idea that humans are influenced by the meanings of their thoughts is shared with the behavioral and cognitive theories. All of these concepts of postmodern constructivism and social work theories are important aspects of human beings as they experience their living and their dying.

Assisting an individual in assessing and interpreting their experience of a traumatic situation is an important skill of social work practice. Using a constructivist perspective allows the practitioner to take the stance of learner as the individual tells of their experiences in their life. Martocchio (1982) offers that in order to gain an understanding of a person's experience of the dying process, it is important to discover the individual's interpretation of the situation. Seeing the person as the authority of their lives is one of the main concepts of postmodern philosophy.

It is through dialogue with the dying individual and reading of the text, two main components of postmodern constructivist thought, that the meaning the individual has constructed to make sense of their life, and dying, is interpreted.

Existential Philosophy

The philosophy of existentialism supports the perspective of postmodern constructivism in this study and adds other important concepts. According to Turner (1996), there are four common themes in existential literature: 1) the uniqueness of each individual; 2) humans will make meaning of their lives during the process of change; 3) the impact of freedom of individual choice; 4) the importance of living in the moment. These themes do not exist separate from each other, but rather are woven together by a singular force within each person that creates a personal meaning for their individual life.

Uniqueness

According to existential philosophy, within each individual the singular, creative force of uniqueness organizes and integrates the meanings that the person places upon their lived experiences. This force moves a person towards expression of their uniqueness in thought and behavior. This unique response to each new situation gives personal meaning and purpose to each person's living and to their dying (Holcomb, 1993; Martocchio, 1982; Pattison, 1997). "When all else falls away, the personal meaning we attribute to our lives is perhaps the most essential and valuable part of our individual humanness" (Lattanzi-Licht et al., 1998, p. 131).

Process of Change

According to Turner (1996), no matter what a person's history or clinical diagnosis, they continually have the ability to change, grow and develop. Humans are always in the process of change and this process is never complete. Humans experience change rationally and experientially, in a circular pattern, each experience adding another layer of meaning to a person's life. Within this never-ending pattern of change, an individual will first experience a situation within their own unique constructed personhood, then self-reflect upon their thoughts and behavior within the situation, thereby gaining a deeper understanding of themselves. Finally, they integrate this new information to construct a deeper meaning to their life, which in turn is what responds to the next situation, and so forth. It is within this process of change that humans are offered a chance to transcend difficult and troubling situations.

In addition to physical pain, those with a terminal illness experience suffering, psychological and emotional pain. In existential philosophy, suffering is an inevitable part of human experience and has the potential to facilitate human growth. Researchers studying responses to a wide range of traumas have noted that as a general reaction to severe and unexpected negative life events, humans experience a persistent need to make meaning in their lives (Neimeyer, 2001).

However, the transcendence of suffering needs honest, open dialogue between the individual and their environment, which includes communication within significant relationships. There are many emotions and thoughts during the dying process and if the communications and messages between people are congruent, then the dying person can make sense out of the experience of dying (Kubler-Ross, 1969; Pattison, 1997).

Impact of the Freedom of Choice

The power to change comes from having the freedom of choice. Outside forces may influence the thoughts and behaviors of a person, but these forces cannot make a person change. Only the individual can change his or herself. The loss of choice, the loss of control over one's ability to choose how to live, is a loss that many with a terminal illness face. The power to change one's internal structure is often the only choice the dying have available to them. According to Turner (1996), it is in the act of normalizing pain and problems, not minimizing them, that an individual is able to take responsibility for their own thoughts and/or behaviors and facilitate change.

Within each person is the ability to choose their response to their environment. In a stressful situation, a person may choose to develop a defensive belief system to allow them to cope and endure their suffering. This may include denial of one's impending death. This defensive belief system will alleviate suffering, possibly for a long time. Although this system is not seen as pathological, it can impede the natural process of change and growth.

Other times a person may choose to be involved in their living and aware of their environment rather than turning away from it. To choose to fully experience the life in front of oneself is to be committed to the process of change. Through open and intimate relationships with others, an individual allows for honest feedback that they can use in reassessing their thoughts and behaviors (Turner, 1996). This commitment to living, and dissolving the defensive belief system, if even for a short time, allows a person move to from powerlessness to choosing to create a deeper, transcendental, meaning to their life.

Living in the Present Moment

In Turner (1996), the existential encounter between the individual and their world happens in the here-and-now, the present moment. To live in the present moment is to choose to experience life with full self-awareness of oneself in response to one's environment. According to existential philosophy, to live in full self-awareness is the ultimate moment of freedom of choice and meaning making (Turner, 1996). It is within this moment of being that the person experiences a sense of transcendence.

Summary

Rationale for the use of postmodern constructivism and existential philosophy as conceptual frameworks allows for a unique and holistic perspective in understanding the complexities of the dying process. In Chapter Four, the next chapter, hermeneutics, the methodology used for this study, is discussed.

Chapter Four: Methodology

Overview

This chapter restates the research question, defines the important concepts and terms used in the methodology of hermeneutics, and discusses the study population and the protection of subjects.

The Research Question

The research question used in this study is, what is the personal experience, and further, the shared meaning, of the dying process for individuals with a terminal illness.

Hermeneutics as Research Design

This study employs the method of hermeneutical interviewing of participants and interpreting the text to discover meaning in a particular phenomenology. Using the hermeneutic method of inquiry, participants were interviewed, the texts of these interviews were interpreted with the tool of circularity, and common themes were identified and explored, allowing for greater insight into the dying process. Using the method of hermeneutics allowed for capturing a deeper meaning and understanding of the subjective experience of living while one is dying.

