A HERMENEUTIC PHENOMENOLOGICAL STUDY:
LIVING WITH THE CERTAINTY OF DEATH

A Dissertation in
Nursing

by
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Submitted in Partial Fulfillment
of the Requirements
for the Degree of
Doctor of Philosophy

May 2012
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Supporting individuals through their end-of-life transitions is an integral part of nursing practice. One particular transition relates to the final weeks and months of the individual’s life and their shift from an attitude of uncertainty about the anticipated time of their death to a sense of certainty about the limited time that remains.

Van Manen’s hermeneutic phenomenological method was used to explore the lived experience and associated meanings of living with the certainty of death among a number of individuals enrolled in hospice care. Phase I of the study took place in central Pennsylvania in 2007 with interviews of five individuals enrolled in hospice care to assess the feasibility of conducting a research investigation with end-of-life patients enrolled in hospice. Phase II was conducted during 2011 with five additional hospice patients in the same area of central Pennsylvania, who participated in two interviews at their home. An audio-recorded protocol was implemented whereby the participants were asked to record their thoughts and experiences for three days after the first interview.

Following the thematic analysis of the Phase II transcribed data, the Phase I and Phase II data sets were merged and the following essential features of living with the certainty of death were identified and described: (a) Beating the Odds, (b) Living With, Not Dying From, (c) Separating and Connecting: Shifting Relations, (d) Transcending the Everyday World Through Spirituality, (e) Getting My House In Order, and (f) Living With Pain. A critical reading of related texts was conducted to gain additional insights and perspectives on the research. The lifeworld existentials of lived body, lived space, lived relations, and lived time, as delineated by Max van Manen (1990), guided the
researcher’s reflection on these essential features. Among the findings in the study were
that the hospice patients interviewed were living with purpose and actively engaging life
even though they knew their death was imminent. Finally, the methodological, nursing
practice, and research implications are presented with a view towards developing better
end-of-life care.
# TABLE OF CONTENTS

LIST OF FIGURES ........................................................................................................... ix  
LIST OF TABLES ............................................................................................................. x  
ACKNOWLEDGMENTS ................................................................................................. xi  

CHAPTER 1  
Introduction to the Phenomenon of Interest ........................................................................ 1  
  
Background ..................................................................................................................... 3  
Defining End-of-Life Care .............................................................................................. 6  
Illness Trajectories .......................................................................................................... 7  
End-of-Life Trajectories: A Rhythm of Certainty/Uncertainty ........................................ 9  
Hospice Services ............................................................................................................. 18  
Purpose, Method, and Significance of the Study .............................................................. 19  

CHAPTER 2  
Literature Review ............................................................................................................. 21  
  
Introduction to Heidegger’s Being-in-the-World ............................................................ 21  
Heidegger: Being-Toward-Death .................................................................................... 23  
Literature and Art: Living With the Certainty of Impending Death ................................ 31  
Living With the Certainty of Death: Theories and Research ........................................... 35  
  
Awareness of Dying: Ambiguity and Empowerment ...................................................... 36  
The Process of Dying: Stages, Tasks, and Intervals ......................................................... 46  
  
Kubler-Ross: Stages of dying ........................................................................................... 47  
Pattison: The living-dying interval ................................................................................. 50  
Corr: Task-based approach .............................................................................................. 52  
Summary ......................................................................................................................... 54  
  
Dying Trajectories .......................................................................................................... 56  
  
Social science perspective: Glaser and Strauss ............................................................. 56  
Medical community perspective: Lunny, Lynn, and Hogan ........................................... 58  
Cancer trajectory ............................................................................................................. 60  
ALS trajectory .................................................................................................................. 61  
Heart failure trajectory .................................................................................................... 62  
End-of-Life Transitions Within Trajectories ................................................................... 64  
Quality End of Life ......................................................................................................... 71  
  
Communication with healthcare providers .................................................................... 72  
Family and social relationships ....................................................................................... 73  
Safety, security, and self-preservation ............................................................................ 76  
Spirituality: Hope, meaning, and self-worth ................................................................... 79  
Preserving and enhancing dignity ..................................................................................... 83  
Summary ......................................................................................................................... 86  

The Hermeneutic Phenomenological Approach .............................................................. 88
CHAPTER 3
Method.................................................................106

Van Manen’s Hermeneutic Phenomenological Approach .......... 106
  Turning to the Nature of the Lived Experience .................... 107
  Investigating the World As We Live It .......................... 108
    Using personal experiences as a starting point .............. 108
    Tracing etymological sources ................................ 108
    Searching for idiomatic phrases ............................... 109
    Obtaining experiential descriptions of others .............. 109
  Hermeneutic Phenomenological Reflection ..................... 110
  Hermeneutic Phenomenological Writing ........................ 111
  Maintaining a Strong and Oriented Relation .................. 112
  Balancing the Research Context by Considering Parts and Wholes .... 112

The Feasibility Study Protocol .................................. 113
  Recruitment ..................................................... 114
  Data Collection Protocol ....................................... 116
    Interview #1 .................................................. 117
    Audio-recorded protocol .................................... 117
    Interview #2 .................................................. 118
    Interview #3 .................................................. 119
  Analysis .......................................................... 119
  Insights Derived From the Feasibility Study ................... 120
    Revised recruitment recommendations ....................... 120
    Revised data collection protocol ............................ 120

Phase II Research Protocol ...................................... 121
  Sampling Procedures ........................................... 122
    Inclusion criteria ............................................ 122
    Recruitment .................................................. 122
  Sample .................................................................. 124
  Data Collection: Interviews and Audio-Recorded Protocol ....... 124
    Interview #1 .................................................. 125
    Audio-recorded protocol .................................... 126
    Interview #2 .................................................. 127
Analysis .................................................................................................................. 128
Thematic analysis .................................................................................................. 129
Lifeworld existentials ............................................................................................. 132
Experiential descriptions in literature and art ...................................................... 132
Written Description/Product .................................................................................. 133
Human Subjects Protection .................................................................................... 133
Trustworthiness of the Research ......................................................................... 135
Credibility ................................................................................................................. 135
Dependability .......................................................................................................... 136
Confirmability ........................................................................................................... 136
Transferability ........................................................................................................... 136

CHAPTER 4
Results and Analysis............................................................................................... 138

The Context: Profiles of Living With the Certainty of Death ............................... 138
Jack .............................................................................................................................. 139
Paul ............................................................................................................................ 140
Nancy ......................................................................................................................... 140
Carl ............................................................................................................................. 141
Vera ............................................................................................................................ 141
Laura ......................................................................................................................... 142
Elaine ......................................................................................................................... 142
Frank .......................................................................................................................... 143
Mildred ....................................................................................................................... 144
Larry .......................................................................................................................... 145

Essential Features: Living With the Certainty of Death ...................................... 146
Beating the Odds ....................................................................................................... 148
Living With, Not Dying From ................................................................................. 150
Separating and Connecting: Shifting Relations .................................................... 154
Transcending the Everyday World Through Spirituality ....................................... 159
Getting My House in Order ..................................................................................... 162
Living With Pain ........................................................................................................ 165

Summary: Essential Features of Living With the Certainty of Dying .................... 170

Lifeworld Existentials: Living With the Certainty of Death ............................... 171
Lived Body .................................................................................................................. 171
Lived Space ............................................................................................................... 176
Lived Human Relations ............................................................................................ 180
Lived Time .................................................................................................................. 184

Summary: Lifeworld Existentials .......................................................................... 187
Chapter Summary .................................................................................................... 187
CHAPTER 5
Discussion.............................................................................................................. 189

Re-examination of the Literature............................................................................. 189
  Awareness of Dying ............................................................................................. 190
  The Process of Dying ......................................................................................... 191
  Dying and Illness Trajectories ............................................................................ 194
  Transitions ......................................................................................................... 195
  Quality End-of-Life Care .................................................................................... 196
  Rhythmicity of Certainty/Uncertainty ................................................................. 197

Limitations of the Study ....................................................................................... 200
  Recruitment ....................................................................................................... 200
  Data Collection Protocol .................................................................................... 201
  Hospice-Enrolled Participants ........................................................................... 203
  Feasibility Study ................................................................................................. 204

Implications ........................................................................................................... 204
  Methodology ...................................................................................................... 204
  Implications for Nursing Practice ....................................................................... 212
  Implications for the Discipline of Nursing/Future Research ............................... 216
  Conclusion .......................................................................................................... 218

REFERENCES ........................................................................................................ 221

APPENDIX A
Recruitment Information for Hospice Clinical Nurses........................................... 239

APPENDIX B
Participant Recruitment Letter.............................................................................. 241

APPENDIX C
Interview Guide ..................................................................................................... 242
LIST OF FIGURES

Figure 1. Trajectories of Dying ........................................................................................................59

Figure 2. Boonma’s “Nature’s Breath: Arokhayasala” .................................................................162
LIST OF TABLES

Table 1. The Feasibility Study, Phase I ................................................................. 116
Table 2. Phase II of the Study .............................................................................. 124
Table 3. Phase I (Feasibility Study) and Phase II Integrated ............................. 131
ACKNOWLEDGMENTS

A special thank you to Dr. Janice Penrod, my advisor and committee chair, for your guidance, patience, encouragement, and your support throughout this entire process.

Thank you, to my committee, including Dr. Judith Hupcey, Dr. Susan Loeb, and Dr. Timothy Slekar who each helped me in a unique and caring way to finish this research.

I am also grateful to the following individuals who did not stop believing in me and kept cheering me forward:

• Dr. Paula Milone-Nuzzo and Dr. Raymonde Brown for being true leaders who care and support each of us faculty
• Dr. Suzanne Kuhn, my friend, who never lost faith in my ability to finish
• The nursing faculty at Penn State Altoona—my own personal cheering squad. (Who could ask for anything more?)
• Dr. Veronique Foti and Dr. Glen Mazis, who helped me come to know Heidegger and Merleau-Ponty
• Dr. Dee McGonigle and Dr. Kathleen Mastrian for words of encouragement all along the way
• Hazel Hunley, my dissertation editor, who guided me into the home stretch with her wisdom, energy, time, and humor
I will be forever indebted to Kim Krantz, Kathy Baker, and all of the hospice nurses who took the time to assist me in recruiting participants and helped to make this research possible. My greatest appreciation and deepest respect go to the 10 special persons who, even though they were experiencing great pain and weakness, opened their doors and their hearts and souls, and changed my world forever with their insights, courage, and faith.

And finally, most importantly, I will never be able to thank my family enough for always being there for me, encouraging me, and loving me each and every day. Your many sacrifices so that I could accomplish this goal have not gone unnoticed.

Thank you to my loving and patient husband, Paul; my wonderful daughters Heather and Anna, and my supportive son-in-law, Kevin; and my four beautiful granddaughters, Gracie, Caroline, Libby, and Jane (Grandma can’t wait to finally join you at the beach).

Thank you to my brother Dennis, my sister Darene, and my brother-in-law Jim for assuming so much responsibility for family so that I could finish this research; and my sister-in-law Margie, who has given her all for her family.

And most of all, thank you to my mother, Maxine Sloan Scott, my favorite nurse and my loudest supporter in finishing this research. Thank you, Mom and a belated Happy 90th Birthday. This one is for you and for Dad, who I know is watching over all of us.
This dissertation was funded in part by a Sigma Theta Tau, Beta Sigma Chapter Research Grant. I am grateful to the Beta Sigma Chapter for this award.
CHAPTER 1

Introduction to the Phenomenon of Interest

Supporting individuals through their end-of-life transitions is an integral part of nursing practice; yet the nature of this experience has only recently received attention in nursing research. One particular transition relates to the final weeks and months of the individual’s life and the shift from an attitude of uncertainty about the anticipated time of one’s own death to a sense of certainty about the limited time that remains. What is the individual experiencing prior to, during, and following this transition? What can health professionals do to support the individual and the family during this transitional phase? The goal of nursing is to assess and diagnose these transitions as human responses, but the ultimate goal is to treat the patient and the family system.

Meleis (2010) identifies transition as central to the domain of nursing and has developed a middle range theory of transitions. She has developed her definition of transitions over the past 20 years and presently defines a transition as “a passage from one fairly stable state to another fairly stable state” (p. 11). Meleis emphasizes that transitions may contribute to increased vulnerabilities at critical junctures in individuals’ health-illness experiences, developmental and lifespan experiences, and social and cultural experiences. These increased vulnerabilities place the individual at risk for adverse health effects and/or an altered sense of well-being. The discipline of nursing focuses on assessing these vulnerabilities at critical junctures and diagnosing the risks for adverse health effects and an altered sense of well-being. An understanding of such transitions enables nurses to intervene and support the individual prior to, during, and following the transition. Various studies have used this organizing framework to examine
transitions experienced at such vulnerable times as motherhood (Mercer, 2004; Shinn & White-Trout, 2007), divorce (Sakraida, 2005), transition to a nursing home (Davies, 2005), and role transition (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Facing the end of one’s life is another critical transition. A priority care issue in nursing practice and research is in identifying specific interventions to support individuals through this vulnerable time of living with the certainty of death.

The experience of living with the certainty of one’s own death has been influenced by the changing dynamics of health care in the United States. Murray, Kendall, Boyd, and Sheikh (2005) reported that a century ago death was usually sudden, with the leading causes being infections, accidents, and childbirth. While sudden death is less common today, individuals often acquire serious progressive illnesses, such as cardiovascular disease, respiratory disease, and cancer. Moreover, better management of these illnesses and advanced technology have enabled individuals to live longer even while new and different therapies are trialed in an attempt to delay death. Trajectories have been developed to show the progression of an illness and the anticipated decline in a person’s functional capacity, but little research has focused on describing the particular experiences of individuals progressing through end-of-life transitions, such as facing certain death. It goes without saying that those who are dying are the most appropriate persons to provide a rich, descriptive theory of living with the certainty of death. A study revealing and explicating the insights and understandings of individuals in response to “living” with their impending death could deepen the meaning of this experience for nurses in clinical practice in order to provide appropriate care.
Background

A focus on defining the phase “end of life” and research related to end-of-life care has intensified in the healthcare field over the past two decades. It began with the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT Principal Investigators, 1995), a Robert Wood Johnson Foundation (RWJF)-funded research study (1989-1994). This study revealed that hospitalized terminally-ill patients either did not have advanced directives or the advanced directives were often ignored; and these patients were dying in uncontrolled pain while connected to machines (SUPPORT). These findings prompted the RWJF and the Soros Foundation to concentrate funding on improving end-of-life care. Since then, research initiatives by both foundations have advanced the field of end-of-life care. Promoting Excellence in End-of-Life Care (1998), sponsored by the RWJF, was dedicated to making long-term changes to improve health care for dying people through facilitation by collaborative work groups, centralized health care resources, and funded innovative projects for improving end-of-life care. National work groups, comprised of clinicians and researchers in specific areas of medicine, were created to extend palliative care to challenging domains and special patient populations. Clinical assessment and educational instruments related to these patients were compiled and are accessible to healthcare providers via the Internet or by direct request. Innovative projects were funded for the purpose of improving the quality of care for terminally-ill people and their families across a full range of clinical settings. The Soros Foundation Open Society Institute’s Project on Death in America (PDIA) ended in 2005, having distributed $45 million in grants to organizations and individuals working to improve care for dying patients and
their families. Over nine years, the PDIA funded initiatives in professional and public education, the arts and humanities, research, clinical care, and public policy. A report titled *Transforming the Culture of Dying: The Project on Death in America 1994-2003* (Open Society Institute, 2004) summarized the initiatives and provided insights and recommendations for others seeking end-of-life care funding.

Specific nursing research initiatives have also contributed to improving end-of-life care. Triggered by the 1997 publication of the Institute of Medicine (IOM) report *Approaching Death: Improving Care at the End of Life* (Field & Cassel, 1997; IOM, 1997), the National Institute of Nursing Research (NINR) began to focus research initiatives on end-of-life care. The NINR (2003) reported that a significant number of Americans were dissatisfied with the way the healthcare system provides care to the dying, with 93% of Americans believing that improving end-of-life care is important. Enhancing the end-of-life experience for patients and their families became one of five funding themes the NINR identified in 2003 for research initiatives. Since then, the NINR has sponsored research initiatives in end-of-life care, including, but not limited to such areas as: (a) pain management and related symptoms; (b) communication patterns among patients, families, and health care providers; (c) caregiver support; (d) end-of-life care in diverse populations; (e) complementary and alternative medicine; and (f) ethics and healthcare decision-making (NINR, 2010). In 2010, the National Institutes of Health (NIH) awarded the NINR funds to conduct the End of Life and Palliative Care Needs Assessment to derive comprehensive analytic data in order to identify historical funding trends in end-of-life and palliative care research since the release of the 1997 Institute of Medicine Report.
In 2004, The National Consensus Project for Quality Palliative Care (NCP), comprised of five major palliative care organizations, released the first edition of the *Clinical Practice Guidelines for Quality Palliative Care*. This document described the core precepts and structures of clinical palliative care programs. A second edition of the guidelines was released in 2009. The document was updated to include current references and definitions reflecting a growing evidence base for practice in palliative care; to include all preferred practices within the domains; and to provide real examples of how the guidelines have been used in practice to “operationalize optimal end-of-life care” (NCP, 2009, p. iv).

In August 2011, the NINR and its partners across NIH Institutes, Centers, and Offices convened a three-day national summit called The Science of Compassion: Future Directions in End-of-Life and Palliative Care. The purpose of the summit was to “examine the state of research and clinical practice in end-of-life and palliative care” (NINR, 2011, p. 1). Issues raised during this summit and summarized during the closing keynote address focused on strengths, resources, and future directions for end-of-life and palliative care (EOL PC) research. These issues included (a) increasing a research focus on the influence of comorbidities at end of life; (b) integrating technological innovations to improve the health of patients and their families; (c) increasing community participation in EOL PC research; and (d) developing and nurturing the next generation of scientists through collaborative interdisciplinary training activities.

As these developments suggest, end-of-life research initiatives have contributed to changing the face of end-of-life care. At the same time, these initiatives have broadened rather than narrowed the focus for end-of-life care to include those receiving palliative
care, which can be delivered to individuals at any stage of illness and can be administered alongside curative treatment. The question remains, however: How is the end of life defined and what transitions encompass this experience? There continues to be a lack of consensus on the definition of end of life and a description of end-of-life transitions. During a conference on Improving End-of Life Care, sponsored by NIH (2004), one of the concerns addressed was about developing a definition of this kind of care. Conference participants concluded that no evidence supports a definition of the phase of care referred to as end of life or the major transitions inherent to that course of care. The conference participants recommended the following areas for research: developing conceptual models/frameworks to guide the full range of systematic research in end-of-life care as it affects patients, families, and care providers; and increasing efforts for further development and consensus about common definitions and constructs as they relate to end-of-life and palliative care (Grady, 2005).

This ambiguity surrounding the definition of the term “end of life” hinders the development of science, delivery of care, and communication between patients and providers. In addition, circumstances surrounding the end-of-life phase are poorly understood, leaving many to struggle through this life event.

**Defining End-of-Life Care**

Defining and describing the characteristics of the transitions within the end of life are essential for providing quality care to individuals and their family members. Although there is still a lack of consensus on the definition of end of life, the one used in this study encompasses both the processes of living with the illness and dying from the illness. Teno and Coppola (1999) suggested two states: persons living with a life-threatening
illness where death is probable, but the exact timing of death is uncertain; and individuals who are actively dying, with death expected within a specific time frame. In other words, the end-of-life rubric includes both the process of living with the functional decline associated with the anticipated certainty of death within weeks or months and the process of dying from the illness experienced as the rapid, irreversible decline in function with an anticipated certainty of death within hours or days. The pattern of functional decline has provided a framework for studying the course of various illnesses through trajectories.

**Illness Trajectories**

Social science and medical research focus on the study of illness trajectories to describe the course of a disease. A trajectory is defined as “the path of any body moving under the action of given forces” (Online *Oxford English Dictionary*, 2012). Illness trajectories are illustrated by a specific shape representing a flow of events that can be mapped over the course or duration of a disease. Social science research has traditionally focused on the changing organization of the work of healthcare providers based on the interacting perspectives of awareness of the certainty of death among patients with a specific course of disease, their families, and health care providers. The social science perspective has evolved from Glaser and Strauss’ seminal work on the trajectories of dying. Glaser and Strauss (1965) addressed the question of whether individuals die socially before they die biologically and what this means for human relationships. Using a grounded theory approach, they studied the interactions of hospital staff and patients through intensive interviews and observations in six different California hospitals. They reported the results of their classic theory in a series of books describing the organization around the work of dying (Glaser & Strauss, 1965; 1968; Strauss & Glaser, 1970).
Work regarding the trajectories of illness and decline has continued within the medical and nursing community. Research initially focused on the pattern of functional stability and functional decline related to the course of specific diseases or groups of diseases. Lunney, Lynn, and Hogan (2002) used Medicare claims to evaluate a clinically-based classification scheme and to seek a better understanding of Medicare expenditures and health care in the last year of life. They identified four trajectories including sudden death, terminal illness, organ failure, and frailty. Each trajectory differs in length and slope of functional decline.

Research has also focused on defining and describing the patterns of functional decline with individuals experiencing specific illnesses including amyotrophic lateral sclerosis (Gordon, et al., 2010; Mitchell & Borasio, 2007; Radunovic, Mitsumoto, & Leigh, 2007), heart failure (Goldstein & Lynn, 2006; Hupcey, Penrod, & Fenstermacher, 2009), chronic fatigue syndrome (Ciccone, Chandler, & Natelson, 2010), end-stage renal disease (Jablonski, 2004); stroke (Kirkevold, 2002), and cancer (Constantini, Beccaro, & Higginson, 2008; Murray, et al., 2007). Finally, the study of trajectories has expanded to include healthcare issues such as cognitive functioning in older adults (Chodosh, Miller-Martinez, Aneshenseil, Wight, & Karlamangla, 2010), disabilities at the end of life (Gil, Gahbauer, Han, & Allore, 2010) and trajectories for informal family caregivers providing end-of-life care (Penrod, Hupcey, Baney, & Loeb, 2012).

Trajectories have been helpful in assisting healthcare personnel plan and organize the medical and physical care of individuals and in providing individuals and family members with information regarding the anticipated course of the illness. Healthcare providers are astute at recognizing physical signs and symptoms at various phases of an
illness trajectory and organizing work around the awareness and anticipation of impending death; but at the same time, these trajectories have not represented the ways in which patients experience the certainty of death during their end-of-life experience.

End-of-Life Transitions: A Rhythm of Certainty/Uncertainty

Death is a certainty in life. This fact cannot be doubted. Certainty evolves from the root word ‘certain’ which means the firm conviction that something is the case (Oxford English Dictionary Online, 2010). Synonyms for certainty include sure, dependable, inevitable, and indisputable. A proposition is said to be certain when it is indisputable; and a person is certain of a proposition when he or she cannot doubt it. Wittgenstein in his final work titled On Certainty (1969) asserted that some concepts are not open to skepticism and doubt; they are more like a background against which we come to know other things. He illustrates this through the metaphor of the riverbed. A riverbed provides the support for what we claim has meaning. The riverbed itself is not something we can know or doubt, but unusual circumstances can occur and what was part of the riverbed can shift and become part of the river. Death as a concept is one such riverbed. Many individuals, particularly those raised in western society, while not doubting the fact that death is a part of life, live as if death is unrelated to one’s life and choices. It is something remote and happening to others or to one’s self at some distant time in the future. When faced with the prospect of their impending death, individuals transition to a different way of viewing the world and viewing their self in relation to the it. This is consistent with Wittgenstein’s claim that a proposition has no meaning unless it is placed in a particular context. “Knowledge is in the end based on acknowledgement” (Wittgenstein, 1969, p. 378). When the knowledge of one’s impending death becomes a
certainty, what was once part of the riverbed is stirred up and becomes part of the flowing river of life, according to Wittgenstein’s analogy.

Within the context of the certainty of impending death, vulnerabilities may arise at this critical juncture, exposing the individual to uncertainties. Often the thought of impending death can invoke a corresponding sense of uncertainty with anxiety, questions, and issues surrounding one’s own dying and about those who will be left to carry on after one’s death. In the midst of certainty about the limited time one has to live, multiple uncertainties may come to the forefront.

While there is a lack of research reported on the concept of certainty in the nursing literature, several nursing theorists have developed and tested the concept of uncertainty. This may be related to nursing’s interest in transitions. Transitions, or turning points, are vulnerable points (Penrod, 2007). There is nearly always uncertainty related to vulnerability. Therefore, it is reasonable to understand why nursing research has predominantly focused its theoretical work on the state of uncertainty. At the same time, there is a void in the research on the coexisting state of certainty.

Research and theory development regarding uncertainty have focused on individuals’ experiences of vulnerability at transitional times in life, including acute or chronic illnesses (Bailey, Wallace, & Mishel, 2007; Bailey, et. al., 2010; Clayton, Misgel, & Belyea, 2006; Mishel, et al., 2005; Mishel, et al., 2009), and on caregivers of individuals with a chronic or terminal illness (Greenwood, Mackenzie, Wilson, & Cloud, 2009; Hupcey, Fenstermacher, Kitko, & Penrod, 2010; Penrod, 2001; 2007; Penrod, et al., 2012; Stone & Jones, 2009). In these studies, uncertainty is commonly viewed as a
stress response accompanying an illness, and intervention strategies focus on assisting the individual with managing the uncertainty and minimizing this stress response.

The uncertainty model developed and tested by Mishel (1981; 1988; 1990; 1997; 1999) is widely used in nursing to examine and assess uncertainty in patients with acute and chronic illnesses. Mishel defines uncertainty as the “inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes” (Mishel & Braden, 1987, p. 48). Mishel’s model emphasizes antecedents of uncertainty expressed as a stimuli frame, which is the form, composition and structure of the stimuli contained in the illness, including the system pattern and event familiarity. When symptoms form a pattern, there is less uncertainty and less ambiguity about the state of the illness. Symptom patterns are characterized by consistency, predictability, saliency, and distinguishability. Event familiarity refers to the degree to which a situation is habitual, repetitive, or contains recognizable cues. Therefore, knowledge and support by credible individuals reduce uncertainty when the healthcare provider assumes power. The individual adopts the healthcare providers’ view and uncertainty is decreased (Mishel, 1999).

Wiener and Dodd (1993) emphasized intertwining work processes with interactional and sociological processes as a way to view how individuals cope with chronic illness. They identified changes in body, temporality, and identity during the vulnerable times of change, and engaged in uncertainty abatement work to lessen the impact of the individual’s uncertainty about time, body, and identity. Their study contributes to the developing theory of uncertainty experienced by individuals during the
chronic illness trajectory. The coping strategies are directed toward assisting individuals to manage the illness in ways that enable them to live with it in more comfortable and positive ways.

Uncertainty emerged as a phenomenon of interest when Morse and associates were linking the concepts of enduring and suffering (Morse & Penrod, 1999). Morse’s research program on suffering began with an examination of the concepts of enduring and suffering (Morse & Carter, 1996). Enduring was described as an emotionless state that focuses on the present. She identified three types of enduring: enduring to survive, enduring to live, and enduring to die. Suffering was defined as a state in which the individual acknowledged the event and moved into an emotional response (Morse & Penrod, 1999). This emotional state was accompanied by an expanded perspective of the incomprehensible past, the altered present, and the anticipated future. “The state of uncertainty grows out of the enduring phase of suffering when a person is ready to recognize what has happened, a goal to emerge from or to change the present is identified, yet no means for achieving the goal can be identified” (Morse & Penrod, p. 148). Various options are available, but the person is unable to choose one. While research has been conducted using the model of suffering (Morse, 2001; Morse, Beres, Spiers, Mayan, & Olson, 2003), little research has focused on uncertainty as conceptualized within this model.

Janice Penrod, through her collaborative work with Morse (Morse & Penrod, 1999) and her own research on uncertainty, conducted an extensive concept analysis of uncertainty using the four principles of concept maturity delineated by Morse, Mitcham,
Hupcey, and Tason (1996), which she refined (Penrod, 2001). Penrod proposed the following interdisciplinary definition of uncertainty:

Uncertainty is a dynamic state in which there is a perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation that may be affected (reduced or escalated) through cognitive, emotive, or behavioral reactions, or by the passage of time and changes in the perception of circumstances. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control that may be highly specific (event-focused) or more global (a world view). (p. 241)

Penrod (2001; 2007) then conducted a phenomenological investigation of the uncertainty among informal caregivers of chronically ill individuals, to further describe this what it is like to live with this phenomenon. As a result of this study, she identified the two major elements of caregiver uncertainty as confidence and control. Control was defined as sensing an ability to influence the outcome of the situation. She defined confidence as sensing an ability to read a situation. Penrod identified four types of uncertainty and two modes of uncertainty. Types of uncertainty reflect the levels of caregiver control and confidence. These included minimal uncertainty (high confidence and high control); pervasive uncertainty (high confidence and low control); role uncertainty (low confidence and high control); and overwhelming uncertainty (low confidence and low control). She described two modes of uncertainty, situational and existential, which refer to the underlying nature of the sense of uncertainty. From this analysis, she was able to identify strategies for managing uncertainty and develop an assessment guideline for practitioners to use when assessing states of uncertainty.
Certainty and uncertainty are interwoven in the experience, co-existing situationally and existentially as one lives the dying process. The rhythmicity is manifested in the dynamic nature of the dominant pattern of certainty or uncertainty, based on the individual’s sense of situational and/or existential control and confidence (Penrod, 2007). When does the sense of certainty become dominant? What triggers the dominance? Wittgenstein (1969) has suggested that certainty arises as a result of learning new information from a trusted expert. At the same time this certainty of death brings uncertainty to the forefront. A terminal prognosis provides a degree of certainty of impending death, but it also opens individuals to uncertainties about living with/and closing their life. Nurses must come to understand the phenomenon of living with the certainty of death that will be experienced by an increasing number of individuals who are living their dying days for longer periods of time and are facing the final transition of living with the certainty of death.

Two scenarios of living with the certainty of impending death based on this researcher’s own practice experience illustrate the interwoven rhythms of certainty and uncertainty that occur during the final weeks and months of life, and the importance of addressing both in the care of dying patients. The first scenario was a situation in which a young man with a terminal illness was living predominantly with a sense of the certainty of death while maintaining a sense of uncertainty expressed by looking toward a future. The second scenario describes a corporate executive who also was terminally ill. She chose to live predominantly with the uncertainty of her dying by looking toward and planning for the future while avoiding any reminders that death was imminent.
In the first scenario, a young man named Thomas was diagnosed with cancer on his 17th birthday. He went through surgery and chemotherapy, but the cancer continued to metastasize. Consistent with the terminal illness trajectory (Lunney, et al., 2002), he functioned reasonably well with his illness for a long time before the disease became overwhelming and nonresponsive to treatment. For two years he was living with the illness while attending a prestigious Ivy league university, maintaining a straight ‘A’ average in his courses, continuing to develop his musical talents, and falling in love. A few weeks before leaving for his junior year of college, Thomas was informed by his oncologist that the cancer was not responding to treatment and that he wanted to try one last experimental medication. Thomas made the decision to postpone attending college during the fall semester and enrolled in the experimental trial. His health began to decline over the next few weeks and he voluntarily discontinued the experimental treatment. He also agreed to the doctor’s suggestion to enroll in hospice care. Thomas developed a close relationship with Steven, his hospice nurse, and they talked frequently about what to expect during Thomas’s last days and hours. Thomas continued to plan for the spring semester of college, obtaining the reading list and required books for his classes; spent time with his girlfriend and his family, laughing and crying and talking for long hours about the many happy experiences they had shared over the years; composed and recorded a new song, and wrote instructions for it to be played as he was dying; and planned every aspect of his own funeral. He died four weeks later surrounded by family with his recorded song playing, as he had requested.

This second scenario describes another individual living the same trajectory, but having a very different experience. A 48-year-old female corporate executive named
Alicia was diagnosed with multiple myeloma, but went into remission following a series of chemotherapy treatments. Two years later the myeloma returned with metastasis to the liver. She was told by her doctor to go home and spend her remaining time with family. She was not given a time frame, but she was given the certainty that this illness would progress to death.

In a conversation with her husband Alicia refused his suggestion to take a leave of absence from work and travel for the next few months. She said this was not the time to take a leave of absence since the large company merger she had been working on was about to go through. She continued her daily routine as she lived with the illness and her decreased physical capabilities. Even though her pain increased over the next three months and her breathing became more difficult, she insisted on driving herself across town to work every day, putting in an eight-hour day, and driving home. After several suggestions by her physician over a four-week period, she reluctantly agreed to enroll in hospice for pain management. The hospice nurse was permitted to come into the home to assist with medication adjustment, but Alicia refused to read or discuss the material left by the nurse. When it was obvious that she was days away from death, Alicia’s husband asked the hospice nurse to talk to her and let her know she could no longer drive to work. Alicia looked surprised when told she could no longer drive and asked how long she had to live, explaining that she had a scheduled board meeting next week. The hospice nurse told her she would need to cancel the board meeting, letting her know, based on her signs and symptoms, she probably had less than a week to live. Alicia acknowledged the fact that she was dying. She thanked the hospice nurse and let her know she was no longer needed. She made arrangements for someone else to chair the board meeting in case she
could not be there. She told her husband he could write her obituary and pick out her coffin and burial site when the time came. She told her husband she only wanted him and their three children with her at the end. Alicia died two days later surrounded by her husband and three daughters.

Individuals live and die in unique ways even within a common trajectory. The experience is contextual and the vulnerabilities at critical junctures are expressed and managed from a perspective that reflects the meaning of the experience for each. The two scenarios involving Thomas and Alicia demonstrate the rhythmicity of living with the certainty of death as uncertainty is interwoven in the experience, co-existing situationally and existentially as the individuals each uniquely lived the dying process. The question is asked once more: When does the sense of certainty of death become dominant? What triggers the dominance? An examination of the experience of living with the knowledge of impending death, as was the purpose of this study, could reveal answers to these questions and provide a description of what it is like to live with the certainty of impending death.

For this reason, individuals who acknowledge an expectation of their death within weeks or months are the most appropriate informants for uncovering the lived experience of the certainty of impending death. While individuals experience their dying in a variety of healthcare settings, the most appropriate care delivery model for accessing this specific group of informants is hospice services. According to the Hospice Foundation of America (2010), hospice is best defined as care that is designed to improve the quality of a patient’s last weeks, days, and hours of life. The goal is to enable patients to be comfortable and free of pain, so they may live each day as fully as possible. Patients are
referred to hospice care when life expectancy is approximately six months or less, but physicians may certify continued care beyond the six months if needed. Individuals receiving hospice care have made an informed decision about accepting these services, and their doctor must certify they are expected to live six months or less.

**Hospice Services**

The holistic care model of hospice represents a valuable resource for providing complete and comprehensive end-of-life care. The eligibility criterion for hospice service is that the disease process has progressed to the extent that further treatment cannot cure the illness (Hospice Foundation of America, 2010). Thus, the hospice team focuses on controlling the patient’s symptoms, providing emotional, social, and spiritual support, and offering a variety of bereavement and counseling services.

The hospice concept originated in the nineteenth century in England and gained momentum in the United States during the 1970’s in response to the work by Kubler-Ross (1969) on death and dying. In 1982 Congress enacted legislation to provide coverage for hospice services under Medicare through a provision in the Tax Equity and Fiscal Responsibility Act of 1982. The Medicare benefit became permanent in 1986, and states were provided the option of including it in their Medicaid packages. As a result, individuals with terminal illnesses now have the option of staying at home during the end-of-life experience, with support services available to assist them and the family members.

Palliative care has been suggested as an alternative to hospice care and often thought to be synonymous with hospice, but according to the National Hospice and Palliative Care Organization (NHPCO, 2009), the goals of palliative care are to improve
the quality of a seriously ill person’s life and to support that person and their family during and after treatment. The basic tenets of palliative care are symptom control, psychological and spiritual well-being, and care for the family. While hospice focuses on relieving symptoms and supporting patients with a life expectancy of months, palliative care may be provided at any time during the course of an illness. Hospice then is the most appropriate delivery care context for accessing informants who are experiencing the phenomenon of living with the certainty of impending death.

**Purpose, Significance, and Method of the Study**

Information acquired directly from patient experiences is needed to reveal the phenomenological perspective of living with the certainty of death. Therefore, the purpose of this study was to explore the lived experience and associated meanings of living with the certainty of death among individuals enrolled in hospice care. It was believed that a deeper awareness of the experience of living with the certainty of death could contribute to nursing science by developing a description of this experience that would be useful for advancing care strategies for the dying. It could also contribute to the body of nursing science by developing theories of caring for the dying and a descriptive theory of living with the certainty of death.

This investigation was designed to address this question: “What is the experience of living with the certainty of death among individuals enrolled in hospice services?” Accordingly, van Manen’s (1990) hermeneutic phenomenological approach was considered the most appropriate way to address this question because he identified the first activity in this research methodology as turning to a phenomenon that seriously interests us and commits us to the world. Moreover, turning to this phenomenon was an
exploration of the researcher’s own quest to understand the dying process, particularly the final phases of dying when no cure is available and only comfort care is offered. Her interest in the phenomenon of living with the certainty of impending death has evolved over years from experiences of professional nursing practice. As a practicing nurse she experienced many incidences of dying and death, all uniquely different but with some commonalities among them. As a clinician, these commonalities were often manifestations of physical changes that alerted her and other healthcare personnel to the impending death and prompted them to notify family members. This is the final stage of dying when the outcome is indisputable. When initiating this study, the researcher believed the lived experience of individuals experiencing hospice care would provide insights and a descriptive theory of ways of living with the certainty of impending death. She believed that individuals experiencing this phenomenon are the most appropriate informants regarding this phenomenon. At the same time this study would not be limited to descriptions of end-of-life experiences, but would include interpreted meanings from the body of evidence in science, literature, art, and philosophy.
CHAPTER 2

Literature Review

There is one common certainty among all people. This is the certainty that everyone will die. While nobody would dispute this fact, living with the certainty of death rises to the level of consciousness only with an awareness of one’s own dying. This is the point at which the individual’s life takes a new direction with hopes, dreams, and future goals taking on new meaning. For the individual experiencing a terminal illness, this is the critical transition within an illness trajectory. During the everyday life and routines of this individual, communication, behavior, and emotions are expressed with a single enveloping certainty: death is imminent.

