

**BETWEEN THIS WORLD AND THE NEXT:  
THE LIVED EXPERIENCE OF HAVING A LIFE-THREATENING ILLNESS**

by  
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## ABSTRACT

**Title of Dissertation:**            **Between This World and the Next: The Lived Experience of Having a Life-Threatening Illness**

**Janna C. Roop, Doctor of Philosophy, 1998**

**Dissertation directed by:**    **Maggie T. Neal, Assistant Professor  
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Wonderings about hospice patients' experience of dying evolved into the question, "What is it like to have a life-threatening illness?" That question guided this interpretive phenomenological inquiry. Phenomenology is a philosophy that seeks to rediscover the rich meaning lying hidden beneath the surface of everyday.

Phenomenology's quest is to coax that which has been concealed out into the light. It is a call to re-dis-cover what Martin Heidegger (1959/1966) might call the mystery of Being.

What is it that anesthetizes us to the wonder of our everydays? What is it about the ordinary that blinds us to its depth? We numbly plod or madly race along the surface of our lives, forgetting that great mysteries surround us, above, below and within.

The discovery of a life-threatening illness is an unwelcome shock. It abruptly tears away the familiar and plunges a person into the unknown. Nothing is as it was before. And

yet, almost everything is as it was before. For the ten participants in this study, encounter with a life-threatening illness propelled them into a journey that none would have chosen. Life felt very broken. My journey with the participants has suggested, however, that the irony may be that we are more broken when we are blissfully unaware. The pain and brokenness of illness can be catalysts that expand the spirit. For some, the encounter with illness--with the shadow side of health--became a deep and meaningful experience.

The study uncovered new perspectives on what it means to be mortal, embodied beings. New meanings regarding the blessings hidden within suffering, re-ordering priorities, living with unpleasant symptoms, and relationships among friends, family and health care providers emerged.

In the final chapter, the quest to consider the meanings that dwell beneath the surface of our lives was likened to an underwater dive. Like a dive, it requires preparation and effort. Like a dive, the effort can be sustained for only short periods of time because the ordinary concerns of life demand attention. Yet, like a dive, it revealed new and important perspectives on concerns that give essential grounding to our lives.

**Key words: hospice, dying, life-threatening illness, phenomenology**

**Dedicated to my husband Al**

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Though a dissertation is said to be an individual work of research, this study is anything but a solitary effort. Love, encouragement, support, and challenges from friends, family, and colleagues have sustained and nourished me. They have both led me and driven me to become the person that I am today. My debt to them is immense.

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Dr. Anne Belcher guided my studies in oncology nursing and professional

development. Her unwavering support and belief in me as well as her very gentle refusal to let me avoid needed steps of growth have shaped my development as a researcher and as a person. Her enthusiastic response to my early graduate work helped me to persist on this arduous path of scholarship. Anne has somehow managed to weave together seamlessly a genteel Southern manner with an almost wicked sense of humor. My life is richer and certainly more fun because of her.

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## **CHAPTER ONE**

### **TURNING TO THE PHENOMENON OF THE LIVED EXPERIENCE OF HAVING A LIFE-THREATENING ILLNESS**

**“Nancy”<sup>1</sup> was admitted to a home hospice program in the final months of her fight against tongue cancer, and I was her primary nurse. Her tongue had been amputated, she had frequent bleeding from her tracheostomy, the tumor had eroded all of the skin under her chin, and the drainage was so copious that she used a sanitary napkin under her chin for a dressing. Saliva and mucus drained continuously from her nose and mouth; she used the same suction catheter for both. A gastrostomy tube provided the means for her nutrition, hydration, and medications. Alert and in charge, she directed her own care through gestures and her frequent articulate descriptive writings in a notebook.**

**The first time the social worker, Kathleen, went to see Nancy, Nancy admitted that her suffering was so intense that she certainly did have thoughts of suicide. This admission coincided with an increase in Nancy’s pain level that indicated a need for morphine.**

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**<sup>1</sup>Names of all patients and families have been changed to protect their anonymity.**

Uncertain of how to handle the pain management of a patient who was seriously considering suicide, Kathleen and I asked for a consultation with the ethics committee. During the course of that meeting, as we discussed many facets of the case, we were advised that it was our obligation to inform Nancy of her right to refuse all treatment. When Kathleen and I said, "OK, if she brings it up again, we'll tell her," we were told it was our responsibility to inform her. When health professionals wait for patients to bring up sensitive subjects, only the most assertive patients receive the information. Many patients never have the chance to explore the option of refusing treatment because they worry about offending or angering the health professional and they fear being abandoned or judged negatively. So Kathleen and I did present Nancy with the option of refusing all treatment. Her response was, "I don't think I'm ready for that yet."