Hermeneutic research is focused on a collection of firsthand experiences that is meaningful in qualitative research (Benner, 1994). This method of qualitative design was chosen for this study for two main reasons. First, the complex process and social interactions inherent in the process of dying would benefit from the in-depth process of inquiry and investigative approach that hermeneutics offers. Secondly, according to Packer & Addison (1989), empirical research is inadequate for capturing the meaning of the social activity of an individual or to illuminate the social and cultural context where these interactions take place.

Understanding phenomena that has been shaped by the person's culture, intra-psychic experiences, lifestyle and tradition, and expressed in language is the basis of hermeneutical philosophy (Benner, 1994; Packer & Addison, 1989). The meaning of each story is made in how each story is told, to whom it is told to and the relationship between the researcher and the participant (Neimeyer, 2001).

Heiddeger, a German existential philosopher who lived during World War II, believed that death is at the core of human existence. He applied the idea of hermeneutics (the use of text and language) to understand how humans come to know themselves and their world through the subjective and shared experience of "being" human. Main themes are found in the text of the interviews using the method of hermeneutics. The main themes can be used as paradigms that can embody meaning in everyday life (Benner, 1994).

Hermeneutics comes out of the constructivist theories where text and dialogue are the main components of the social construction of meaning (Goolishan & Anderson, 1992). In order to reflect the participant's perspective and context, the interpreter uses circularity of understanding. Using this method of interpretation, the researcher looks at the whole of the text collected, examines it, interprets it for its meaning and gains a perspective of the story told to them. With this perspective, the researcher looks over the data again and with each re-examination and reinterpretation made (circularity), she comes to a deeper understanding of the phenomena studied. Eventually themes (the story within the story) emerge from the interviewee's texts and a shared meaning of the phenomena is recognized (Benner, 1994).

Dying from a terminal illness has inherent stresses. According to

Benner & Wrubel (1989), the phenomena of stress challenges the understandings and meanings a person had created about their self-identity in relation to their previous situation and environment because these past understandings are no longer relevant. In order to create new meanings a person needs to have the freedom to choose a new approach to the situation and acquire new skills to live within the changed environment (Benner &Wrubel, 1989).

Participants

The participants are two individuals in the process of dying from a terminal illness. They are under medical care and involved with hospice care. One person is in a nursing home that has a visiting hospice social worker and the other person is cared for in his home by family members with the support of a visiting hospice social worker. The participants were voluntary and had no complicating mental health or physical health diagnosis, such as organic brain syndrome, that would impede their ability to understand and communicate.

The snowball method of sampling was used to obtain the participants. Snowball sampling is a non-probability sampling method that is used when it is difficult to locate participants due to the peculiarities of its membership (Rubin & Babbie, 1997). I first spoke to the administrator of the hospice program who asked the social workers to call me when they had a patient who seemed interested in participating in the interview process. Once the patient agreed, I called them to introduce the study, and myself and to set up an interview time.

Data Collection and Analysis

The interviews were conducted using hermeneutics. The main question in the interview was: What is the personal experience of dying from a terminal illness? There were prompting and probing questions and are listed in Appendix A. These questions were open-ended and sensitive to the complexities of the dying process. The flow of the interview was as natural as possible while keeping a focus on the meaning of living while the person was dying. There was allowance made for the possibility of being led by the story.

The information gathered from the two interviews was similar enough to increase the comprehensiveness of the data (Patton, p.116). These interviews were audio-taped and then transcribed into written text. Each interview lasted from 60-90 minutes.

It is not possible to pre-test a hermeneutics study. However, as a part of an interpretive study, colleagues were asked to read the text from the interviews and give feedback to the researcher.

Protection of Human Participants

The participants of this research are at a crucial point in their lives. In any qualitative research design, it is important to communicate respect for the person and their environment and even more so in the case of the dying. They were voluntary participants. Giving words of feedback, appreciation and support aided the participant in assessing whether the interview process is worth it to them (Patton, p.127).

To ensure protection of the participants, the proposed study was reviewed by the IRB procedures of Augsburg College and I received approval (IRB #2001-32-1). In addition, I communicated clearly to the participant the reason for the research and respectfully allowed them to stop the process at any time.

Confidentiality and informed consent was explained to the participants. All information collected either written or taped will be destroyed after the completion of the thesis project.

Summary

In Chapter 4 the research question was restated, the use of hermeneutics as the research design was presented, the snowball effect for the finding of the participants was discussed, the method of data collection and analysis and the protection of the participants were explained. In Chapter 5, the findings are discussed.

Chapter Five: Study Findings

Overview

The dying process is a profound, core experience for humans as they face the end of their existence. Dying is a complex process, as complex as the humans who experience it, as dying carries within it the complete meaning of the individual's life. This chapter contains the exploration and interpretation, through hermeneutical analysis, of the stories presented by two adults with terminal cancer.

The following interpretations of Betty and Tom's narratives reveal two main themes. First, the theme of *choosing* is expressed within the context of the individual processes of living with a terminal illness. There are many choices facing the participants everyday, such as, choosing one's attitude, choosing to hope vs. giving up hope, choosing to develop coping and adapting skills, and choosing to struggle with living in the two worlds of living and dying. The second theme found is, *finding a purpose and creating meaning in living one's dying*. As each task of dying is accomplished, the person constructs and reconstructs the narratives of their dying, uncovering the perceived purpose of their life, and creating new or revised meanings for their living.