In this literature review this certainty will initially be examined through Martin Heidegger’s (1927/1996) philosophical framework of being-in-the-world and being-toward-death. Heidegger’s philosophical examination of being-toward-death will provide a general framework for introducing specific works of literature and art that address the experience of dying. Theories and related research addressing the concepts of the awareness of death, the process of dying, illness trajectories, transitions, and quality of the end of life will then be critically examined. Finally, in preparation for this hermeneutic study, a philosophical description of hermeneutic phenomenology will be provided from the perspectives of Martin Heidegger and Maurice Merleau-Ponty.

Introduction to Heidegger’s Being-in-the-World

In order to discuss Heidegger’s being-toward-death, it is important to understand his concept of being-in-the-world. Stambaugh’s 1996 translation of Heideggers’s Being and Time, originally published in 1927, was used in this review.
In *Being and Time* (1927/1996), Heidegger studied the phenomenon of Being, which he referred to as Dasein, German for “being-there” (p. 7). It is the entity which each of us is, our humanness, and the distinguishing characteristic of Dasein is the fact that in its being this entity is concerned about its very being. Dasein always understands itself in terms of its own existence, in terms of its possibility to be itself or not to be itself. In other words, the Dasein’s humanness is reflected in the capability of thinking about one’s own existence and non-existence. Human beings have the unique capability of asking such questions as ‘What would the world be like if I had never been born?’ and ‘What will the world be like after I die?’

Being-in-the-world is a unified concept meaning that Dasein cannot be viewed separately and independently of the world. Heidegger reserves the term ‘world’ to refer to a kind of being belonging to Dasein. This world is the world in which a “factual Dasein” lives, the contextual world (Heidegger, 1927/1996, p. 56). With its facticity, Dasein’s being-in-the-world is dispersed in multiple ways of being-in, all of which have the kind of being of ‘taking care of’ (Heidegger, p. 57). The being of Dasein [being] itself is made visible as care, and the term ‘taking care’ designates the being of a possible being-in-the-world. When an individual describes an experience, the contextual description reveals the individual’s unique care structure, reflecting their own unique perceptions, interests, involvements, and relationships with others.

Relationships are understood as fundamental and integral aspects of being human. We exist already as beings-in-a-world we share with one another, not as isolated individuals who develop relationships or deal with the world. Dasein understands itself initially and for the most part, in terms of its world and meets others in their being-in-the-
world. Being-with existentially determines Dasein even when another is not physically present.

Involvement with others within the world is integral to who one is. The things one does, the work one performs, and the interests shared with family and friends are the very ways through which one expresses humanness. An individual describes the world of work, that person’s world of concerns (or care structure). One’s behaviors and actions are always behaviors and actions for others and with others; therefore, the being-with-others must always be investigated from the description of the world of concern to the individual. When inquiring about what one thinks or feels, it is best described by that person as an experience, one’s contextual world of work or concerns.

In summary, Heidegger reveals the essential characteristics that define one’s humanness. Humans are the only living creatures that have the capability of contemplating the possibility of non-existence, or death, as well as contemplating and choosing possibilities during every moment of existence. These choices are never made in isolation, but rather from the contextual world, which includes relationships with others. People meet others and learn about them in their contextual world, their world of work, their world of concern toward others. This understanding of Dasein with its focus on being-with-others and being-toward-others forms the framework for a discussion of being-toward-death.

**Heidegger: Being-Toward-Death**

Heidegger (1927/1996) discussed the certainty of death existentially as the truth of existence that Dasein dies. Heidegger examined Dasein’s ways of inauthentically and authentically being-toward-death. He described inauthentic being-toward-death as the
experience of everydayness in which death is viewed as an actuality that happens sometime in the future, while the awareness of the possibility of one’s own death at any moment is concealed. Authentically being-toward-death is living with the revealed possibility of one’s own death and the accompanying awareness of its non-relational and unsurpassed nature. The full existential-ontological conception of death is explained, according to Heidegger (1927/1996): “As the end of Dasein, death is the ownmost nonrelational, certain, and. as such, indefinite and not to be a bypassed possibility of Dasein” (p. 259). For the most part, everyday Dasein covers up the ownmost possibility of its being, that possibility which is non-relational and not to be surpassed. This is a factical tendency to cover up; therefore, Dasein as factical is in the ‘untruth’ and is inauthentically being-toward-death (Heidegger, 1927/1996).

Inauthentic being-toward-death dominates an individual’s life as one lives in the average everydayness. Heidegger (1927/1996, p. 127) describes the average everydayness of the self as the ‘they-self’. The ‘they’ is constituted by the way things have been publicly interpreted, the norms, customs, and rules that determine how individuals interact within a social context. While retaining one’s own facticity, or unique contextual ways of being-in-the-world with others, the individual has difficulty distinguishing their own interests and concerns from those of the ‘they’, the social context, which has no specific identity. The individual experiences a sense of tranquility in the world of the ‘they-self’ because the public ‘they’ takes away the burden of making choices. Consequently, the individual lives with indifferent tranquility as to the fact that one dies (Heidegger, 1927/1996).
In average everydayness, the fact of death is evasively concealed and death is described as a “case of the death” of others (Heidegger, 1927/1996, p. 253). This kind of being is called ‘falling’ and is characterized by temptation to cover up being-toward-death from one’s ownmost self. As falling, everyday being-toward-death is “constantly fleeing in the face of death. It gives new explanations for it, understands it inauthentically, and conceals it” (Heidegger, p. 254). In an attempt to console a dying person (and in turn be consoled), others will “talk the dying person into the belief that he will escape death and soon return to the tranquilized everydayness of the world of his concerns” (Heidegger, p. 254). It insists on bringing him back into Dasein, while in addition it helps him to keep his own non-relational possibility of being completely concealed. Individuals concede the certainty that someday they will die, but not right away. In this state of mind everydayness acknowledges a higher certainty of death and yet is not authentically certain of its own death. The everydayness of Dasein is acquainted with death’s certainty, the certainty that death occurs; and yet evades being-certain, the awareness of one’s own finite lifespan and the definiteness of one’s own death, the when. While an individual talks about the definiteness of death as a fact of life, it is deferred to a later time in a distant future, thereby covering up the possibility that it could occur at any moment. The everydayness of Dasein covers up what is characteristic of death’s certainty, that it is possible at any moment; it covers up the indefiniteness of when death will occur. Everyday being-toward-death evades this indefiniteness by conferring definiteness upon it, meaning it is no longer viewed as real possibility, but rather an event in the future. Everyday evasion of death is an inauthentic being-towards-death (Heidegger, 1927/1996).
In the first scenario described in Chapter 1, Alicia chose to live with the knowledge of her impending death by going to work everyday and avoiding any discussion of her death. Individuals face some of these same decisions daily without a diagnosis of terminal illness. Conformity to group behavior and going about the daily routine making choices about one’s own life in relation to others without a thought about the consequences of these choices are all examples of living in the everydayness, attempting to reduce or minimize the anxiety of facing the possibility of one’s own uniqueness in relation to others.

Being-towards-death is essentially anxious. Anxiety is the attunement (or mood) of anticipation. Anticipation brings one “face-to-face with the possibility of being in an impassioned freedom towards death—a freedom that has been released from the illusions of the ‘they’ and which is “factual, certain of itself, and anxious” (Heidegger, 1927/1996, p. 266). However, in adopting the average sameness with others, “Dasein fails to hear its own self because it loses itself in the publicness of the ‘they’” (Heidegger, p. 322). The everyday state of mind is anxiously concerned about death while, at the same time, seemingly free from anxiety. The public ‘they’ does not permit one the courage for anxiety in the face of death. The ‘they’ concerns itself with transforming the anxiety into fearing in the face of the upcoming event. As fear, it can then be passed off as a weakness. Anticipation reveals one’s being lost in the ‘they’ showing that the ‘they’ cannot help one with death (Heidegger, 1927/1996).

Authentically being-toward-death reveals itself as anxiously confronting the possibility of no longer being, of dying alone even when among others, and as unavoidable (Heidegger, 1927/1996). When death is understood authentically, it is
understood as the possibility of not having any more possibilities. An individual is authentically being-toward death when death is revealed as a real possibility.

Authenticity is a call to conscience. Heidegger (1927/1996) explains that conscience gives one “something to understand; it discloses” (p. 269). Conscience is revealed as a call or appeal to Dasein to disclose itself as its potentiality-for-being in terms of the ‘world’ of its concerns. A person is already a potentiality-for-being-itself; but this needs to be attested to or confirmed (Heidegger).

An individual resolves to attest to a potentiality-for-being-one’s-self and this decision is made from a call to conscience, a call which reaches the “they self of concernful Being-with-others” (Heidegger, 1927/1996, p. 272). “If the Dasein is able to get back from this lostness of failing to hear itself and if this is done through itself, then it first must be able to find itself...as something which has failed to hear itself and which fails in that it ‘listens away’ to the ‘they’” (Heidegger, p. 315). The ‘listening away’ is broken off; and there is no hubbub, ambiguity, and idle talk characteristic of ‘they-self’. When an individual chooses to hear his own inner voice, this brings him back to his authentic self. This is the choice of resoluteness (Heidegger).

Resoluteness is a decision to be authentic, a resolve in which one is ready for anxiety (Heidegger, 1927/1996, p. 296). Resoluteness brings Dasein into being-with-others alongside things as one’s own most self, not as the ‘they.’ In other words, a choice for resoluteness occurs in relationship with others, not in isolation and apart from the ‘they.’ When resolute, an individual resolves to be an authentic self and not the public ‘they-self.’ An authentic self chooses its own possibilities, meanings, and ways of being-in-the-world. Resoluteness is always a resoluteness of some factual Dasein at a particular
time. In other words, the situation is given; it is not created by the individual. In a given situation, resoluteness confirms the potentiality-for-being and, therefore, non-being; resoluteness confirms the certainty of one’s own death (Heidegger).

In the example of Thomas presented in Chapter 1, if someone had asked him to describe what it is like to be living with the certainty of death, he might have been able to describe it more clearly from his world of concerns, the experience of making the decision to sit out of school for a semester, while, at the same time, feeling hopeful that he might be able to return the following semester. He might also have described the creativity he was experiencing as he wrote a song that would be the last sound he would hear as he was dying. This young man chose a unique way of being with others in the face of impending death. He decided not to return to college and used his remaining days to creatively prepare for his own dying and share this experience with his family.

Alicia might have described a very different experience in response to the same question about the certainty of her impending death. She might have described the experience of driving across town to work, completing specific tasks during the day, and stopping to fill the car with gas on the way home. But with further questioning and examining the meaning these daily activities have for her, she might have given the following explanation:

I like to drive myself to work because it is the one time in my day when I can quietly listen to music and pray. I pray for healing and I pray that my family will be ok if I die. I go to work every day and I work hard when I am there, in spite of the pain and fatigue. I don’t want anyone to think I cannot do the job because I have two more weeks until I am vested and my husband will receive my
retirement if something happens to me. He will need that money for the children’s college education funds. I stop for gas every day on the way home from work, because I will be giving my daughter the car when I can no longer drive and I want to make sure she starts out with a full tank of gas.

Alicia might never have mentioned the word death, but the certainty of dying emerged from and was expressed in her everyday contextual experiences, especially her unwavering commitment to her job and company, and her concerns about her husband and children’s futures without her.

Heidegger’s (1927/1996) examination of being-toward-death is not limited to an explanation of an individual’s linear progression from birth to the end of life. Rather, it is a description of an individual’s way of being in the world moment by moment. Individuals are not isolated beings who interact with or react to just an external world around them. Individuals-in-their-world reflects a unitary concept, whereby the individual co-constitutes a given situation with others and gives meaning to that situation based on his or her own past and perceived future possibilities.

Similarly, authentic being-toward-death, as conceptualized by Heidegger, is revealed in the expressed meaning one gives to a situation or the decisions one makes in situations that reflect a unique relationship with others in the world. It is the risk to be different, to face the anxiety of decision-making and/or death rather than avoid the discomfort that may accompany this experience.

In reviewing the authentic and inauthentic relatedness with others, it is important to realize that both ways of being in the world are essential and that the meaning of one’s way of being-toward-death is manifested in the inauthentic everydayness as well as the
authentic relatedness and resoluteness. It appears from Heidegger’s description of authentic relatedness that one is moving away from relatedness with others and toward a unique individualism that is one’s own, separate and apart from the everydayness where self is defined by society’s norms and expectations. Yet, one cannot define self in relation to others apart from the experience of everydayness. In the everydayness, Dasein "fails to hear itself" because of the deafening "noise" of the "they"; it is the call of conscience which breaks through this noise and summons Dasein to its own self, "to its most unique possibilities" (Heidegger, 1927/1996, p. 273).

As Heidegger states, “Authentic existence is not something which floats above falling everydayness; existentially, it is only a modified way in which such everydayness is seized upon” (p. 179). When Dasein is authentic the world does not change. And the “circle of the others is not exchanged for a new one. What is different is that they are now defined in terms of their ownmost potentiality-of-being-their-selves” (Heidegger, p. 298). Therefore, it is not essential that an individual’s way of being-toward-death can only be realized by talking with someone who is experiencing the resoluteness and its accompanying anxiety. One’s way of being-toward-death is also manifested in the concerns at hand. In the examples of Thomas and Alicia, an observer might be inclined to conclude that Thomas was living with the certainty of death, while Alicia was not. In fact, both individuals were living with the certainty of death. It was manifested not only in Thomas’ authentic relatedness, but also in the everyday concerns expressed by Alicia. Returning to Wittgenstein’s (1969) analogy of the riverbed, when the knowledge of one’s own impending death becomes a certainty, what was once part of the riverbed is stirred up and becomes part of the flowing river. Within this context of certainty, vulnerabilities
at this critical juncture expose the individual to uncertainties. This rhythmicity of certainty and uncertainty is manifested and can only be revealed through each individual’s description of relationships with others in their everyday experiences.

**Literature and Art: Living With the Certainty of Impending Death**

As previously mentioned, a common characteristic shared by all persons at all times is in living each moment with the certainty of impending death, while simultaneously living with the uncertainty of when and how death will occur. Uniqueness is expressed as the way in which each person chooses to live with this certainty of impending death with the intertwining uncertainty of just when and how it will occur. Most individuals live with a sense of unawareness that the next moment may bring an end to their existence. They live life as if their existence is permanent, that it is an absolute truth that they will be here when the sun rises tomorrow, next week, next month, and next year. It is reflected in relationships that leave words and feelings unexpressed; in work that is a continuous focus and always incomplete; and in immediate, noisy, thoughtless pleasures that are valued more than quiet contemplative meditation. The following examples of art (Poshyananda, 2003) and literature (Albom, 1997; de Beauvoir, 1965; Edson, 1999; Rinpoche, 1992; Tolstoy, 1828) illustrate this rhythmicity of certainty and uncertainty.

This rhythmicity of certainty and uncertainty is revealed in the art of Montien Boonma (Poshyananda, 2003). Boonma, an artist from Thailand, was influenced by the Buddhist teachings about living and dying during the time his 33-year-old wife was ill with breast cancer. As she lay dying in her hospital room, he plastered the walls with question marks and exclamation marks, his representation of the uncertainty and certainty
of death. His later work depicts this theme in his use of question marks, i.e., representing the unknown, and exclamation points, i.e., representing a sense of hope and discovery.

Living with the certainty of impending death in an authentic way, as described by Heidegger, would be consistent with living with an awareness of the impermanence of one’s existence. “The Tibetan Buddhists have a saying: I wake up in the morning and think about death. In the afternoon I think about death. In the evening I think about death” (Rinpoche, 1992). In thinking about death, one is enlightened and appreciates each moment of life, leaving no words unexpressed, no time wasted in tasks that have no value in unnecessary work or pleasures. This is also the resoluteness described by Heidegger. This resoluteness about living with the awareness of death has been illustrated in the reflections of Professor Morrie Schwartz in the book *Tuesdays With Morrie* (Albom, 1997) when he was living with ALS. As the author of this book, Mitch Albom explained that even though Morrie was becoming weaker, he refused to be depressed. Instead, he became a lightning rod of ideas and “bite sized philosophies of living with death’s shadow” (p. 18). Over a period of months, the meetings between Albom and Schwartz produced numerous audio-taped discussions of various topics about the world they live in, the relationships they value, and the meaning of living and dying. These audiotapes became the basis for the book, *Tuesdays With Morrie*.

In another reflection on death, Margaret Edson’s screen play titled *Wit* (1999) followed the fictional character Vivian Bearing through her experience of living and dying with ovarian cancer. The inauthentic everydayness of her living with death was transformed into an authentic awareness through her relationship with her primary nurse who spoke honestly with her about her dying while the other health care professionals
focused only on her physiological changes and the successes and failures of experimental treatments. Throughout the play, Vivian talks about her everyday world of work as a college professor who was rigid and uncompromising when teaching her students the poetry of John Donne. She reflected on a conversation she had years earlier with her respected English professor and mentor, Dr. Ashford, who suggested replacing the semi-colon in the last line of John Donne’s poem “Death Be Not Proud” with a comma to suggest a different meaning of the transition to death. Dr. Ashford was emphatic that the punctuation be: “And death shall be no more, comma, Death thou shalt die” (Edson, 1999, p. 14). As Dr. Ashford explained, “Nothing but a breath—a comma—separates life from life everlasting” (p. 14). For Vivian, this memory of a conversation long ago brings awareness and understanding of death as a pause and comfort in the midst of her pain and suffering. Dr. Ashford’s comment suggests, as Donne had, that death is a natural transition.

Rinpoche, in The Tibetan Book of Living and Dying (1992), speculates on the reasons individuals fear and avoid thinking about their own death, stating, “Perhaps the deepest reason is because we do not know who we are. Our identity depends on a collection of things to prop it up: our name, our biography, our partners, family, home, job, friends, credit cards ….Without our props we are faced with just ourselves, a person we do not know” (Rinpoche, 1992, p. 16). He claims that Western society participates in a form of active laziness expressed by cramming their lives with compulsive activity so there is no time to confront the real issues. Heidegger would call this the inauthentic being-toward-death or the everydayness of one’s existence.
In ordinary everydayness, the fact of death is evasively concealed and it is described as a ‘case of death’ of others (Heidegger, 1927/1996). This characteristic of everydayness is vividly described by Tolstoy (1828) in *The Death Of Ivan Ilych*: “Ivan Ilych’s death aroused in all who heard of it the complacent feeling that ‘It is he who is dead and not I’” (p. 2). Usually the general attitude is that death is something that happens to others and, therefore, an event that people need not address or reflect on because it is in the remote future.

Ivan Ilych was initially unable to accept his own dying, and the secrecy and avoidance among doctors and family members only confirmed the illusion that his illness was temporary and death was not an outcome. As he became increasingly aware of the reality of his own dying he realized that “None of them know it or wish to know it, and they have no pity for me… It’s all the same to them, but they will die too! Fools! I first and they later, but it will be the same for them” (Tolstoy, 1828, p. 43).

Toward the end of his life, Ivan Ilyich’s revelation was that he had lived for himself, and now felt compassion for others who he hoped would be set free by his death. He also hoped that he would be set free in death. So while his dying was an experience of suffering, his death was a freeing experience.

Another experience of living in the everydayness of dying was expressed by Simone de Beauvoir (1965) in *A Very Easy Death*, an account of her mother’s dying. Her mother feared dying of cancer her entire life, so after she was actually diagnosed with cancer following abdominal surgery at age 78, her family and healthcare providers told her it was a case of peritonitis. Her daughter felt increasingly guilty about withholding the truth, but at the same time realized that her mother did not want “these intimate
conversations” (de Beauvoir, p. 90). A nun once said to de Beauvoir, “I cannot understand. Your mother is so religious and so pious, and yet she is so afraid of death” (p. 91). Mlle. de Beauvoir felt that her mother thought as she did: “If you love life, immortality is no consolation for death” (p. 92). When her mother died, it was not like the physician had described it would be, “she should go out like a candle” (p. 88). Instead she felt the anguish of being unable to breathe, the fear of not wanting to die, and the consciousness to know that the end was near before slipping into a coma. While the family saw her dying as an anguishing experience for her, the nurse who never came to know this patient described her passing as “a very easy death” (de Beauvoir, p. 88).

The themes expressed in these works of literature and art, of rhythmic certainty and uncertainty, impermanence and resoluteness, emerging authentic relatedness in the everyday context of the world of work, and the transitional experience of living one’s own dying are examined again through the descriptions of the participants in this study of their lived experience of living with the certainty of death.

**Living With the Certainty of Death: Theories and Research**

For the purpose of this study, the end of life is defined as both the process of living with the functional decline associated with the anticipated certainty of death within weeks or months and the process of dying from the illness experienced as the rapid, irreversible decline in function with an anticipated certainty of death within hours or days. The individual may experience various responses to the certainty of impending death.

Theories and research have focused on examining the behavior of both patients and healthcare providers when individuals are at the end of life. However, the question
remains: Do the known theories and research regarding end of life capture the essence of living with the certainty of death? This review will focus on relevant theories and related research and examine the state of the science of living with the certainty of death.

A search of the literature included the electronic databases Proquest, Cumulative Index for Nursing and Allied Health Literature (CINAHL), and PubMed. Key words used to search the literature included death and dying theories, end of life, awareness of dying, quality end of life, end-of-life transitions, illness trajectories, uncertainty and dying, and certainty and dying. This search and review was limited to articles published between 2000 and 2012 with a few notable exceptions published prior to 2000 and included for their relevance in establishing a knowledge base. In addition, reference lists of reviewed articles were reviewed for relevant and current research. Finally, a manual search of the table of contents from a limited number of peer-reviewed nursing research journals published within the last five years was conducted for applicable research articles. A representative sample of studies is reported in this literature review and grouped according to the following categories of theorized and researched information: awareness of dying; process of dying; dying trajectories; end-of-life transitions within trajectories; and quality end of life.

**Awareness of Dying: Ambiguity and Empowerment**

Using Wittgenstein’s (1969) metaphor, becoming aware of one’s own dying stirs up the riverbed, which is reflected in the rhythmic pattern of the certainty that death is imminent and the uncertainty about how or when death will occur. Research reveals that uncertainty is expressed in the ambiguity or doubt about the reality of one’s own dying.
Certainty is expressed in a sense of empowerment as individuals become actively involved in their own care decisions.

Individuals may become aware of their dying as a result of a discussion with their healthcare provider, enrollment in hospice, the experience of physical changes, and/or changes in relationships with others. Research regarding the awareness of dying has focused primarily on the communication between dying individuals and their family and healthcare providers (Dobratz, 2002; 2011; Fine, Reid, Shengelia, & Adelman, 2010; Francke & Willems, 2005; Glaser & Strauss, 1965; Moss, et al.; 2010; The, Hak, Koeter, & van der Wal, 2000). Studies have revealed that while awareness about the diagnosis and the incurability of the disease is generally communicated to patients, a pattern of collusion between patients and healthcare providers may follow that avoids discussion of the prognosis with the dying person (Glaser & Strauss, 1965; Moss, et al., 2010; The, et al., 2000). This avoidance contributes to the patient’s increased ambiguity and a false optimism about their future. On the other hand, their ongoing communication with others after initially becoming aware that they are dying may contribute to their empowerment, as they tend to become more actively involved in care decisions (Dobratz, 2002; 2011; Francke & Willems, 2005).

In 1965 Glaser and Strauss studied the experience of the awareness of dying as part of a six-year funded research study titled “Hospital Personnel, Nursing Care and Dying Patients” (Glaser & Strauss, 1968). They conducted extensive field observations and interviewed patients, families, and personnel at six hospitals in a major metropolitan area. They focused initially on the “awareness context”, which they defined as “what each interacting person knows of the patient’s defined status along with his recognition of
the others’ awareness of his own condition” (Glaser & Strauss, 1965, p. 10). They described various types of context awareness, which have a profound impact on the interplay between patients and personnel. The various types of context awareness reflect the way individuals talk and act in accordance with who knows what and with what certainty. These types include closed awareness, suspected awareness, mutual pretense awareness, and open awareness. In closed awareness, the patient does not recognize impending death even though the hospital personnel have this information. In suspected awareness the patient does not know but suspects with varying degrees of certainty that the hospital personnel believe him or her to be dying. The interaction between patient and personnel becomes a “fencing match wherein the patient is on the offensive and staff are carefully and cannily on the defense” (Glaser & Strauss, 1965, p. 47). In mutual pretense, patients and staff both know the patient is dying but pretend otherwise with both agreeing to act as if the patient were going to live. Finally, open awareness occurs when both staff and patient know that death is impending and acknowledge it in their actions. Glaser and Strauss emphasized the ambiguity that accompanies open awareness. For example, the unknown of when death will occur accompanies the knowledge of dying. Patients may think their death is months away, while staff may conceal their own knowledge of the expected time of death and the deterioration that is expected prior to it. Patients and staff may also have different ideas about how a patient should die, focusing around issues of placement, dignity, and privacy.

Glaser and Strauss’ findings and conclusions are considered a milestone in death and dying research and theory development. They provided a structure for dealing with an event (death) that was common in health care, but was previously taken for granted
and seldom discussed. Their work provided healthcare personnel with a framework for understanding the perspectives and needs of dying patients so that they could better assist them and their families through the dying process. Their research program also provided a framework for grounded theory research, a qualitative research method focusing on such processes. This method continues to be used extensively in social science and healthcare research and theory development when investigating individuals and groups’ concerns and the basic social processes that help them resolve these concerns.

The, Hak, Koeter, & van der Wal (2000) ethnographic study of patients’ optimism in the face of a cancer diagnosis with no possible cure revealed the ambiguity of open awareness resulting from collusion between the patients and physicians to avoid discussions of the prognosis. The investigators initiated this study after finding that virtually all of the patients being treated with chemotherapy for small cell lung cancer in their local university hospital interpreted their prognosis more optimistically than their physicians did. In a two-stage study with a sample of 17 and 18 patients, respectively, The, et al. (2000) observed the patients in the hospital and clinic from diagnosis to death, and interviewed the patients and their physicians and nurses. They examined aspects of communication between the physicians, nurses, and patients that contributed to the patients’ lack of knowledge about their prognosis.

The, Hak, Koeter, & van der Wal (2000) identified a common illness trajectory consisting of five stages in 29 of the 35 patients. These stages included:

- Existential crisis at diagnosis;
- Focus of therapy during the first chemotherapy treatment;
- Relative peace of mind when the cancer was not visible on x-ray;
• A return of the existential crisis when a reoccurrence occurred; and
• A final crisis when no further treatment was feasible. (p. 1378)

Optimism was usually observed in the first and third stages.

The, Hak, Koeter, & van der Wal (2000) found that physicians emphasized
treatment and did not provide a prognosis until the patient was no longer treatable. In
addition, the patients often did not ask for a prognosis, and in each of the first four stages
asked questions about treatment options. Some interpreted the clean x-ray in the third
stage as a cure without further questioning the physician about its meaning. The authors
also reported that three patients who did not experience this optimism were able to use
the time provided to achieve their personal goals.

Their study supports the work of Glaser and Strauss in describing how
communication between patients and healthcare providers can contribute to a
predominant pattern of ambiguity about one’s own dying. However, this study needs to
be replicated in other settings with different populations of cancer patients with a focus
on describing the characteristics of the five-stage illness trajectory and the
communication patterns among patients, families, and healthcare providers.

A patient’s experience of ambiguity occurs in a relationship with one’s healthcare
providers. Their willingness to accept the reality that their patient is dying will influence
their recommendation of treatment options and the patient’s perceptions and acceptance
of these options. Moss, et al. (2010) investigated the use of the “surprise question” with
four oncologists at a university hospital cancer center, which asks, “Would I be surprised
if this patient died in the next year?” While this question had been beneficial as a
component of an integrated prognostic model in identifying patients with a poor
prognosis, it had not been studied to determine its feasibility and outcomes with cancer patients. The four oncologists prospectively classified patients with breast, lung, or colon cancer who came into the cancer center for follow-up visits over a four-month period as ‘yes’ or ‘no’ in response to the surprise question. Of the 826 patients assessed, 131 (16%) were classified as the ‘no’ group and 695 (84%) as the ‘yes’ group. They described the ‘no’ group as “older, more likely to have a diagnosis of lung cancer, and more likely to have Stage IV disease” (Moss, et al., p. 838). At the end of 12 months, 41% of the ‘no’ patients had died compared to 3% of the ‘yes’ group.

While other studies have focused on the ambiguity experienced by patients, the Moss, et al. (2010) emphasized the ambiguity experienced by physicians. Their study found that collusion occurs when both patient and healthcare provider live with the predominant sense of uncertainty regarding their awareness of the patient’s dying. While these results appear impressive, they must be considered tentative since they were the results of data collected by just four oncologists who were familiar with the patients selected for this convenience sample in one local clinic. The surprise question also cannot be considered apart from an integrated prognostic model which considers additional factors in determining prognosis.

A systematic review of the research literature revealed patterns of communication that interfere with the ability to guide the patient through an honest and open discussion of end-of-life options (Fine, et al., 2010). These investigators examined 20 research articles focusing on patient-physician discussions in palliative and end-of-life care, which included “descriptive, quantitative, both descriptive and quantitative, and interventional investigations” (Fine, et al., p. 596). Four common themes emerged from this review:
(a) physicians focus on medical and technical issues and avoid emotional issues (n=9); 
(b) sensitive topics were perceived by physicians to take longer to discuss (n=4); 
(c) physicians dominate conversations (n=9); and (d) patient and family satisfaction is associated with supportive physician behaviors and greater family and patient participation (n=5). The review concluded with areas for improvement in both the content and process of physician communication, offering suggestions for improving communication. This systematic research review adhered to the steps of the research process when conducting the investigation, including explicit inclusion and exclusion criteria for the sample, consistent and appropriate data extraction criteria and procedures, and an extensive qualitative analysis. The sample size was small which may have limited the findings. A more exhaustive search of the research literature may help verify current findings or contribute to different thematic conclusions.

While ambiguity about the exact timing of death and the possibility for a cure is always present, research reveals that ongoing communication between healthcare providers and patients may contribute to a sense of empowerment and greater patient involvement in end-of-life decision-making. Dobratz (2002) reported findings from a grounded theory study that was part of a larger mixed-methods study (Dobratz, 1993) in which she examined psychological adaptation with 97 participants enrolled in hospice. She described the pattern of becoming-self revealed by 15 of the participants. Becoming-self was one of seven patterns representing “high and low levels of death awareness that moved over time in a dialectical of opposing positive and negative forces” (Dobratz, 2002, p. 138). These were patterns of the transcending-self, the becoming-self, and the reconciling-self, along with the patterns of the agonizing-self, the relinquishing-self, the
avoiding-self, and the repressing-self.

Becoming-self was a pattern of dying that Dobratz (2002) called “fully human” (p. 138). This pattern grew and became more vivid as the patient’s physical function declined. Dobratz suggested that for those exhibiting this pattern of being fully human, “death was their conscious awareness, fears were overcome, and cognition was directed toward living to the fullest within their compromised situation” (p. 138). The ‘becoming-self’ individuals focused their consciousness on life’s meanings rather than on life’s details. Components of becoming-self included (a) interpreting meaning, creating meaning over time in which they felt more fortunate than others and found meaning in little things; (b) connecting with others, including family, friends, and hospice staff; (c) weighing expectations, envisioning self in a better place, unafraid of fate, and surrendering control of fate to a higher source; (d) sustaining acts; (e) adjusting expectations, learning to adapt by accentuating and cherishing few remaining functions; and (f) bodily feeling, acknowledging physical changes, but not dwelling on suffering.

Dobratz (2002) emphasized that the becoming-self occurs in patients who have good pain management, thereby emphasizing the importance of a more holistic integrative approach to care of the individual at the end of life. The results reported in this article represented only one aspect of a larger mixed-methods study, which included a quantitative causal model design, measuring quantitatively the social-psychological processes of dying at home. She subsequently reported additional findings from her grounded theory study, including an examination of the concept of the self-transacting self (Dobratz, 2002) and a secondary analysis of the concept of life-closing spirituality (Dobratz, 2004). Finally, she reported her findings from comparing two groups within the
original sample of 97 home hospice patients regarding their expressed spirituality and nonexpressed spirituality (Dobratz, 2006).

In 2011, Dobratz published a middle-range theory of psychosocial adaptation in death and dying based on a synthesis of empirical findings from her earlier studies. She conceptually defined psychosocial adaptation in death and dying as “using spiritual and social resources and managing physical symptoms to maintain self-integration” (Dobratz, p. 373). Dobratz identified these three theoretical assumptions: “Psychosocial adaptation in death and dying is influenced by pain and physical functioning”; “…is promoted by connecting to supportive others”; and “…is influenced by spirituality” (p. 373).

Dobratz’s (2011) middle-range theory demonstrates a conceptual-theoretical link to Roy’s adaptation theory (RAM). She refers to the coping processes of RAM, including the regulator subsystem which responds through neural, chemical, and endocrine coping channels; and the cognator subsystem which processes through perceptual and information processing, learning, judgment, and emotion. She further explains that dying individuals strive to adapt to the influences that the two subsytems are constantly processing. Consistent with RAM, observable human responses are reflected in four adaptive modes including: (a) physiologic-physical, (b) self-concept, (c) role function, and (d) interdependence. According to Dobratz, the concepts of pain, physical function, social support, and spirituality revealed in her research studies are linked to these four adaptive modes.

Dobratz’s middle-range theory advances nursing knowledge through a synthesis of findings over several years of investigating adaptation in death and dying. Her
conceptual-theoretical structure is also linked to Roy’s adaptation model, thereby contributing to the scientific foundation for studies of dying and the discipline of nursing.

Using a grounded theory approach, Francke and Willems (2005) investigated terminal patients’ awareness of their impending death and the consequences this has for expressing care needs. The authors interviewed 19 Dutch terminal patients with a life expectancy of less than six months and 23 relatives who provided direct care to family members with terminal illnesses who had died within the last year. The results revealed great differences in the degree to which individuals understood they had a short time to live. Patient awareness was often related to a physician’s open communication and the amount of explicit information provided about the prognosis. Those who were aware they would die soon (a) thought more about the palliative care or complementary therapy to choose, (b) were more prone to approach their doctors and nurses with specific demands, (c) often looked for information about what to expect in the last few weeks or days before death, and (d) were more likely to foresee that there would be an increasing physical and emotional burden on the family and recognized the need to arrange for professional help. On the other hand, those who had little or no awareness of their impending death hoped for a cure or remission and either went through various tests and treatments or took a more passive wait-and-see approach, paid little attention to the care they needed in the near future, and were scarcely aware of the heavy care demands they might be making on their relatives, assuming that the family would look after them and be able to handle their care demands in the future. Francke and Willems’ study further strengthened the need for open and honest communication with the patient and its influence on their participation in their own end of life care. A limitation of this study was the minimal
awareness of impending death reported by family members. However, the authors believed they had reached theoretical saturation with the patients, but not with family members. Therefore, they were unable to describe the differences between the patients’ awareness of their impending death and their family members’ awareness of it.

In summary, a person’s response to the awareness of dying occurs in relationships, particularly one with their health care provider. It is expressed in the rhythmic patterns of ambiguity and empowerment. This is consistent with Heidegger’s description of the authentic self being revealed in the everyday world of concerns and always in relation to others. Awareness of dying is not an absolute and constant perception. The individual lives with both the certainty and uncertainty of this awareness. Relationships with others in everyday life and the world of the dying individual will influence whether certainty or uncertainty becomes dominant.

**The Process of Dying: Stages, Tasks, and Intervals**

The process of dying has been described by theorists and researchers in a variety of ways, including stages, tasks, intervals, trajectories and transitions. Early theories were based on observations of patients (Kubler-Ross, 1969) or a review of clinical cases (Pattison, 1977; Corr, 1992), but very little research has been conducted to verify these theories. This critical review of the process of dying offers a representative sample of the theories that are commonly referred to and used in health care to plan care for the dying patient. The limited research available utilizing a theory as a framework or testing theoretical concepts will also be reviewed.
Kubler-Ross: Stages of dying.

One of the most well-known theorists on death and dying, Elizabeth Kubler-Ross (1969) outlined a five-stage process of dying based on her observations of over 200 patients. Dr. Kubler-Ross began interviewing hospitalized patients weekly while students enrolled in her seminar on death and dying observed. She and her students then met to discuss the observations and responses of each patient. Over time she and different groups of students enrolled in the seminar described the process of dying commonly experienced by the patients they had observed. Kubler-Ross organized this information into her five-stage theory of dying.

According to Kubler-Ross (1969), an individual initially experiences shock and numbness when informed they have a terminal illness. They then progress through the distinctly defined stages of denial, anger, bargaining, depression, and, finally, acceptance. She noted that hope is a characteristic present in all stages; patients have the opportunity to work through all of the stages, but they may need assistance from family, friends, and healthcare providers.

Little research has been conducted to verify Kubler-Ross’ five-stage theory. Griffin and Rabkin (1998) expressed concern about using Kubler-Ross’ approach when caring for individuals with AIDS. They reported the results of an investigation of the association of perceived control over illness and realistic acceptance in 42 individuals with late-stage AIDS and overall psychological adjustment, anxiety about death, and planning for death. Quantitative scales were used to measure perceived control, realistic acceptance, psychological adjustment, depression, hopelessness, and death anxiety. Questions were asked to reveal the degree to which the AIDS patients had planned for
their illness and death. The results revealed the following: (a) perceptions about the day-to-day course of the illness were strongly and positively associated with several measures of psychological adjustment; (b) a coping style characterized by realistic acceptance was associated with more psychological distress; and (c) beliefs in personal control became more important as one’s health became more uncertain and predictable. The study also revealed that levels of depressive symptoms and death anxiety were high on the sample of those who were realistic and accepting of death, but scores on hopelessness were not highly elevated and were not associated with disease severity. Griffin and Rabkin acknowledged that their results might have been different if the individuals had been in the last days of life. The authors expressed concerns that their findings were contrary to the peaceful acceptance of death put forth in Kubler-Ross’ theory, an approach they claim is widely used to care for individuals with AIDS. However, Griffin and Rabkin recommended that a different approach be considered when caring for individuals with AIDS, since they generally experience an unpredictable course in the illness.

A second study, the Yale Bereavement Study (Maciejewski, Zhang, Block, & Prigerson, 2007) was designed to test Kubler-Ross’ five-stage theory through an empirical longitudinal examination of grief among those who had lost a loved one from natural causes. The sample consisted of 233 newly bereaved (less than 6 months) who had lost a loved one. They were recruited from community-based settings in two New England cities. Using the Inventory of Complicated Grief Revised (ICG-R), the investigators collected data to measure the frequency of the occurrence of disbelief, yearning, anger and acceptance. Depression was measured using the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1960). Three interviews were conducted with
each participant at two-year intervals. The data were analyzed to test for significant differences in the magnitude of each of the five indicators within each of the post-loss periods. Maciejewski, et al. reported that although the temporal course of the absolute levels of the five grief indicators did not follow Kubler-Ross’ theory, when rescaled and examined for each indicator’s peak, the data from the Yale Bereavement Study fit their own hypothesized sequence exactly. In terms of absolute frequency, acceptance, rather than disbelief was the initial dominant grief indicator. Maciejewski, et al. also reported that yearning for the loved one who had died was the most salient psychological response to the loss of a loved one through natural death. While depressive mood did not occur prior to 2 months post loss and peaked at 6 months post loss, yearning was reported throughout the study.

The strength of this study was its large sample size and that it was a longitudinal investigation, which is beneficial when investigating possible changes in response to grief over time. A limitation of this study was the particular instruments selected to test identified stages of loss and grief. The investigators chose their data collection instruments based on the notion that loss involving an orderly progression through distinct stages is widely accepted by clinicians and the public. The study would have had greater validity if the investigators had preceded it with a qualitative study examining the process of dying and bereavement, then testing those characteristics identified from a systematic investigation of the process.

Although Kubler-Ross’ theory has been widely accepted and used by healthcare providers and the general public, it was not formulated as the result of a systematically organized research study. Moreover, very little research has been conducted since 1969 to
verify or substantiate her theory. It has been criticized for being interpreted mechanistically and prescriptively with the dying individual expected to move through each sequential stage of the dying process and come to acceptance as the final stage (Kastenbaum & Thuell, 1995). At the same time, it continues to be expanded and used as a bereavement theory for those who are grieving the loss of a loved one.

**Pattison: The living-dying interval.**

Pattison (1977) reviewed the descriptions by healthcare providers of approximately 20 different clinical cases of individuals of various ages who were dying. He wrote a book about these experiences titled *The Experience of Dying* (1977) and proposed that dying persons demonstrate a wide variety of emotions which ebb and flow throughout their living-dying. He suggested that the task of healthcare professionals was to determine the stress and crises at a specific time, to respond to the emotions generated by the issue, and to respond to where the individual is in his or her living-dying. Pattison believed this could be accomplished more effectively if the living-dying process were viewed in dimensions that have clinical utility rather than in the stages previously theorized by Kubler-Ross.

Pattison’s work was intended to extend that of Glaser and Strauss. In his introduction to *The Experience of Dying*, Pattison stated that his goal was to provide a “broader, in-depth portrait of the dying process in its many personal forms” (p. 1). He attempted to fill perceived gaps in research and theory development, including describing different transitions within the living-dying interval. With advances in technology and the ability to prolong the period of dying, Pattison suggested that many people now might experience a new phase of life called the “living-dying interval.” He stated, “Death itself
is not a problem of life, for death is not amenable to a treatment or intervention ... but the process of dying is very much a part of a person’s life” (Pattison, p. 43). Pattison divided this interval into three clinical phases: the acute crisis phase; chronic living-dying phase; and the terminal phase. During the acute crisis phase, the individual experiences increased anxiety that will reach a peak of tolerance. At this time the individual initiates behavior to reduce anxiety. Pattison suggested five aspects of crisis: (a) stressful dying poses a problem that is insolvable; (b) the problem takes one’s psychological resources because it is beyond traditional problem-solving methods; (c) the situation is perceived as a threat to the life goals of the person; (d) the crisis is characterized by tension that mounts to a peak, then falls; and (e) the crisis situation awakens unresolved key problems from both the near and the distant past. During the chronic living-dying phase the individual faces a number of fears including fears of loneliness, the unknown, sorrow, loss of family and friends, loss of body, loss of self-control, suffering and pain, and loss of identity. The terminal phase begins when the dying person begins to withdraw into self in response to internal body signals indicating a need to conserve energy. In this phase, the individual experiences ‘changes of hope’ from expectational hope, which includes hopes for remission, arrest, or cure to desirable hope, or hope that one might not die. While this is a desirable hope, it is no longer expected. At this phase the individual may experience four types of death (not in any prescribed order). Sociological death is characterized by withdrawal and separation by the patient from others; psychic death occurs when a person accepts death and regresses into self; body organ death occurs when the organism as a human being no longer exists (such as an irreversible coma); and physical death occurs when the vital organs no longer function.
Pattison claimed that his theory was an alternative to the stage-of-dying theory offered by Kubler-Ross and an extension of the transition work of Glaser and Strauss. Pattison’s theory was based on descriptions of patients presented by healthcare providers and did not emerge from a formal research study.

**Corr: Task-based approach.**

Corr (1992) reviewed the literature regarding what had been learned about dying and coping over the past few years, and from these results, proposed a task-based approach to coping with dying. A task is defined as work that may be undertaken by those who are coping, and coping is defined as the process of seizing control of events. Corr proposed that individuals who are dying confront four primary areas of discretionary task work in coping with dying. These include (a) physical, relating to satisfying bodily needs and minimizing physical distress; (b) psychological, including maximizing psychological security, autonomy, and richness of living; (c) social, involving sustaining and enhancing interpersonal attachments and addressing the social implications of dying; and (d) spiritual, concerning the need to identify, develop, and reaffirm sources of spiritual energy and fostering hope. Corr emphasized the task-based approach as a holistic approach to care in contrast to theories that attend to specific aspects of people’s lives. He proposed that the tasks are meant to empower individuals coping with dying, an attribute he finds missing in stage or phase theories. He also described the tasks as enhancing participation or sharing in life rather than a process that a dying individual goes through alone. Finally, Corr emphasized that a task-based approach provides guidance to all those involved in assisting the individual who is coping with dying.
While the theories of both Pattison and Corr have been discussed as examples of death and dying theories in publications (Copp, 1998; George, 2002), only two research studies were located that use the theories as a framework. Engle, Fox-Hill, and Graney (1998) was interested in the unique care needs of Black and white nursing home residents during the living-dying interval. Using Pattison’s theory as an organizing framework for the study, Engle recruited a purposive sample of 13 residents from two county-financed nursing homes managed by a for-profit corporation in a large mid-south city. Using a semi-structured interview format, she asked questions related to their comfort, the meaning of dying and important things nurses should know. She also asked them to describe a typical day and asked them if they ever think of passing on. The audio-taped interviews were transcribed and coded. The general conclusion was that the residents, regardless of race, think more about living day-to-day than dying. Common themes identified in attitudes toward dying were their thinking about dying, having little fear of dying, and finding comfort in their religious faith (Engle, et al.). While this study provided insights into the concerns of individual living in a nursing home, it did not enhance or expand the living-dying interval proposed by Pattison. No additional research based on or testing this theory during the last 10 years has been located in a search of the research literature.

Coyle (2006) conducted a more recent investigation into patients’ perspectives regarding the work of living with advanced cancer while also facing death. Using Corr’s task-based approach, she recruited a sample of seven patients with advanced cancer who were being followed as inpatients and outpatients at a pain and palliative care service located in an urban cancer research center. These patients had each expressed a desire for
a hastened death. During the interviews, the patients were asked to “describe their lives before they were sick and their lives at the present time” (Coyle, p. 268). The themes that emerged from the data analysis included the work of orienting to the disease and maintaining control, creating a system of support and safety, and struggling to find meaning and create a legacy. Coyle examined the results against both Pattison’s living-dying interval theory and Corr’s task-based theory and concluded that while these were useful frameworks they “do not capture the hard work involved and its impact on the individual experience and on individual lives” (p. 273).

Both studies (Coyle, 2006; Engle, et al., 1998) were systematically conducted with attention to the rigors of qualitative research. They interviewed participants two to six times and ended the interviews if the participants became too ill to continue or if no new information was being obtained. The results stand alone in describing the living-dying process, but have little impact on the living-dying interval theories or the task-based theory.

**Summary.**

In summary, the process of dying has traditionally been described from various schematic frameworks, including stages, phases, and tasks. These theories were developed unsystematically, and little published research is available to verify the interrelating concepts addressed in the theories.

Although Kubler-Ross’ work eventually moved beyond the stages of dying to examine the transitional process of living with dying and beyond dying (Kubler-Ross, 1997), healthcare providers unfortunately have not made a similar move and continue to use Kubler-Ross’s (1969) theory of death and dying as a prescriptive plan for assessing
all individuals’ experiences of dying in a manner similar to checking off a list of completed activities. Stage theories may also encourage a more passive role of supporting these individuals through these stages with the hope they will achieve acceptance before dying. For example, an individual believed to be experiencing denial is supported in this denial until he or she shows signs of moving forward toward anger. This denial could also be the everydayness of living with this certainty as described by Heidegger, but unless healthcare providers can listen to patients’ stories and capture the meaning the everyday experiences have for them, it is difficult to comprehend their unique reality and assist them in preparing for the dying process.

Pattison (1977) and Corr (1992) attempted to move away from and reject the stage approach to dying. Pattison focused more on the emotional responses and behaviors of individuals and Carr on tasks to be accomplished as individuals progress through the dying process. Although these theories are more applicable to assisting individuals prepare for living with the certainty of death than the previous stage theories, they continue to be framed within a specific structure, such as stress-crisis or primary areas of task work. Pattison discusses anxiety as an emotion to be reduced or minimized, while Heidegger suggests that anxiety, as a mood of anticipation, brings an individual closer to the authentic awareness of being-toward-death. These traditional theories of dying do not address the experiences of individuals living their dying, but instead structure the dying process in stages and phases or in crises to be eliminated or managed and tasks to be accomplished.
Dying Trajectories

The concept of trajectories was introduced in Chapter 1, with an introduction to the social science research of Glaser and Strauss (1965) and the medical research conducted by Lunney, et al. (2002). Following a description of these frameworks, this section will describe the patterns of functional decline with individuals experiencing specific illnesses, including amyotrophic lateral sclerosis (Gordon, et al., 2010; Mitchell & Borasio, 2007; Radunovic, et al., 2007), heart failure (Goldstein & Lynn, 2006; Hupcey, et al., 2009), and cancer (Constantini, et al., 2008; Murray, Kendall, Boyd, & Sheikh, 2005; Murray, et al., 2007).

Social science perspective: Glaser and Strauss.

In A Time for Dying (1968), Glaser and Strauss discussed the characteristics of the dying experience as contributing to the organization of end-of-life care. Their theory described the interplay between the organization of work (activities performed by healthcare providers in the care of the dying patient) and duration of dying (or the course of dying). It focused on the question of whether or not the person is going to die in the hospital and, if so, when the person die would. The first part refers to the certainty of death while the second part refers to the time of death. According to Glaser and Strauss, certainty in combination with time yields four types of death expectations, including (a) certain death at a known time, (b) certain death at an unknown time, (c) uncertain death but a known time when certainty will be established, and (d) uncertain death at an unknown time when the question will be resolved. From this perspective, they identified three trajectories that influence the organization of work and the behavior of care.
providers toward patients during the dying process, including expected lingering, expected quick, and unexpected quick trajectories.

Each of the three trajectories reflects a specific duration and shape on a graph. According to Glaser and Strauss (1968), dying trajectories differ in the time between onset and death and the predictability of the dying process. They described courses of dying as reflecting variations in two outstanding properties, duration of the dying experience and the shape of the dying trajectory when graphed. These two properties, duration and shape, are not objective characteristics, but rather perceived by professional care providers, families, and/or even patients themselves. Defining the dying trajectory is an open-ended process as the staff may continually redefine the trajectory as the patient’s condition changes.

Expected lingering trajectories describe those situations in which individuals are expected to live for some time while dying. The typical patient has one or more chronic illnesses and there is a wide variation among patients in how long a time will pass between entry into the trajectory and death. Physical decline toward death is gradual with a slow but steady downward sloping of the graph and there are few surprises before death (See Frailty Trajectory in Figure 1).

The expected quick trajectory describes the situation where it is clear to staff that the patient will die within days. The duration of this trajectory is typical of individuals with cancer who linger for several months or years with initial entry into the trajectory then a possible expected quick trajectory and a continual downward slope of the graph at the end (See Terminal Illness Trajectory in Figure 1).
Unexpected quick trajectories occur when the individual is expected to die, but there is an unexpected worsening of the patient’s condition and the individual dies sooner than anticipated. Related to this trajectory is the unexpected quick dying trajectory reflecting the occurrence of death with a patient who is not dying, is expected to recover, then suddenly dies. This duration is short with a sudden downward trajectory on the graph (See Organ Failure Trajectory in Figure 1).

**Medical community perspective: Lunney, Lynn, and Hogan.**

Work regarding trajectories has continued within the medical community with hospitalized patients. Lunney, Lynn, and Hogan (2002) used Medicare claims to evaluate a clinically-based classification scheme and to seek a better understanding of Medicare expenditures and health care in the last year of life. They identified four trajectories that appear to account for most persons’ last phase of life. Each trajectory differs in length and slope of functional decline. The four trajectories include sudden death, terminal illness, organ failure, and frailty (See Figure 1).
Figure 1. Trajectories of Dying (Lunney, et.al., 2002, p. 1109).

Those experiencing the sudden death trajectory progress from normal or high functioning to death in a brief period of time. There is little forewarning and little or no interaction with the health care system before dying. A perpendicular line on a graph represents the slope from high functioning to death.

The terminal illness trajectory represents primarily cancer patients who function reasonably well with their illness for a long period of time before the disease becomes overwhelming and non-responsive to treatment. Individuals then decline rapidly and die.
within six weeks. Graphically, they tend to be high functioning until a downward slope toward death near the end of the trajectory.

Individuals with an organ failure trajectory include those with heart failure, chronic obstructive lung disease, or other serious organ system failure. They experience a gradual diminishing of functional status with periodic exacerbations of their illness. Their prognosis remains ambiguous. Graphically, the trajectory appears as a saw-tooth line progressing gradually downward to death. The saw-tooth appearance represents the periodic acute exacerbations of their illness.

Finally, the frailty trajectory group experiences a slower decline with steadily progressive disability before dying from complications associated with aging, stroke, or dementia. The trajectory is initiated at a low functioning level on a graph with a steadily progressive slant toward death.

The research regarding trajectories has been beneficial in defining and describing the patterns of functional decline with individuals experiencing a variety of illnesses. Trajectories have been helpful in assisting healthcare personnel to plan and organize the medical and physical care of individuals living with an illness and preparing for death. It is also beneficial in providing individuals and family members with information regarding the anticipated course of the illness.

**Cancer trajectory.**

The expected quick trajectory and the terminal illness trajectory describe the course of cancer. The decline in physical health is predictable and occurs over a period of time, which could be weeks, months, or years (Murray, et al., 2005). The individual is
high functioning until the last one to three months of life when there is a marked decrease in functional status and increased disability.

Constantini, Beccaro, and Higginson (2008) tested whether the trajectory was universal or whether there were differences related to age, gender, and primary cancer diagnosis. They interviewed a random sample of 1,900 informal caregivers of patients from local health districts in Italy and asked questions about the functional decline of the patient. All patients were deceased and interviews of the caregivers were conducted an average of 234 days after the patient’s death. Constantini, et al.’s findings confirmed the onset of functional decline about three to four months before death for all age groups and both genders. This trajectory provides healthcare personnel an opportunity to work closely with patients and families to provide care throughout the transition to the end of life.

**ALS trajectory.**

Research related to the care of individuals with ALS reflects Glaser’s trajectory of expected lingering. Radunovic, et al. (2007) suggested four phases, including coming to terms with the illness, coping with substantially impaired function, end of life, and after death. Mitchell and Borasio (2007) suggested a similar, but more specific, seven-phase trajectory, including breaking the news, psychological support, symptomatic treatment, percutaneous endoscopic gastrostomy home ventilation, end-of-life decisions, terminal phase and death, and bereavement counseling. The focus of care is on educating the patient and family about the disease, the management of symptoms and progression of the illness. Patient and family involvement in care decisions is important, and the first phase is essential in establishing a positive relationship with the multidisciplinary team so
that treatment may begin as soon as possible. The focus on symptom management is specific to each patient’s care needs. End-of-life decisions are emphasized with the patient participating actively in deciding specific end-of-life care issues. Finally, bereavement counseling is available for families following the person’s death.

Gorden, et al. (2010) challenged the linear course of ALS and the predictability of survival based on functional status. They studied the shape of the progressive curve using the ALS functional rating scale (ALSFRS-R) and manual strength testing of 30 muscles, and assessed which features of the disease most influenced the rates of decline and survival. Their findings revealed a curvilinear decline in function and strength with the fastest rates of decline occurring in the first 18 months of symptomatic disease. They also found that the rates of decline increased toward the end stage of the disease. This curvilinear trajectory supports the practice of testing for effective therapeutics early in the course of the disease. Unfortunately, they report that most patients present themselves to the specialty care center one year after symptoms occur during the time when the progression curve shows a slowing. This delay has implications for treatment. These authors all agree that early entry into multidisciplinary care is important for the well being of the patient and the family over the course of the illness.

**Heart failure trajectory.**

Individuals with heart failure typically follow Glaser’s (1968) unexpected quick trajectory and Lunney, et al.’s (2002) organ failure trajectory. Goldstein and Lynn (2006) describe the heart failure trajectory as “long-term limitations on function with intermittent exacerbations” (p. 11). While those with progressive heart disease have multiple symptoms near the end of life, death remains unpredictable and, for family
members, often unexpected. Goldstein and Lynn recommend that the healthcare provider meet with and establish a comprehensive advance care plan with the patient and family, documenting agreement among all participants about how to manage certain complications.

Hupcey, et al. (2009) further emphasized that the unpredictable heart failure trajectory limits the services available beyond medical management for the chronic illness. They recommended palliative care, as a philosophy of care, as a “viable approach for integrating symptom management, the discussion of the life-limiting nature of the illness, advance planning, and psychosocial interventions together with optimal medical management” early in the course of the disease (Hupcey, et al., p. 400). They proposed an alternative to the current model of care recommended by the National Consensus Project (NCP) for Quality Palliative Care, and suggest that palliative care interventions be introduced as a philosophy of care early in the illness trajectory along with life-prolonging treatment. While initially the patient is minimally supported, as needed, with palliative care interventions, the intensity of the interventions increases when sporadic intensive therapies are required. When functional status slowly declines as a result of cardiac decompensation, the palliative care interventions “assume a more dominant position in the balance of care” (Hupcey, et al., p. 402). In contrast to the NCP model, life-prolonging therapy would continue since the end-of-life phase is unpredictable.

This proposed trajectory offers a more pragmatic approach to care of the patient with heart failure since death is unpredictable even when the patient is experiencing functional decline associated with the illness. It also provides opportunities to assist the
family through the psychosocial and spiritual challenges faced when experiencing transitions within the trajectory.

**End-of-life Transitions Within Trajectories**

Trajectories were created to provide physiological markers of illness; yet many life-limiting illnesses lead to long periods of diminished function and involve multiple unpredictable and serious exacerbations of symptoms (Lunney, et al., 2003). Cancer is a terminal illness that has a phase that can be clearly labeled ‘dying’. It is manifested by an approximate eight-week period (or less) of loss of weight and energy, and a limited ability to carry out tasks. The Medicare reimbursement plan for hospice is built around this dying phase; yet patients with neurological, cardiac, or nonspecific terminal diagnoses make up a growing share of the Medicare hospice patient population. The balance between hospice patients with cancer diagnoses and those with non-cancer diagnoses shifted dramatically between 1992 and 2007. The Medicare Payment Advisory Board’s 2009 and 2010 reports to Congress as cited by Hospice Association of America (2010) revealed that in 1992, 78% of the Medicare patients being treated through hospice had a diagnosis of cancer, while 24% had a non-cancer diagnosis. In 2007, the percentage of Medicare-reimbursed patients with cancer being treated through hospice had decreased to 23%, while 77% of the patients had a non-cancer diagnosis. The timing of death for greater than three quarters of the population insured by Medicare is usually not predictable and not limited to a six- to eight-week time frame. Individuals are living with the knowledge of their impending death for longer periods of time as they experience declining physical functioning. It is essential to identify transitions within the trajectories of functional decline and examine the accompanying psychosocial and spiritual
challenges of individuals progressing through transitions toward the end of life.

Recently published studies conducted with the focus on transitions at the end of life addressed the experience of patients with cancer, heart failure, and hematologic disorders (Dalgaard, Thorsell, & Delma, 2010; Duggleby, et al., 2010; Larkin, Dierckx de Casterle, & Schotsmans, 2007a; Murray, et al., 2007). While some study participants were being cared for in the home, others had recently moved into a palliative care facility, while still others were being treated in outpatient clinic settings. These studies will each be critically reviewed, and the results will then be synthesized with other study findings to summarize and characterize quality end of life.

Using a phenomenological approach, Larkin, et al. (2007a) examined how European patients with advanced cancer described the transition experience toward the end of life. A purposive sample of 120 participants expected to progress to terminal care within 6 to 12 months were recruited from inpatient palliative care agencies in six European countries. One semi-structured interview was conducted with questions designed to explore experiences, associated factors and current reflections of the phenomenon, and an exploration of its meaning.

Four phases of analysis, including substantive, evocative, evaluative, and expositional were completed using transcribed audio-recorded interview data. Descriptive statements of the participants were analyzed using van Manen’s lifeworld existentials. Lived body was described as “seeking stability through safety and security” (Larkin, et al., 2007a, p. 73). Lived space was expressed as a challenge to impermanence. Recalling that these patients were in inpatient palliative care settings, the geographical location, the security, and the personal space created a sense of permanence. Lived time
was summarized as “negotiating time” (Larkin, et al., p. 75). The patients found the time between referral and transfer to be so quick that they had little opportunity to adjust to the change. The importance of negotiating time decreased over the course of the illness to a life reflection. Larkin et al. referred to this as “a shift from challenging time to rationalizing time” (p. 75). Finally, the other lived experience was described as “shifting bonds” (Larkin et al., p. 75), whereby the patients formed emotional bonds with their caregivers and other patients in the palliative care setting, while maintaining strong emotional ties to family and significant others.

In summarizing their analysis Larkin, et al. (2007a) developed an overall essential phenomenon titled “living transiently in the shadow of death” (p. 76). This concept of transience best describes the certainty/uncertainty rhythm. Patients were experiencing a time of mixed messages, poor communication, uncertainty, and while death was a presence, it was not a consuming presence. Patients still had future goals as they also adjusted to moving toward the end of their lives. The strength of this study is the multi-cultural focus since the sample consisted of individuals from six different European countries. This strength may also be considered a limitation when various spoken languages may invoke various interpretations and misinterpretations. Although the results of this study are primarily directed at and limited to experiences of individuals in inpatient palliative care settings, the concept of transience may be one that is universal for all patients experiencing the end of life and should be examined further.

Larkin, et al. (2007b) have continued to develop this concept of transience through a concept analysis, but are limited by the lack of evidence for looking at transience in the palliative care setting. Although Larkin et al. concluded that transience
is an “immature and underdeveloped low-level concept in its own right” (p. 95), they emphasized the importance of delineating the state of transience from the process of transition.

Dalgaard, Thorsell, and Delmar (2010) conducted a grounded theory study to identify and clarify transitions in incurable illness trajectories. Their fieldwork included observations and personal interviews with the participants carried out over three months in an inpatient hematology and outpatient setting. The investigators conducted interviews with 74 incurably ill patients and their relatives (n=11). They conducted 157 hours observing staff functions and four focus group interviews with nurses and physicians. Data were analyzed using open coding, axial coding, and selective coding, and two transitions were identified: the transition from curative treatment to early palliative care and the transition to late palliative care.

The transition from curative treatment to the early palliative phase typically occurred when patients were considered incurably ill and the goal of medical treatment was continued for disease control. This specific purpose of medical treatment was often not explicitly communicated to the patients; instead, the healthcare professionals continued to encourage the patients to hope and fight, thereby offering false optimism. The authors described the patients as being “left in loneliness” (Dalgaard, et al., 2010, p. 90). The patients were fighting a meaningless battle and missing an opportunity to channel hope in a different direction. Finally, the transition to late palliative care occurred when the situation was openly defined as a progression toward death. Interventions were solely aimed at alleviating suffering and improving quality of life (Dalgaard, et al.).
The strength of this study is its approach to using observations of and interviews with a variety of participants, including physicians, nurses, patients, and families. The results of the study are consistent with the ambiguity and empowerment descriptions coinciding with the awareness of dying concept. A limitation of this study was the inclusion of only one unit, a hematological unit in a single hospital. This study was relevant for the developing theory of transitions in incurable illness trajectories, and the results should be considered when developing a transition theory.

Duggleby et al. (2010) focused their grounded theory study of transitions on rural older adults with advanced cancer. They sought multiple perspectives of this transition with individuals receiving palliative home care and their family members. Purposeful theoretical sampling was used to recruit, enroll, and interview 6 individuals with cancer receiving home palliative care services, as well as 10 family members and 12 healthcare providers. The data analysis revealed four themes of transition, including “environmental, role relationships, physical and mental health, and daily activities of living” (Duggleby, et al., p. 4). Environmental transitions related to home and reflected the physical transitions in the home during the illness, as well as being unable to leave home, or transitioning from home to a different care setting. Transitions in role relationships occurred as they progressed from caring for others to becoming dependent on others for their own care. Transitions in physical and mental health occurred as a result of medications and disease progression, while changes in daily activities occurred as a result of the three previous transitions. The researchers titled the process of managing the transitions as “Navigating Unknown Waters” (Duggleby, et al., p. 4). Sub-processes included coming to terms with the situation, connecting with others, and redefining
normal. The patients and their families described coming to terms with their situation as
gaining awareness or understanding of their situation. Connecting with others was
reflected in seeking information and connecting with trusted experts. In redefining
normal, the patients and family members changed what they considered normal, such as
“redefining new standards of what is well” (Duggleby, et al., p. 5).

Similar to other qualitative studies with participants at the end of life, each patient
was interviewed only one time (except in one case where a patient was able to participate
in a second interview). One reason for this limitation in this and other studies is the short
length of time individuals with cancer live following enrollment in hospice or palliative
care. While this limits the opportunity to return to the participant to verify information or
expand on earlier information provided, the common characteristics identified by patients
in this study and across other studies enhance the credibility of the findings. There is a
need to expand the focus of transition research to individuals with other conditions who
may be enrolled in hospice care for a longer period of time or to follow patients prior to
enrollment in hospice.

Murray, et al. (2007) conducted a comprehensive study of what they referred to as
“quality of life trajectories” (p. 394). They synthesized and examined data from two
qualitative longitudinal studies, each conducted over a one-year period, consisting of 112
in-depth interviews with a total of 48 individuals. The participants were receiving
palliative care for diagnoses of advanced lung cancer or heart failure. The purpose of this
study by Murray, et al. was to examine patterns of change in social, psychological, and
spiritual needs as the illness progressed. They analyzed the serial interviews as “case
studies longitudinally, and then conducted repeated, cross-sectional analyses of both data
sets according to the stage of physical illness” (Murray, et al., p. 396).

They found that patients expressed social, psychological, and spiritual problems at various times during their illness. In lung cancer, they identified four specific transitions when these problems appeared to recur or increase in intensity. These transitions were identified as diagnosis, discharge after treatment, disease progression, and terminal phase.

Socially, they experienced decreased social involvement at the time of diagnosis because others feared the diagnosis of cancer. Treatment side effects decreased their social involvement even more. As the disease progressed and physical limitations increased, they experienced a decreased sense of well-being and during the terminal phase their world tended to diminish to family and then self.

Psychologically, they experienced anxiety, uncertainty, and emotional distress while waiting for initial test results and the beginning of treatment; after treatment when no longer in contact with supportive staff; during relapse or disease progression when feeling challenged by the disease; and during the terminal phase as they contacted health services for reassurance.

Spiritually, distress and questioning were experienced at diagnosis when they were “coming face-to-face with the prospect of suffering and death” (Murray, et al., 2007, p. 398); struggling to return to their old life following treatment; reflecting on achievements and focusing on what needs to be done before death as the disease progressed; and accepting death during the terminal phase.

In advanced heart failure, social and psychological decline ran parallel with physical deterioration (Murray, et al., 2007). Their social world was shrinking with the progressive physical decline and acute anxiety that often accompanied acute
exacerbations. Some expressed frustration and low mood while others were resilient. Spiritual well-being gradually decreased as they experienced a loss of identity and increasing dependence. They searched for meaning as the disease progressed and during the terminal phase asked specific questions about life after death (Murray, et al.).

The results of this comprehensive study were strengthened by the use of data from serial interviews across the length of the study period. They were able to track the social, psychological, and spiritual concerns and needs at different times in the illness trajectory. The limitation of this study was the sample, which was restricted to individuals in a region of Scotland. The original longitudinal study with serial interviews should be replicated with other populations and additional illness trajectories.

Quality End of Life (QEOL)

Quality end of life is referred to as the patient’s perspective on what is meaningful and of value, and includes the multidisciplinary assessment of physical, functional, emotional, and family/social well-being (Cella, 1992;1994; Cella & Patel, 2008). In the following review, common themes that have emerged from the transition studies as well as additional studies relevant to specific dimensions influencing QEOL are summarized. These dimensions include (a) communication with healthcare providers, (b) family and social relationships, (c) safety, security, and self-preservation, (d) spirituality: hope, meaning, and self-worth, and (e) dignity preservation and enhancement. Physical and functional well-being will be discussed in reference to their influence on the psychosocial dimensions.
Communication with healthcare providers.

Communication with healthcare providers is one of the most influential contributors to a quality end-of-life experience. The findings in several studies have revealed the anxiety related to the rapid timing of the transition from curative to end-of-life care, which has left patients unprepared, and the vague or falsely optimistic explanations by healthcare providers when explaining this transition to them (Dalgaard, et al.; Duggleby, et al., 2010; Larkin, et al., 2007a).

Larkin, et al. (2007a) described this rapid transfer under the Lifeworld Existential called lived time (van Manen, 1990). Patients discussed the urgency of agreeing to enter a palliative care facility even if they were not emotionally ready to make this decision. Dalgaard, et al. (2010) found that explicit communication regarding the transition to the late palliative care phase often occurred very late in the terminal phase. The approach to care was then based on an “avoidance-logic” (Dalgaard, et al., p. 90) whereby the staff would begin to wonder whether specific life-prolonging interventions should be avoided or discontinued. Duggleby, et al. described the most significant transitions of palliative care patients and their families as being “unexpected, sudden, and new” (p. 4). The suddenness of this rapid transfer caused anxiety, distress, and uncertainty. Factors positively influencing the transition included timely communication, trust in healthcare providers, and the provision of essential and honest information (Duggleby, 2010; Heyland, et al., 2006). Heyland, et al. reported the results of a survey of quality of life among dying patients in five tertiary care hospitals across Canada. The eligibility criteria included patients with advanced disease and a 50% probability of survival at 6 months. They distributed a 28-item questionnaire that was generated from literature
reviews and semi-structured interviews with seriously ill hospitalized individuals. The 28 items representing elements of care were organized into five domains: (a) medical and nursing care, (b) communication and decision-making, (c) social relationships and support, (d) meaningful existence, and (e) advance planning of care. Responses from 434 participants were analyzed. The most frequently rated elements of end-of-life care by the patients were “to have trust and confidence in the doctors looking after you” (56%); “not to be kept alive on life support when there is little hope for a meaningful recovery” (56%); and “that information about your disease be communicated to you by your doctor in an honest manner” (44%). The elements least frequently rated as extremely important were “to have the same nurses looking after you”; “to receive help making difficult treatment decisions”; and “to be able to contribute to others” (14%-16%) (Heyland, et. al., p. 629). The results of this study are strengthened by the fact that it was a multisite study with a large sample size. Although their original intent was to study elderly patients at the end of life, they expanded the inclusion criteria in this study to those 55 years of age and older. This enhanced the generalizability of the study results.

Family and social relationships.

The influence of relationships with family and others on quality end of life has been emphasized in studies by Duggleby, et al. (2010), Gourdji, McVey, and Purden (2009), Larkin, et al., (2007a), Murray, et al. (2007), and Shahidi, Bernier, and Cohen (2010). Murray et al. found that even though the illness trajectories of the patients with advanced lung cancer and heart failure were very different, the social isolation and loneliness expressed by both groups occurred throughout the illness trajectory. The patients with lung cancer reported that social relations began to diminish at the time of
diagnosis. They expressed loneliness and uneasy relations with friends. Declining social well-being paralleled the occurrence of treatment side effects and increasing physical limitations. Patients stated that they felt “useless, dependent, and sometimes excluded from family and social roles” (Murray, et al., p. 397). They also reported that toward the terminal phase their social world diminished to family and then to self.

Patients with heart failure reported a parallel decline in social relations as the disease progressed. Some stated that just planning to go out was “fraught [with anxiety] due to the fluctuations in the illness and having to find a toilet frequently due to the diuretic medication” (Murray, et al., 2007, p. 398). They perceived family members as treating them as invalids, further increasing a sense of “imprisonment”, and a loss of independence and previous identity (Murray, et al., p. 398).

The themes of loneliness and isolation continued as increasing physical limitations and the inability to leave the home were expressed by participants in a study of rural older adults with advanced cancer who were receiving palliative care in their homes (Duggleby, et al., 2010). They found the presence of family and a supportive community network to be factors that helped patients adapt to increasing physical limitations. Duggleby reported that these particular transitions within the home environment were difficult for patients and their family, and required further research.

Larkin et al. (2007a) reported that the changing dynamics of family and social relationships had the most profound influence on a patient’s ability to transition to the end of life. Remembering their sample included patients who had been admitted into a hospice or palliative care facility, they identified this time as “shifting bonds” (Larkin, et al., p. 75). They described this transition as finding meaningful people involved in the
transition process, rebalancing relationships, and developing relationships with other patients in the hospice/palliative care center. These shifting bonds could be interpreted differently with patients who remained in their homes during the end-of-life transition.

Shahidi, Bernier, and Cohen (2010) reviewed 286 responses from completed questionnaires from a larger longitudinal study of 110 patients with cancer who were receiving palliative care. These authors completed a content analysis of repeated responses to an open-ended question from the revised version of the McGill Quality of Life in Life Threatening Illness questionnaire (QOLLTI-P). The question referred to what had been important in their quality of life (QOL) in the previous two weeks. The patients were asked to complete this question every two weeks for as long as possible during their last six months of life, and all of their responses were included in the analysis. Fifty-eight themes emerged and were divided into 8 domains. Relationship and support was the second most frequently mentioned QOL domain (197 times) after physical conditions and symptoms (257 times). Relationships with and support from family were most important, followed by relationships and support from friends, healthcare professional, and pets. Since the participants completed the same question every two weeks, the results of Shahidi, et al.’s study could have been strengthened if the researchers had analyzed the temporal sequence of changing relationships and support reported by respondents. Instead, they just reported the frequency responses focusing on a specific domain. The results of their study must also be cautiously considered in light of the fact that validity and reliability were not reported for this unpublished revision of the original McGill Quality of Life Questionnaire.
Gourdji, et al. (2009) used a qualitative descriptive design to explore the meaning of quality of life with 10 patients one week following admission to a palliative care unit. Broad open-ended questions were used at the beginning of the interviews, and patients were asked what quality of life means to them. They were then asked to describe their QOL experiences since arrival on the unit. Unfortunately only two follow-up interviews could be scheduled, so the perspectives of the patients were those obtained shortly after arrival onto the unit. The audio-taped interviews were recorded, transcribed, and analyzed independently by two different researchers. The three main themes for quality end of life focused on “maintaining a sense of normalcy, contributing to the well-being of others, and experiencing care and support” (Gourdji, et al., p. 44). The results revealed that relationships with family, friends, and healthcare providers were perceived by the participants to have the greatest effect on their QOL. This study yielded rich descriptive data that provide a framework for future studies in quality end-of-life care. Once again, the limitation of this study, as with similar studies, was the inability to follow up with patients because of their deteriorating conditions or death.