Participants

Both participants in this study are Caucasian and dying of a terminal illness. Both participants have cancer and are involved with hospice care. Betty is in her late 80's, widowed and has been living in a nursing home since her husband passed away six years ago. Tom is in his early 60's, married and living with his spouse in their home. The average length of time in hospice is approximately a month. Betty has been involved with hospice for four months and Tom has been involved with hospice off and on for ten months. Both of the participants' illnesses have lingered, thus placing the participants in a unique situation by allowing them more time than most to gain an understanding of themselves in relation to the process of dying.

Choosing

Both of the participants have experienced moderate to severe physical pain due to their cancer. Due to good pain management (palliative care), their physical pain has been ameliorated for the most part. Good pain management and working with a hospice social worker for support of the emotional and psychological sufferings they have aids them in developing coping strategies.

Tom knows that he cannot change the path of his terminal illness so he chooses to change what he can, which is his attitude towards living the life that is in front of him. Everyday as Tom wakes up he consciously chooses to live each moment the best he is able to. During his first hospitalization five years ago, the physicians found numerous cancerous tumors found growing throughout his body. He describes the night in the hospital that he decided to how he wanted to live shortly after he found out about the cancer:

> I had an ex-brother-in-law that had Lou Gehrig's Disease...He was the orneriest person you'd ever want to see in your life. He just, he made life miserable for everyone around him. When I laid in that hospital bed that night, that's when I made my decision I was not going to be like him.

Tom's decision to choose to stay positive as much as he is able to is a coping skill that he uses when he struggles with the losses he has suffered. During the year after he was diagnosed with terminal cancer, Tom cared for his mother who was also dying of cancer. A week after his mother's funeral his physician told him that he was going to die soon and so he began to prepare for his own death. Two weeks later, he and his physician were stunned when they found that all of his tumors had spontaneously disappeared. Unfortunately, just over a year after the cancerous tumors had disappeared, the slow-growing lymphoma came back and he has been living with this cancer for the past three years. He has experienced many disappointments and struggles with a steady decline in his physical condition and additional health issues that are stripping him of who he used to be and what he use to enjoy. Sometimes staying positive is difficult for him to do:

> ....you know this disease I got now...diabetes. That affects my vision so now I can't read and I just, that's a tough one for me now, and my vision is constantly changing. Even as I eat, my vision changes. The blood sugar, it changes my vision. I can watch a little TV, maybe listen to it....I grieve. I cry, I cry, but I also grieve and I accept. I have to grieve ...it's time lost....For about three years...I was nauseated the whole time...but then all of a sudden I had three months that everything was wonderful. Everything tasted good....it was like being in heaven...and then the diabetes shows up. [he chuckles]....oh well, you know, what can I say....

For the most part, it appears that Tom has a coherent understanding of his losses, as well as an awareness of his feelings, thoughts and behaviors (Balk, 1999; Neimeyer, 2001), which aids him in grieving the losses as they come along. He recognizes that the loss of his vision and loss of his ability to eat what he wants to are not only physical losses. The loss of being able to enjoy reading and eating is affecting him emotionally and psychologically. The experience of these recent losses is yet another reminder of his mortality and powerlessness over the situation.

It appears that Tom is struggling with the two opposing forces of his hopes and disappointments. As he reflects on these new physical changes, he begins the choosing again to continue to experience his life as it changes. He hopes that he can continue to adjust to future changes (Benner & Wrubel, 1989) and "...just deal with the things [I can] today." In addition, Tom chooses to express how he feels and chooses to respond to the losses how he has in the past, with an accepting attitude. According to Kubler-Ross (1969) accepting the changes made in one's life by a terminal illness is a form of adaptation to a traumatic loss.

Betty does not identify with the use of a positive attitude nor self-awareness as coping skills. She uses her faith in her God as a coping skill and believes that she will be better off in a future life after death (Benzein, et al., Lauhkuf & Werner, 1998). Her firm belief, and possibly her hope, is that she will be united with her God, her deceased husband and other family members, appears to be a coping mechanism she uses to help increase her psychological adjustment to dying (Daaleman & VandeCreek, 2000) and to deal with her impatience of not being dead yet:

> ....I am not afraid of dying. I am looking forward to it....I ask God...to take me home with Him...Evidently, my work is not finished....Nobody knows [when they will die]. Nobody needs to know. I've heard people say, "Why do I have to die?" and I say, "Why do I have to live?" I want to go....I want to graduate from this man-made world, enter God's

> world and be with God and all of my loved ones....I will be happy.

Betty's choosing is different than Tom's. Betty speaks more in terms of her religious beliefs based on her upbringing in a Christian-based religion. She chooses to have faith in her God and in an afterlife. Her struggle does not appear to be between two opposing forces like Tom's struggle. She is focused on a future time and place, possibly a form of denial of her discomfort of her current situation, life in a "man-made world." Unlike Tom, she expresses no fears, or any emotion, of any past, present or future losses, not even about the last moments of her life when she may experience pain and suffering, "Every pain I ask God to increase it and take me home with Him." Betty's religious faith appears to be a singular coping skill for her.

Tom has found that by coupling two coping mechanisms together he has had more success in adapting to the painful and traumatic changes in his life. Besides choosing the most positive attitude he can each day, Tom uses what he calls *present moment living—choosing* what he *can* do in each moment:

> ....I made up my mind [when he found out he couldn't walk]...that I was going to be grateful for what I could do and wasn't going to gripe about what I couldn't....I really believe that each day I get up and I do what I can and I try to make each day worthwhile and if I laughed, I won....you just deal with the things you can today....We [he and his wife] lived, even though I was going to die, we lived and this has been my whole theory...we're not putting up with cancer, we're not side stepping, we're *living* with cancer....We're not letting

> the fact that I have cancer stop me from living....It's what *can* I do rather than what I can't....the cancer is there, but I am here and I'm going to live....so, the *present moment living* is really a big part of my life....The last option is our choice...

Tom adapts to the physical and psychological changes by consciously understanding and accepting the fact that he has terminal cancer. He knows and accepts that there will be further losses. Once again by *choosing* his attitude and *present moment living* (the way he lives each day), he decreases his sense of powerlessness over painful experiences, physical and emotional. He admits to having "good days and bad days", however he has made a decision to not let the disease of cancer define who he is and how he will live. He describes himself as a person with cancer, not a cancer patient. In knowing that the only thing he has control over is himself, he decides to have an attitude of accepting his mortality, and living life with his terminal illness. According to existential philosophy, to live in full self-awareness is the ultimate moment of freedom of choice and meaning making (Turner, 1996).

Betty does not speak in terms of powerlessness and losses and so does not seem to have the existential struggles as Tom does. The struggle for Betty is in trying to understand why God has not taken her yet. For many years, she and her husband lived and worked at a Christian nursing home until he died. They were at the deathbed of many people, praying with them and for them. Through the lens of her religious background, she chooses to define each of her losses (loss of vision, loss of strength, loss of her husband) as a step closer to being with her God:

> ....God is so good to me and I have been so happy to be

> living.... Death is a blessing and a graduation from this life, a celebration of whatever your life....It's beautiful....We were at almost every deathbed...for days...there was always a blessing [death] from their own suffering....they don't want to die and we have to try and convince them that they graduate from all the suffering...and Man's world, to be in God's world and it is beautiful....I am not afraid of dying. I am looking forward to it....

The dynamic process between opposing forces and the description of the stages/phases of dying described in the literature is not observed in Betty's narrative. Betty appears to have no fears and she identifies only two hopes, the hope that death will come soon and an underlying hope that there is an afterlife as she imagines. She does not seem engaged in Kubler-Ross' stages of dying: denial, anger, depression, bargaining, and acceptance.

Betty does not appear to experience an existential struggle as she speaks about being a "sinner", as she is certain she has already received salvation for her soul when she dies: "...I am a sinner. I always have been. I know it. He's sent me out of the sins...happy to be forgiven by Jesus....I am not afraid of death, life or death". Perhaps her struggle is in the past, or possibly her self-identity is so strongly defined by her religious beliefs that she does not recognize the human struggle of being good and being a sinner. It may be that Betty's beliefs in the power and benevolence in her God has aided her in adjusting to her prolonged terminal illness and may have abated any fears she might have had (Balk, 1999). Another possibility is that Betty may have no more energy for struggling and in order to cope she has opted for a familiar, comforting way of believing, which may not necessarily be of her own description.

Tom is also ready to die and, like Betty, would prefer, for the most part, to die soon. He also has expressed no fear of the exact moment of his death. However, unlike Betty, he is afraid of what the last days and moments might be like and he hopes to be able to continue to have a choice over his dying until the last moment. His struggle between his hopes and fears are evident in the following:

> ....I did have one terrifying experience when this diabetes set in. I didn't know who I was. I was totally out of it. I was totally confused....When I started coming out of that, that really scared me....that was the most difficult thing I had to face....I may head back into that on the way out [death]....you can come to the point where you can no longer choose for yourself....you are no longer in control...That would be so difficult for me because....my goal is to die pleasantly and cooperatively and so forth....

Fear of powerlessness, pain, hopelessness, loss of bodily functions, loss of self-control, loss of self-identity (uniqueness) and being a burden to his family are some of Tom's fears and are common fears among those facing death (Kübler-Ross, 1969; Lattanzi-Licht et al., 1998; Mahoney & Miller, 1998; Munley, 1983; Pattison, 1997). For Tom, accepting the possibility that his situation may continue to worsen before he dies does not mean that he is giving up hope. Tom hopes that he will be able to have choices right up to the end so that his self-identity of being a kind, loving, caring man stays intact within the unique life context he has constructed (Benzein, et al., 2001; Lauhkauf & Werner, 1998).

Although at times in his narrative Tom seems to accept the fact that he will probably die sooner than later, he experiences the struggle of wanting to die soon and wanting to live six more months in order to celebrate he and his wife's 40th wedding anniversary:

> ....Our 40th anniversary is going to be [in six months] I cannot believe I'll be alive....No way can I believe that I'm going to be alive six months from now, but six months ago I surely thought I wasn't going to be alive today. I mean it just goes on and it goes on and it goes on [his living]. It just (he chuckles to himself for a couple of seconds).

It appears that Tom is struggling with hanging on to his life and letting go. He and his wife have just entered their retirement years and the cancer is unfairly taking this time away from them. Although Tom has some competency in using the coping and adapting skills he's developed, separating from the person he has felt the closest to is a task of dying that is and may well continue to be difficult for Tom.

Later on in the interview, the struggle between Tom's desire to be alive for another six months and his belief in the importance in *present moment living* comes up:

> ....Well, my nurse today, she, I'm going downhill. See, anything can happen. I could break a blood vessel....You know, we go through phases....and I'm choosing to live a little bit more, but I don't want to go through that denial again. See, that's the part, you know you are going to die, you go through the grieving process, but then if you get back into that denial [that he might be able to live another six months], then you got that grieving process to go through again. I guess I don't want to delude myself into thinking

that I am going to be here five years from now...