**Safety, security, and self-preservation.**

Seeking safety, security, and self-preservation were identified as important concerns by individuals with advancing disease in several studies of QEOL. Larkin, et al. (2007b) described their study participants’ lived body experiences as “seeking stability through safety and security” (p. 73). These concerns were prompted by their physical limitations, decreasing independence, and the fear and losses the patients were experiencing with their advancing disease. These participants also believed that the
palliative care center offered them safety and security at this increasingly vulnerable
time.

Maintaining independence within a safe and caring environment was also
important. The findings from Gourdji’s, et al.’s (2009) study revealed that patients who
reported that living in a caring environment where their independence and autonomous
decision-making capabilities were maintained enabled them to have quality of life within
their illness context. Being independent was described as being able to do things they
usually did and being helpful to other people.

The theme of being helpful to other people was expressed by the participants in a
study conducted by Fegg, Wasner, Neudert, and Borasio (2005). These researchers
evaluated the relationship between personal values and individual quality of life (iQoL)
as perceived by 64 patients with advanced cancer (n=36) and ALS (n=28) being treated
in palliative care. They found that benevolence was an important value demonstrated by
patients. This was expressed as concern about the welfare of family and friends during
the palliative care experience. Personal values in this study were defined as “cognitive
representations of goals or motivations that are important to people” (Fegg, et al., 2005,
p. 154). The participants were asked to complete Karofsky’s Performance Scale (KPS),
which included a Portrait Values Questionnaire based on Schwartz’s values theory. They
also completed the Schedule for the Evaluation of Individual Quality of Life-Direct
Weighting (SEIQoL-DW). No significant differences were found between ALS and
cancer patients regarding the value dimensions. Compared to healthy individuals, the
palliative care patients rated self-enhancement values, security, and stimulation
significantly lower and benevolence significantly higher. All the patients rated self-
transcendent values (universalism and benevolence) higher than self-enhancement values (power, achievement, hedonism). They further revealed that novelties or challenges in life were not important; nor were prestige, dominance, or personal success.

Finally, Fegg, et al. (2005) reported that patients receiving palliative care appeared to seek self-preservation, as well as the enhancement of the welfare of friends and family. The strength of this study was the inclusion of persons with both advanced cancer and ALS in the study sample. A limitation was the sample size. Repeating this study with a larger sample could further verify patterns of personal values at the end of life. Additional research focusing on different stages of disease progression for both patient populations may also reveal changing personal values through the transitions within the illness trajectories.

The theory of self-preservation developed by Calvin (2004) was derived from a grounded theory study involving 20 individuals undergoing hemodialysis for end-stage renal failure at outpatient centers in central Texas. Twelve individuals were interviewed and the results analyzed to identify themes and categories through a constant comparative method. Eight additional individuals were interviewed to validate the findings. Calvin identified three phases of the personal preservation theory.

In the first phase, knowing the odds for survival was characterized by patients who acknowledged the certainty of the nearness of death, but uncertainty regarding when and how they would die. In the second phase, defining individuality was expressed through the interaction of knowledge and beliefs. Knowledge about the medical plan for the end of life was mediated with their own stories of ‘beating the odds’ regarding their own illness events. During the third phase, the patients constructed their own meanings of
health and death. Their beliefs were characterized as optimism and faith in a higher force and consisted of two dimensions, including prayer and divine control. This final phase was expressed as accepting the situation and moving forward.

This conceptual model is limited to individuals with end-stage renal failure receiving hemodialysis. Continuing the grounded theory approach with samples of individuals experiencing other life-limiting illnesses as well as non-life-limiting illness could help verify this as a model limited to the specific population of ESRD on dialysis or further expand the model to be applicable to individuals with other life-limiting illnesses.

**Spirituality: Hope, meaning, and self-worth.**

Spirituality is defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski, et al., 2009, p. 887). Spirituality is often expressed in a person’s sense of self-worth and ability to see value in one’s life and relationships. For the purpose of this review, spirituality will also encompass the related concept of hope.

One’s sense of self-worth and value to others may fluctuate throughout the illness trajectory. As reported earlier, Murray, et al. (2007) found that with patients diagnosed with lung cancer, spiritual distress occurred at four different times: (a) at diagnosis when they experienced a sense of emptiness; (b) at the end of inpatient treatment when they questioned their self-worth and value to others; (c) as the disease progressed and they wondered what they had achieved in life and what they needed to accomplish before death; and (d) in the terminal phase accepting death and questioning whether they had
been good enough in case there was an afterlife. Those confident in their faith perceived death as a transition, not as an end. These researchers found that spiritual distress fluctuated in patients diagnosed with heart failure, and spiritual well-being gradually decreased as they experienced a progressive loss of identity and increasing dependence. Patients questioned their value and place in the world and searched for meaning with their increasing incapacitation.

Attention to meeting the spiritual needs of individuals at the end of life may influence the choice of hospice care versus aggressive treatment. Balboni, et al. (2010) reported the results of their Coping with Cancer study which investigated how psychosocial factors influenced end-of-life care and quality of life near death. They found that patients whose spiritual needs were largely or completely supported by the medical team had more than 3-fold greater odds of receiving hospice care at the end of life.

The Religion and Spirituality in Cancer Care study, a multisite, cross-sectional, mixed methods study of 68 adults with advanced incurable cancer, was conducted to establish an empirical basis for spiritual care (Alcorn, et al., 2010). Patient religiousness and spirituality were examined qualitatively using two items from a previously validated Fetzer Multidimensional Measure of Religiousness/Spirituality (R/S) for use in Health Research. The questions were: “Has religion or spirituality been important to your experience with your illness?” (Alcorn, et al., p. 582). Religious and spiritual concerns were examined both qualitatively and quantitatively. Qualitatively, they were asked: “What spiritual issues have you had as you have been dealing with your illness?” (Alcorn, p. 582). Pargament’s validated negative religious coping items were used to assess the patients’ struggles previously shown to be associated with decreased QOL. The
qualitative analysis included a multidisciplinary perspective and the use of reflexive narratives. Quantitative analysis was completed using an $\chi^2$ test and $t$ test, and Wilcoxon-Mann-Whitney Test. Potential predictors of spiritual concerns were analyzed by simple linear regression and ANOVA.

Five themes emerged from the qualitative analysis of the importance of R/S to the patients’ cancer experience: coping through R/S (74%), R/S practices (58%), R/S beliefs (28%), R/S transformations (20%), and R/S community (11%). Responses to the ways R/S facilitated coping included extended longevity, promise of potential cure, strength, meaning, comfort, acceptance, and emotional stability. The most frequent R/S practice important to their cancer experience was prayer. R/S beliefs were indicated in the patients’ references to R/S beliefs important to their cancer experience, including the importance of religion in their lives independent of cancer, beliefs in the afterlife, and beliefs in the spiritual, but not in religion. R/S transformation included expressions of a new or deeper reflection on faith and mortality, enhanced personal faith, increased involvement in faith-based activities, a heightened sense of companionship with a higher power, and greater appreciation for life and health. The R/S community referred to clergy or other spiritual supporters who put them on prayer lists and the importance of friends’ beliefs and support.

The strengths of this study were the mixed methods approach to data collection and analysis and the multidisciplinary triangulated method of data analysis. This approach and method revealed rich qualitative data evaluated from various professional perspectives (medicine, sociology and theology) and objective data that were evaluated for predictive value. The limitations of the study were the number and profile
characteristics of the sample. A larger sample would have greater generalizability related to correlation and predictive factors. The sample was selected from one region of the country and consisted primarily of Caucasians (85%) and Christians (54%). A more diverse population could reveal different results.

The paradox of hope in the face of death was the subject of a qualitative analysis by Elliot and Oliver (2009). They interviewed 28 patients with an awareness of a prognosis of less than three months. Their aim was to “explore not only how hope is perceived by patients approaching death, but also how hope is constructed in talk by and consequences to these patients” (Elliott & Oliver, p. 614). Three aspects of hope emerged in response to the questions, such as “Can you talk to me about hope?” and “What does hope mean to you?” (Elliott & Oliver, p. 614). They included (a) hope as essential to and for life; (b) hope, life, death, and others; and (c) hope changing during life. The participants referred to expressing degrees of hope as quantifiable. This degree of hope was often associated with the possibility of a cure. In summary, the comprehensive discussion of the discourse analysis results clearly provides a rich description of hopefulness in the face of impending death, with the hope for a cure expressed by the majority of participants. Even though this study was described as part of a larger qualitative study with the interview focusing primarily on euthanasia, alternative medicine, and perceptions of decisions to resuscitate a terminally ill patient following cardiac arrest, their discussion of the discourse analysis related to hope was comprehensive and informative.
Preserving and enhancing dignity.

Quality end of life focuses on preserving one’s dignity, self-identify, and connectedness with significant others. To be treated with dignity is to be treated with respect, to be considered worthy of the regard of others. Dignity is defined as “the quality or state of being worthy, honored, or esteemed” (Chochinov, et al., 2004). Dignity enhancement provides the rationale for all interventions focusing on quality end of life. Treating an individual with dignity requires, above all else, recognizing that this person is unique among all others, and even though their trajectory of illness is similar to others, their unique care needs must be addressed. When care that targets dignity becomes the model of the end-of-life care, the options may expand beyond the symptom management paradigm and encompass the unique needs of each individual experiencing the end of life.

The Dignity in the Terminally Ill Model has been developed and empirically tested over an eight-year period with terminally ill individuals (Chochinov, 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov, et al., 2004). The model has led to the development and testing of the 25-item Patient Dignity Inventory (Hack, et al., 2004) and the development of an intervention called Dignity Therapy (Hack, et al., 2010).

This model is based on a qualitative study that examined the dignity perceptions and concerns of 50 terminally ill cancer patients (Chochinov, 2002). The participants were recruited over a 15-month period from an outpatient and inpatient palliative care unit located in an urban extended care hospital. Of the 50 participants, 27 were outpatient and 23 were inpatient. A semi-structured interview was conducted to explore and detail
their perceptions of dignity and get their descriptions of how they were coping with their advanced cancer. Data were analyzed using latent analysis and constant comparative techniques, with analysis continuing until all categories were saturated. Three major categories emerged from the analysis, representing experiences where dignity or lack of dignity becomes a concern during the patient’s dying process. They included illness-related concerns (factors associated with the underlying illness), a dignity-conserving repertoire (psychological and spiritual considerations), and a social dignity inventory (social or externally mediated factors). Individuals with a diminished sense of dignity were more likely to experience psychological and symptom distress, heightened dependency needs, loss of the will to live, increased desire for death, depression, hopelessness, and anxiety (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002).

Additional studies were conducted to validate the Dignity in the Terminally Ill Model and develop and test the Patient Dignity Inventory (PDI) instrument (Chochinov, et al., 2006; Chochinov, et al., 2008; Hack, et al., 2004). Over a three-year period, 211 patients with end-stage cancer were recruited from two palliative care units to participate in an empirical study to validate the characteristics of the model (Chochinov, et al., 2006). They were asked to rate on a Likert-type scale of 1 to 5 (1 = strongly agree to 5 = strongly disagree) the extent to which their own personal dignity was related to 22 items derived from the model and representing psychological, physical, social, and existential issues. The patients were also asked to rate their sense of dignity on a 7-point Sense of Dignity item with 0 representing “no sense of lost dignity” and 7 representing “an extreme sense of lost dignity.”

The frequency of item endorsement was calculated across the 22 items with over
half endorsing 21 of them (the exception being thinking about how life might end); and 7 items were endorsed by more than 80% of the participants. After the participants were divided into two subsets, those with a sense of dignity intact (scoring ≤ 2 on the SD) and those reporting a significant fracturing of their dignity (scoring ≥ 3 on the SD), a forward stepwise regression was conducted to examine the predictive value of individual item endorsement with sense of dignity. This study was relevant because it represented the first validation of and support for the findings of earlier studies related to the Dignity Model. The limitations of this study included the convenience sampling method, the single diagnostic category included in the study, and the older age of the participants (average age being 67). Instrument validity and reliability were established using tests of face validity, internal consistency, test-retest reliability, and factor analysis (Hack, et al., 2004; Chochinov, et al., 2008). The factor analysis revealed that low quality of life, increasing levels of hopelessness/depression, and greater dependency on others for activities of daily living, were positively associated with a fractured sense of dignity (Chochinov, et al.).

This same group of researchers has developed Dignity Therapy which they describe as a “novel therapeutic approach designed to decrease suffering, enhance quality of life, and bolster a sense of dignity for patients approaching death” (Hack, et al., 2010). In protocol therapy, patients are asked to select and respond to any of a written series of nine core questions that are meaningful to them. The actual therapy session is scheduled for a few days later. This session is audio-recorded, transcribed and shared with the patient in a follow-up session for final modification. The patient is provided with a hard copy of the document. The research team reports that dignity therapy is considered
acceptable and valuable to most terminally ill patients (91%), enhancing the dignity of 76% of patients, and heightening life meaning in 67% (Hack, et al.). However, research needs to be conducted with this intervention before effectiveness can be established. In the meantime, research is continuing with other areas of dignity enhancement, including psychosocial and spiritual variables that influence QEOL under the general framework of dignity preservation.

Summary

In summary, do the known theories and research regarding end of life capture the essence of living with the certainty of death? Research has revealed that an awareness of dying may be accompanied by an ambiguity about one’s prognosis or an empowered sense of control for one’s own decision-making. While the ambiguity may be examined in light of the known essences of uncertainty that emerged through Penrod’s phenomenological research (2001; 2007), no research has described the essences of certainty. Therefore, any suggestion that the empowerment or enhanced control over decision making is an expression of living with the certainty of death is mere speculation.

One might assume that living with the certainty of impending death is inherent in the process of dying. Yet, at the same time, traditional stage, interval, and task theories with their seemingly sequential nature do not reveal any rhythmic pattern of certainty and uncertainty about death. Instead, they describe the patient’s progressive path toward acceptance of dying. Trajectory theories reflect the functional changes experienced by individuals with certain illnesses, but transitions experienced by individuals at certain points within these trajectories, with their accompanying descriptions of behavioral and socio/emotional changes, offer researchers an opportunity to explore the phenomenon of
certainty. Although transition research is increasing, investigations of transitions need to be expanded to various points within trajectories to provide an enhanced understanding of these processes that influence care of individuals experiencing terminal illnesses. The conceptual findings then need to be synthesized into a model that can provide guidance for caring for individuals at points within the illness trajectories.

An examination of variables contributing to quality end of life also could provide a framework for healthcare providers to understand what is meaningful and of value to individuals during these end-of-life transitions. Are the variables that describe quality end of life also the variables that describe living with the certainty of impending death? Does quality end of life contribute to a predominant sense of certainty while living with impending death? Is there a reciprocal relationship between quality end of life and certainty? These questions and many more would best be addressed by exploring this phenomenon of living with the certainty of death from the descriptions of those experiencing end of life.

The meaning of the phenomenon of living with the certainty of impending death exists within contexts; therefore this study sought to describe and interpret associated meanings of the experience of living with the certainty of one’s own dying with individuals who are aware of their expected death trajectory. A hermeneutic phenomenological approach seemed the most appropriate way to investigate the phenomenon of living with the certainty of impending death. The final section of Chapter 2 is designed to provide an understanding of the philosophical framework of phenomenology that guides the hermeneutic phenomenological method. This discussion
will frame the dialogical relationship that occurred between the researcher and the participants during the phenomenological investigation reported here.

**The Hermeneutic Phenomenological Approach**

Phenomenology is the metaphysical study of phenomena in general (*Oxford English Dictionary* Online, 2010). Husserl (1859-1938) is credited with establishing the fundamental principles of phenomenology and for the descriptive and transcendental approaches to it (Welton, 1999). Husserl (1927) defined phenomenology as the science of the essence of consciousness and emphasized the description of conscious experiences and the value of descriptive experiences to the scientific study of human motivation, since human actions are influenced by people’s perceptions of reality. Husserl’s phenomenological approach seeks answers to questions about the world and the objects within it. He attempted to do this by bringing to reflective awareness the natural events experienced in one’s natural attitude. “The natural attitude of everyday life, or the life world, is the original, pre-reflective, and pre-theoretical attitude” (van Manen, 1990, p. 7). Husserl believed in eidetic structures or universal essences, the common essences among people. The intent of the research is to identify commonalities or common essences in the experience of the participant, with a generalized description as the expected outcome.

Husserl (1927) took on the Kantian idiom of transcendental idealism, which refers to the process of turning away from any reality beyond phenomena. Husserl's interest in transcendental idealism also involved the method known as *epoché*, from the Greek meaning ‘abstaining from belief’ (Husserl, p. 127). He also proposed reductionism or bracketing, whereby the researcher holds in abeyance their own ideas, preconceptions,
and personal knowledge when listening to and reflecting on the lived experiences of the
research participants. In bracketing, one turns attention, in reflection, to the structure of
one’s own conscious experience. The result is the observation that each act of
consciousness is a consciousness of something that is, intentional, or directed toward
something.

While Heidegger and Merleau-Ponty both credited Husserl with introducing
phenomenology, they differed in their view of this philosophical approach. This section is
designed to provide an understanding of the phenomenological beliefs of Martin
Heidegger and Maurice Merleau-Ponty as background for the present study. Although
Heidegger’s theories were already discussed in Chapter 2, they were limited to “being-in-
the-world” and “being-toward-death” whereas this section discusses Heidegger’s and
Merleau-Ponty’s beliefs about hermeneutic phenomenology to provide a foundation for
understanding the use of this method in this study.

**Heidegger’s Hermeneutic Phenomenological Method**

Martin Heidegger introduced the hermeneutic phenomenological method in his
classic work *Being and Time* (1927). The researcher in this study used a 1996 translation
by Stambaugh of *Being and Time* to examine Heidegger’s philosophical assumptions
underlying hermeneutic phenomenology.

**Phenomenology**

According to Heidegger (1927/1996), phenomenology is ‘the science of
phenomenon’ and expresses the maxim “to the things themselves” (p. 28). It does not
characterize the ‘what’ of the objects of philosophical research in terms of their content,
but the ‘how’ of such research (Heidegger, p. 28). Heidegger viewed this type of research
as not merely a process of extracting themes and categories from data, but as a way to understanding human beings, what happens to them, and what meaning specific events or experiences hold for them. This approach, in turn, contributes to the understanding of the meaning of being human. Each search for understanding is guided by the unfolding of the content and context that speaks a language pertinent to the research.

According to Heidegger (1927/1996), to understand a phenomenon, we must first understand and establish the meaning of its two components, phenomenon and logos. The term phenomenon means “to show itself” (or self-showing) or “the totality of what can be brought to light” (p. 29). Phenomenon refers to a distinctive way an event can be encountered. Logos refers to the way in which the phenomenon is made manifest in speech. Logos has the fundamental meaning of “making manifest” or “letting something be seen as something”; therefore logos has the structural form of synthesis (p. 33). The synthesis of phenomenon and logos enables one to bring a distinctively encountered event into explicit view.

Logos lets something be seen, but since words may have various meanings to different persons, logos is viewed from a phenomenological perspective as either true or false. Being true means to take a phenomenon talked about out of concealment, to be seen as something unconcealed or uncovered. Truth is found in the simple sense as the perception of something. “Perception is always true” (Heidegger, 1927/1996, p. 33). From this it follows that being-false involves some kind of covering up or concealment or passing something off as something it is not.

Entities can show themselves in various ways, depending on the mode of access to them. Heidegger (1927/1996) describes three different ways that entities ‘show’
themselves, including: seeming (Ger., Scheinen); appearance (Ger., Erscheinung); and mere appearance (p. 29). A phenomenon can show itself as what it is not; it can be described as something else. This is called seeming or semblance (Heidegger, 1927/1996). Self-showing and semblance in a phenomenon are interconnected as both claim to show themselves in accordance with the meaning of the phenomenon. An example of seeming might be the distortions revealed when looking at one’s self in a concave or convex-shaped mirror. The body seems to be smaller or larger, but it is visible in its ‘factual way’ to the self. It just seems larger or smaller. In descriptive phenomenology, when describing an actual experience, the experience is a semblance of the phenomenon and therefore reveals the phenomenon. The description of Thomas’ experience of living with the certainty of death as described in Chapter 1 is an example of semblance. His way of preparing for his death, while simultaneously planning for his future, resembles the rhythmic characteristics of certainty and uncertainty.

Appearance is something that shows itself in such a way as to indicate something else that does not show itself. With this occurrence, Heidegger (1927/1996) explains, “their showing themselves goes together with being-present-at-hand” (p. 29). The manifestation of the phenomenon is viewed objectively. Heidegger explains this with the example of the symptoms of a disease. Symptoms are visible manifestations of a disease that does not show itself except through the symptoms. In this instance, the phenomenon is not delineated or defined, but is a hidden presupposition. Examples of appearance may also be found in literary and artistic expressions, since these are visible manifestations of a phenomenon that is not delineated, but is a hidden presupposition. One might recall an example of impending death presupposed in the work by the artist Boonma, who depicts
the theme of uncertainty with question marks, or the unknown, and a sense of hope and discovery by exclamation points.

Finally, mere appearance announces ‘the thing in itself’ in such a way that it can never, in principle, become manifest or appear (Heidegger, 1927/1996, p. 29). The appearance shines forth from the non-manifest in such a way that what is announced is essentially covered up. It describes the logos of being-false, which involves some kind of covering up or concealment or passing something off as it is not. Alicia’s response to her impending death, described in Chapter 1, represents the concept of mere appearance. Her behavior does not explicitly or visibly reflect the experience of living with the certainty of death. At the same time, it is important to remember that the meaning of living with the certainty of death emerges out of the one’s description of everyday experiences, the structure revealing what the individual cares about; and what seemingly does not appear to be certainty may, in fact, be the unique way in which one lives with and expresses the experience of living with the certainty of death in everyday life. True perceptions may only be revealed through an interpretation of the individual’s care structure, the expressed everyday experience.

Heidegger describes which entities are to be addressed as phenomena. The ordinary conception of a phenomenon is the object of intuitions, “that which is perceived” (Heidegger, 1927/1996, p. 30). It is an appearance, but falls under the formal concept of phenomenon in as much as it involves a kind of showing. The phenomena in the phenomenological sense do not simply show themselves; they show themselves unthematically, as descriptions of everyday experience. They must be brought to show themselves in a more direct (thematic) self-showing. A phenomenological investigation
attempts to thematize the unthematic manifestation of the phenomena. Given this structure, that being is for the most part something hidden and phenomenology is directed at the question of the meaning of being, the logos appropriate to this phenomenon has the character of interpretation. Hence, the way to gain access to this and make it manifest is through hermeneutics.

**The Hermeneutic Method**

Heidegger (1927/1996) formulated the hermeneutic method, which focuses on the interpretation of the meanings of human experience. Interpretation is the basic mode of being human. Humans are engaged in interpretative understanding that involves grasping one’s own possibilities for being within a situational context and against a background of significance. The existential analysis of being human begins with the account of everyday practical activities. These activities provide the data from which understanding and meaning emerge. Heidegger attempted to uncover the basic structures of human beings that make possible the everyday activities of particular human beings, but this is nothing else but uncovering the being of human beings.

Heidegger’s theory of interpretation begins with what he calls the forestructure, which involves a prior awareness—unnoticed and not yet described. The forestructure represents an intuitive pre-understanding or the contextual interpretation of a phenomenon at a point in time and space. There are three components of forestructure, including forehaving, foresight, and foreconception. Forehaving, which in German is *Vorhabe*, means intention and refers to the fact that in interpreting anything, an individual already has a tentative sense or idea of what is being interpreted (Heidegger, 1927/1996,
Intention is viewed as having a totality to it in the forestructure. It has a definite character and there is a unitary view of the full phenomenon.

Foresight is the literal translation of *Vorsicht* (Heidegger, 1927/1996, p. 150). Foresight means to look at something in an effort to understand the unifying character that holds the totality together. It is that which makes the parts cohere as a whole. Therefore, to interpret a phenomenon, one must approach it by looking at the whole.

Foreconception, or *Vorgriff*, usually refers to being able to conceptualize the object (Heidegger, 1927/1996, p. 150). The conceptualization is sometimes seen as recognizing the structure of the object being interpreted. Foreconception emphasizes the perception of the distinct parts, which make up the whole. In hermeneutic phenomenology, interpretation occurs as the unity of the totality of the structurally manifested entities of the phenomenon is revealed.

When the researcher writes about a phenomenon, the forestructure is constituted by their entire history, including cultural conventions. The investigator has an expectation of what will be uncovered, which is included in the unifying whole. Against this background the phenomenon is to be interpreted. “Meaning … gets its structure from a fore-having, a foresight, and a fore-conception” (Heidegger, 1927/1996, p. 151). Any investigation takes a long look into one’s past. It sorts out related phenomena, meanings, and structures encountered in the past, which are similar or different from the phenomenon currently being interpreted in an attempt to understand the present phenomenon. One’s past enables the researcher to see the phenomenon as a whole separate from other wholes, a complex structure with interrelated parts. Therefore, Heidegger rejected the notion of the bracketing described by Husserl. Heidegger believed
bracketing to be inconsistent with being-in-the-world where the meaning of a phenomenon was interpreted in the everyday context of researcher and participant.

**The Question of Being**

As stated earlier, Heidegger studied the phenomenon of being, which he referred to as Dasein. Dasein always understands itself in terms of its existence, in terms of its possibility to be itself, or not to be itself. Existence is decided only by each Dasein itself in the manner of seizing upon or neglecting such possibilities.

Being cannot be understood by comparing it with individuals or things. It is not an entity; nor is it a property of an entity. The nature of individuals is to obscure the essential nature of being within an everyday understanding. When talking about everyday experiences, individuals are always concerned about being, although they are not aware of it. This everyday understanding is pre-ontological.

Phenomenological research involves interviewing individuals about their experiences of living a phenomenon. It reveals their everyday pre-ontological experiences, but these descriptions do not explicate the authentic nature of the phenomenon and the meaning of Being. It is therefore the purpose of the researcher through hermeneutic interpretation to reveal the authentic nature of the phenomenon, which will contribute to answering the question about the meaning of Being.

According to Heidegger (1927/1996), to formulate and answer the question of Being, one must first discuss what belongs to a question in general; then explicate the questions of Being in regard to three characteristics of them: (1) What is in question? (2) What is the issue? and (3) What is interrogated? In asking ‘What is in question’, he explains that every questioning is a seeking; and each seeking takes its direction
beforehand from what is sought” (Heidegger, p. 5). In other words, to ask the question you must first know something about the answer. This is consistent with the idea of an average, everyday understanding or self-evidence of the phenomenon. An average everyday understanding is the pre-ontological understanding of the phenomenon. In regard to the question of Being, its meaning must be available to individuals as a certain everyday understanding. As Heidegger states, “We always conduct our activities in an understanding of Being” (p. 5). When asking ‘What is Being?’, we have an everyday pre-ontological understanding of Being without understanding it conceptually or ontologically. We also do not know the context in which we are expected to grasp the meaning. We may not be aware of this everyday understanding, or we may have an everyday understanding based on traditional theories and opinions. Only when we can grasp the conceptual understanding does the everyday understanding become clear. The ontological distinction of being (the everyday description) and Being (the conceptual understanding) provides a direction for interrogation.

The second characteristic of the question, ‘What is the issue?’, refers to the aim of the question. The Being of entities itself is not an entity. It does not mean telling a story and tracing their origins back to another being. Being does not have the character of another being. Being requires its own demonstration.

Finally, ‘What is interrogated?’ also belongs to the question. Entities are interrogated with regard to their being. “The right way of access to entities needs to be obtained and secured in advance with regard to what will lead to Dasein” (Heidegger, 1927/1996, p. 7). Dasein includes inquiring as one of its possibilities of being. There are particular ways of behaving that constitute the inquiry. These include looking at
something, understanding and conceiving its meaning, choosing the right exemplary being or entity, and elaborating on the genuine mode of access to this entity (Heidegger). The inquirer must choose a way of access so that this entity can show itself in itself and from itself. This means that it is to be shown as it is proximally and for the most part in its average everydayness.

When structuring the question of the meaning of Being, there is a circularity in the structure (or elements) of the question, in that seeking is directed toward what is sought; but seeking is also guided in advance by what is sought. This circularity relates to the back-and-forth nature of the relationship between the question and the questioner. It is a circularity moving in the context of interpretation. Heidegger describes the circularity of the interrogation as determining “the nature of entities in their being beforehand and then on this foundation first poses the question of Being” (Heidegger, 1927/1996, p. 8). Entities can be determined in their being without the explicit concept of the meaning of Being having to be already available. The question of the meaning of Being has a relatedness backward and forward. In other words, what we are asking about is a mode of being an entity. There is a special way in which entities with the character of being are related to the question of Being. We are always involved in the pre-ontological everyday understanding of being, which ultimately belongs to the essential constitution of Being itself.

To understand the meaning of Being is to create a fundamental ontology. Heidegger (1927/1996) does this by examining Dasein’s being-in-the-world which gives access to the being of other entities and allows them to show themselves as they really are. Heidegger emphasizes that the manner of access to being is through Dasein’s average
everydayness and that the aim of this access is to expose the horizon (or context) for the most elemental interpretation of Being. In this everydayness, essential structures will be demonstrated, structures that remain determined in every mode of being of factual Dasein. “By having regard for the basic state of Dasein's everydayness, Dasein’s Being is brought out in a preparatory fashion” (Heidegger, p. 17). Through this analysis of Dasein, the horizon is exposed and the ontological analysis of Dasein’s Being can begin. The horizon provides the limits for the understanding of Being. According to Heidegger, temporality is a horizon for all understanding of Being. Individuals are temporally situated in the world and become embedded in real-life experiences as they unfold in their everydayness.

Meaning

When entities in the world are discovered along with Dasein, they are said to have meaning (Heidegger, 1927/1996). Meaning is that which can be articulated in a disclosure that is understood and gets its structure from a forehaving, a foresight, and a foreconception. Meaning is an existentiale of Dasein, not a property attached to entities. Dasein only has meaning insofar as the disclosedness of being in the world can be “filled in” and by the entities discoverable in that disclosedness (Heidegger, p. 151). Therefore, only Dasein can be meaningful or meaningless.

Merleau-Ponty’s Perspective on Phenomenology

Merleau-Ponty (1962/2004) presented a view of phenomenology that captures the essence of humankind’s interrelatedness with the world in *The Phenomenology of Perception*. Smith’s (2004) translation was used here to examine the philosophical assumptions underlying Merleau-Ponty’s hermeneutic phenomenology.
Phenomenology offers accounts of experiences as they are described. According to Merleau-Ponty (1962/2004), the world is “always already there before reflection begins” (p. vii). Therefore, the focus on experience in phenomenology is a focus on human involvement in the world.

Perception is recognized as one’s own reality. It is this perceptual evidence that is considered to be the foundation of science and knowledge. From a phenomenological perspective, perception is the background from which all acts stand out, and is presupposed by them (Merleau-Ponty, 1962/2004). Individuals are not products of the environment. Instead, they are enmeshed in the environment and discover their world by electing to carry on traditions, choosing horizons, and giving meaning to selected objects in the environment. While cognitive thoughts and spoken language provide representations of the world, perception provides access to an experience of the world as it is given prior to any analysis of it.

**Intentionality**

According to Merleau-Ponty (1962/2004), intentionality means that consciousness is the consciousness of something. To be conscious is to be conscious of seeing something, hearing something, and feeling something. Merleau-Ponty believed that the unity of the world, before being posited by knowledge in a specific act of identification, is lived as ready-made or already there. All actions are meaningful, although individuals are not automatically conscious of their intentional relation to the world and its meaning. Intentionality is only retrospectively available to consciousness. Individuals must delve into the existential meaning that emerges with each perspective.
Merleau-Ponty (1962/2004) also discussed the concept of bracketing, as it was previously by used by Husserl and Heidegger. Merleau-Ponty regarded bracketing in relation to intentionality and emphasized that the researcher must be aware of their own intentionalities during a study, explicating what is meaningful about the phenomenon being investigated. Alluding to Husserl’s (1927) concept of bracketing (or reduction) as holding in abeyance ideas, preconceptions, and personal knowledge when listening to and reflecting on the lived experiences of research participants, Merleau-Ponty added that the most important lesson that reduction teaches us is the impossibility of a complete reduction. He emphasized, instead, that without consideration of one’s own awareness of the experience with its historical sense and preconceived ideas, the other “will be no more than an empty word” (Merleau-Ponty, p. xv). Therefore, consistent with Heidegger, Merleau-Ponty emphasized including consideration of one’s own preconceived ideas and history in the interpretation of a phenomenon.

**Embodiment**

The body is one’s entrance to being in the world. In other words, humans experience the world through the body. All spatial and temporal perspectives center on the body and involve all the senses. These sensory-perceptual processes cannot be reduced and objectified. Merleau-Ponty (1962/2004) considered the body to be “a living organism which rises toward the world and the possibilities of the world” (p. 87). Being a body is having certain projects and being continually committed to them. Palliative care patients in a study conducted by Larkin et al. (2007a) often discussed their disease progression and decreased functional abilities when asked about the meaning of being transferred to a palliative care facility. One individual stated, “I don’t think I’ll ever be
able to go home. I can’t put weight on this foot at the moment. Personally I don’t know if I’ll ever be able to walk on it” (Larkin, p. 73). While this individual knew his admission to the palliative unit was for end-of-life care, he perceived and framed this experience as the inability to walk, still thinking about walking. Bodily experience is always in a particular and unique situation within the world (or being within the world), and this relation establishes the framework of one’s experience.

**Space**

Spatiality is an important concept closely related to perception and embodiment. Spatiality does not refer to localizing points in space or saying, ‘I am two feet from the person sitting across the table with whom I am talking and trying to understand an important concept.’ Spatiality is defined more by the interaction with the other from one’s own corporeal position. As Merleau-Ponty (1962/2004) states, “Space is not the setting in which things are arranged, but the means whereby the position of things become possible” (p. 284). Space connects all things. If a person across the table is trying to explain a concept and I cannot grasp what they are saying, I feel distant from that person. This may be reflected in bodily movements facial expressions, silence, focusing attention on other thoughts, or feeling the anxiety that is manifesting itself in an inability to hear the other’s words. In contrast, if the other is speaking and I finally grasp and share the meaning of their words and thoughts related to the concept being discussed, I may experience a sense of ‘aha’ which is manifested in a sense of overwhelming relief, an expression of relaxed joy, and a sense of connectedness with the other.

A conversation between Susie, the nurse, and Vivian, the patient, in the one-act play *Wit* (Edson, 1999) demonstrates the connectedness of spatial relations when these
two came together in conversation and developed a trusting relationship. Vivian pinched her IV tubing to set off the alarm and cause the nurse to come into her room.

Susie: Ms Bearing? Is that you beeping at four in the morning?
Did that [occluded IV tubing] wake you up?
Vivian: I was awake….
Susie: You can’t sleep?
Vivian: No. I just keep thinking.
Susie: If you do that too much, you can get kind of confused.
Vivian: I know. I can’t figure things out. I’m in a quandary, having these… doubts.
Susie: What you are doing is hard.
Vivian: Hard things are what I like best.
Susie: It’s not the same. It’s like it’s out of control isn’t it?
Vivian: (crying, in spite of herself). I’m scared. (Edson, pp. 64-65)

Susie continued to sit with Vivian, honestly addressing her concerns and questions regarding the effectiveness of her experimental treatment and alternatives. The conversation eventually moved to the question of whether or not Vivian wanted a full code if her heart stopped. At the end of the conversation, Vivian said, “Let it stop.” Then she asked Susie if she would continue to care for her. A relationship that was once very clinical and distant, and focused on aggressive treatment, became one of trust and confidence in knowing that they were both moving toward the same goal, comfort care for Vivian.
Time

Time is not viewed as a succession of seconds, minutes, and hours, but rather in relation to things or a situation. “Within things themselves, time is in a kind of eternal state or pre-existence and survival” (Merleau-Ponty, 1962/2004, p. 478). Past, present, and future are horizons of meaning. What is past or future is present in the world. The horizon is the body inhabiting the regions of the landscape with a history that then comes back into the perception. Habit is the history of ways individuals come to be in the landscape. The past is wholly caught up and grasped in the present bodily context, and the future has its horizon of immanence. One’s present is seen as the future of the past. The present possesses past and future only in bodily intention, for the past one claims to recapture is not the real past, but the past as one now sees it.

Regarding time, Merleau-Ponty (1962/2004) states, “When individuals recall a remote past, they reopen time and carry themselves back to a moment in which it still had before it a future horizon now closed, and a horizon of the immediate past which is today remote” (p. 483). Time is not linear, but rather a network of intentionalities. The past and the future spring forth when one reaches out to them.