With each new problem, Tom is faced with another existential struggle. His ambivalence is not a behavior of denial, but instead it is the struggle of trying to understand himself as living in two worlds, that of the living and that of the dying. He is feeling the dynamic process of going back and forth between hope and fear, hope and disappointment, hanging on and letting go, and hoping for something and living in hope (Benzein, Norberg & Saveman, 2001; Munley, 1983). The ultimate, existential moment of freedom of choice and making meaning for himself happens when he is living in self-awareness, fully, in the present moment (Turner, 1996).

Finding Purpose and Creating Meaning

For both Tom and Betty finding a purpose in their life is an important and powerful aspect of living their dying (Balk, 1999; Daaleman & VandeCreek, 2000; Neimeyer, 2001; Saunders, 1996). One of the tasks necessary to create meaning in their life for a person with a terminal illness is to develop and maintain a warm, honest, compassionate relationship. It is within this relationship that the dying are able to receive assistance in organizing, interpreting and integrating the revised meaning of their life with each new experience/struggle (Kubler-Ross, 1969; Martocchio, 1982; Neimeyer & Mahoney, 1999; Pattison, 1997; Pozatek, 1994).

Betty has only a couple of close relationships. One is with her hospice social worker and the other is with her daughter. She also has a son, but does not see him often as he lives far away. The meaning of her life is enriched through the closeness she feels with her daughter. Dying is seen as relational in the literature (Lattanzi-Licht, Mahoney & Miller, 1998; Martocchio, 1982; Neimeyer, 2001; Pattison, 1997) and maintaining and experiencing close, loving relationships have been found to be an important need of the dying (Knox, 1989). She and her daughter share the same religious beliefs and values and so she is able to speak more freely to her daughter about the dying process than to anyone else. She sees her daughter near daily and sometimes she will get a visit with her grandchildren, which brightens her day:

> It's a gift from heaven. I call them "God's gift" to me. All of them. They are wonderful....My daughter has the most wonderful children....My daughter understands it [death] just like I do....

It is important to Betty that she have someone to understand the value she places in her religious beliefs and death and be able to talk about them. She values the visits with her daughter as they reinforce her beliefs in her God and strengthens her hopes for a positive afterlife.

One of the ways in which a person can find a purpose in their life is through experiencing their values by performing deeds (Lattanzi-Licht, 1998). Tom has been actively sharing his story with many people besides his family. He speaks to groups of hospice clients and their families and attends his own support group. Tom has found that by sharing his story and philosophy of living while dying, he has given and has received love from many people outside his family as well as within his family. He feels needed in his role of helping others and recognizes how others value his experiences:

> ....The experience of going through this [dying] has actually been a very positive experience. I have never met so many people. I had no idea how many people love me. I had no

> idea of what a value I was to other people. It was a real, real awakening to find out how many people loved me and cared about me. I just thought I was an ordinary jerk going through life, and I found out that I've affected an awful lot of lives in the way that I've gone through the process of expressing my faith with other people and just living the process day to day, just living the process....

He values the work he does for others by telling and retelling his story of how he lives his dying and has found that he is valued in return. Tom's self-regard and self-identity increase in sharing his story, adding another dimension to his perceived purpose in his life (Balk, 1999; Neimeyer, 2001). This fills a spiritual need for Tom and gives him a personal sense of well-being (Saunders, 1996).

Tom believes that his purpose is to help others through telling his story of the dying process. Betty believes her purpose is to bring others to God:

> ....I have tried to put God into the hearts of everyone I meet. If they don't know God, I pray that I am reaching some.
>
> Many of the prayers have been answered and are wonderful.

Although they differ in the meaning and purpose of their lives and their experience of the dying process, both Tom and Betty believe that God has a purpose for them. This belief sustains and comforts them as one of their spiritual needs is met (Kubler-Ross, 1969).

Besides speaking to groups of persons with a terminal illness and their families, Tom serves others by co-facilitating support groups in loss and grieving. He listens to people's stories and helps them to "problem solve." During these interactions, he is aware that he is being "tender", compassionate and caring, towards others. These loving interactions strengthen his self-identity, values and positive outlook on his life:

> "....My father was a person who had always stopped to help somebody if they were in trouble....I've been tender with people....you'd see someone and you would try and talk to them and give them a suggestion....The tenderized people looked for the reason or answer to work. When people leave me, I want them to feel better than when they came. In our support groups I go to...we find that the more a person has been through you either become hardened or tenderized....You know there are so many good people in this world and we miss so much [opportunities to help others]....[We don't realize] how many good people [there are]...how many people there are willing to help you....There are so many tender people, so many tenderized, wonderful people around."

This sense of service to others helps Betty and Tom ascribe a sense of purpose in their life (Kubler-Ross, 1969) and gives them a role to perform. To be of help to others is incorporated in Erickson's task of ego integrity (Ashford, LeCroy & Lortie, 1997) and assists the dying person in developing a stronger sense of self-identity and purpose in life.

In spite of how his many health issues continue to strip him of his physical capabilities, Tom maintains a sense of self-identity by remembering his quest for a purpose:

> "Get up, get going. Get dressed and try to be cheerful and helpful and just a pleasant person and laugh and joke....I've got a pretty good sense of humor and I manage to keep people

> happy. There are times when I get down and then I bitch and moan and all that but, for the most part, I find joyfulness in the day....we search for our purpose and when we are pretty much following our purpose, our lives are pretty smooth and we can face anything..."

Tom demonstrates how he has gained competence in using *choosing* as a coping skill. He feels he has some control over something in his life, choosing his attitude, at a time when terminal cancer seems to have so much control. As a reaction to traumatic events, humans experience a persistent need to construct meaning in their lives (Turner, 1996). Tom talks about his daily search for a reason to get up and out of bed everyday. He understands that he might be crabby or not feel well, but he has responded to this type of situation before and has faith that he will be able respond to it again. He will try to create some meaning through either his humor or suffering. He appears to have integrated his terminal illness into his life and synthesized the experience of dying into his daily living. The result is the transcendent experience of joy.

As he is choosing to have a positive meaning in his life on a daily basis, it appears that he finds hope in living that day. Tom believes that hope and faith are essential to his spiritual development (Balk, 1999; Benzein, Norberg & Saveman, 2001). He talks about the existential meaning of these factors in his life and how they give new meaning to his life now:

> ...I take all my strength from God. He has all the credit for my being calm....I just totally trust in God. See I believe that faith is a gift and you have to use it. If I give you a car and you never used it and all of a sudden, you had to go

> someplace and you jumped in that car, you would probably get yourself in trouble....But, if you haven't ever used it, it's a burden rather than a gift. I believe in using my faith everyday so that when things happen my faith will be polished and bright and ready to go and is going, and it won't just be something that I have to stumble over and try to work around....Actually, I truly, truly believe that God gives us everything that we need.

Tom has experienced many changes due to living the traumatic experiences of dying from his terminal illness. He struggles with his hopes and fears and with each problem, he chooses to find and use coping skills. He integrates this new information to construct a deeper meaning to his life. One of the most important choices he makes is to live as fully as he is able to and live in the present moment. As a result, he has deepened his understanding of his self. He has found a purpose in his life through his terminal illness, to help others through their losses, which in turn has helped him in creating a deeper meaning in his life. The ability to maintain a meaning in his life has given Tom a sense of spiritual well being and has enhanced his belief that he will be able to cope with most of the changes that will continue to come with his terminal illness.

Summary

In this chapter, two main themes were found in the interpretations of the text of two interviews with persons dying from terminal cancer: *choosing* and *creating meaning and purpose in living one's dying*. Although each of the participants experience the process of dying in their own unique manner, they share the desire to strive to create their own meaning and purpose for their lives.

Chapter Six: Discussion and Implications

Discussion

This study of the personal meaning of the dying experience of persons with a terminal illness uses the narratives of two individuals dying from a terminal illness, cancer. Two main themes emerged from these narratives. The shared experience was not strong in these themes. In addition, in Tom's narrative the process of the dying experience emerges with a resemblance to the process of change, as described in the literature. This experience was not found in Betty's narrative.

The findings of this study demonstrate that although the process of an individual's dying is unique and complex there are some shared meanings of the dying experience. These include *choosing* and *finding purpose and creating meaning.* These themes appear to be more strongly supported in Tom's narrative than Betty's.

Throughout Tom's narrative, the theme of *choosing* is prominent and he uses *choosing* as a coping skill through each part of his dying process. Similar to the individual's involved in the studies by Benner (1994) and Martocchio (1982), Tom has found that the freedom to choose his own way of problem solving is necessary for him to develop other coping skills in order to adjust to the stresses of dying. In Benner & Wrubel (1989), dying form a terminal illness has inherent stress and challenges. A response or adaptation to a previous situation and environment may no longer be relevant in the new situation. The freedom to choose a new coping mechanism will impact the dying person's ability to adapt. Essentially, what choices each person makes influences how they live their dying (Kubler-Ross, 1969).

Betty chooses to be involved with hospice, which she uses for pain control and daily visits from the hospice social worker. She also chooses to believe in an afterlife where she will live with her God, her husband and other friends and family. The closest she comes to using a coping skill is to have faith that her God will eventually take her from this "man-made world." She does not appear to struggle with the stress from her terminal illness or from the process of dying. The existential struggles apparent in Tom's narrative do not appear in Betty's. It may be that she is in denial of these struggles or does not have the physical and psychological strength to do the internal work. This apparent lack of struggling with the losses and trauma with dying may be due to her age as she is nearly 20 years older than Tom and may have answered some of these existential questions at a younger age.

Dying can be isolating experience. Both participants in this study chose to not go it alone. Tom and Betty relied on their close family relationships to support them physically, emotionally, psychologically, and spiritually. Interviews with dying persons in Feifel (1977), Kubler-Ross (1969), and Pattison (1997), support this study's finding that both Tom and Betty needed warm, honest and loving relationships in order to sustain them through their dying process. Similar to Tom's experience, the research by Daaleman & VandeCreek (2000) and Pattison (1997) found that the process of dying is relational and that the person dies in relation to themselves and to significant others. On the other hand, Betty did not appear to experience her dying in relation to anyone, even her daughter. She did express that she received emotional support from her daughter. Betty does not identify an emotional connection, nor a deepening in the meaning of her relationship with herself, others or with her God.

The idea that humans experience their life as a process and make meaning of it through narratives/stories is found in the theory of postmodern constructivism, existential philosophy, and the social work theories of behavioral/cognitive therapy and client-centered therapy. Both Tom and Betty experience the need to have a purpose to their lives while dying (Lattanzi-Licht, Mahoney & Miller, 1998). They share a similar purpose, that of serving others. There is a difference, however, in how serving others serves to deepen the meaning of their own lives. Betty's service to others is to tell them about her God and to convince them to believe in God as she does, which seems other-prescribed. Tom also has a strong belief in a God, however in his service to others he shares his own truth and knowledge of his struggles and triumphs in finding a way to live while dying, which seems self-prescribed. It seems that Betty does not experience transcendence as she looks towards her future afterlife. Tom is in his *present moment living* and experiences the pain as well as the joy.