Reflection is a way the past becomes the present and takes on new meaning. The meaning expressed about past events is always relative to the present situation, as well as one’s perceived future. Like a helix which changes its shape and direction as each spiral twists and turns, the past influences the perceived meaning of the present situation, while the present is reciprocally giving new meaning to the past based on the current context. At the same time, the individual is simultaneously making choices about the future that reflect the meaning of the current situation.
This interrelating of past, present, and future are revealed in the thoughts and feelings expressed by Tolstoy’s Ivan Ilyich in *The Death of Ivan Ilych* (1828). During the loneliness of his final days, even when surrounded by friends and family, Ilych “lived in the memories of his past” (Tolstoy, 1828, p. 66). Tolstoy explained that these memories always began in the nearest time, within the context of Ilyich’s current situation, such as when thinking of the stewed prunes offered to him that day, and his memories went back to what was most remote—his childhood and “rested there” until it was too painful. He would then bring himself back to the present and think of the details of the sofa that he lay on. There was a merging of “what was good in life and more of life itself” (Tolstoy, 1828, p. 66). From this context Ilyich could also see himself flying into a future of increased suffering toward the end. During Ivan Ilych’s last days, he suffered with great agony, feeling as though he was being thrust into the “black sack” of death while trying to resist because of his conviction that his life had been a good one. As Tolstoy states, “This very justification of his life held him fast and prevented him from moving forward, and it caused him the most torment of all.” As long as Ilych maintained the belief that his life was good and that this should not be happening to him, he could not go willingly into the “black hole” of death (Tolstoy, 1828, p. 72). The past he had so frequently visited in recent weeks had been defined as a good one from his current context. It was only when he fell into the black sack of death and saw that his life was not what it could have been, but could be rectified, was he able to express his concern and caring for his family and move from the darkness of regret into the light with a sense of joy. In conclusion, when describing an experience, a person is opening a window to the past that gives meaning to the present and possibilities for the future.
In summary, Heidegger and Merleau-Ponty offered approaches to viewing persons and relatedness to the world as they search for the meaning of their existence. Heidegger’s Dasein means “being-there”, signifying that it is not being in a specific place, but always a unified being-in-the-world. Dasein transcends the situated world, although one accesses Dasein by everyday experiences of the situated world. The focus in phenomenology is also the individual’s care structure, the person’s world of concerns as described in everyday experiences. Merleau-Ponty (1962 /2004) believed that the body is one’s entrance to being in the world and that all spatial and temporal perspectives center on the body and involve all the senses. The focus of hermeneutic phenomenology is in accessing the lived experience through an analysis of the participant’s lived body, lived spatiality, lived temporality, and lived human relations.

Regardless of which philosophical approach one assumes when conducting phenomenological research, the aim remains the same: to gain a deeper understanding of the meaning of the everyday experience (van Manen, 1990). This understanding of individuals’ ways of living with and perceiving the world enables the investigator to conduct the inquiry through a hermeneutic phenomenological approach and to “uncover and describe the structures, the internal meaning structures, of lived experience” (van Manen, p. 10). Phenomenology was the most appropriate method for an interpretative investigation of the phenomenon of living with the certainty of impending death for the present study.
CHAPTER 3

Method

The purpose of this study was to explore the lived experience and associated meanings of living with the certainty of death among individuals enrolled in hospice care. This chapter includes a description of van Manen’s (1990) methodological approach to hermeneutic phenomenology, followed by a description of the protocol applied in the 2007 feasibility study (Phase I). The research protocol for Phase II (i.e., study design, sampling, data collection, and analysis processes) is then discussed. Finally, the procedures used to ensure human subject protection and trustworthiness of the research are described.

Van Manen’s Hermeneutic Phenomenological Approach

A hermeneutic phenomenological approach as described by van Manen (1990) was used in this two-part study to answer the research question: What is the experience of living with the certainty of death among individuals enrolled in hospice care? The phenomenological method was used for this study because it enabled the researcher to come to a greater understanding of what it means to uniquely live the one experience common to all persons—the certainty of death—while taking into account the sociocultural and historical traditions that contribute to the uniqueness and the commonality of this experience.

Van Manen’s (1990) hermeneutic phenomenological method was selected for this study because it is interpretive and emphasizes dwelling with the phenomenon through a reciprocal process of dialogue with the subject and reflection on their experience. Van Manen describes interpretive research as a systematic search for deep understanding of
the ways in which an individual experiences the world. He developed a systematic methodological structure that has a dynamic interplay of six research activities, including (a) turning to the nature of lived experience, (b) investigating experience as we live it, (c) hermeneutic phenomenological reflection, (d) hermeneutic phenomenological writing, (e) maintaining a strong and oriented relations, and (f) balancing the research context by considering parts and wholes (p. 30). Van Manen emphasizes the dynamic interplay of these research activities, indicating that they should not be viewed or used as a sequence of procedural steps. With this in mind, each of the six activities that structured the process of sampling, data collection, analysis, and reporting as employed in this study is discussed.

Turning to the Nature of the Lived Experience

According to van Manen (1990), the lived experience is the starting and ending point of phenomenological research. Although an individual continuously experiences a non-thematic, non-reflective consciousness of daily life, their lived experiences gather hermeneutic significance as they reflectively gather them by “giving memory to them” (van Manen, p. 37). Lived experiences have temporal characteristics in that they can only be reflected on as past experiences. Their meaning can never be grasped in their fullness and richness because it pertains to past experiences.

The aim of phenomenology therefore is to transform the lived experience into a textual expression of its essence. Meaning is assigned to the experience through a description of the lived experience. The questions posed must be explicit and focused, and formulated in such a way as to encourage a rich description of the experience. Finally, when focusing on the nature of the lived experience, it is also important to
explicate certain assumptions and pre-understandings. As van Manen (1990) states, “The problem of phenomenological inquiry is not always that we know too little about the phenomenon, but that we know too much” (p. 46). Investigators must be careful to avoid interpreting the nature of the phenomenon before and during the study.

**Investigating the Experience As We Live It**

The world of the lived experience is both the source and object of the research, so the investigator must use multiple data sources for material about it. These can include personal experiences, etymological sources, idiomatic phrases, interviews, observations, experiential descriptions of the literature, biographies, diaries, journals and logs, art, and phenomenological literature.

**Using personal experiences as a starting point.**

Using their own personal experiences as a starting point provides the researcher with an opportunity to review and write about their own reflections on experience in light of the research question. The researcher examines this experience in order to be aware of their own meanings of it and to realize that it could be the experience of others and provide clues for orienting their self to the phenomenon under study.

**Tracing etymological sources.**

Van Manen (1990) emphasizes the importance of being attentive to the etymological origins of words used to refer to a phenomenon. He suggests that words often lose their original meaning over time and that attentiveness to their origin may put the researcher in touch with “an original form of life where the terms still had living ties to the lived experience from which they sprang” (p. 59).
Searching for idiomatic phrases.

Idiomatic phrases are those born out of the lived experience. The researcher must be attentive to the multiple possible uses and interpretations of the linguistics of the phenomenon and “hold onto the verbal manifestations that appear to possess interpretive significance for the actual phenomenological description” (van Manen, 1990, p. 62).

Obtaining experiential descriptions of others.

The experiential descriptions of the individuals living the phenomenon are essential to the hermeneutic phenomenological process. These descriptions inform, shape, and enrich the experience and enable the researcher to “render the full significance of its meaning” (van Manen, 1990, p. 62). In eliciting information from informants, the researcher is less interested in reporting the ontic (concrete) experiences and particular viewpoints of individuals and more interested in coming to understand the deeper ontological meaning of the phenomenon being studied as an essentially human experience. The experiential descriptions may be obtained from the participants by three different activities: protocol writing, interviews, and observations.

Protocol writing. Van Manen (1990) suggests that study participants be encouraged to initially write their experiences down for the purpose of generating original texts from which the researcher can work. In their writing, the participants are asked to provide a description of the experience as an example of how it was lived. This includes describing their feelings, moods, and emotions, and focusing on the experience using all of their sensory data.

Interviewing. Van Manen (1990) describes specific purposes of the interview. It may be used to gather experiential narrative material that will serve as a resource for
developing a richer and deeper understanding of a human phenomenon; or it may be used to develop a conversational relationship with the participant. The participant is typically asked to relate a story or incident describing the phenomenon, then asked questions to encourage providing the fullest description of the experience possible.

**Observing.** While interviewing the participant, it is important to closely observe their non-verbal cues and the surrounding environment that may enhance an understanding of their experience. The researcher should keep a record of cogent anecdotes that may be used later when looking for emerging themes from narrative and written data.

In addition to protocol writing, interviews, and observations, other resources for experiential descriptions can be used, including diaries, logs and journals; literature, biographies and art; and consultation with phenomenological writings.

**Hermeneutic Phenomenological Reflection**

The purpose of phenomenological reflection is to contemplate the essential meaning of a phenomenon. This is accomplished through analysis of themes, which van Manen (1990) refers to as the “experiential structures that make up the experience” (p. 79). According to van Manen, theme analysis refers to “the process of recovering a theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (p. 78). The hermeneutic process involves a systematic analysis of the whole text, including a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts as well as an understanding of the whole in relationship to its parts.
**Hermeneutic Phenomenological Writing**

In hermeneutic phenomenological research, writing is not only the outcome, but also part of the process of the study. Writing, as a method of phenomenology, “fixes thought on paper” and externalizes what was internal and makes the lived experience reflectively understandable (van Manen, 1990, p. 125). It is a reciprocal process of separating us from what we know and, at the same time, uniting us more closely with what we know; distancing us from the life world, while simultaneously bringing us closer to the life world.

Writing is an important component of van Manen’s approach. He emphasizes that the phenomenological method consists of the “art of being sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak” (van Manen, 1990, p. 111). One subtle undertone of language that can be powerful as well as limiting is silence. Van Manen suggests various categories of silence operating in human science, including literal, epistemological, and ontological silence. Literal silence, or the absence of speaking, may be effective in eliciting a reflective response; or in the process of writing, communicating textual quality by leaving certain things unsaid rather than writing too much and focusing merely on communicating information.

Epistemological silence is equivalent to tacit knowing, whereby an individual may have knowledge but is unable to express it in language. At these times, “what remains beyond one person’s linguistic competence may be put into words by another … such as a philosopher, poet, or fiction writer or a person with a certain verbal talent” (van Manen, 1990, p. 113); it may be expressed better in another type of discourse; or it may
be better captured in the next moment of conversation. Finally, ontological silence may be the sense of feeling speechless following those moments of greatest insight and meaning.

**Maintaining a Strong and Oriented Relation**

Van Manen (1990) emphasizes the need to relate the findings to the standard of one’s own work. The researcher must remain strong in an orientation to the fundamental question and take care not to become side tracked. The text must be oriented, strong, rich and deep.

**Balancing the Research Context by Considering Parts and Wholes**

One must constantly measure the overall design of the study against the significance that the parts must play in the total textual structure. Throughout the study, the researcher must step back and look at the total and how each contextual part contributes to the total. In regard to planning the research study, van Manen (1990) emphasizes that the researcher must find approaches and procedures uniquely suited to the project and the individual researcher. He suggests several ways to structure the research study. The researcher may engage in any or all of these at different phases of the project. One may structure it thematically, using the emerging themes as generative guides for writing the research study. A second structural approach is the analytic, whereby in-depth interviews may be reworked into reconstructed life stories or analyzed for relevant anecdotes, including only information that highlights a theme. The theme becomes the hermeneutic tool by way of which the phenomenon under study can be meaningfully understood. A third approach is called “exemplificatively” (van Manen, 1990, p. 170) and is described as beginning the description by “rendering visible the
essential nature of the phenomenon and then filling out the initial description by systematically varying the examples” (van Manen, p. 171). Each variation is intended to enlighten some aspect of the phenomenon. A fourth approach is to engage one’s writing in a dialogical or exegetical fashion with the thinking of some other phenomenological author. The discussion is organized around the identified text of the tradition and the structural themes that have been identified and discussed by the author. The final suggested approach is existential and involves weaving one’s own phenomenological description with the existentials of temporality, spatiality, corporeality, and sociality. Regardless of the approach or combination of approaches, van Manen reminds us that research as writing is an original activity.

**The Feasibility Study Protocol**

A study was conducted in May 2007 to assess the feasibility of conducting a research investigation with end-of-life participants enrolled in hospice care. This study was conducted under an IRB-approved modification of the study, which was titled Living With Uncertainty: Caregiving at the End of Life. Since the terminally ill are a vulnerable population, the feasibility study (Phase I) was conducted to identify any problems related to recruitment and data collection for Phase II of the study. Inclusion criteria were that the subjects be adults aged 18 or older; diagnosed with an illness that is terminal; and able to converse in English.

The participants in the feasibility study were five hospice patients: three males and two females, ranging in age from 70 to 92. One participant had been diagnosed with inoperable lung cancer, and the remaining four with congestive heart failure. The two
participants with congestive heart failure (CHF) had also been diagnosed with chronic obstructive lung disease (COPD).

**Recruitment**

One regional office of the hospice agency in central Pennsylvania was used for recruitment of the participants. The researcher explained the study during a scheduled meeting with the office coordinator and one hospice nurse. The coordinator agreed to share this information with the other hospice nurses at the next staff meeting to engage them in recruitment. A written description of the interview purpose, eligibility requirements, and recruitment procedures was distributed to all of the hospice nurses in the office. The coordinator designated the hospice nurses as the individuals responsible for approaching their patients about being interviewed. The patients who agreed to participate were asked to complete an Agency Authorization to Release Information Form; the nurse then notified the researcher of the availability of a completed form, and she would pick up the form and the participants’ contact information at the hospice agency. She then called the prospects to ask them to participate in interviews for the study.

Within a week following the staff meeting, two participants were recruited for the feasibility study. Two additional participants were recruited within the next month, but one was discharged from hospice before a face-to-face meeting with the researcher could be arranged.

Three additional patients were recruited into the study, but one died before a face-to-face meeting could be arranged. Thus, a total of five participants was recruited for the feasibility study (See Table 1, *The Feasibility Study*, for a list of participants, P1-P5).
No additional patients were recruited for the feasibility study following procurement of the fifth participant, even though the researcher made repeated phone calls to the coordinator. It was later learned during a meeting with the hospice director that a communication breakdown had occurred between the office coordinator and the hospice nurses. The hospice nurses stated that they were unaware that additional patients could have been recruited.

In summary, the participants were being approached and agreeing to participate during active recruitment for Phase I, so recruitment of willing patients for Phase II of the study was not expected to pose a problem.
Table 1

The Feasibility Study, Phase I

<table>
<thead>
<tr>
<th>Participant</th>
<th>Interview #1</th>
<th>Audio recording Protocols</th>
<th>Interview #2 (When collecting recorder) &amp; Interview #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>X</td>
<td>4 recordings</td>
<td>X X</td>
</tr>
<tr>
<td>P2</td>
<td>X</td>
<td>2 recordings</td>
<td>Visitors in the home X</td>
</tr>
<tr>
<td>P3</td>
<td>X</td>
<td>3 recordings</td>
<td>Too ill to talk Hospitalized and died</td>
</tr>
<tr>
<td>P4</td>
<td>X</td>
<td>Refused to record</td>
<td>Hospitalized on day of scheduled interview and died</td>
</tr>
<tr>
<td>P5</td>
<td>X</td>
<td>1 short attempted recording</td>
<td>X</td>
</tr>
</tbody>
</table>

Feasibility Sub-total 5 10 4

Data Collection Protocol

The data collection protocol for the feasibility study was written to include at least two interviews that had been arranged with each consenting participant, to take place within a 10-day to 3-week time frame. At the start of the data collection, no more than two interviews were to be scheduled with the participants in a week. All the interviews were conducted and audio-recorded by the researcher in the participants’ homes. Prior to the first interview, they each signed an informed consent form.
Interview #1.

The first interview was expected to take approximately one hour. Initially, the researcher informed the participants that if they became too tired or did not feel well enough to continue, they could tell her, and she would stop the interview.

Each interview started with a broad, open-ended question such as “Can you tell me about your illness?” or “Can you tell me about your illness and your decision to receive hospice care?” The participants spoke freely about their illnesses and about their impending death. An interview guide the researcher had prepared adequately provided additional questions and probes to focus the discussion. Four of the five interviews exceeded the one-hour designated time. The researcher asked each participant if he/she would like to stop at the one-hour point, but in each case they stated that they wanted to continue talking. However, no interview exceeded 90 minutes (See Table 1 for frequency of participants P1-P5 for Interview #1).

Audio-recorded protocol.

Each participant was then provided with an audio recorder to communicate any thoughts and ideas they had during the week following the initial interview. The following written instructions were provided: “Please select a time each day to record any thoughts, feelings, changes or experiences. Feel free to discuss whatever you are thinking or feeling at the time.” Instructions were also provided for operating the audio recorder. The researcher called the participants after a couple of days to check on their progress with the recordings and to ask if they were having any difficulties with the recorders or had any questions about completing the recordings. At the end of week #1, the researcher returned to retrieve the recorders and conduct a 30-minute interview to discuss the
themes she had identified following the initial interview. There were various responses to the use of the audio recorder, although one participant refused to record anything.

- Participant #1 spoke at great length over a four-day period about his experience of knowing he was going to die.

- Participant #2 completed two long recordings on the first two days. In the initial recording, she talked about death and her feelings about dying. During the second day’s recording she repeated some of the information from the first day, and spoke at great length about her political views.

- Participant #3 completed three short recordings on the first three days. On all three recordings he spoke about how great the hospice nurses were who cared for him.

- Participant #4 refused to keep a recorder.

- Participant #5 turned on the recorder and stated her name, then turned it off. She later stated that she did not know what to say and did not want to continue with the recording (See Table 1 for frequency of participants P1-P5 audio-recording protocols)

**Interview #2.**

The second interview was scheduled on the day the audio recordings were being retrieved from the participants. A 45-minute, face-to-face interview was conducted with Participant #1. Participant #2 had several unexpected visitors in the home; therefore, the interview was conducted at another time. Participant #3 was too ill to talk. The final interview was scheduled with Participant #5 on the day the recorder was retrieved, since
she had not used the recorder herself (See Table 1 for frequency of participants P1-P5 in Interview #2).

**Interview #3.**

A third interview was conducted with two participants after the data from Interview #1 and the audio recording protocols were transcribed and reviewed for possible themes. These interviews lasted 30 to 45 minutes. The themes were shared during Interview #3 and the participants had an opportunity to elaborate on the meanings of them. Interviews were completed with Participants #1 and #2. However, Participants #3 and #4 were each hospitalized on the scheduled interview date and subsequently died (See Table 1 for frequency of participants P1-P5 in Interview #3).

**Analysis**

During data analysis, the researcher highlighted statements and phrases in the interview and audio recording transcripts that revealed the themes of the phenomenon of the experience of living with the certainty of death that had emerged. The identified themes were shared with the participants in subsequent interviews so that they could reflect on their own experiences and explore their deeper meanings.

After the initial interviews, a meeting was scheduled between the researcher and two experts in qualitative research methods. The purpose of this meeting was to review and critique the researcher’s interviewing style. The experts reviewed the transcripts for two of the participants, including one opening interview and one later interview that demonstrated the researcher’s hermeneutic stance. They provided recommendations for enhancing the quality of the interviews and the examination of the data for themes. The
data generated in the feasibility study were judged to be of high quality and integrated into the Phase II data set during final analysis.

**Insights Derived From the Feasibility Study**

Following her review of the recruitment and data collection procedures, the researcher made minor revisions in the recruitment and protocol for Phase II of the study.

**Revised recruitment recommendations.**

Recruitment during the feasibility study was slow after the initial weeks. This may have been related to the limitations of recruiting from only one office in the hospice agency and to the lack of direct communication between the researcher and the staff who were recruiting.

During a meeting with the vice president of the hospice agency, it was agreed that when Phase II of the study commenced, two offices within the agency would be utilized for recruitment. In addition, the researcher would be invited to a scheduled monthly staff meeting at each office to maintain a presence and remind the nurses about participant recruitment activities.

**Revised data collection protocol.**

The 10-day to 3-week time interval for the interviews was too long for these individuals who were ill and at the end of life, as they might succumb before finishing the interviews. After all, two had done so during the feasibility study. Therefore, a proposed revision for this protocol was to schedule 2 interviews within a 3 to 5-day interval. The participants would audio record for three days following the first interview. The recorder would be collected at the end of the third day, and a follow-up interview would be scheduled on approximately the fifth day. New participant interviews would be scheduled
approximately two weeks apart to provide time for the researcher to transcribe and review all the data from the previous interviews, and to create and/or refine a description of the phenomenon of living with the certainty of death. The interview guide would continue to be used during the first three or four initial interviews, since it prompts discussion of experiences of living with the certainty of death. As subsequent interviews progressed to a more hermeneutic stance, this interview guide would no longer be needed.

**Phase II Research Protocol**

Phase II of the study was initiated in June 2011 following Institutional Review Board Approval. Following van Manen’s (1990) systematic methodological structure, the researcher applied his six research activities to this phase of the study (See: Van Manen’s Hermeneutic Phenomenological Approach described earlier). The first two activities were applied in preparing for this study; hermeneutic phenomenological writing was ongoing throughout the study; and the remaining three activities were applied during the interrelating processes of sampling, data collection, and data analysis.

Turning to the nature of lived experience was presented in Chapters 1 and 2 as the background on the phenomenon of living with the certainty of death was described from philosophical and theoretical perspectives, and a review of research in the area of death and dying was examined. Investigating the experience as previously known was accomplished through an explication of the researcher’s own pre-understandings of the experience, also provided in Chapter 1.

The researcher investigated the experience of living with the certainty of death by interviewing individuals in hospice care who were aware of and acknowledged their
impending death. Throughout the ongoing, cyclical process of data collection and data analysis, interviews were conducted and data were analyzed for the purpose of identifying patterns and themes, and for creating a detailed and informative description of the phenomenon of living with the certainty of death, as revealed by several hospice patients.

**Sampling Procedures**

The following describes the composition of the sample for Phase II of the study and the recruitment procedures.

**Inclusion criteria.**

A sample of adults enrolled in a community hospice agency for end-of-life care was recruited for this Phase II of this research investigation. Again, the inclusion criteria for the sample included adults who were aged 18 or older with an acknowledged prognosis of impending death as indicated by enrollment in a hospice program, and able to converse in English. It was anticipated that a sample of 5 to 15 participants would be sufficient to provide a rich and comprehensive description of the phenomenon (living with the certainty of death).

**Recruitment.**

The participants were recruited through two regional offices of a local community hospice agency, using a purposive sampling technique. This specific hospice was selected because it had a broad service area with an average daily census of 160 patients with an average length of care of 75 days in 2010. The researcher was invited to an office staff meeting to discuss the research purpose and recruitment process. Information describing the research purpose and inclusion criteria was distributed at this meeting (see Appendix
A for Recruitment Information for Hospice Clinical Nurses). Copies of a letter describing
the study were also given to the nurses for distribution to their patients (See Appendix B
for Participant Recruitment Letter). The hospice director designated one supervisor as the
contact person. However, the supervisor left the agency a few weeks later and no
participants were recruited for two months. Therefore, the director of the hospice agency
assumed responsibility for the remaining recruitment and maintained regular
e-mail or
phone contact with the researcher.

During the recruitment process, the director of hospice or her designee received
from the nurses the signed permissions using the Agency Authorization to Release
Information Form to release the names and phone numbers of the volunteer participants
to the researcher. The director then contacted the researcher who obtained the signed
forms from the office.

The researcher initially contacted the potential study participants by phone to
explain the general purpose of the study. The participants were given the opportunity to
ask questions during the initial phone conversation. Initial phone calls were made to each
participant on the day their signed forms were received. One participant was in the
hospital, so the researcher was advised to call back in one week. The daughter of a
second potential participant requested a call back in two weeks because her mother was
ill. She died within the two-week period. During the first face-to-face meeting, each
participant provided written informed consent to participate under the principle of full
disclosure.
Sample

Five participants were included in the sample during Phase II. Three participants were diagnosed with cancer; one was diagnosed with COPD; and one with cirrhosis of the liver. The participants included two males and three females ranging in age from 43 to 72. One participant became too ill to continue after the first interview and withdrew from the study (See Table 2, *Phase II of the Study*, for a list of the participants P6–P10).

Table 2

*Phase II of the Study*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Interview #1</th>
<th>Audio-recordings</th>
<th>Interview #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>P6</td>
<td>X</td>
<td>2 recordings</td>
<td>X</td>
</tr>
<tr>
<td>P7</td>
<td>X</td>
<td>Attempted; became ill and could not record; withdrew from study before second interview due to declining health and died</td>
<td></td>
</tr>
<tr>
<td>P8</td>
<td>X</td>
<td>2 recordings</td>
<td>X</td>
</tr>
<tr>
<td>P9</td>
<td>X</td>
<td>Refused to record</td>
<td>X</td>
</tr>
<tr>
<td>P10</td>
<td>X</td>
<td>Refused to record (blind)</td>
<td>X</td>
</tr>
<tr>
<td>Phase II Subtotal</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>14</td>
<td>8</td>
</tr>
</tbody>
</table>

Data Collection: Interviews and Audio-Recorded Protocol

Data were collected using the approach outlined by van Manen (1990). The initial data collection activities included the gathering of personal experiences and experiential descriptions from the participants’ verbal description of their illness and the hospice
experience. The data were collected through interviews and audio-recorded protocols, an adaptation of protocol writing.

It was anticipated that two interviews would be arranged with each willing and able participant within a 3 to 5-day time frame. However, only two participants could meet within this time frame. Two additional participants postponed and rescheduled the following week due to illness. One participant postponed, and then withdrew from the study two weeks following the first interview due to declining health status.

Following each interview the researcher recorded notes in an audio-recorded journal. These recordings included descriptions of the interview scene and reflections of her own experience, thoughts, or insights about the interview. The audio-recorded journal entries transcribed by the researcher became part of the data set for the analysis.

**Interview #1.**

During Interview #1 the purpose of the research was discussed and the participant’s consent to participate was reviewed and signed. The recorder was then turned on. The caregivers were permitted to stay in the room at the participant’s request. Two participants invited a family member to stay in the room during the interview. There was no difference in the quality of the data generated when a caregiver was present during the interview.

The interview consisted of open-ended questions designed to explore the respondent’s experience of living with the certainty of death. The initial questions did not focus on death or dying. Even though patients enroll in hospice with an awareness of impending death, they do not always acknowledge their dying. Therefore, each initial interview with the participant began with a grand tour question: “Tell me about your
illness.” This informed the researcher about the gestalt of the experience, revealing the patient’s experiential states, primary response modes, perceived outcomes, and meanings assigned to the overall experience. An interview guide provided additional interview questions and probes to explore the experience of living with the certainty of death, but it was not used after the second participant interview (See Appendix C for the Interview Guide).

Based on the initial dialogue, the interview turned to linguistic markers of certainty (examples included “I knew I was going to die when”…. or “I realized there was nothing more they could do…. or “I knew it was over when…”). This enabled the researcher to explore these experiences with the participant in greater depth so that complete descriptions of the antecedents, reactions, strategies, and outcomes of each experience could be derived. If there were no markers, the participant was asked to talk more about enrolling in hospice. Some participants began immediately discussing their dying, while others discussed it at different points during the interview. One individual did not mention dying during the interview. The initial meetings with each participant lasted from 45 to 60 minutes. The audio-recorded interviews were transcribed verbatim and reviewed prior to the second interview (See Table 2 for the frequency of participants P6-P10 in Interview #1).

Audio-recorded protocol.

An audio-recorded protocol was initiated following the first interview. The participants who agreed to record their thoughts between interviews received a recorder for a 3-day period. They were asked to select a time each day to record any thoughts, feelings, changes, or experiences. Written instructions were provided for turning on and
off the recorder. Arrangements were made with the participants during Interview #1 to return on the third day and pick up the recorder. A follow-up phone call was made on day two to check for any recording problems, answer any questions, and arrange a time to pick up the recorder toward the end of day three.

One participant refused to record due to poor vision. A second participant preferred not to audio record, but gave no reason. A third participant tried to record but asked for a different recorder on day two stating that the recorder was not working. A second recorder was delivered on day two, but the participant became too ill to record. The participant deteriorated rapidly, withdrew from the study, and subsequently died during the data collection phase. The two remaining participants recorded a total of four messages. The recordings were transcribed verbatim and the transcripts were included in the data set for each participant (See Table 2 for the frequency of participants P6-P10 audio-recording protocols).

**Interview #2.**

Four participants were visited for a second interview, which was scheduled within approximately five days following the first interview (See Table 2 for the frequency of participants P6-P10 Interview #2). This interview transitioned from unstructured experiential to a more hermeneutic interview with the initial participants following the thematic analysis of the data collected during the first interview and the audio-recorded protocol. “A hermeneutic interview is an interpretive conversation wherein both partners reflectively orient themselves to the interpersonal or collective ground that brings the significance of the phenomenological question into view” (van Manen, 1990, p. 98). Through hermeneutic conversations, the researcher can mobilize participants to reflect on
their experiences (once these have been gathered) in order to determine their deeper meanings or themes. Together the researcher and participant weighed the appropriateness of the theme by asking, “Is this what the experience is really like?” The participants were reflective and actively engaged in a hermeneutic dialogue as the themes were discussed and related to personal experiences. The researcher was sensitive to the progressive weakness and decreased functioning of the participants enrolled in hospice care. The interviews lasted from 30 to 45 minutes, and no more than two interviews were scheduled with each participant.

As themes and thematic descriptions developed, the researcher took a hermeneutic stance when interviewing new participants. A hermeneutic stance occurred when, after beginning the interview with the grand tour question of “Tell me about your illness”, the researcher then progressed to more specific questions, seeking verification of newly emergent themes and descriptions. In hermeneutic conversations the themes become objects of reflection in which the researcher and the participant collaborate. This enables themes to be examined, articulated, reinterpreted, or reformulated, thereby strengthening the emergent themes and contributing to the credibility of the phenomenon.

Analysis

First, the Phase II data were analyzed to derive their themes. The feasibility study themes were not reviewed or considered until the analysis of the Phase II data was completed. This analysis involved hermeneutic phenomenological reflection for the purpose of trying to grasp the essential meaning of the phenomenon under study. “Insight into the essence of a phenomenon involves a process of reflectively appropriating,
clarifying and making explicit the structure of the meaning of the lived experience” (van Manen, 1990, p. 77).

**Thematic analysis.**

Thematic analysis guided the discovery and structure of the meaning of the phenomenon in this study. This analysis began as each initial Phase II interview was transcribed. The researcher read the interview transcripts three times in their entirety. While reading the transcripts, a selective reading approach described by van Manen (1990) was used whereby statements and phrases were highlighted that revealed the thematic aspects of the phenomenon. Initially the transcript was read through in its entirety. During the second reading, phrases were highlighted that revealed thematic aspects of the phenomenon. During the third reading, the text was read more closely for additional phrases. Key notions describing the phrase in one or two words were written in the left margin by the highlighted phrase. Themes uncovered and discussed in earlier interviews were shared with the participants in subsequent interviews. The structuring of the meaning according to the themes was continued through writing and rewriting.

Following each interview the researcher wrote a description of the participant’s experience. Each writing began with an overall sentence, trying to capture the themes within a whole. A description of the themes was written as it emerged within the context of each interview. This process was applied to all the data generated during the Phase II study.

After this process of reflective thematic analysis of the Phase II data, the datasets from the feasibility study and the Phase II study were integrated (See Table 3). Themes were generated within and across both datasets. Frequent iterative cycles of reflecting on
thematic derivations and confirming assertions in the integrated data set ensued. One of the experts in qualitative research consulted previously participated in the final analysis, reviewing the decisional audit trail, posing questions to confirm or refine the derived themes, and establishing the supportive evidence in the integrated dataset. Throughout this analytic process, thematic statements were clarified and collapsed. The final analytic schema included six themes that were determined to capture the essential features of living with the certainty of dying.
Table 3

*Phase I (Feasibility Study) and Phase II Integrated*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Interview #1</th>
<th>Audio recording Protocols</th>
<th>Interview #2 (When collecting recorder) &amp; Interview #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>X</td>
<td>4 recordings</td>
<td>X X</td>
</tr>
<tr>
<td>P2</td>
<td>X</td>
<td>2 recordings</td>
<td>Visitors in the home X</td>
</tr>
<tr>
<td>P3</td>
<td>X</td>
<td>3 recordings</td>
<td>Too ill to talk Hospitalized and died</td>
</tr>
<tr>
<td>P4</td>
<td>X</td>
<td>Refused to record</td>
<td>Hospitalized on day of scheduled interview and died</td>
</tr>
<tr>
<td>P5</td>
<td>X</td>
<td>1 short attempted recording</td>
<td>X</td>
</tr>
<tr>
<td><strong>Feasibility Sub-total</strong></td>
<td>5</td>
<td><strong>10</strong></td>
<td><strong>4</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant</th>
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<tr>
<td>P8</td>
<td>X</td>
<td>2 recordings</td>
<td>X</td>
</tr>
<tr>
<td>P9</td>
<td>X</td>
<td>Refused to record</td>
<td>X</td>
</tr>
<tr>
<td>P1</td>
<td>X</td>
<td>Refused to record (blind)</td>
<td>X</td>
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<td><strong>Phase II Subtotal</strong></td>
<td>5</td>
<td><strong>4</strong></td>
<td><strong>4</strong></td>
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<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>10</strong></td>
<td><strong>14</strong></td>
<td><strong>8</strong></td>
</tr>
</tbody>
</table>
**Lifeworld existentials.**

According to van Manen (1990), the “lifeworld existentials” (p. 101) of lived space, lived body, lived time, and lived relation also guided the analysis through question posing, reflecting, and writing. The discussion of each existential as it related to the data was considered individually. At the same time the researcher was aware that each existential cannot be separated from the other existentials.

**Experiential descriptions in literature and art.**

A second type of reflection took place as the analysis progressed. Additional data sources were introduced during the process of reflection when writing descriptions of themes. The data sources included phenomenological writings, literature and art sources, and scientific research. Experiential descriptions in literature refer to the careful study of related texts in the search for insights or perspectives that may further the research (van Manen, 1990). A phenomenological literature review of selected works by Heidegger was conducted after the initial analysis of the interview data. The books *Tuesdays With Morrie* (Albom, 1997) and *Ivan Ilyich* (Tolstoy, 1828), a screenplay titled *Wit* (Edson, 1999), and an artwork by Montien Boonma were examined for additional thematic insights and perspectives. Finally, research studies discussed previously in Chapter 2 were re-examined for additional supportive evidence.

In summary, the hermeneutic process involved a systematic analysis of the whole text, systematic analysis of specific components of the text, and a comparison of the two for an understanding of the phenomenon. Van Manen (1990) refers to the analysis of thematic meanings of a phenomenon as a complex and creative process of “insightful invention, discovery, and disclosure” (p. 79). As a result of this process, new patterns,
themes, and exemplars emerged, were identified and described. Thematic analysis was complete when no new themes were identified and no new interpretations were introduced.

**Written Description/Product**

A description of the phenomenon was written and rewritten as the study progressed to include the essences as they emerged and became more defined with ongoing reflection. When interpreting the meaning of living with the certainty of death from the data collected, examples of situations described by the participants were included. In addition, anecdotes related to literature and art were included in the written description.

The product of this research was a descriptive text reflecting elements of the common patterns of certainty toward death. The description of the phenomenon included a discussion of its relatedness to other end-of-life research and its applicability to other settings and other contexts. This phenomenological text is presented in Chapter 4.

**Human Subjects Protection**

An Institutional Review for the Use of Human Subjects application was submitted to The Pennsylvania State University Office of Regulatory Compliance for Human Subject Research and approved in June 2011. This research was conducted in central Pennsylvania. The researcher received a written letter of agreement from the Senior Vice President of Hospice and Palliative Services to assist with recruitment. Sample inclusion criteria included adults aged 18 or older; diagnosed with an illness that was terminal; and able to converse in English.
During recruitment, the researcher attended a scheduled staff meeting with the agency hospice nurses from two hospice agency offices to request help with recruitment of hospice patients for the Phase II study. Copies of Participant Recruitment Letters and Participant Recruitment Information were distributed to each hospice nurse for distribution to potential participants. The Participant Recruitment Information form for the staff included the researcher’s contact information, a description of the study sample, and a summary of the recruitment procedure. The participant recruitment letter was a general information document explaining the purpose of the study to the patients. This brief recruitment letter was distributed by the hospice nurse to their patients along with the Agency Authorization to Release Information Form. The researcher received no contact information about the patients until the patient had signed the agency release form.

The participants were exposed to no risks beyond those experienced in everyday life. Some of the questions may have prompted recollections of experiences that might have caused minimal discomfort. To minimize this risk, the participants were advised that they could share as much or as little about their experiences as they were comfortable doing.

Data management protected the participants’ confidentiality. Their confidentiality was protected by the removal of any identifiers from the transcribed data and careful storage of the transcribed data. All interviews were audio recorded with participant knowledge and in full view of the digital recorder at all times. The researcher transcribed all of the interviews herself to minimize any threats to confidentiality and to begin the reflective analytic process. All identifiers were removed from the transcribed data and a
participant number was assigned to each transcribed interview. All audio recordings were stored on a password-protected flash drive that remained in the researcher’s locked office at all times and was stored in a locked fireproof file cabinet. All audio recordings were destroyed at the completion of the project. The publication of findings, as well as all future publications, focused on group-level data. Pseudonyms were assigned to any profiles and quotes in order to protect the identity of the participants.

**Trustworthiness of the Research**

Lincoln and Guba (1985) identified four criteria for establishing trustworthiness, including credibility, dependability, confirmability, and transferability.

**Credibility**

Credibility refers to confidence in the truth of the data and their interpretation (Lincoln & Guba, 1985). It is demonstrated through activities contributing to prolonged engagement and persistent observation. Conducting in-depth interviews with 10 participants focusing on the phenomenon contributed to credibility. Audio-recorded protocol used to obtain additional participant reflections following Interview #1 was included in the data set. Member checking with the participants was achieved by sharing tentative interpretations with the research participants during the second interview to assess the consistency of themes with their understanding of the phenomenon. During the second interview the researcher shared with the participants the interpreted themes from Interview #1 and asked them: “Is this what the experience is really like?”

Multiple data sources were used to reflect on the themes and the consistency of their meaning across sources. In addition to the interviews, these sources included the phenomenological writings of Martin Heidegger, a popular non-fiction book titled
Dependability refers to the stability of the data over time and conditions. The inclusion of data from the feasibility study contributed to the stability of the data over time (Lincoln & Guba, 1985). Following completion of the Phase II interviews, the data from the feasibility study were integrated with the Phase II data set. Themes were consistent across both data sets, thereby contributing to the dependability of the thematic results.

Confirmability refers to the congruency between two or more people about accuracy and relevance (Lincoln & Guba, 1985). Involving a senior qualitative researcher during the verification/confirmation of themes enhanced the data’s confirmability. During this process, analytic questions were posed and evidence (i.e., data) was used to support theoretical assertions. The decisional audit trail was reviewed and discussed to confirm the logical progression of the derivation of the essential elements of the experience.

Transferability of this work was enhanced by the thick description provided in the profiles of living with the certainty of death illustrating the contextual features of the experience (Lincoln & Guba, 1985). The integration of quotations in the description of the essential features of the phenomenon also contributes to transferability. Since the illness trajectories were varied, transferability was enhanced; living with the certainty
death is a human experience that transcends an illness trajectory. Given this insight, these findings are thought to be applicable to the common human experience captured in the phenomenon of living with the certainty of death.
CHAPTER 4

Results and Analysis

The purpose of this study was to explore the lived experience and associated meanings of living with the certainty of death among 10 individuals enrolled in hospice care. The data collected from the five participants recruited in Phase II were combined with the data procured from the five participants in the Phase I feasibility study for a total sample size of 10. The sample included five males and five females, ranging in age from 43 to 92. Four participants were diagnosed with cancer; four with congestive heart failure (CHF), one with chronic obstructive lung disease (COPD), and one with cirrhosis of the liver. Two of the participants diagnosed with congestive heart failure were also diagnosed with COPD. This chapter profiles all 10 participants and describes the essential features of this phenomenon based on the data analysis, the literature review, and reflections using the lifeworld existentials of lived body, lived space, lived relations, and lived time.

The Context: Profiles of Living With the Certainty of Death

In order to establish the context for the study, a profile of each participant is provided to illustrate the contextual features of their living with the certainty of death. The names assigned to the participants in the profiles are fictional and all identifying details are altered slightly in order to ensure their confidentiality. Following the descriptive profiles, the essential features of living with the certainty of death, as derived from these data, are discussed.
Jack

Jack is an 85-year-old male who has COPD and congestive heart failure. He has been in and out of the hospital several times this past year. He lives with his wife in a high-rise apartment building. The apartment consists of a living room and kitchenette area, one bedroom and a bath. Jack receives continuous oxygen and depends on the hospice home health aides to assist him with his shower. His wife helps him dress in the morning because he is too weak and tires easily. Sometimes he stays in his bedroom during the day if he does not feel well. On days when he feels well enough to come out to the living room, he sits in his recliner. He speaks in a low, quiet voice and pauses frequently to take a breath. Jack misses being able to go outside and take walks. He attributes his inability to walk far to the heavy oxygen tank he must carry with him or to being unable to go in the wheelchair because of changing weather patterns. He repeatedly brings up going for walks. He was receiving physical therapy until his last hospitalization and does not understand why the doctor refused to continue to order it. He described this therapy as “very simple: walking up the hall.”

He repeatedly talks about the boredom of the day: little company (too much company tires him out); unable to read (cataracts), and poor concentration. His poor hearing makes it difficult for him to listen to books on tape or television unless it is turned up loud.

He says his religion is the only thing he has to lean on and he prays for the strength to keep going. His concern when going into the hospital is whether or not he will be coming home again.
Paul

Paul, 66, was diagnosed with advanced throat cancer, with possible metastases. He lives with his girlfriend in a duplex apartment. He stays in bed most of the morning, dresses himself around 11:00 AM and goes into the kitchen where he spends his day. He sits at the table with his chair turned sideways to watch the television, also located in the kitchen. His voice is raspy and he states that it ‘a little painful’ to speak. He believes they got all the cancer, but he is concerned that his bowels are not moving and is planning to see the doctor. He brings this subject up several times during the interviews and is wondering if he will need to have a colonoscopy. Home health aides assist him with showering.

Nancy

Nancy, who is 61, was suffering with end-stage COPD and fibromyalgia. She lives alone in a second floor apartment that had no other tenants at the time of the interviews. The first floor entrance to the apartment is accessible only by a coded lock, so she keeps the apartment door open during the day. She experiences difficulty breathing and pain throughout her body when she moves. She says the incontinence is the hardest part of her illness to deal with. She needs assistance with her care. A hospice home health aide assists her with bathing, and her fiancé comes each day and helps her with meals and getting into and out of bed. She keeps a nightgown and robe on during the day and lies on her right side on the sofa in the living room. She keeps her phone, a tablet, calendar, and numerous papers on the stand beside the sofa. Her small living room is filled with family photos, along with a television and a scanner, which is always on. A large picture
window runs the entire length of the living room wall and she keeps the curtains open at all times during the day.

**Carl**

Carl is 72 years old and was diagnosed with liver disease and neuropathy. He lives in a mobile home and stays in a hospital bed in the living room close to the front door. He has been enrolled in hospice for nine months. His ex-wife is his caregiver. She states that when she was asked to care for him the doctors had told her he might live two weeks. She comes each day to care for him and leaves each evening. When hospice services began, he and his caregiver explained that he was in a fetal position and had open sores on his buttock. He was in pain and had “given up”; however, the supportive care provided by hospice generated improvement in his physical condition. For the past two weeks he has been slowly standing and pivoting to sit in a wheelchair and during Interview #2 he was sitting in a wheelchair at the kitchen table. Hospice home care aides assist him with bathing. His ex-wife assists him in getting dressed and fixes his meals.

**Vera**

Vera, 82, lives alone in a two-story home on a quiet street. She was diagnosed with congestive heart failure. She has no children. She recently returned to her home after spending several months in a personal care home. She found out that her niece who lives in another state and is her executor and power of attorney was planning to sell her home to a neighbor, so Vera changed her power of attorney to a cousin and moved back home “to die” in her own home. She sits in a recliner chair with her feet up in her living room with continuous oxygen running via a nasal cannula.
Vera requires assistance with personal care. The hospice home health aide assists her with bathing. Vera’s cousin (who lives down the street) provides her with care by fixing her meals, checking in on her during the day, and staying all night. This cousin helps Vera put on her robe each morning and walks her from her bedroom into the living room where Vera stays all day. Several neighbors also check in on Vera during the day, visit, and bring her meals.

Laura

Laura is 43 and has been diagnosed with metastatic cancer. She was discharged the previous week from the hospital following treatment for a blood clot and has recently moved into the home of a friend. She does not mention a husband, but her children come and visit when they can and bring the grandchildren. During the interview she sits in a recliner chair in the living room. She has a stand to the left side of the chair where she keeps her phone, Bible, schedule book, and other papers. Before the interview begins, she states that everything she needs is on the stand within reach. Laura is weak and speaks softly, slowly, and clearly. She sits very still during the interview because she is concerned about the blood clot. Hospice home health aides assist her with care. Her sister and aunt also come by during the day to help her with her care and meals.

Elaine

Elaine, 65, has metastatic cancer. She is also blind in one eye and has only 10% vision in the other. She is planning to have cataract surgery in a couple of months on the eye with partial vision, claiming that she will “be the happiest person on earth when she can see again!” She has difficulty walking due to recent hip surgery and has oxygen in the home, which she says she uses when going out. She moved into a high-rise apartment
about a year ago after selling the home she had lived in since she was married. She is apart from her husband for the first time in their 43-year marriage. He was diagnosed with Alzheimer’s and was placed in a personal care home nearby this past year. Elaine could not take care of the home, her three small dogs, and her two cats. She had to put one dog down because he was too old to be adopted out. The other dogs and the cats were adopted out to nice homes. The buyer of her home told her she could wait and clean out the house in the spring when the weather was warmer. Her daughter drove her past the house a few weeks later. The house was torn down and her possessions were sitting in the front yard wet and destroyed. She says she lost a lot of memories that day. The manager of the apartment complex brought her a cat a few months ago.

Her cat stays by her side at all times. Elaine has four children who all live within a 50-mile radius and all work. She has several grandchildren. One daughter lives about 30 minutes away and comes to visit every Saturday. Sometimes she brings Elaine’s husband over for the day, but he does not recognize her anymore. Elaine takes care of her own bathing and dressing. A hospice home health aide comes in and cleans and runs errands for her. Elaine likes to cook and bake, but cannot do much until she has her cataract surgery.

**Frank**

Frank is a 75-year-old widower diagnosed with cancer and living alone in his own mobile home. He walks very slowly holding onto furniture and says his greatest fear is falling when he is alone. He wears an alert necklace, but sometimes takes it off and forgets where he put it. There is a sign on the front door saying ‘No Smoking: Oxygen in Use’. He smokes cigarettes constantly throughout the day and says it’s too late to quit
now. He spends most of his days at the kitchen table. He has four children, but the closest one lives 20 miles away. The closest child visits a couple of times a week and calls every day. Two other children call regularly. He has not seen his fourth child (who moved out West many years ago and only contacts her family occasionally) for many years.

Frank’s wife died six years ago from cancer. He gave donations to hospice every year in her name because they took such good care of her. When they sent a fund raising request letter last year after he was diagnosed, Frank put a note on the back of the letter and returned it telling them why he could no longer donate. He received a call from the hospice agency and was asked if some representatives might come to see him. Frank thought they were going to ask for money, but when they came they offered him services. He is amazed at the generosity and kindness of the hospice workers. The hospice home health aides assist him with his bathing and clean his house.

Mildred

Mildred, who is 72, was diagnosed with congestive heart failure and emphysema. She is a widow and lives alone in a federally-funded townhouse. Her home is a small two-story residence with a living room, kitchen/dining area and bath on the first floor and two bedrooms and a bath on the second floor. At each visit Mildred sits at the far end of the kitchen table near the window that faces the front of the home. She wears a robe during each visit. She is small in stature with a frail appearance that belies her feisty strong-willed personality. She has a stand next to the table where she keeps papers and objects of value within reach. She wears an oxygen cannula constantly with the tubing running into an O2 tank in the living room. Mildred has employed Donna as a caregiver for the past five years. Donna is very caring and supportive of Mildred, and their
relationship is one of mutual respect and trust. Donna cooks and cleans and stays with Mildred all day, and the home health aides assist her with bathing.

Mildred has 6 children and 17 grandchildren. She doesn’t see five of her children too often even though they all live in the same community. One daughter lives down the street and spends her days at Mildred’s watching television while her children are at school. Two grandchildren visit every day and sometimes stay over night. Mildred speaks in a raspy voice, which she explains is the result of a gunshot wound that destroyed her vocal cords. Her diminished vocal capacity does not limit her from voicing her opinion and making her position known on a variety of issues. She is a religious woman who speaks frequently about her faith and beliefs and trust in God. She likes to talk politics and keeps a scrapbook filled with over 40 years worth of letters to the editor she has written to several area newspapers.

Mildred described her near-death experiences, explaining how she has died three times and has “come back.” She says she has no fear of death because she has already been there and looks forward to going back someday. At the same time, she wants to live another few years to be able to celebrate 80 years of life.

Larry

Larry is 92 and has congestive heart failure. He receives continuous oxygen therapy. He lives with his wife in a two-story older home in a quiet neighborhood. He is a tall thin man and very distinguished looking. He is legally blind, hard of hearing, and walks with a cane. His two children live nearby and check in on him daily after work. The hospice nurse checks in on him several times a week. His son helps him with his bathing and dressing. Larry believes nobody should live to be his age, because he has had
so many health problems and “had so much replaced that I feel like a robot.” He laments that he can no longer drive, cannot go anywhere, and is unable to watch television. He attributes not being able to go fly fishing to his wife who “won’t let them take me fly fishing because she thinks I might fall in the creek.” Larry is quick to argue that he would not fall in the creek, although he discusses several falls he has had in his home during the past few months. He has had to give up hunting turkey and deer, but since he can no longer hunt, he feeds the turkey and deer that come into his yard.

Despite these losses, Larry is proud of his garden and his well-groomed yard. He spends a portion of everyday working in the garden. This activity is no small feat: Larry lies down on a small platform with wheels that his son made for him, and slowly rolls along the rows in the garden feeling for and pulling weeds.

**Essential Features: Living With the Certainty of Death**

The concepts of certainty and uncertainty are interwoven in the phenomenon of living with the certainty of death, co-existing situationally and existentially. When does the sense of certainty of death become dominant? What triggers this dominance? The researcher maintained a focus on these questions when conducting the data analysis. Six essential features of living with the certainty of death emerged during the thematic analysis of the participants’ lived experiences described in their interviews and audio-recorded protocols, and an examination of the researcher’s observations and reflections from her audio-recorded journal entries. The essential features included (a) Beating the Odds, (b) Living With, Not Dying From, (c) Separating and Connecting: Shifting Relations, (d) Transcending the Everyday World Through Spirituality, (e) Getting My House In Order, and (f) Living With Pain. Each essential feature is initially discussed
using the participants’ own words and the observations from the researcher’s journal entries to enrich the context and understanding of the emerging description.

Phenomenological writings, selected readings from literature and art, and related theory and research presented in Chapter 2 are included to provide additional insights and perspectives regarding each essential feature.

Van Manan (1990) suggested the use of phenomenological literature as a source of information and an opening for dialogue and reflection on the lived experience, enabling the researcher to transcend the limits of their own interpretive sensibilities. Van Manen also recommended a critical and creative reading of related texts for insights and perspectives that further the research.

Heidegger is the most appropriate phenomenological source of information for examining living with the certainty of death. His work on being-toward-death provided a framework and guided this examination throughout the investigation. Heidegger’s writings are examined as they relate to specific essential features.

The selected readings from literature and one work of art used to reflect on the phenomenon under study included the non-fiction novel Tuesdays With Morrie (Albom, 1997), the stage and screen play Wit (Edson, 1999), the novella Ivan Ilyich (Tolstoy, 1828), and a discussion of Montien Boonma’s (Poshyananda, 2003) artwork “Nature’s Breath: Arokhayasala.” An introduction to these works was presented in Chapter 2 and discussed in relation to the rhythmicity of the certainty and uncertainty of death. In this chapter, they are integrated into the discussion of one or more essential features of living with the certainty of death. Finally, selected theory and research also presented in
Chapter 2, supporting the emerging essential features of living with the certainty of death, will be integrated into the discussion.

**Beating the Odds**

*Beating the Odds* refers to the participants’ realization that they have outlived their original prognosis. The participants discussed their prognosis, and several boasted of surpassing their life expectancy. They spoke about having exceeded the time they were expected to live when initially enrolled in hospice, with expressions such as “I showed them, I beat it, and I outfoxed them.” Some participants talked about beating the odds of dying each time they were hospitalized and not expected to live. As Jack stated,

> I’ve been in and out of the hospital five or six times this year. The one time I was taken to the hospital the doctor told my wife there was so much wrong with me he didn’t know where to start. I was on the respirator for three days and nobody thought I’d come out of it. But here I am.

The participants credited their own will power, stubbornness, and spunk for exceeding the projected dates of their demise and surviving exacerbations, and each expressed a determination to keep going. Elaine stated, “Yeah, I shock the doctor all the time cause he said I wouldn't be around in six months, and I’ve been around over a year now. I got the willpower. I do what I want to do.”

Uncertainty rises to the forefront of perception as doubts regarding the ability to sustain *Beating the Odds* were acknowledged. Some doubted their diagnosis, while others expressed concern that they would die soon. Jack followed up his conversation about his multiple hospitalizations by discussing his increasing weakness over the past couple of days and concerns about another hospitalization, saying, “Every time you get sick you
think about it [dying]. As far as going to the hospital, I’m afraid I’m not coming home.”

Many acknowledged the limited amount of time they were expected to live and expressed thankfulness for each day. Elaine aptly captured the common sentiment of several participants when she said, “He told me I could die in my sleep. So every morning, I wake up, open my eyes to see that I’m still here, and say thank you God for one more day.”

Heidegger (1927/1996) suggested that humans are the only living creatures who have the capability of contemplating the possibility of non-existence, or death, as well as contemplating and choosing possibilities during every moment of existence. These choices are never made in isolation, but rather from the contextual world, which includes relationships with others. The participants in this study live with this awareness of the possibility of non-existence each moment of the day. They are given a time when they will die, and their pain, their breathing difficulties, and their limited mobility are constant reminders. Yet they celebrate **Beating the Odds** of their prognosis and repeated hospitalizations.

Awareness of their own dying and a sense of **Beating the Odds** seem to have given these participants a sense of empowerment. Empowerment comes from the root word empower which is defined as “stronger and more confident, especially in controlling their life and claiming their rights” (*The Oxford English Dictionary* Online, 2012). Empowerment was discussed in Chapter 2 as a characteristic accompanying individuals’ open awareness of their own dying, as described by Glaser and Strauss (1965). Open awareness occurs when both staff and patient know that death is impending and acknowledge it in their actions. Glaser and Strauss emphasized that ambiguity
accompanies open awareness, describing ambiguity as the unknown regarding when death will occur that accompanies the knowledge of dying. The interviewees’ awareness apparently contributed to their empowerment, all the while experiencing the ambiguity Glaser and Strauss alluded to.

The subjects described in the study by Constantini, et al. (2008), reported in Chapter 2 under Trajectories, also described the participants’ experience of Beating the Odds of their original prognosis. Their subjects believed they could have several months or years to live; yet at the same time, they remained realistic in acknowledging a more rapid decline in function within the last couple of months and doubts about their ability to beat the odds too much longer.

Jack’s experience of repeated hospitalizations and his physician stating he did not know where to start when caring for Jack’s numerous problems are consistent with Hupcey’s, et al.’s (2009) description of the unpredictable illness trajectory of heart failure patients and the “lack of prognostic indicators to identify the end of life” (p. 401). According to Hupcey et al., while physicians tend to overestimate their patients’ mortality rate, the patients tend to overestimate their life expectancy. This would lead individuals like Jack to have a sense of Beating the Odds even while acknowledging his declining health.

**Living With, Not Dying From**

The theme Living With, Not Dying From reflects the participants’ attitudes about having good and bad days. Descriptions of bad days revealed a sense of uncertainty prompted by the perceptual revelation of the certainty of death. In contrast, good days reflected the certainty of continuing to beat the odds as rising to the forefront of
perception. Two common components in the description of a good day are the ability to follow a daily routine with productive activities and the ability to move better on a particular day.

When asked to describe a bad day, the participants in this study often cited a day when the pain was worse than usual, their breathing was more difficult, or they could not move as well or as far. These are days when uncertainty rises to the forefront and they think about their dying, wondering about not only how much time they have, but also how they might die: “Sometimes my breathing is so bad it feels like I’m not going to get my next breath and, I think, I don’t want to go like that. I want to go quick. I wouldn’t want to hang around either.”

When prompted to describe a good day, the participants often started the conversation by stating that it “would be” one without as much pain or when they could breathe more easily or walk more distance than usual. The focus on the ideal day then promptly shifted toward discussing a more realistic perspective of a good day: being able to accomplish routine, everyday activities. The importance of the daily routine and being able to accomplish tasks and feel productive is often described as a way to block everything out, forget about the pain, and make the day go more quickly.

Frank bought a sewing machine to take in his clothes when he began to lose weight. Even though he had never sewn before, he said he now spends hours sewing. He also keeps busy writing the family history and sending thank you notes to people he has met who have influenced his life. He summarized the importance of productivity in his everyday routine:
You do these things to take your mind off the pain, but also you like to accomplish something in the end. So your emails to your daughters, your family history, your sewing—all of that has an end product. So you certainly are still living, producing, working, and trying to manage the pain.

Movement is a measure the participants used for determining if they were doing better or worse each day. Elaine who, despite her difficulty walking, emphasized that she doesn’t “slow down”, capturing expressions surrounding the importance of movement. When questioned about what might happen if she slows down, she replied “probably die.” Limited mobility was equated with limited life. In contrast, mobility equals life.

Jack expressed the optimism he felt on days when he could move from his bedroom to his kitchen table: “Well, I think it’s normal when we have a good day like that and I think, ‘Boy, I’m getting better. It’s normal. Maybe if I keep this up, maybe in a month or so I can go for a walk.’”

Consistent with Heidegger’s (1927/1996) statement that humans contemplate and choose possibilities during every moment of existence, the participants have made a choice of living with the certainty of death by choosing among the possibilities each day brings. Maintaining a perspective of Living With, Not Dying From opens up possibilities and mobilizes individuals toward an expanding world of activity and relationships with others.

This notion of choosing among possibilities was expressed in Tuesdays With Morrie (Albom, 1997). During one meeting with Mitch, Morrie talked about feeling sorry for himself. He related that sometimes in the morning he would feel around his body, move what he could still move, and mourn what he had lost. He states, “I mourn the
slow, insidious way in which I’m dying. But then I stop mourning” (Albom, p. 57). He further explained that he allows himself a little self-pity in the morning with a few tears. But then he concentrates on all of the good things still in his life. Morrie realized that staying with his sadness and self-pity was immobilizing and prevented those important moments of enjoyment.

Dobratz (2002; 2011) who discussed characteristics of self-becoming with individuals who were aware of impending death also described adjusting their expectations as physical functions declined. Individuals with these declining functions adapted by accentuating and cherishing the few remaining functions they had left. This is similar to the experience of Nancy, one of the most introspective participants interviewed during this study and one of the few who talked about her enjoyment of humor and laughter. She was confined to the sofa every day, lying on her right side. Because she could not engage in everyday activities requiring physical movement, she spent her days looking out a window, reading, listening to music, and working through in her mind issues of relevance for herself and those she loved.

A few studies discussed in Chapter 2 focused on the transitions within the illness trajectory. Even though most of the studies reviewed reported on the experiences of individuals transitioning from curative to end-of-life care, some of their experiences were similar to those described by the participants in this study. Larkin, et al. (2007a), for example, examined how European patients with advanced cancer described the transition experience toward the end of life. They summarized their analysis as “living transiently in the shadow of death” (p. 76). For the patients in their study, like those in this study, death was a presence but not a consuming presence. They still had future goals as they
adjusted to moving toward the end of their lives. This is consistent with the essential element *Living With, Not Dying From*, found in the current study.

**Separating and Connecting: Shifting Relations**

All of the participants in this study discussed shifts in relationships with family members and friends as their illnesses progressed. They described the loneliness of separating from friends who used to visit, but no longer called or dropped by. Others related stories about family members with whom they are no longer in contact, often stating that some of their family cannot deal with their dying. Paul, an emaciated, severely impaired participant said,

Oh, I’ll talk to my daughter someday, but I don’t know when. But it’s the first time in my life this really happened and we just had our outs and one time she said she didn’t want to see me like this and that’s why she doesn’t stop. I said, ‘Well it’s like this, either see me while I’m alive or don’t come and see me when I’m dead.’

The participants described situations when family members did visit. Commonly, they wanted to do things while visiting and didn’t want to sit and talk for long. Nancy explained the impact of doing for versus being with during her family’s visits:

Sometimes you feel like you’re a burden to people. They want to help by doing something, but something you really need is for them to sit and take the time with you and touch your hand and talk with you and laugh with you and just there’s not a lot of that anymore. It gets less and less. And I miss that.

Relationships sometimes shifted with the participants’ acknowledgement of the dying experience and desire to talk about it. Some family members were willing to
discuss dying, whereas others refused to discuss or even acknowledge the certainty of death. Often children of the participants did not want to discuss dying, but younger grandchildren regularly talked with them about death or dying. These conversations were described as sometimes serious and sometimes as “joking around.” The participants expressed a special affection for these grandchildren with whom they have connected through conversations about dying.

Reconnecting with family and friends occurred in new and different ways. In one case, a lifelong friend, recently married, with the help of her new husband opened her house to care for Laura. Carl’s ex-wife who came to care for her dying husband (thinking that he only had two weeks to live) was still caring for him nine months later. Carl expressed his gratitude:

She has been here everyday for me. She always said she would be there for me but when I was boozing she wanted no part of me and it was like I was just all alone in the world. I didn’t care. But she’s really been great. I don’t know what I’d do without her now.

Finally, new relationships formed as a result of the terminal illness experience. Professional and informal caregivers were involved with the patients in this study, and, over time, were referred to as “members of the family” who were willing to sit and talk, becoming a constant source of care during the illness. Nancy stated she felt very blessed because this illness has brought many people into her life that she would not have known otherwise. These new relationships described by the participants included their caregivers’ family members, the hospice chaplains, and hospice care providers:
So if it wasn’t for the girls at hospice and the ones who come in and take care of me I don’t know what I’d do because they are my family now. I mean I love my children and my fiancé and my grandchildren, but I guess it gets to be too much.

Heidegger’s work on authentic and inauthentic being-toward-death discussed extensively in Chapter 2 provides an understanding for the essential feature Separating and Connecting: Shifting Relations. The reluctance of family members to discuss death may reveal their not wanting to acknowledge it as a real possibility for their loved one similar to inauthentic being-toward-death. Heidegger (1927/1996) described inauthentic being-toward-death as the experience of everydayness in which death is viewed as an actuality that happens sometime in the future, while the awareness of the possibility of one’s own death at any moment is concealed. The participants in this study, on the other hand, are authentically being-toward-death and living with the revealed possibility of their own death and the accompanying awareness that dying must be experienced alone (non-relational) and it cannot be avoided ( unsurpassed).

When living authentically, though, the world does not change. And as Heidegger (1927/1996) stated, the “circle of the others is not exchanged for a new one. What is different is that they are now defined in terms of their ownmost potentiality-of-being-their-selves” (p. 298). Therefore, according to Heidegger, it is not essential that an individual’s way of being-toward-death only be realized by talking with someone who is experiencing the resoluteness and its accompanying anxiety. One’s way of being-toward-death is also manifested in the concerns at hand. Family members who come to the homes of the patients in this study are living with the certainty of death through the
activities of helping and doing for their loved ones. The relationship with family and friends still exists, but it shifts in light of each member’s way of being-toward-death and being with the other. Letting go of the previous ways of being with one another will broaden the circle to new and different possibilities for being together and apart. Broadening the circle provides opportunities to welcome others into the circle of caring and concern. It also enables individuals to separate from previous ways of being with others and connect with them in new and different ways. The way of being with others at any given time reflects each person’s way of being-toward-death.

Tolstoy’s (1828) character, Ivan Ilyich, began to separate more and more from family and friends as he longed to be comforted and they continued to act as if he were simply ill and not dying. Ilyich developed a close relationship with Gerasium, the butler’s young assistant. As Tolstoy described it, “Ivan Ilyich felt his [Gerasium’s] presence as such a comfort, he did not want to let him go” (p. 50). Only Gerasium recognized that Ilyich was dying “and in Gerasium’s attitude towards him there was something akin to what he wished for, and so that attitude comforted him” (Tolstoy, pp. 52-53).

Murray, et al. (2007) studied the changing family relationships that occur following diagnoses of lung cancer and heart failure, and found that even though the illness trajectories of the patients with advanced lung cancer and heart failure were very different, the social isolation and loneliness expressed by both groups occurred throughout the illness trajectory. Patients with lung cancer reported that social relations began to diminish at the time of diagnosis. They expressed loneliness and uneasy relations with friends. This is consistent with some of the experiences of the participants in the current study as well as in Tolstoy’s character, Ivan Ilyich.
In the screenplay *Wit* (Edson, 1999), the main character, Vivian Bearing, initially developed a connection with Dr. Kelekian, who like her, was highly intellectual and unemotional. Together, they focused on the details of experimental chemotherapy. As Vivian’s cancer progressed, she began to talk less like a detached intellectual and more like a person with feelings and memories and fears. The doctors refused to talk about her dying and continued to focus on a higher dose of chemotherapy and her important contribution to science. Vivian’s relationship with her nurse, Susie, transformed one night as Vivian, feeling frightened and alone, kinked her IV tubing so the alarm would bring Susie into the room. This perceptive young nurse recognized Vivian’s fear and sat with her, speaking honestly and compassionately with Vivian about her dying. This conversation eased Vivian’s fears, and a strong bond developed between this patient and her nurse.

In *Tuesdays with Morrie*, Morrie talked about family on the fifth Tuesday meeting with Mitch. He said that part of what family is, other than love, is “letting others know there is someone watching out for them” (Albom, 1997, p. 92). He called it spiritual security. The theme *Separating and Connecting: Shifting Relations* is reflected in Morrie’s discussion of spiritual security. The different participants in this study expressed a sense of spiritual security as they embraced particular caregivers who were with them daily as well as hospice personnel who were there when they needed them to help them through a sick night, run errands for them, or just to sit and talk. Morrie also talked about encouraging his children to go about their lives as they normally would to avoid letting his disease ruin all of them. What appeared to be his separating from children because they were not physically nearby was actually an act of connecting
in a caring expression of being for others rather than being for himself.

Transcending the Everyday World Through Spirituality

All of the participants in this study spoke about faith in God and thankfulness for each new day. Some discussed a renewed faith and related stories about being raised a Christian, then as adults getting in with the wrong crowd or not being the best example of a Christian. Experiencing advanced illness and visits from the hospice pastors helped them renew their faith. The comfort of spiritual relatedness that transcended the everyday world was profound as revealed in this description by Nancy:

Oh it’s wonderful. Its like I’m never alone. I am never, never alone. At times when I am really in pain or am sick, I’m not alone. It gets you through so many nights and days. It’s like I have someone to talk to all the time. And I can feel His comfort. Very rare do I ever ask to be held but at night when I am thinking about my deepest sorrows and I ask Him if He would just hold me and honest I can just feel this and see this giant white and feel this giant arm, and I see myself with Him and I snuggle and the comfort. I’m afraid to ask for too much. I don’t want to take advantage of it, but it feels so good to snuggle. It must be like a baby feels. You don’t have a worry in the world. It is the most wonderful feeling. I don’t see His face. I just feel His arm around me. And it is so comforting. No bed is that comfortable. It’s so amazing. The warmth, peace, comfort, excitement.

The research regarding spirituality may have implications for the developing essential features of the phenomenon of the certainty of death. Spirituality is defined as “the aspect of humanity that refers to the way individuals seek and express meaning and
purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski, et al., 2009, p. 887).

Alcorn, et al. (2010) examined the importance of spirituality in the illness experience of patients with advanced incurable cancer. They reported that religion and spirituality facilitated coping, comfort, acceptance, and emotional stability. Like so many participants in this certainty of death study, the most frequently reported religious/spiritual practice in the Alcorn, et al. (2010) study was prayer. Their subjects also expressed a deeper reflection on faith and mortality, enhanced personal faith, and a heightened sense of companionship with a higher power.

Spirituality is not only expressed in religious beliefs, but also in transcending an everyday world that gets smaller as the illness progresses. Carl expressed this transcendence in his diminishing physical world:

I’ve spent so many months in here. I thought all I owned was a living room. I mean you’re in this bed and all you see is the hall and if you turn around you can see the kitchen. You wouldn’t know I had bedrooms and bathrooms. But I liked this window here. I could still look outside and watch the neighbors raking leaves. I always liked the smell of leaves burning. They can’t burn leaves here, but I like watching the neighbor kids jumping in the leaves like we used to do as kids. They were out there yesterday playing in the snow. I can’t go outside yet, so that keeps me going.

During these moments, living with the certainty of death rises to the forefront of perception, stimulating and sustaining religious faith. But also, there is a sense of present awareness as in watching an activity the participant can no longer engage in. Even with
their physical limitations, those who still had mental acuity could appreciate the present moment through their memories, and be more deeply aware and appreciative of it. Despite their decline, they engaged life to the best of their ability in the here and now.

Heidegger’s later work *Building Dwelling Thinking* (1951) offers insights into the essential feature Transcending the Everyday World Through Spirituality. He discussed ‘dwelling’ as an experience of transcending the boundaries of one’s physical space. According to Heidegger (1951), to dwell means “to remain at peace within the free, the preserve, the free sphere that safeguards each thing in its essence” (p. 327). Heidegger also talks about the oneness of the fourfold—the earth, sky, divinities, and mortals. Individuals (mortals) are in the fourfold by dwelling. Mortals dwell in the way they preserve the fourfold units of essential being—its presencing. Spirituality can be expressed through a relationship with God, with nature, or a realm of one’s own choosing. Those living with the certainty of death may be able to transcend the daily world by dwelling in their own particular spirituality.

In *Tuesdays With Morrie*, Albom (1997) wrote about a moment of transcendence experienced by Morrie. Consistent with the essential feature Transcending the Everyday World Through Spirituality and Heidegger’s ‘dwelling’, Morrie talked about a peacefulness amidst his suffering. He related to the author that he had a terrible spell that went on for hours and he thought he would not make it. He described it as:

…no breath. No end to the choking. Dizziness…then peace…’a certain peace I felt I was ready to go. I was thinking about a dream I had last week, where I was crossing a bridge into something unknown. Being ready to move on to whatever is next. (Albom, 1997, p. 172)
During a time when he thought he might die, Morrie transcended his suffering and found peace through a memory of a dream of moving toward the unknown.

The artist Boonma expressed the experience of transcendence in his art. In “Nature’s Breath: Arokhayasala”, his depiction of fragile lungs represents the human body and its frailty (See Figure 2). Poshyananda (2003) described this work of art as a metaphor of propulsion and respiration, “an herbal installation with cast metal lungs” (p. 32). The work represents a contradiction between the aroma of herbs and the hanging lungs or a calming place in the midst of anxiety. This work of art resonates with the essential feature Transcending the Everyday World Through Spirituality, which was exemplified by the participants in several ways in this study.

![Figure 2. Boonma’s “Nature’s Breath: Arokhayasala” (Frais, 1995).](image)

**Getting My House in Order**

Getting My House in Order as a feature of the experience of the certainty of death captures the participants’ process of preparing for death in various ways. Many participants expressed the need for order, literally—a need to keep their home orderly, keep their kitchen clean, or their furniture dusted (even though they have someone
coming in regularly to clean). This fastidiousness seemed directly related to the possibility of dying and having others come into the home and see its condition. For others, Getting My House in Order was a matter of pacing, of getting things done in a timely manner as another sense of order in their lives:

I think it’s important to try and get things done timely, because I may not be here tomorrow to finish them. And I might have started a good project that is useful and then I wouldn’t get finished. And that time I’d spend on it was lost. So time’s important.

During one audio-recorded message, Frank talked about putting his affairs in order so that his loved ones didn’t have to worry about them after he was gone:

I already have the gravesite bought because [my wife] and I are together. My obituary’s made out. The casket’s paid for. The opening of the grave’s paid for. That’s all pretty much settled. So my kids don’t have to worry.

Wanting to be prepared or “in order” was often expressed as thinking about others instead of self. Vera, who left a nursing home so she could die at home, wanted to be prepared for the eventuality, so she asked a nurse what would happen when she was actively dying. She said the nurse honestly replied, “Well, you’ll either die in your sleep or you’ll have a big bang and you’ll go.” Vera expressed how much she appreciated the nurse’s honesty because she wanted to be prepared by knowing who should be called and who should not be called. She went on to discuss an episode that occurred the night before the interview. She was having severe chest pain, and nothing was working to relieve it. She thought she was experiencing what she called the “big bang” and knew she had to ‘get her house in order’:
Last night she [caregiver who spends the night] was really beside herself here because she had done everything that she could, and, what can you do? So I said to call the priest. She said ‘Do you want me to call the neighbors?’ and I said ‘Yeah, but don’t call Sheila next door because she can’t handle this kind of stuff.’ Well, I was surprised when Sheila walked in because they had called her. I didn’t want her to be scared.

Wanting to be prepared, having everything in order, and finishing projects in time are all components of the feature of preparing for the final moment, or *Getting My House in Order*. Certainty about dying and the uncertainty about when they actually would die mobilizes individuals to prepare for their death out of concern for others after they are gone.

Heidegger (1927/1996) referred to involvement with others within the world as integral to who one is. The things one does, the work one performs, and the interests shared with family and friends are the very ways through which one expresses humanness. An individual describes the world of work—that person’s world of concerns (or care structure). One’s behaviors and actions are always behaviors and actions for others and with others; therefore the being-with-others must always be investigated from the description of the world of concern of the individual. The essential feature *Getting My House in Order* is the dying person’s expression of concern for others, just as the study participants tried to complete certain tasks as part of preparing for their death so that others need not be concerned with them.

_Tuesdays With Morrie_ illustrated the essential feature of *Getting My House in Order* because Morrie, who suffered with ALS, wanted to share his thoughts on the
meaning of life with others before he could no longer speak. His confidante Mitch Albom (1997) explained that even though Morrie was becoming weaker, he became a lightning rod of ideas and “bite sized philosophies of living with death’s shadow” (p. 18).

Vivian Bearing in *Wit* (Edson, 1999) put her house in order when she told her nurse Susie that when her heart stopped, “Let it stop” (p. 68). She wanted no full code to try and revive her.

Consistent with the recommendations by Goldstein and Lunney (2006) and Hupcey, et al. (2009) that plans should be in place regarding how to manage complications, the patients in this study had discussed with hospice personnel how they wanted to manage their complications and their own end of life. While Jack continued to express the desire to be hospitalized when his exacerbations occurred, Nancy and Vera both expressed a desire to die at home “when the time comes.” Vera had requested specific details about the end and shared a story about taking charge when she thought she was dying related to the essential feature in *Getting My House in Order*. Jack was hospitalized shortly after completing the audio-recorded protocol and had to withdraw from the study. These cases may lend support for the need to increase the intensity of palliative care interventions recommended by Hupcey, et al., so that individuals are better prepared for expected and unexpected complications and can express their wishes about how to manage exacerbations and their dying process.

**Living With Pain**

*Living With Pain* was a universal feature that cut across all other essential features. Most of the participants talked about the constancy of their pain. They would make statements such as “I have pain all the time, I wake up with pain and go to bed with
pain.” When talking about a good day, no participant ever said it would be a day without pain; rather, it was usually a day with less pain. While living with constant pain, most of the participants focused on anticipation of more severe pain episodes during the day or night:

I can’t stand it. It hurts. It is a fear. I dread when it comes on. I mean you’ve seen nothing here. If I got real bad, I’d ask you to leave right away. That’s how bad I get.