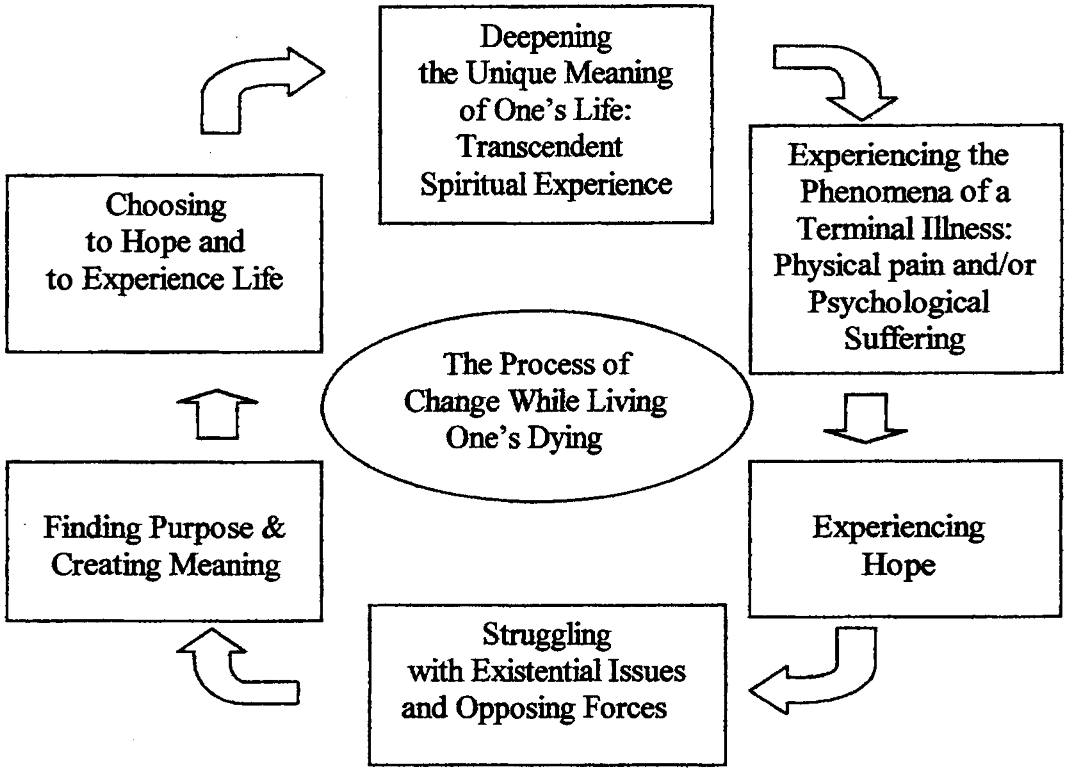
The Process of Change While Living One's Dying with a Terminal Illness

This study adds to the literature on the process of dying by relating the similarities of the dying process to the process of change. The literature reviewed for this study supports the idea that humans experience the process of change throughout their lives, including their dying. The theme that a process of change is brought on by the phenomena of a terminal illness is supported in the studies of Benner (1994); Holcomb, Neimeyer & Moore (1993); Kubler-Ross (1969); Lattanzi-Licht, Mahoney & Miller (1998); Martocchio (1982); and Pattison (1997). In general, the subjective phenomena of living while dying from a terminal illness is a dynamic experience for the individual as they construct and reconstruct the narratives of their lived experience to find the purpose of their living and create the meaning living while dying.

Several subjective studies of the personal stories of the dying, including, Balk (1999); Benner & Wrubel (1989); Benzein, Norberg and Saveman (2001); Feifel (1977); and Kubler-Ross (1969), corroborate the findings of this study that there is an ongoing existential struggle as a person with a terminal illness searches for a purpose to their life. Tom's narrative describes several struggles in hoping vs. fearing, choosing to live while dying, and living in two worlds (hoping to live and hoping to die) at the same time (Munley, 1983). Building coping and adapting mechanisms to deal with these struggles involves the freedom to choose new problem-solving skills. This in turn renews a sense of competency and then hope (Benner & Wrubel, 1989; Lattanzi-Licht et al., 1998; Martocchio, 1982).

Results from the new experiences is reflected upon, organized and then integrated with the stories from experiences, to reconstruct the purpose and deepen their personal meaning of their unique life (Kubler-Ross, 1969; Martocchio, 1982; Neimeyer, 1999; Pattison, 1997). In responding to the next new experience/stress, the person follows a similar circular path. This creative force moves the person towards synthesis often resulting in a transcendent, or spiritual experience. This process is part of being human and is present at all stages of a person's life, from living one's life through living one's dying (Kubler-Ross, 1969).

Figure 1. The Process of Change



Implications for Social Work Practice

To focus merely on the physical and medical issues of a terminal illness dehumanizes the personal experience of the dying person. A client-centered focus of working with the dying would further support and validate the experiences of the dying, promote a culturally diverse perspective and humanize contemporary clinical diagnostic practices that focus on the disease of dying versus the natural process of dying.