Pain management is always a concern. Laura said her worst day would be a day when she has run out of medicine. Other participants stopped the interview long enough to remind someone in the home to have a prescription filled even though there were several days of medication left. Without warning, Elaine picked up the phone in the middle of the interview and called hospice to see who would be coming the next day so she could call in the prescription. She later apologized and said it’s always on her mind.

Conflicts surrounding decisions regarding whether to take the medication and be drowsy or live with the pain were common. Pain management threatened the capacity to complete those tasks that were elemental to other essential features. Frank stated:

Boy, I’ll tell you I couldn’t stand a lot more pain. I just positively couldn’t.

But, of course then I don’t want to walk around like a zombie either so I don’t want too much narcotics and stuff.

Trust in the hospice nurses eased some of his anxiety about pain management:

Hospice does a fantastic job for me. They really do. The nurse who comes here, she goes out of her way to try and solve my pain problems and my
sickness problems. She spends extra time, I know. She’s trying her best to make me comfortable because that is the goal of hospice.

Many of the participants in this study used the phrase “living with pain” when describing each of the essential features. Those in health care often understand the implications of this phrase as something physical that does not go away and presents a challenge when managing patient care. But this does not explain the comments similar to one expressed by Elaine, who experienced constant physical pain from cancer that had metastasized to her bones, yet exclaimed, “I’ll be the happiest person alive when I can see again.” Living With Pain refers to an experience of living with the certainty of death that includes, but is not limited to, a discussion of physical pain. This discussion does encompass individuals’ unique perspectives of pain and the universality of Living With Pain across all other essential features.

Heidegger (1971) refers to pain in a an expansive way in Poetry, Language, Thought:

Pain rends. It is the rift. But it does not tear apart dispersive fragments. Pain indeed tears asunder, it separates, yet so that at the same time it draws everything to itself, gathers it to itself. It’s rending, as a separating that gathers, is at the same time that drawing which, like the pen-drawing of a plan or sketch, draws and joins together what is held apart in separation. (p. 202)

Heidegger was not referring to physical pain, but rather the pain of situational or existential struggling; and he suggested that pain has a separating and connecting
effect. He stated, “We should not imagine pain anthropologically as a sensation that makes us feel afflicted” (Heidegger, 1971, p. 205). In other words, pain is not something outside or apart from the individual. It is the being, the individual, and it opens up a world of possibilities, including ambiguity and empowerment. This is consistent with the observation that Living With Pain crosses all other features encompassing the experience of living with the certainty of death. It is revealed in the painful expressions when doubting one’s own longevity, followed quickly with a determined expression to keep going and live each day; the discouragement of limited mobility along with the ability to block everything out with daily routines; the loneliness of separating from family and friends and the joy of connecting with new relationships and old relationships in new ways; the frustration with diminishing physical space, while transcending and expanding time and space; and the sadness of leaving others with impending death, while sensing a feeling of accomplishment when taking care of unfinished business.

Living With Pain is observed in the four tasks described in Corr’s (1992) holistic theory of a task-based approach to coping with dying. While he does not define coping, the Oxford English Dictionary (2012) refers to it in its definition of ‘handle’, which is defined as “possessing the mental or emotional resources necessary to accept or face up to (something challenging or difficult).” Corr proposed that individuals who are dying confront four primary areas of discretionary task work in coping with dying. The physical tasks relate to satisfying bodily needs and minimizing physical distress. This is consistent with the essential feature of Living With Pain. Individuals focus on pain management through not only medication, but also by engaging in daily routine activities that help to
focus away from the pain. Corr addresses the social task, involving sustaining and enhancing interpersonal attachments and addressing the social implications of dying. These are consistent with Separating and Connecting: Shifting Relations and Getting My House in Order in this study. Finally, the spiritual task concerning the need to identify, develop, and reaffirm sources of spiritual energy and fostering hope are consistent with the essential feature of Transcending the Everyday World Through Spirituality. These all-encompassing coping activities reflect the experience of facing up to the challenges of living with the certainty of death revealed in Living With Pain.

This connectedness of essential features around Living With Pain can also be observed in the findings discussed in Francke and Francke and Willems’ (2005) grounded theory study. They investigated terminal patients’ awareness of their impending death and the consequences this has for expressing care needs. One or more participants in this study discussed focusing on Living With, Not Dying From, working with hospice personnel to manage Living with Pain, planning with hospice personnel and others about the last weeks and days when Getting My House in Order, and experiencing the Separating and Connecting: Shifting Relations as they spoke more with hospice personnel about their dying rather than family members who they recognized were uncomfortable with this subject

Living With Pain crosses all other essential features and the quotes of the participants and the excerpts from literature and art discussed with each feature reveal how individuals living with the certainty of death live with pain. These were described with earlier essential features and are summarized once again from the perspective of Living With Pain.
Jack was living with pain when he shared the excitement of Beating the Odds of dying during his last hospitalization, but followed this with an expressed concern that his declining physical function might require another hospitalization and a fear that he might not come back home this time.

Frank was living with pain as he talked about Living With, Not Dying From and summarized his description of daily activities by saying, “You are still living, producing, working, and trying to manage the pain.”

Paul was living with the pain of Separating and Connecting: Shifting Relations when he talked about not seeing his daughter, stating, “She didn’t want to see me like this and that’s why she doesn’t come around.”

Nancy was living with pain when she Transcending the Everyday World Through Spirituality as she described lying in bed in pain and feeling sick and feeling the comforting arm of God around her, bringing her “warmth, peace, comfort, excitement.”

Vera was living with pain as she experienced the sensation of dying and proceeding to follow her plan of Getting My House in Order by telling her caregiver who should be present during her final moments and who should be spared the fear of watching her die.

In summary, Living With Pain, in whatever context it occurs can be a simultaneous experience of limiting and expanding possibilities when living with the certainty of death.

**Summary: Essential Features of Living With the Certainty of Dying**

The essential features presented here begin to characterize the phenomenon of living with the certainty of death. Taking it day by day, defeating the prognosis, and
engaging in everyday activities and routines while living with constant pain helps the
dying person recognize and simultaneously distance the certainty of death. Connecting
with new relationships or renewing others in new and different ways helps dispel their
loneliness of being separated from others. Living with the certainty of death predisposes
one to transcend the everyday world spiritually, gaining a sense of peace and comfort
from having concern for others by preparing for death so that their survivors are spared
certain tasks.

**Lifeworld Existentials: Living with the Certainty of Death**

Van Manen (1990) refers to the lifeworld as the “lived world as experienced in
everyday situations and relations” (p. 101). He suggests the use of Merleau-Ponty’s
(1962/2004) fundamental structures of the lifeworld existentials as helpful guides for
reflection on the essential features. These existentials include lived body (corporeality),
lived space (spatiality), lived human relations (relationality), and lived time
(temporality). Each existential will be discussed in relation to the experiences of the study
participants and the essential features of living with the certainty of death to further guide
the analysis. Each existential is discussed separately for clarity; however, the four
lifeworld existentials co-exist and co-constitute every situation. Therefore, the discussion
of each must also thread the other co-existing existentials reflecting the complexity of the
lifeworld.

**Lived Body (Corporeality)**

Individuals experience the world through their bodies. In bodily presence
individuals both reveal and conceal something about the self (van Manen, 1990).
Merleau-Ponty (1962/2004) considers the body to be “a living organism which rises toward the world” (p. 87).

Merleau-Ponty states that habit, and the production of schemes in regard to the body’s mobilization, “gives our life the form of generality and prolongs our personal acts into stable dispositions” (p. 146). All spatial and temporal perspectives center on the body and involve all the senses. He speaks of the habitual body acting as a “guarantee for the body at the moment” (p. 95) so that even with bodily changes experienced as painful movement or decreased vision, a person continues to engage in activities that have meaning for them, calling on other senses, such as touch, smell, and taste. Elaine talked about her love of baking and the limitations she experienced because of her decreased vision and inability to read the recipes. Yet, she also described a day when she said she was feeling sorry for herself, wondering why she was still alive when she was supposed to be dead by now, feeling frustrated because she couldn’t see, and also wondering how much longer she could live with the constant pain; so she decided to bake cookies for her neighbors.

I made pumpkin cookies and I couldn’t read the recipe book so I just figured I’m gonna throw this cookie dough together cause I remembered it, so I threw some leftover pumpkin in it and some walnuts and it came out good. I couldn’t see the baking soda or measure it but I knew where I put it in the cupboard and I knew what the box felt like, so I grabbed and said ‘I hope you’re the baking soda.’ The same with everything else. I took my glass measuring cup and filled it with milk until I felt about a cup on the mark on the side. I took the measuring cups and lined them up, then felt for the right one. I didn't measure teaspoons. I just took
the salt in my fingers and threw it in. The cookies were real big and that...they were pumpkin cookies and my sister said, ‘Boy were they good.’ And my neighbor asked me for it—over here—she wanted to know what the recipe was and I told her I couldn’t tell you what the recipes was, I just threw it together. I said I didn’t go by no recipe and I can’t remember it. [She chuckles]

The habitual and intentional nature of her bodily involvement in the world revealed several essential features as Elaine described never thinking she would be baking cookies when she shouldn’t even be alive, characteristic of Beating the Odds; keeping her kitchen cabinets in order so she knew where everything was located, characteristic of Getting My House in Order; her desire to engage in daily activities to ‘block everything out’ and to “pass the time”, characteristic of Living With, Not Dying From as well as Living With Pain; and connecting with her neighbors through baking cookies for them, an expression of Separating and Connecting: Shifting Relations.

The lived body tries to find meaning in perceptual experiences, which is often expressed in Transcending the Everyday World Through Spirituality. Mildred found meaning in describing a routine day:

Like did you ever get the same routine and get up one day and everything seems different and you’re at peace with everything no matter what it is, you are at rest and peace with it? And you think it aint any different than yesterday, but you have this peaceful feeling on you all day long; no matter what, nothing gets you down. Well, that’s God’s way of showing you, hey, you did good so I’m goin’ to give you a restful day today.
Transcending the Everyday World Through Spirituality and Separating and Connecting: Shifting Relations are also the lived body’s expression of finding meaning across spatial dimensions. Such was Nancy’s experience of feeling “this giant white arm…and I snuggled and felt the comfort.” “Feeling God’s arm around her” reflects the experience of spiritual corporeality. She found meaning in this experience and “did not have a worry in the world.” It provided comfort and peace, and a sense of connectedness she needed during this time of “deepest sorrow.”

Living With Pain influences a person’s way of being with others and is expressed through lived corporeality. On a good day there is movement, conversation, and productive work. On a bad day there is limited mobility and a desire to avoid others. There is always an intentionality to lived corporeality, and individuals have a specific intention of getting all their affairs in order, preparing to die and making it better for their loved ones, i.e., Getting My House in Order. Moving forward toward goals mobilizes the body in spite of Living With Pain. Small goals as described by Carl, such as moving onto a sliding board, then standing, then pivoting, and finally sitting in a wheelchair is a bodily expression of goal-oriented behavior.

Merleau-Ponty (1962/2004) refers to the body as the “power of natural expression” (p. 211), and speech as well as gestures are the expressions of thought. As the study participants living with the certainty of death talked about Beating the Odds of a prognosis timeline, they bodily experienced a sense of excitement. Their facial expressions revealed a look of satisfaction, they sat or stood upright, and they talked with a certain enthusiasm in their voice.
Separating and Connecting: Shifting Relations was also revealed in the bodily acts of talking to others about matters of importance. These experiences were accompanied by a sense of relief, laughter, calm, and excitement. Talking about the visits of the hospice chaplains and nurses, as well as their grandchildren brought smiles to their faces, while discussion of family members who could not talk about death was accompanied by concerned facial expressions.

Bodily gestures and spoken words reveal intentions that are not immediately grasped until elaborated on. For example, during the interviews, Paul usually talked about his experiences in a low mumbling voice as he sat at the kitchen table with his chair turned sideways and his back to the interviewer, gazing at the television with the volume muted. His responses were usually short, and sometimes his voice drifted off as he was completing a sentence. He described a good day as “winning the lottery, buying a Winnebago and driving across country.” When asked to describe what such a trip would be like, he sat silent for a few seconds, and then turned to face the interviewer, leaned on the table, and stated,

It would take a lot of my problems away just to go sightseeing and everything.
Well, it would save me from sitting around here at the house all the time, thinking, thinking. If I got out so I could see things, I wouldn’t worry about anything like that. I think I would be in a better mood.

Paul continued to face the interviewer and talked more about what he thinks and worries about during the day. This power of natural expression was revealed through an anecdote about traveling cross country in a Winnebago that opened opportunities for Paul to discuss the meaning of living with the certainty of death.
**Lived Space (Spatiality)**

Van Manen (1990) refers to lived space as felt space (p. 102). It is the way individuals experience their day-to-day existence while uncovering more fundamental dimensions of lived life (p. 103). As Merleau-Ponty described it, “Space is not the setting in which things are arranged, but the means whereby the position of things become possible” (p. 284).

An individual looks for meaning in lived space as well as positing meaning from a situation. Jack looked for the meaning in having the strength to walk to the kitchen table on some days, while on other days being unable to get out of bed. “When I can walk down the hall I am getting better and on days I need to stay in bed, I am getting worse.” Being able to walk to the kitchen table from the bedroom means “maybe in a month I can go for a walk.” Movement means life. Limited movement means limited life. This relationship between movement and life was experienced by all of the participants as described in the essential feature *Living With, Not Dying From*.

Carl looked for meaning in this lived space of lying in a fetal position in a chair and simultaneously posited a meaning from the situation of not caring whether he lived or died. This meaning went beyond his limited physical movement and revealed the intentionality of movement in space.

I have severe neuropathy. I probably haven’t walked for 15 years. I can’t walk at all. I was sitting, actually sleeping in my recliner so I wasn’t really turning much and I wound up with terrible bedsores. I had the feeling where I just didn’t care no more. Just didn’t matter… so tired and couldn’t do nothing. And everything you tried to do you couldn’t do, and it was like I was totally dependent on somebody
else to do everything. I guess just total depression set in. Really made it bad. You
don’t want to do anything, you don’t want to try. You more or less give up. You
just don’t care whether you live or die. That’s basically how I felt for a long time.
Carl described being all alone in the world. When he was no longer alone, and
someone was caring for him, it changed the meaning of his lived space and he was able to
move beyond the bed to an upright position. Then he looked forward to expanding his
lived space.

Really been improving. It started out the only way I could get out of bed was
either someone picked me up and put me in a wheelchair; then they started me on
a slider board. Well, that worked and I finally got enough strength in my legs that
I can push up enough that now I don’t have to use the slider board. I can go
straight from the bed to the wheelchair by turning and getting in the wheelchair.
I’ve really come a long ways this last month. You really have to be determined
and want to do it. I’ve had that determination I’m gonna be back in my wheelchair
and be outside in the summertime.

As revealed in Carl’s experience, the body is the way in which space opens up
and is shaped. Opening up lived space is also reflected in Beating the Odds, or living
beyond a designated prognosis. It gives the individual a sense of overcoming obstacles or
anything that gets in the way of progress or moving forward. As Carl stated:

When I went to my doctor this last time he said, ‘I just can’t believe the change in
you. How much you’ve changed. How far back you’ve come.’ I mean, I’ve been
doctoring with him for years. He said ‘I can’t believe how far you’ve come in the
past few months.’ So it’s a world of difference.
A sense of moving forward among the participants who have been *Beating the Odds* expands their sense of lived space.

Space opened up for Paul when he moved beyond his kitchen. He spends most of his days sitting in a small kitchen watching television and worrying. He says he gets irritated and cries often. Yet on one of the days he completed the audio-recorded protocol while sitting outside on his porch, his voice on the recording seemed to be stronger than in previous recordings and during the interviews.

It’s Saturday. Feeling good today. Sitting here on the porch goin’ day by day.

That’s all I gotta do. My neighbor’s out cutting the grass. I’m tryin’ to think of something to do. I might cut our grass, but it’s too dry. And I love life and everything. Thank God I’m still living. Thank you.

Through the bodily movements of going outside, Paul not only opened up his physical space, but also expanded his perceptual space as he talked about mowing the lawn, loving life, and thanking God for one more day.

The shifting nature of relations as individuals separate and connect also expresses a movement in space. Some participants sense a distancing by friends and family, even when they are nearby. They feel as if their loved ones are moving away by choosing to do things for them rather than just being there with them. In contrast, lived space opens up when there is laughter and talking and a sense of connectedness to another individual.

Nancy commented about a visit from the chaplain: “The chaplain. Oh my, I just love her. She is one super person. And we laugh and it’s so funny. It’s so much like family. All the crazy things that go on. I just love it.”
Connecting with others increases lived space and gives one a sense of family. The concern for others when *Getting My House in Order* increases lived space and expands to those they care about. The certainty that they will someday be apart from others and the uncertainty about when this will happen mobilizes them to prepare for death in several different ways.

The sense of being able to manage *Living With Pain*, particularly through a trusting relationship with the hospice nurse, expanded lived space as the individual is willing to interact with others and the environment.

Conversely, *Living With Pain* and the experience of limited mobility in *Living With, Not Dying From* decreases lived space. Those with severe pain do not want others near, or do not want to be touched or become frustrated and irritated at those around them. One participant warned the researcher during an interview: “If it gets real bad, I’d ask you to leave right away. That’s how bad I get.” The uncertainty of how long the pain will last and whether it will become even more severe also decreases one’s sense of lived space as one tries to minimize the environmental stimuli.

Space connects all things. In an environment of decreasing physical space owing to limited mobility, an individual can expand their lived space by the intentions of thoughts, feelings, and specific behaviors. The possibilities of expanding lived space in situations of decreasing physical space support Merleau-Ponty’s (1962/2004) emphasis that space may be defined as a form of external experience, rather than as a physical setting in which external objects are arranged. Transcending space through one’s own imaginings enabled Paul to wish to travel cross country in a Winnebago and experience the feeling of leaving his worries behind.
Carl’s experience of decreasing physical space was revealed in his description of living in one room with his limited view, yet as he watched others out the window he expanded his lived space by the intentions of his thoughts and feelings. Transcending the four walls of his small room, he traveled back through time to childhood and experienced the sights, smells, sounds, and feelings of playing in the leaves on an autumn day.

Nancy related an experience that revealed how she expanded her lived space while resolving the issues and giving meaning to the changing experience of decreased physical space and time. She illustrated this with an experience that occurred a couple of months after her diagnosis and prognosis.

I had been very sad for a couple of months. One day I woke up and decided I was through with the sadness. It was one of those days. I thought just knock it off. You know, enough is enough. I imagined going down to the river and throwing all of the sadness in the water and watching it float away. That night I patted myself on the back and said, ‘Today was your day not to worry. Get with the program.’ I still have sad days, but most days I’m just happy to be here.

‘Going down to the river’, or going to another place and time while watching children outside the window, or thinking about taking a trip in a motor home were all experiences of transcendent lived space for the participants where possibilities opened up with expanded spatiality even though the physical space remained unchanged.

**Lived Human Relations (Relationality)**

Expanded spatiality and temporality enable one to recall the relationships that have influenced perceptions and experiences. Merleau-Ponty (1962/2004) believed that
dialogue was important in connecting with people. It is through dialogue that individuals are affirmed. In the context of living with the certainty of death, the dialogue between healthcare providers/informal caregivers and a person with a limited life expectancy influences how that person will live out that time. Individuals who are Beating the Odds credit their own will power, desire to remain with loved ones, and need to complete projects for living beyond their expected prognosis.

Living With, Not Dying From is closely related to the strength derived from lived relationships. Carl expressed this when he related the story about not caring about living, sitting immobile and developing bedsores. He was ‘dying from’, but when his ex-wife began caring for him he was no longer alone and slowly transitioned to ‘living with.’ The dialogue that occurs through Frank’s acts of giving valued possessions to others and taking care of affairs before dying, and Vera’s concern that her dying might scare a friend both speak to a concern for others. The dynamic flow of relationality within the context of the illness experience is illustrated by the experiences of these participants.

The sense of Separating and Connecting: Shifting Relations decreases and increases spatiality, respectively. Being able to talk to hospice care providers, friends, or family members about their own dying brings individuals closer. They are able to share thoughts, feelings, and meanings manifested as a sense of connectedness and expressed as family. At the same time, they feel a distancing from loved ones who may no longer visit or may visit but refuse to sit and talk with them. They miss the sense of connectedness, which they described as occurring through touching a hand, talking, and laughing.
Elaine talked about her physical separation from her former home, her husband, and her dogs. She also talked about the emotional separation she feels because he suffers from Alzheimer’s and does not always remember her during their visits.

My lifestyle changed. I used to have my dogs up at the house, my own house and I had my husband. Now I don’t have anyone. I had lots of neighbors I went and talked to, and friends, and now it’s so lonely when you’re down here by yourself and he’s over there. We’ve been married 44 years, going to be 45. Now at 44 years we finally had to get separated. He has his good days and he has his bad days. Sometimes he don’t remember and sometimes he does. So it’s rough.

Transcending the Everyday World Through Spirituality reflects the lived relationship of expanding one’s spatiotemporal boundaries and connecting individuals with loved ones who have passed before them. Frank shared an experience of reading the Bible his father had given him. He said he did not have pleasant memories of his father, but when he opened the Bible and saw his father’s handwriting in the margins of the Bible, he felt a closeness and a love for him that he never experienced when he was alive.

I haven’t read my Bible in 25 years. It was given to me in 1938 by the church. I had a tough life when I was a kid. Got beat around a lot with a switch and my own belt. I was 14 when my dad dropped me off at a corner and said ‘I don’t think you can come home. There won’t be no home there.’ Sure enough there wasn’t. I didn't see him for 25 years.

We used to have to memorize Bible passages when I was a kid. Look at the margins in my Bible. You can see it in red. [There was red writing in the margins directing the reader to a passage]. That’s something my Dad did. [Reads]
‘For God so loved the world’ [then lifted his head and recited the remaining phrase from memory]. Isn’t that something? I remember that. I was thinking. I really loved him [Dad]. My Dad could do anything.

Frank went on to explain how he was going to give his granddaughter his Bible because she sits and writes passages out of it, and he thinks she would appreciate having it.

Getting My House in Order for Frank meant giving away valued possessions, enabling him to continue his lived relations across time and space.

Mildred talked about taking one day at a time, knowing her health was going slowly downhill, but was working to fulfill her perceived purpose of putting her children and grandchildren on the right track and right with God. “We’re going to straighten that little girl and these nine kids out. That’s when I die. I won’t go with great peace until they’re on the right track.”

Larry talked about Living With Pain and its purpose for another as he related the following:

Life is too hard when you’re over a certain age and you can’t do anything. That’s why I say, I wonder why I’m still living and I should have been dead a long time ago when I had that heart attack. And I was 57 when I had it. And all these years I’ve been living like this and you wonder why. I always say I am suffering for someone else.

Living With Pain, can be experienced as greater or lesser in intensity in the context of lived relationships. As the participants found, being with others or being with an activity can ‘block out the pain’ or ‘take [their] mind off the pain.’ Frank writes letters
to others as a way to keep his mind off of his pain and to thank those who have made a
difference in his life.

I think of the people who die suddenly in a wreck or an accident or heart attack. I
often wonder if the last few seconds of their life if they hadn’t wished in those
millimeters of a second that they would have had the chance to say ‘thank you’ to
a lot of people that helped them through—helped them get along in life. This[cancer] gave me the opportunity to write to my friends. I didn’t want sympathy. I
just wanted to thank them for their part in my life…for becoming part of my life.

**Lived Time (Temporality)**

Time is not viewed as a succession of seconds, minutes, and hours, but rather as a
network of intentionalities viewed in relation to specific situations. The perception of
time is contextual. As Merleau-Ponty (1962/2004) stated, “A perceptual field is a field in
which perceptions are present in time and space” (p. 478). With the theme **Beating the
Odds**, individuals who are told they will be dead in six months have a perception of six
months that is very different from someone who is planning a long-awaited vacation or
who is expecting a baby in six months. The perception of wanting to control the speed of
time is also contextual. A person with six months to live wants time to go slowly, yet
when a participant talks about the moment of dying, he or she wants it to happen quickly.

This perception of the desired pace of time is further reflected in the essential
feature **Living With, Not Dying From**. Elaine related the speed of movement with time.
In spite of her pain, she did not want to slow down because she said she “would probably
die.” The participants said that daily routines and productive tasks made the day go faster,
yet if one of them was watching the clock waiting for the time when she could have her
pain medication, time seemed to go very slowly. Although the participants were always Living With Pain, Frank was experiencing severe pain during one interview and did not want to be alone. He stated that he had taken his medicine and knew the pain would pass in a few minutes, and wanted to continue with the scheduled interview. He sat, leaning on his kitchen table, and began to talk as the pain eased.

I wish I wasn’t so sick, especially today. I have to catch up on so much stuff. I can’t put off my bills any more. If this stuff takes effect, I’ll be ok in about 10 minutes. They’re helping us live longer beyond our time and then we suffer a lot of pain. My time was up when I was 62, not 65 or 75, or 80 [he was 75 at the time of the interview]. The world goes too fast and they’ve slowed it up.

In the network of intentionalities, the past and the future come to the forefront when one reaches out temporally (Merleau-Ponty, 1962/2004, p. 483). Frank presented a perspective on time related to the regularity of work and life, suggesting how one’s perception of time and habits change with illness and severe pain, illustrating his way of Living With, Not Dying From:

Everything is 9 to 5; 9 to 5; 9 to 5. What time do you eat dinner? Oh, it should be around 5:30. Oh, you work 9 to 5. What about me? When am I going to eat dinner? When I get hungry and then keep it down. Maybe at 5:30 or 6. Or it may not be today.

Jack provided varying perspectives on the future from the present moment as he said, “What does the future hold? There is no future for either one of us [referring to himself and his wife]. Am I going to feel better tomorrow? Am I going to feel as good? Or what’s tomorrow going to be like? Or the next minute?” Jack was talking about the
future in the context of his concern that he might go back into the hospital soon. Thus, he talked about no future, tomorrow as the future, and the next minute as the future. His reflections were centered around his concerns about how he would feel in the immediate future and whether or not he could continue to *Beating the Odds* by staying alive. The perception of the past and future are always viewed within the context of the present situation, as Jack confirmed.

Reflection is a way the past becomes present and takes on new meaning. The meaning expressed about past events is always relative to the present situation, as well as one’s perceived future. Memory is a capacity to recall or recognize the past and may be influenced by a person’s changes in perceptions of the present and future. As Merleau-Ponty (1962/2004) stated, “When individuals recall a remote past, they reopen time and carry themselves back to a moment in which it still had before it a future horizon now closed, and a horizon of the immediate past which is today remote” (p. 483). Frank, who was writing a family history, had a sense of urgency about completing and leaving it with his children when he died. He remembered relationships and events that he had not thought about in years. Memories of his father whom he did not care for as a child were softened with time, and he talked about loving and missing his father.

Memories can also take one to a different place as “space is modified and restructured by time” (Merleau-Ponty, 1962/2004, p. 438). This was reflected in the essential feature *Transcending the Everyday World Through Spirituality*, which is what Nancy described from the memories that came to her when looking out her large picture window as she lay on her sofa and saw the church steeple rising above the treetops. She began to reminisce about her childhood and going to the same church. She spoke about
wearing her favorite blue dress, stopping to meet her girlfriend, and the two of them laughing and talking as they walked to Sunday School together. She then talked about the hymns of her youth and began recalling the “old Methodist hymns.” As the researcher was walking out the door that day, she could hear Nancy beginning to hum one of the old hymns.

The melding of past, present, and future was also reflected in the essential feature of *Getting My House in Order*. The tasks or strategies in this essential feature encompassed past, present, and future as several participants gathered up valued meaningful possessions (past) and gave them away (present) in preparation for the future when they would no longer be living. They felt that taking care of these affairs in the present would relieve their loved ones from this burden in the future.

**Summary: Lifeworld Existentials**

Individuals experience their contextual world through the lifeworld existentials of lived body, lived space, lived human relations, and lived time. As these existentials are interwoven through each of the six essential features that characterize living with the certainty of death, they also contribute to understanding the complexities of these essential features and their relationship to the rhythmic flow of certainty and uncertainty.

**Chapter Summary**

In conclusion, a thematic analysis of the data from the study and reflections on the essential features in terms of the four lifeworld existentials provided an increasingly complex description of the phenomenon of living with the certainty of death. The concepts of certainty and uncertainty are interwoven in the phenomenon of living with the certainty of death. While always mindful that certainty brings uncertainty to the
forefront, this description will focus on the dominant pattern of certainty. Living with the certainty of death is sometimes Beating the Odds and exceeding the time the participants were expected to live. It is expressed as Living With, Not Dying From as the study participants focus on everyday routines and movement. Their routine activities are productive, help them forget their pain, and help the day go faster, grounding them in the present, rather than focusing on a diminishing future. Living with the certainty of death involves their connecting with new relations or current relations in a new or different way while experiencing the loneliness of separating from others in shifting relationships. Separation may occur when certain friends no longer visit. Separation is also experienced with family and friends who visit but spend their time “doing for” rather than “being with” their dying family member. Living with the certainty of death is experienced as Transcending the Everyday World Through Spirituality as individuals experience creating and sustaining their faith, and hopefulness in the future. Living with the certainty of death involves preparing for death by Getting My House in Order. Most of the participants wanted to be prepared, having everything in order, giving away valued possessions, and finishing projects as quickly as possible so that there would be no unfinished business by the time they die. Finally, living with the certainty of death is Living With Pain, a universal feature that cuts across all other essential features. Pain is a constant in each participant’s life. It includes, but is not limited to physical pain, and it can be a simultaneous experience of limiting and expanding possibilities when living with the certainty of death.
CHAPTER 5

Discussion

The discussion in this chapter will re-examine the literature reviewed in Chapter 2 in light of the study participants’ descriptions of living with the certainty of death, describe the limitations of the study, and discuss the methodological implications, as well as the implications for nursing practice and nursing research. During this study six essential features were identified as characterizing the experience of living with the certainty of death. They included (a) Beating the Odds, (b) Living With, Not Dying From, (c) Separating and Connecting: Shifting Relations, (d) Transcending the Everyday World Through Spirituality, (e) Getting My House in Order, and (f) Living With Pain. In Chapter 2 the following question was posed: Do known theories and research regarding end of life capture the essence of living with the certainty of death? The relevant literature presented in Chapter 2 was also integrated into the phenomenological text in Chapter 4. In this chapter the discussion will focus on the integration of the essential features and address the following question: How did this research inform an understanding of the end-of-life literature discussed in Chapter 2?

Re-examination of the Literature

This section re-examines the topics relevant to this study of living with the certainty of death, including the awareness of dying, the process of dying, illness trajectories of the dying, transitions, quality end of life in the face of impending death, and the rhythmicity of certainty/uncertainty.
Awareness of Dying

The theory and research presented in Chapter 2 focused on the individuals’ awareness of their dying based on a discussion of their prognosis with their health care providers. A pattern of collusion was observed when healthcare providers avoided further discussion of a prognosis with the patient, which can lead to a sense of ambiguity and false optimism in the patient. However, ongoing and honest conversations about their prognosis seemed to contribute to the patients’ empowerment. The participants in this study were all aware of dying as acknowledged by their enrollment in hospice services; therefore, the researcher observed no indication of such collusion. Each participant was informed of a prognosis of 6 months to a year. The openness between patients in this study and their providers was consistent with the level of open awareness described by Glaser and Strauss (1965) in their study of the levels of awareness. Open awareness occurs when both healthcare staff and patient know that death is impending and acknowledge it in their conversations and actions. Nonetheless, Glaser and Strauss emphasized that ambiguity accompanies open awareness. They described this ambiguity as the unknown regarding when death will occur that accompanies the patient’s knowledge that they are dying. Patients may think their death is months away, while hospice staff may conceal their own knowledge of the expected timing of death and the deterioration that is expected prior to death. This is consistent with the participants’ perspectives that they were Beating the Odds, meaning that they had outlived the time they had been given to live. According to Glaser and Strauss, patients and staff may also have different ideas about how a patient should die, focusing on issues of placement, dignity, and privacy.
Although the participants in this study did express ambiguity about the unknown as to when their death would occur, their conversations with hospice personnel remained open and inclusive of what to expect as they approached death. They had planned for their placement, privacy, and dignity, as well as symptom management at the end of life.

Glaser and Strauss published the results of their grounded theory on the awareness of dying in 1965. Their description of patients’ open awareness was based on their observations of the relationship between hospitalized patients and their physicians and nurses. It is interesting to note that the first hospice in the United States was not opened until six years later in 1971. The hospice program, consistent with the open awareness context described by Glaser and Strauss, is built on the belief in acknowledging the patient’s prognosis by informing them of it, so that they can be aware of their dying. Glaser and Strauss’ theory of open awareness accurately reflects the descriptions by several individuals in the present study of *Beating the Odds*, that is, living beyond their prognosis. However, there are many individuals at the end of life who are not enrolled in hospice or palliative care services. Research should continue to explore the awareness contexts of individuals experiencing the end of life who are enrolled in hospice, as well as individuals who are not.

**The Process of Dying**

The process of dying was described in Chapter 2 according to theorists and researchers in a variety of ways, including the stages, tasks, and intervals associated with this process. A discussion of these theoretical sequences as related to this study is not really possible since the participants were only interviewed twice and not observed over a very long period of time. However, when the participants responded to the request “Tell
me about your illness,” they did provide descriptions similar to characteristics identified in the stages, tasks, and intervals in the dying process found in the research. These characteristics were contextual. For example, Kubler-Ross’s (1969) five stages of death, including denial, anger, bargaining, depression, and acceptance were recognizable in the descriptions of the participants in the present study, but not in any particular order; and sometimes several occurred at the same time. For example, Frank talked about the fact that he still smokes, saying “it is too late now”, but he also questioned whether or not smoking really does cause cancer, which suggests his denial that his cancer was related to his smoking. Several participants expressed anger about their situation, and their inability to function as they had prior to their illness. But they usually followed this with the recognition that anger does not change anything, and talked about moving forward. A couple of participants revealed having bargained with God to let them live long enough to see their grandchildren grown or until they could make sure their children were doing what they expected of them. Several participants admitted sadness and depression at times during their illness when they thought about leaving their loved ones behind, but these feelings did not occur at a particular time in the illness and did not resolve completely. They seemed to ebb and flow throughout the illness in relation to specific anniversary events or an exacerbation of the illness or a visit to their doctor. Although each participant acknowledged the certainty of their death, their acceptance of this prognosis also brought forth questions and doubts whenever the expected date of their death had passed.

The behaviors and emotions expressed during the living-dying intervals identified by Pattison (1977) also occurred throughout the illness, but it is questionable whether
they appeared at specific times or, once again, related contextually to the concerns of the dying individual. Pattison described fears experienced by the individual during the chronic living-dying phase, including fears of loneliness, the unknown, sorrow, loss of family and friends, loss of body, loss of self-control, suffering and pain, and loss of identity. Several descriptions by the study participants revealed similar responses, but not in the context of fear.

These theories, along with Corr’s (1992) task-based approach discussed in Chapter 4 with the essential feature of Living With Pain, all have characteristics consistent with those described by the participants in the current study. These theories have been criticized for their perceived stage/phase or task presentations as well as the lack of empirical evidence supporting their development and continued use. However, each theory may provide important contributions to end-of-life theory and research, and should be re-examined within the context of other developing end-of life theories.

Cooper (2010) suggests conducting systematic theoretical reviews to explain a particular phenomenon. Accordingly, the theories are “compared for breadth, internal consistency, and the nature of their predictions” (p. 4). Critical research related to each theory is reviewed, and assessment is completed regarding which theory is the “most powerful and consistent with known relations” (p. 4). Abstract notions from different theories are reformulated and integrated into a synthesized theoretical framework. A comprehensive integrative theoretical review of these and other theories of dying could provide an opportunity to systematically examine the elements of the various theories against one another and against a broader framework, such as the dying and illness trajectories, thereby contributing to a synthesized theory of the process of dying.
Dying and Illness Trajectories

Glaser and Strauss introduced the concept of illness trajectories, but Lunney, et al.’s (2002) description of them more specifically fit the diagnoses of the participants in this study. Research related to the cancer trajectory (Constantini, et al., 2008) was discussed in Chapter 4; therefore, this discussion will focus on the organ failure trajectory and Hupcey, et al.’s (2009) recommendations for managing care with heart failure patients.

The CHF/COPD trajectory is described as “long term limitations in functions with intermittent exacerbations” (Lunney & Goldstein, 2006, p. 11). While functional decline occurs throughout the trajectory, death is often unpredictable and unexpected. Hupcey, Penrod, and Fenstermacher (2009) recommended that palliative care interventions be introduced as a philosophy of care early in the illness along with medical management. The intensity of the interventions while minimal early on would increase when sporadic intensive therapies are required. The functional status of all of the participants diagnosed with heart failure in this study was at a point where the hospice care assumed a dominant role, although life-prolonging medications continued. Only one participant, Jack, hesitated when speaking about death, although he did talk about not knowing what the future meant—the next week, day, or minute. He also expressed concern that if he went back into the hospital, he might not come home. The remaining participants spoke more often about their concerns about the end and how they would die, and all seemed prepared. Each participant had very limited mobility, but appeared hopeful on days when they could move a little further or breathe and talk a little more easily. At the same time, they expressed concern about their limited time on the days when movement was more
difficult, breathing was more labored, and talking was interrupted more often with the need to catch their breath.

Moreover, the unpredictable progression of the organ failure trajectory was observed in the participants in this study. Those with cancer were aware of the meaning of their declining function in relation to their dying, but the participants with organ failure, while anticipating their end, were never sure when and how that end might occur. The dominance of palliative care provided to the participants in this study supports the philosophy-of-care approach suggested by Hupcey, et al. (2009) to introduce palliative care interventions early in the illness along with medical management and increase the intensity of the interventions, as needed.

**Transitions**

Several studies focused on the transitions within illness/dying trajectories and the experiences of individuals, particularly as they transitioned from curative to home-based or institutional palliative care facilities (Dalgaard, et al., 2010; Duggleby, et al., 2010; Larkin, et al., 2007a). Murray, et al. (2007) conducted a secondary analysis of two longitudinal studies, each lasting one year and focusing on inoperable lung cancer and heart failure, respectively. They analyzed “quality of life trajectories” (p. 394), focusing on social, psychological, and spiritual problems at various times during the illness. Even though these were limited in their focus on problems in these three areas, their research contributes to a beginning understanding of transitions occurring within trajectories.

Longitudinal studies would be beneficial in identifying transitions as well as examining the ebb and flow of certainty/uncertainty throughout the dying trajectories. Lloyd, White, and Sutton (2011) conducted a research review of cross-cultural studies
examining ethical, cultural, and methodological issues in end-of-life research in older adults. Methodologically, they found the power of the smaller longitudinal studies reviewed was increased by their “extended duration and by numerous contacts between researchers and participants” (p. 399). Miakowski (2011), reporting on Symptom Trajectories, Palliative Care and Quality of Life during the NINR summit on The Science of Compassion, stated that substantial gaps in the literature “include a preponderance of cross-sectional rather than longitudinal studies” (p. 5). In summary, future research should focus on the longitudinal method for examining transitions within trajectories to provide a more comprehensive understanding of transitions within them.

**Quality End-of-Life Care**

When re-examining the literature, this researcher asked, “Are religion and spirituality the same, or are there differences? If there are differences, does the experience of transcending the everyday world through spirituality encompass religion?” Most participants in the study discussed their renewed or strengthened faith in God since becoming ill. In Chapter 2, and again in Chapter 4, spirituality was defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Pulchalski, et al., 2009, p. 887). Alcorn, et al. (2010) in the Religion and Spirituality in Cancer Study investigation, did not differentiate them, but rather referred to the terms throughout the study as Religion/Spirituality (R/S).

The word “religion” comes from the Latin word “religio”, meaning, “bound by religious vows and a system of faith and worship, belief in superhuman powers” (Oxford English Dictionary Online, 2012). Spirituality is taken from the Latin “spiritus” meaning
“smooth breathing” (OED Online). According to Worthington and Sandage (2001), while religion focuses on “a search for the sacred within formal institutional structures” (p. 473), spirituality is more experiential and dynamic, referring to “personal meaning and transcendence” (473). Hill (2000) views spirituality as multidimensional and identifies three categories of it, including (a) God-oriented, (b) world-oriented (or nature), and (c) humanistic (or human achievement or potential) (p. 57). Consistent with Pulchalski, et al.’s (2009) definition of spirituality, then Transcending the Everyday World Through Spirituality, as revealed in the present study, encompasses religion and can refer to a transcendence through God, nature, and human potential.

A Rhythm of Certainty/Uncertainty

From this study it is clear that certainty and uncertainty are interwoven in the experience of living with the certainty of death, co-existing situationally and existentially as one lives the dying process. This rhythmicity was revealed in the descriptions of each essential feature derived from the data. Even though the participants in this study were living with the certainty of death, they also expressed a concurrent sense of uncertainty about their dying. This is consistent with Glaser and Strauss’ findings regarding open awareness of dying. While open awareness of impending death can empower an individual, it simultaneously introduces a sense of ambiguity. This study found that individuals’ actions and expressions revealed the dominance of certainty or uncertainty at any given moment. This is consistent with Penrod’s (2007) finding that rhythmicity is manifested in the dynamic nature of the dominant pattern of certainty or uncertainty, based on the individual’s sense of situational and/or existential control and confidence.
In this study’s descriptions of individuals living with the certainty of death, control is viewed as one’s perceived ability to interact with others and events within the context of a situation, enabling the individual to confidently mobilize their perceived possibilities. This finding is similar to Penrod’s definition of control and confidence. Penrod (2001; 2007) defined control as sensing an ability to influence the outcome of the situation, and confidence as sensing an ability to read a situation. However, in light of Penrod’s theory of uncertainty, this study did not reveal levels of confidence and control. Penrod identified four types of uncertainty reflecting the levels of confidence and control: minimal uncertainty (high confidence and high control); pervasive uncertainty (high confidence and low control); role uncertainty (low confidence and high control); and overwhelming uncertainty (low confidence and low control). In the present study, dominant patterns of confidence and control co-constituted the situation and could not be assessed as a high level of one element or the other. Without having a perceived sense of control in a situation, individuals did not express confidence in their ability to positively interact within the context of the situation. This was clearly revealed in the participants’ descriptions of a good day as being able to accomplish daily activities when controlling their own actions within a given situation. Jack expressed a sense of control over his own actions when he could walk from the bedroom to the kitchen. He also expressed confidence that he could possibly walk outside next month. Vera’s confidence in accepting her dying and understanding what might happen during the dying process enabled her to take control of her own actions within the situation and give others instructions when she thought she was dying. According to Wittgenstein’s (1969) claim that a proposition is placed in a particular context and “knowledge is in the end based on
acknowledgment” (p. 378), it is clear that individuals living with the certainty of death express confidence and control in the given situation based on their own acknowledgment of this certainty; and their sense of co-existing confidence and control mobilizes possibilities for their actions.

Elements of Mishel’s theory of uncertainty were also revealed evident in the descriptions of the individuals in this study. Mishel (Mishel & Braden, 1987) defined uncertainty as the “inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes” (p. 48). Mishel’s model emphasizes antecedents of uncertainty, which are expressed as a stimuli frame, which is the form, composition, and structure of the stimuli contained in the illness, including the system pattern and event familiarity. This is similar to Heidegger’s notion of forehaving, or the influence of past experiences on the meaning given to the current contextual situation.

An area of inconsistency is the sense of adaptation to the situation expressed in Mishel’s theory. Mishel (1990) stated that “adaptation, psychosocial behavior within the person’s normative level of functioning, is proposed as the end state achieved after coping with uncertainty” (p. 257). Adaptation suggests that the individual changes as a result of the changing environment rather than interacting mutually and simultaneously with the environment, reciprocally influencing the context of the situation and the sense of confidence and control. Adaptation in this sense diminishes one’s sense of control in a given situation and suggests that events, occurrences, or the knowledge of others controls the situation, which bolsters the confidence of the individual experiencing uncertainty.
The concept of uncertainty may be enhanced and expanded in light of the description of living with the certainty of death and within the context of a mutual and simultaneous relationship of a person and the environment within a given situation. The essential features in this study reinforce the notion that the meaning given to a present situation reflects a person’s past experiences and possibilities for the future. Confidence and control of one’s own ability to interact positively with the environment in a given situation influences the dominance of certainty or uncertainty at any given time. Therefore, it is recommended that future research examine the interacting patterns of certainty and uncertainty that co-exist in all situations and specifically within the context of living with the certainty of death.

**Limitations of the Study**

There were limitations to the study in the following areas, as discussed below: recruitment, data collection protocol, hospice-enrolled participants, and the feasibility.

**Recruitment**

Recruitment was a challenge in both Phase I (the feasibility study) and Phase II of the study. There were two areas of concerns, namely patient recruitment and agency participation in the recruitment. The nature of the participants’ illnesses created a difficulty when recruiting through hospice, as they were enrolled in hospice when their death was imminent. Therefore, they were already experiencing multiple symptoms and often unable to talk to someone who was not there to provide them with care. However, two participants explained the reasons they wanted to participate after reading the recruitment letter for Phase II: “to make a difference for someone else who is going through hospice” and a desire “to talk about the wonderful work that hospice is doing to
help me.” The use of a patient recruitment letter during Phase II informed the participants of the purpose of the study. While it is not known whether or not this made a difference in any other participants’ decision to take part in the study, the recruitment letter was beneficial in providing an explanation of the study from the researcher’s perspective. A patient recruitment letter had not been used in Phase I, relying on the hospice nurses to explain the study to potential participants.

Hospice agency administrators were cooperative and enthusiastic about participating in the research recruitment and remained so throughout the Phase I feasibility study and Phase II. However, unavoidable issues, such as staff and supervisor turnovers and patient care priorities delayed recruitment of participants. The increase in recruitment locations during Phase II from one office to two naturally increased the number of potential participants. While not increasing the total number of participants recruited for Phase II, the period of recruitment for this same number decreased from 12 to 6 months.

The researcher primarily had direct contact with the nursing coordinator and hospice nurses in Phase I. However, having a direct line of communication with the Hospice Agency Senior Vice President and the Director of Hospice enabled the researcher to contact them immediately with concerns during Phase II. When recruitment became a problem due to staff turnovers, the eventual recruitment of patients occurred directly through the office of the Director of Nursing. This increased the efficiency of recruitment in the second phase of the study.

**Data Collection Protocol**

The data collection protocol was also a limitation in this end-of-life research,
particularly in the area of scheduling interviews. Unexpected schedule changes due to hospitalizations or increased severity of manifestations of illness on a particular day resulted in numerous schedule changes and a longer than expected time frame between Interview #1 and Interview #2. This occurred even with decreasing the time between interviews to 5 days in Phase II compared with the feasibility study range of 2 to 3 weeks between interviews. However, the participants expressed a willingness to continue with a second interview at a later time and openly discussed their illness and dying during the interviews. Therefore, this population remains a rich source of information regarding living with the certainty of death. Planning for flexible scheduling when conducting end-of-life research will prepare other researchers for this unavoidable limitation.

Audio-recorded protocols were limiting in that only 2 out of 5 participants in Phase II used the recorders. Two participants refused to record and a third participant tried, but became too ill and withdrew from the study.

The time frame allowed for having the participants record additional information was decreased from 5 days in Phase I to 3 days in Phase II. While there were more recordings during the feasibility study, their quality diminished over days. Participants who continued to record their comments repeated information from earlier recordings or turned the recorder on to follow the procedure for daily recordings but just said a short “hello.”

The two participants in Phase II who recorded did so on 2 out of the 3 days. At least one recording from each participant was of high quality, not only for what was recorded, but also when they recorded and how their voices sounded when recording. Nancy chose to record in the evening when she had gone to bed. This was a lonely time
for her and she spoke about this loneliness during the recordings and the absence of lifelong friends. Nancy, who spoke with an upbeat tone to her voice and optimism during her interviews, recorded her messages with a low voice and a tone of sadness in her voice. In one recording she wondered aloud when God would be taking her home and ended this recording with the phrase “in His time; in His time.”

Paul, on the other hand, usually muttered and spoke in a very low voice during the interviews, often drifting off at the end of a sentence. He chose to record one of his messages while sitting outside on his porch. His voice during the recording was clear, strong, and he spoke distinctly. He talked about feeling good in this recording and thanking God for one more day.

So, while the number of the participants’ recordings were limited to two days, and not everyone agreed to audio record messages, those who did, offered insights through perspectives and behaviors not evident during the interviews. Recordings could continue to be a valuable source of information, but the time for recording should be limited to a couple of days given the condition of the patients and the energy it takes. This might eliminate the redundancy and the perceived sense of obligation to turn on the recorder that was observed in the Phase I feasibility study. In addition, the participants could be provided with other options, such as protocol writing or additional short interviews.

Hospice-Enrolled Participants

The use of hospice only patients in this study may be viewed as a limitation, since individuals experiencing the end of life are not always enrolled in hospice; therefore, the results of this study may only be applicable to those who are receiving hospice services. However, the wide range of illnesses and the participants’ various placement within the
final end-of-life trajectory did provide a broad range of perspectives.

**Feasibility Study**

The time-consuming process of conducting a feasibility study was a limitation, but it was also an important process in helping to identify recruitment and data collection issues and to revise the procedures prior to Phase II. While a feasibility study is not always possible due to time and/or resource restraints, it is highly recommended prior to conducting end-of-life research.

**Implications**

This study has implications for research methodology, nursing practice, and the discipline of nursing and future research. Each of these implications will be discussed in light of this researcher’s own experience in the process, and her recommendations for future research.

**Methodology**

The hermeneutic-phenomenological methodology is useful in capturing the essences of a phenomenon. While descriptive phenomenology is valuable in describing a phenomenon, the interpretive process of hermeneutics is important in revealing the concealed meanings within descriptions of a phenomenon. For example, although a description of *Transcending the Everyday World Through Spirituality* might be common among individuals living with the certainty of death, the meaning of this transcendence is even more valuable when it reveals their concerns and the meaning they give to the present based on past and future possibilities.

Establishing an understanding of the philosophical basis for the research methodology of hermeneutic phenomenology is important. Reading van Manen’s text,
while valuable in identifying and describing the interactive activities involved in the hermeneutic-phenomenological methodology, is inadequate for comprehending the full nature of the hermeneutical-phenomenological process, including the lifeworld existentials. Studying the philosophical frameworks of Heidegger and Merleau-Ponty and dialoging with experts in these philosophical areas is valuable in expanding and enhancing an understanding of this complex methodology. While enrollment in courses and face-to-face meetings with experts in the field is not always an option, interactive electronic communication, such as blogs, discussion forums, and social networking sites, offers alternative means for communicating with the experts on this methodology. As with all interactive communication, it is important to identify credible experts in the field when engaging in online discussions.

The hermeneutic-phenomenological methodology is an intensive, rigorous, energy-consuming process. Even though only five participants were recruited for Phase II, the depth of the data required considerable time for the analysis. The process became even more time consuming since this researcher chose to personally transcribe each interview, audio-recorded protocol, and audio-recorded journal entry. However, the activity of transcribing all this offers a level of immersion in the data that is missing when listening to a recording and then reading a transcript prepared by someone else. The transcribing process requires attentiveness to each word and the changing tone of the conversation. A back-and-forth process between transcribing and remembering the actual conversation enables the researcher to insert notes into the transcription regarding recollections of what was happening between her and the participant as well as in the surrounding environment. These notes became part of the data set for the analysis in this
study. While researchers may not want to transcribe all audio-recorded information, especially if the data set is large and time is limited, selecting the first two or three to transcribe, then randomly selecting others, provides opportunities for gaining additional insights.

The rigors of the hermeneutic-phenomenological analysis process are also time consuming, so some qualitative researchers use software applications for analysis. This researcher chose to review the transcribed data without the use of any software. Van Manen (1990) himself warns against the “mechanical application of frequency counts or coding of selected terms of transcripts and text (p. 78) and the use of software applications for thematic analysis. The nature of the hermeneutic method which Heidegger called “the hermeneutic circle” requires the reader to look at the whole as it relates to the parts; and look at the parts as they relate to the whole, which brings to light the forestructure (Heidegger, 1927/1996, p. 150). This reciprocal process requires attentiveness and full presence in the description. Therefore, while time-consuming, it is essential that analysis remain a process of reading the entire text and reading its structural parts and continually referencing back and forth. The circle of the hermeneutic process does not quite capture the complexity of the process. With each reading, more is revealed, contributing to a greater understanding of the phenomenon, which becomes the background for reading the structural components of the dialogue again with a more enriched perspective. This increasing complexity goes beyond a cyclical process because one never really ‘goes back.’ It is always forward moving with increased complexity and a clearer understanding of a phenomenon that is never absolute, but always relative.

This methodology has implications for the researcher’s own changing world view.
The forehaving component of forestructure (Heidegger, 1927/1996, p. 150), the tentative sense of an idea the individual has about what is being interpreted changes as the analysis progresses and the world view of the researcher is forever changed.

Prior to beginning the data collection for this study, this researcher viewed the certainty of dying as something that naturally occurs with patients during care. This perspective was illustrated with the scenarios of Tom and Alicia’s responses to their terminal illnesses as described in Chapter 1. These were based on observations of two actual patients and their dying processes. The researcher’s perspective has changed during the research process, and her worldview has changed regarding living with the certainty of death, to the extent that each day is a realization that it is the only one guaranteed, and life is viewed and appreciated as a series of moments. An examination of the phenomenon of living with the certainty of death has implications for the way this researcher will view her relationships, life’s priorities, and her own way of practicing nursing in the future, all a result of her involvement with this study and the participants in their various end-of-life circumstances.

Examining the phenomenon of living with the certainty of death was most appropriately studied with hospice patients who had an expected prognosis of six months. As discussed in the limitation section, recruitment is an issue with this population. This issue is not unique to this study, however. Larkin et al. (2007a), Murray, et al. (2007), and Dalgaard, et al. (2010) also reported difficulties in recruiting, as well as retaining subjects for their end-of-life research.

Kirchoff and Kehl (2008) discussed strategies for recruiting participants in end-of-life research. One was to permit family members to be present during the interviews with
patients. This was expected to increase the comfort of the patient and to gain support from the family for their participation in the study. This was not a planned strategy during Phase I of the present study, but it became apparent that some of the participants wanted their caregivers to be near by and often within sight as they completed the interviews. However, their presence did not prevent the participants from speaking about areas of concern, including dying. In fact, some participants may have taken this opportunity to discuss matters of concern in the presence of the caregiver. One caregiver left the room when the participant began to discuss his dying. Another caregiver became teary-eyed during the conversation, said nothing, but leaned over and kissed the participant on the cheek. They held hands as the interview continued.

During Phase II, the participants were informed during the initial phone call that caregivers could be present in the room, with the participant’s permission. This was reinforced during the initial meeting. Two family members stayed during the Phase II interviews. One stayed in the kitchen area and listened, but did not participate. During the second participant interview, a family member arrived at the home and the participant asked her to sit down and join the conversation. She did not participate in the conversation, but occasionally tried to talk to a person in a different room. She eventually left the living room and went to another room. While acknowledging that the entrance or exit of anyone from a situation changes the dynamics of the interrelationships and dialogue, the presence of caregivers in the room did not seem to interfere with the flow of conversation between the participant and the researcher, and did not prevent the participant from discussing issues of importance.

Kirchoff and Kehl (2008) also discussed flexibility in the timing and location of
the interviews. They suggested meeting where the participant felt most comfortable. They also suggested accommodating the participants’ schedules as much as possible, including days of the week and times of the day.

In both the Phase I and Phase II studies, the participants could not leave their homes, so conducting the interviews in their homes was the only way they could participate. The researcher maintained an open schedule and was available to meet with the participants any day or time of the week with the exception of Mondays. While this schedule is not always possible for researchers, maintaining as flexible a schedule as possible is beneficial for recruitment of participants who are nearing the end of life. Using a team of researchers to conduct interviews would also increase the availability for conducting interviews on different days and times.

Issues regarding the hospice agency recruitment of participants was also discussed in the limitations for the present study. Kirchoff and Kehl (2008) identified two areas of concern. They found that professional care providers were often too busy to take the time to give patients information about the research and the researcher. The care providers were also concerned about burdening participants and their families by requesting participation in the research at this sensitive time. A second concern expressed was gatekeeper control. Gatekeepers are those who provide or deny access to potential eligible participants. Their attitudes about the value of the research as well as their desire to protect patients may determine their degree of cooperation in the recruitment process.

It is not known what the professional care providers felt about recruiting the participants for this study, although they were cooperative and willing to participate during scheduled meetings with them to discuss the research. A meeting with clinicians at
the conclusion of the study may provide an opportunity to have staff share their recruitment concerns with the researcher in an effort to improve future recruitment strategies. The hospice agency’s expressed interest in learning about the results of this study will be an opportunity to discuss these concerns with staff.

Gatekeepers are the key to ensuring the success of the recruitment process. In this study both the Senior Vice President for Hospice Services and the Director of Hospice expressed interest in the research and maintained ongoing communication with the researcher. They were very helpful in recruitment. In fact, the Director of Hospice assumed full responsibility for recruitment when staff turnovers slowed the process in the beginning of the study.

Serge, Buckwalter, and Friedemann (2011) identified strategies to engage clinical staff in subject recruitment prior to the beginning of the study and once the study was underway. Their strategies emerged from consultations with three researchers who discussed “recruitment woes” when conducting three different studies in the U.S. (p. 323). Three of the four strategies recommended prior to the present study were implemented in Phase II of this research. They included assessing the suitability for the clinical setting, assessing and engaging stakeholders from the beginning, and marketing the study to the clinical staff members (CSM). Serge, et al. also recommended providing printed educational materials to enhance the CSM’s participation. This is the researcher’s recommendation for future research, as it was never clear if the staff understood the study or its methodology from the printed materials the researcher distributed.

Serge et al. (2011) offered additional recommendations to be implemented after the study has been initiated. They include providing financial incentives for finding
subjects, sharing authorship with CSMs, including CSMs in development of research procedures, providing CSMs with a script to facilitate subject recruitment, and publishing newsletters. Paying staff to recruit patients does not appear to be an ethical practice because it represents a conflict of interest and would not be considered when recruiting within a hospice agency. Sharing authorship in future publications and requesting suggestions for recruitment strategies might encourage a collaborative effort with an agency. While publishing newsletters might be time-consuming and expensive, volunteering to write an article for the agency publication could accomplish the same purpose.

Data collection protocols were another methodological issue identified as a limitation in this study. Flexibility in data collection methods and the timing of data collection are important. Most participants in the Phase I feasibility study were able to complete a 60-minute interview, and some even asked to continue after the 60 minutes. During Phase II the participants were more symptomatic at the time of the interviews, so a few experienced increased tiredness or a slowing of speech after 30 or 45 minutes. Longitudinal studies as previously discussed are other options for data collection. This arrangement could provide the opportunity for more frequent and shorter interviews, as more readily tolerated by the participants.

Secondary analysis is another option for data collection. Dobratz (2002; 2011) gained some valuable insights through secondary analysis of her original research and eventually developed a middle-range theory applicable to end-of-life care. Long-Sutehall, Sque, and Addington-Hall (2011) discuss the value of secondary analysis when exploring sensitive issues or working with an elusive population. They refer to Fielding’s (2004)
definition of an elusive population as one that is difficult to access. Long-Sutehall, et al. recommend that in preparing for a secondary analysis, assessing the fit between the primary datasets and the secondary research questions is essential. The research questions for the secondary analysis should be close to those in the primary dataset as well as the data collection and analysis processes.

Individuals at the end of life are considered a vulnerable population, because they have limited autonomy, independence, and self-determination (Sherman, et al., 2005). This may discourage research with this population. But, as reported in the summary from the latest NINR summit (2011), the term vulnerability is an “extrinsic characteristic assigned by others to persons who may wish to direct their own care, even with recognized risks” (p. 4). The interactions with participants in this study portrayed a group of individuals who clearly have important information to contribute to assist healthcare professionals in providing high quality end-of-life care and should continue to be recruited for end-of-life research studies.

**Implications for Nursing Practice**

This study is significant in that it provides a deeper awareness of the experience of living with the certainty of death through the development of a description that could be useful for advancing strategies of care for the dying. However, phenomenological research does not have as its primary focus the direct application of results into practice. The small sample size in this study also limits the generalizability of the results to the population of individuals experiencing the end of life. In light of this understanding, a general discussion of the implications for practice will be presented.

It is important to remember that the population of individuals experiencing the
end of life reaches beyond those enrolled in hospice. As reported in Chapter 2, the Medicare reimbursement plan for hospice is built around the dying phase of the cancer trajectory which is manifested by an approximate 8-week period of loss of weight and energy and a limited ability to carry out tasks. The timing of death for greater than three quarters of the population insured by Medicare is usually not predictable and not limited to a 6 to 8-week time frame. Individuals are living with the knowledge of their impending death for longer periods of time as they experience declining physical functioning.

While hospice provides multiple services for both the patient and caregivers, fewer support services are available for those who are not enrolled in hospice, who also are experiencing a terminal illness and living with the certainty of death. This includes terminally-ill individuals located throughout the dying trajectories. To address other care needs, Hupcey, et al. (2009) provided an approach for working with organ failure patients early in the organ failure trajectory. This same kind of planning should direct the care of individuals entering the cancer trajectory and organize care around the unique needs of individuals experiencing the transitions within this trajectory.

In addition, individuals at age 65, regardless of their health status, should begin planning and making decisions regarding their care as they progress through the older adult years. Nurses need to be involved in approaching and educating individuals and their families about options for planning care in the future. Nurses must also become advocates for individuals through policy formation directed toward end-of-life planning and care.

Planning for end-of-life care is a family activity, and all members of a household, particularly potential informal caregivers should be involved in the discussion. Some of
the participants’ discussions in this study of *Separating and Connecting: Shifting Relations* were based, in part, on the absence of friends and family members who could not face the dying process. But an equally troubling concern for these individuals at the end of life was the presence of family and friends who avoided sitting and talking with them and were involved with ‘doing for’ rather than ‘being with’ them. Of course, it may be difficult for family members to discuss dying with their loved one. In addition, the 24/7 care responsibilities of caregivers can be overwhelming.

The Family Caregiving Alliance (2012) reported that roughly 66 million unpaid caregivers were providing care to loved ones with chronic or terminal illnesses as well as aging adults and children with special needs. They also reported that 72% of caregivers take care of someone 50 or older. As the baby boomer generation ages, this percentage is expected to increase.

Caregiving can be rewarding, but it can also be an overwhelming responsibility with resulting physical and emotional consequences for the caregiver. Theory development and research is focusing on the needs of individuals facing end-of-life care, and more recently, attention has been focusing on caregiver stress and identifying strategies to assist caregivers. At the same time, there has been little discussion of the family-centered health needs of those experiencing this end-of-life trajectory. Family-centered in this discussion refers to viewing the family as a system and addressing the unitary needs of the family unit. Educating nurses to view the family as a unit will enable them to assist families in discussing end-of-life concerns and promote connections between caregivers and patients in new and different ways. Various family nursing theories focus on the family system and provide resources for application of theory in
practice (Grey, Knafl, & MacCorkle, 2006; Parse, 2009; Wascharasin & Homchampa, 2008; Watson & Woodward, 2010; Wright & Leahy, 2009).

An important focus in nursing education is in preparing nursing students for end-of-life care, particularly regarding the importance of being present with the end-of-life patient and not just doing tasks while caring for them. Wallace (2008) suggested that end-of-life nursing education should focus on individuals with threatening illnesses beginning with diagnosis through the trajectory until death. This would serve to change the paradigm of end-of-life care from the traditional days and weeks prior to death to a complete trajectory of care, including the transitions within care. End-of-life competencies for undergraduate baccalaureate nursing education have been developed and model curricula are currently available for use in nursing education, including the end-of-life care (ELNEC) and the Toolkit for Nursing Education at End-of-life Transitions (American Association of Colleges of Nursing, 2012; Cancer Pain & Symptom Management Research Group, 2011).

A common concern among the participants was symptom management, particularly pain and breathing difficulties. Managing pain seems to be a central focus in end-of-life care. Dobratz (2002) when describing the concept of “fully human” (p. 138) stated that it could only be achieved once the pain was managed. No patient ever said they expected to be pain free, but they were fearful of and trusted hospice personnel to assist them in managing the pain response. They all agreed that hospice nurses work with them to manage the pain and the breathing. Miakowski (2012) suggested that pain, dyspnea, and nausea are the most common symptoms examined in research and “a more comprehensive set of symptoms is needed” (p. 6). This was further reinforced by Murray,
et al. (2007) whose research revealed social, psychological, and spiritual distress at different points in the illness trajectory influence quality of life. If taking a more holistic view of Living With Pain to encompass the any patient-perceived discomforts of living with the illness, then the focus becomes managing the pain at a tolerable level and focusing on other areas of discomfort whether they are emotional, sensory, social, spiritual, or other physical concerns.

**Implications for the Discipline of Nursing/Future Research**

While the metaparadigm of nursing originally focused on the broad interrelated concepts of person, environment, health, and nursing, theory building within the discipline has contributed to modifications of the paradigm. Smith and Parker (2010) reviewed the history of the developing discipline of nursing and concluded that the concepts of “caring and relationships are central to the discipline of nursing” today (p. 12). These concepts provide a focus for the direction of inquiry and study within the discipline of nursing. Areas of future research should explore the contributions of this study to the discipline of nursing and end-of-life care in multiple contexts and from the perspectives of individuals experiencing the certainty of death and the nurses who care for them.

The phenomenon of living with the certainty of death is universal, and the current study revealed essential features of this phenomenon with individuals experiencing a terminal illness while enrolled in hospice. The ebb and flow of certainty and uncertainty in the context of an illness experience was also made evident by this study. The essential features identified in this work begin to illustrate how dynamically the balance of certainty/uncertainty shifts over time, over context, and over relations with others. Future
research may clarify the relationship of certainty/uncertainty against the background of current theories. Many persons are experiencing living with the certainty of death outside of the hospice setting with terminal and non-terminal conditions. Additional inquiries could clarify whether the identified essential features in this study are relevant to the human experience or to the hospice experience, and how the balance of certainty/uncertainty shifts within different contexts of this experience. For example: Do adults experience similar essential features with their shifting balance of uncertainty/certainty when:

- living with multiple comorbidities
- living with a terminal illness outside of the hospice service setting (e.g., acute care, long-term care, and in the home)
- living with organ failure outside of hospice, but with a philosophy of palliative care and medical management
- living with a terminal illness over cross-cultural contexts;
- living with a terminal illness across a dying trajectory from diagnosis to death; and
- approaching the end of the life cycle without a terminal illness?

In order to provide holistic supportive care throughout the healthcare system to individuals experiencing the certainty of death, it is important to examine the essential features of the phenomenon of living with the certainty of death and the balance of certainty/uncertainty in multiple contexts.

Nurses’ interactions when caring for patients may influence the balance of certainty/uncertainty as individuals experience the essential features of living with the
certainty of death. This study provided insights regarding the influence of hospice nurses’ interactions, but it raises additional questions for inquiry, including:

- How do the actions of non-hospice nurses interacting with patients influence living with the certainty of death?
- How do nurses promote a family-centered approach to living with the certainty of death?
- How do the essential features of living with the certainty of death provide a multi-focused perspective of pain management, and
- What are effective teaching-learning strategies for educating nurses and nursing students about end-of-life care?

Finally, as discussed earlier in this chapter, research regarding Glaser and Strauss’ contexts of the awareness of dying should continue with a focus on individuals enrolled in hospice and individuals at the end of life who are not enrolled in hospice. For example,

- What are the awareness contexts of individuals experiencing the end of life who are not enrolled in hospice care?
- What are the awareness contexts of individuals enrolled in hospice?

**Conclusion**

This hermeneutic-phenomenological study provided an interpretive description of living with the certainty of death that captured six essential features from the experiences of 10 individuals enrolled in hospice care in central Pennsylvania. The six essential features of Beating the Odds; Living With, Not Dying From; Separating and Connecting; Shifting Relations; Transcending the Everyday World Through Spirituality; Getting My House in Order, and Living With Pain describe these individuals who, while
acknowledging their dying, were living each day with purpose, faith, trust, love, and generosity. Although they knew that their days were numbered, they were living “in spite” of their dying.

The phenomenological description of these essential features was supported with insightful philosophical writings, art, literature, theory and research. At the same time the outcome of this research shines a new light on end-of-life theory and research that, if examined through this new spectrum, may contribute to higher quality end-of-life care.

Everyone is living with the certainty of death, and continuing to examine this phenomenon has tremendous potential for improving the lives and the health care for individuals throughout the life span within the continuum of preventive care to end-of-life care in multiple settings.

Although this study began with a reference to this population of dying individuals as quite vulnerable, it concludes with a different viewpoint of a resilient group of individuals who view life through a colorful prism of meaningful relationships. The poem “Wild Geese” by noted American poet Mary Oliver (1986) most appropriately describes the participants in this study and the impact they have made on this researcher’s worldview.
Wild Geese

You do not have to be good.
You do not have to walk on your knees
for a hundred miles through the desert repenting.
You only have to let the soft animal of your body
love what it loves.
Tell me about despair, yours, and I will tell you mine.
Meanwhile the world goes on.
Meanwhile the sun and the clear pebbles of the rain
are moving across the landscapes,
over the prairies and the deep trees,
the mountains and the rivers.
Meanwhile the wild geese, high in the clean blue air,
are heading home again.
Whoever you are, no matter how lonely,
the world offers itself to your imagination,
calls to you like the wild geese, harsh and exciting
Over and over announcing your place
in the family of things.
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doi:10.1016/j.profnurs.2008.08.003


APPENDIX A

Recruitment Information for Hospice Clinical Nurses

Title of doctoral dissertation: Living With The Certainty of Death: A Phenomenological Study

Researcher: Nedra Farcus, M.S.N. RN.
Doctoral Candidate, Nursing
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Purpose of the interviews: Discuss the Experience of Hospice/Palliative Care

Sample:

- **Description:** A purposive convenience sample of adults enrolled in a community hospice agency for end-of-life care.

- **Eligibility requirements:** Adults, aged 18 or older with an acknowledged prognosis of impending death as indicated by enrollment in a hospice program; and who converse in English;

- **Sample Size:** It is anticipated that a sample of 5 to 15 participants will be sufficient to provide a rich and comprehensive description of the phenomenon.

Recruitment Procedure:

- The Director of Hospice or a specifically designated hospice nurse will approach patients who meet the inclusion criteria to obtain permission to release their name and phone number to the researcher. All research-related questions from participants should only be answered by Nedra Farcus, the investigator.

- The researcher will initially contact potential participants by phone to explain the general purpose of the study. Participants will be permitted
to ask questions during the initial phone conversation and during subsequent face-to-face meetings.

- During the first face-to-face meeting, each participant will provide written consent to participate under the principle of full disclosure.

**Interview Process:**

- At least two individual interviews will be arranged with each willing and able participant within a five to seven day time frame.

- The first interview will take about one hour. Participants are informed that if they become too tired or don’t feel well enough to continue, they can tell the interviewer and the interview will stop.

- Each participant will be provided with an audio recorder to communicate any thoughts and ideas for three days following the initial interview.

- At the end of three days, the researcher will return to retrieve the audio-recorder. This interaction will last approximately ten minutes. A second interview will be scheduled within one week following collection of the recorder. If participants agree to this follow-up interview, it will take from 30 minutes to one hour.

- The total time contribution for this study will be approximately 3 hours.
Hello,

My name is Nedra Farcus and I am a doctoral student in the nursing program at Penn State University. I am requesting your participation in a research study I am conducting through Penn State University. I am asking individuals who are enrolled in hospice care to participate in this research for the purpose of gaining an understanding about the experience of hospice care. I am interested in interviewing adults, age 18 or older, enrolled in a hospice program, and who speak and understand English.

If you agree to participate in this research study, your participation will include at least two (2) interviews with me scheduled at your convenience within a five to seven day time frame.

During the first interview, I will explain the purpose of the research study and ask you to sign a consent form. I will then ask you some questions about your illness and your experience with hospice care. This first interview will take about one hour. If you become too tired or don't feel well enough to continue, you can tell me and the interview will stop.

Following this initial interview, I will leave an audio recorder with you for approximately three days. I will ask you to identify 10-20 minutes each day for 3 days at the same time each day, preferably when you are feeling the best and record your thoughts, feelings, and insights. I will also arrange a time to come back and pick up the recorder. This second visit will only take about 10 minutes.

After I review the information from our first interview and the information from the recordings, I will schedule a follow-up interview within a few days. During this final interview I will share my interpretations of our initial conversation and ask you to either verify that this interpretation is correct or clarify your interpretation, this interview may take from 30 minutes to one hour. The total time contribution for this study will be approximately 3 hours.

If you will permit me to contact you, please sign the release form provided by your hospice nurse. She will give me the information and I will call you to set up a time to meet and to answer any questions. If you would like to contact me for additional information, you may call my office at (814) 949-5087. If I am not immediately available to take your call, please leave a message and I will return your call as soon as possible. Thank you for taking the time to read this letter. I hope you will agree to participate in this study.

Sincerely,

Nedra Farcus, MSN, RN
(814) 949-5087
APPENDIX C

Interview Guide
The Experience of Hospice/Palliative Care

1. Tell me about your illness.
   a. What is your diagnosis?
   b. When did you receive this diagnosis?
   c. What treatment options, if any, were available to you after diagnosis?
   d. When did you or your health care provider decide the treatments were not effective anymore?
   e. What prompted your decision to enter hospice care?
   f. How effective is hospice in providing you with comfort care?

2. Who provides you with support and assistance during this illness?

3. Was there a time when you changed your focus and goals for your own life and future during this illness?
   a. Was it before, after, or during the time the physician moved from attempting to cure the illness to providing comfort and quality-of-life care?
   b. Describe the changes.
   c. Can you tell me about that experience?

4. Was there ever a time when you felt totally overwhelmed by this certainty—what was that like?
   a. Was it before, during, or after entering hospice care?
   b. What was going on at the time?
   c. What were you thinking during this time?
   d. How did you feel?
   e. Did you do anything to help relieve these feelings?
   f. Did that help? If not, what did you do next?
   g. How did your support persons help or interfere with your sense of feeling overwhelmed with this certainty?

5. Were there times when you felt more confident in being able to deal with the certainty of your prognosis, even though you were still not sure about the questions of “how” or “when”?
   a. What was going on at the time?
   b. What were you thinking during this time?
   c. How did you feel?
   d. How did your support persons help or interfere with your sense of certainty?

6. Can you tell me about other times you felt certain about the illness outcome?

7. Is there anything else about times of certainty during your illness that you think I should know about?

8. Would it be ok if I called you again, if I have further questions?
VITAE
Nedra Kay (Scott) Farcus, MSN, RN

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PhD, Nursing, The Pennsylvania State University 2012
MS, Family Health Nursing, Duquesne University 1979
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Sigma Theta Tau, Beta Sigma Chapter Research Grant 2005
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Publications