The stories of the participants of this study remind caregivers that it is within compassionate listening and understanding of the complexities of dying that the unique experience of dying can be acknowledged and shared. Persons with a terminal illness adjusted better to the dying process when they had the opportunity to share their story of their experiences. Each dying process is unique and there is no one best solution for all of the possible situations that arise. Understanding the unique needs of the dying person will enhance the possibilities of mutually acceptable solutions to problems between the dying person and their family and professional caregivers. Persons with a terminal illness have several tasks to accomplish and they need warm, open, honest and loving relationships to assist them in their tasks.

In addition, expanding an understanding of the phenomena of dying will increase the level of competency of healthcare professionals in the care of the dying. Social attitudes and laws that restrain the individual from having control over their dying need to be revisited. Social workers could educate policy makers about the process of dying and support the dying person's right to self-determination.

Limitations and Suggestions for Further Research

This study design did not control for age (generation), gender, or socio-economic background. These factors could be controlled in further research. The fact that the participants had been involved with hospice for an above average length of time may have impacted Tom's level of competency in his adapting skills and his deep spiritual experiences.

For both of the participants, their relationship with a higher power is a very strong element in their stories. Exploration of the dying experience with those of differing religious and spiritual beliefs would expand the information gathered in this study culturally.

The number of persons in this study was small which probably limited the possible shared meanings in the narratives. Although the number of persons that are in the dying process each day may be substantial, this study was constrained by the specifics of timing of when the study had to take place due to the health and energy of the participants on a given day. In addition, the participants were not available for further questioning due to the decline in their health. Studies with more participants would likely increase the likelihood of finding narratives with more shared meanings. In hermeneutical research, the researcher often returns to the participant with further questions. Further conversation and interviewing with the participants could have clarified some of the questions that arose during the writing of the findings.

The importance of further study of the personal experience of dying is evident, particularly in this day and age of technological advances that have the capacity of taking all control out of the hands of the dying person. Any addition to the literature of the process of dying would aid those in the helping professions to have more authority to assist and guide the dying towards a more thoughtful and humane ending to their physical existence.

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APPENDIX A

Interview Questions

Main question: What is your personal experience of the dying process?

Probing questions:

Tell me of a time when...?

Was this a...?

Could you give me an example of that?

Can you describe a time when you did that?

IRB #2001-32-1

APPENDIX B

Letter to Participants

Date

Dear Ms. or Mr.________,

I am currently completing a graduate degree in Social Work at Augsburg College. The thesis I am writing is focused on the personal meaning of the dying process.

This thesis is a project that will require me to interview two to three individuals who are terminally ill, male or female, ages 35 years or older, and are approaching their death within six months to a year. The interview is in-depth and may last 1-1 1/2 hours.

The purpose of this thesis project is to gain a deeper understanding of common themes of the personal experience of dying. Your participation is voluntary and confidential. The interviews are on audiotape with written notes and then transcribed. All of these documents will be destroyed after six months. A professional who has agreed to keep the information confidential will type the transcriptions. The names of the participants interviewed will be changed to protect their anonymity.

I appreciate the time you have taken to read this over and consider participation in this study. If you agree to participate in this project, you may contact me during the day or evening on my cell phone: 651-246-6269. You may leave a message if you wish.

Sincerely,

Maurine McCort

IRB #2001-32-1

APPENDIX C

Sample of Consent Form

The Personal Meaning of the Dying Process Consent Form

You are invited to participate in a research study of the personal meaning of dying. You were selected as a possible participant by.....Before you agree to be in the study, please read this form and any questions you have I will answer. This study is being conducted by me as a part of my master's thesis in social work at Augsburg College.

Background Information:

The purpose of this study is to gain a deeper understanding of the personal meaning and experience of the dying process.

Procedures

If you agree to be in this study, you will be asked to participate in an interview that will last approximately 60 minutes in length.

Risk and Benefits of Being in the Study

The study has several risks: First, you may become tired from the interview process. Talking for an hour takes energy and if you tire easily this may be a problem for you; Second, you may find that talking about this topic is emotionally stirring and agitating as well as possibly draining; and Third, sensitive memories or unresolved emotional issues may arise in relation to your past. If any of these possible risks become significant during the study, either due to physical, emotional of psychological issues, the interview will be terminated. Your health and well-being are a priority. There will be no direct benefits such as monetary compensation.

The indirect benefits to participation are a contribution to the body of knowledge in the meaning of dying through the experience of those in the process of dying. This will bring improvement in policy and the care, and therefore the well-being, of people who are in the dying process. Another benefit may be a deeper individual meaning of one's living and dying resulting in possible growth and connection with oneself and others.

In the event that this research interview results in an injury, physical, emotional or psychological, treatment will be available including medical care, counseling and follow-up care if needed. If any treatment is necessary, payment for any such treatment must be provided by you or your third party payer such as HMOs, Medicaid, Medicare, etc.

Confidentiality:

The records of this study will be kept private. Any publication of this study will not include any information that would make it possible to identify you. Research records will be kept in a locked file and only the researcher will have access to those records.

The audiotape will be destroyed by September 1, 2001. Only the researcher will have access to the audiotape.

Voluntary Nature of the Study:

Your decision to participate or not will have no affect on your current or future relations with Augsburg College or with the place where you receive care. If you decide to participate, you are free to withdraw at anytime without affecting any of those relationships.

Contacts and question:

The researcher conducting this study is Maurine E. McCort. You may ask question as you have now.

You will be given a copy of this form to keep with your records.

Statement of Consent:

Signature____

Date_______________

Signature of Parent or Guardian____________________________

Date_______________

Signature of Researcher__________________________________

Date_______________

I consent to the audio taping of the interview:

Signature____

Date_______________

I consent to the use of my direct quotations to be use in the published thesis document:

Signature____

Date_______________