Over the next couple months, Nancy's condition continued to deteriorate. She became bedbound and fully dependent on her family for all aspects of her care. Her pain was so intense that she required very large doses of narcotics and was sedated almost to unresponsiveness most of the time. Throughout all this, her family dutifully kept up her regularly scheduled tube feedings, though from time to time, I would suggest that they might want to decrease the amount of the feedings or feed her only when she was alert enough to indicate hunger or thirst. When I would leave her house, I would wonder how they could stand it. Finally, one day, when I examined her, I found that the wound had eroded to expose her jawbone and it appeared that her lower lip and chin would soon become gangrenous. After examining Nancy, I sat down with the family. "Now is the time

to stop feeding her,” I told them. To my surprise, none of them argued with me. In fact, her husband, Fred, walked with me to my car and said, “I had been wondering about that, but I didn’t know how to ask.”

There it was again! That notion that health professionals need to be more active in informing patients and families of their options, especially their option to refuse treatment. It had surfaced again. What had prevented me from recognizing Fred’s readiness to stop the feedings that were prolonging Nancy’s suffering? What had prevented him from seeing my willingness to help him ask his question? What is needed to assist patients, families, and care givers to meet each other more fully at this difficult time of life? I began to wonder if these concerns warranted further study.

### Grounding of the Study

My experience caring for Nancy and her family made me wonder how patients and professionals do make decisions about end-of-life care. This is a concern that has become prominent in the national consciousness as well (Seale & Addington-Hall, 1994). Highly publicized court battles such as those involving Karen Quinlan<sup>2</sup>, Nancy Curran<sup>3</sup>, and Dr.

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<sup>2</sup> Karen Ann Quinlan went into a coma on April 15, 1975 at the age of 21 after drinking alcohol and taking Librium and Valium. Her family went to court to win the right to turn off her respirator and did so in June of 1976. She remained comatose, but alive, however, sustained by antibiotics and tube feedings until her death in 1985. Her case focused national attention on the right to die (Callahan, 1995).

<sup>3</sup> Nancy Cruzan entered a persistent vegetative state following a car accident in 1983. Her family pursued court battles through to the United States Supreme Court and eventually were allowed to remove her feeding tube. She died in 1990 (Callahan, 1995).

Jack Kevorkian<sup>4</sup> have drawn attention to the question of how one should die. The possibility of legal physician-assisted suicide is being debated in state legislatures. The Patient Self-Determination Act, passed in 1990, highlighted the individual's right to predetermine what kind of health care that person would receive if illness or injury prevented the individual's participation in such decisions (Badzek, 1992). Practitioners, ethicists, and lay people alike have grappled with issues surrounding care of the dying. While some see honor and comfort in responding to a terminal diagnosis with quiet acceptance, others subscribe to a moral imperative to fight. Where there is life, there is hope, they say. Still, much confusion abounds, and frequently, the personal values of patients, health care providers, and families may be very different.

Recently, I was afforded a closer look at the ambiguities of communication between patients and professionals when I approached a large local hospice to ask for access to patients for this study. Because hospices are committed to serving the needs of dying patients and their families, I have always assumed they are places where death is acknowledged openly. As I explained that I was inquiring into what it is like to be dying, I was astonished to hear the research coordinator respond, "We don't talk about death much--we talk about getting the most out of life." Of course I expect that staff will encourage the patient to search for the most in the life that person has left, but if the

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<sup>4</sup> Jack Kevorkian is a retired Michigan pathologist who has been arrested several times for assisting in the suicides of over 20 terminally ill individuals. His ensuing activities and court cases have continued to focus national attention on ethical issues regarding the right to die (Logue, 1994).

patient is not “supposed to” talk about death to the hospice staff, to whom can that patient talk about death?

I was further surprised to read Bernie Siegel’s preface to the Kramers’ book, *Conversations at Midnight: Coming to Terms with Dying and Death* (1993). Kay Kramer is a psychologist who works primarily with dying patients. When her husband Herb was diagnosed with terminal prostate cancer, they wrote a book about their final journey together. In the foreword to that book, Siegel wrote, “...but this is not a book about dying and death. It is a testament to living and life” (p. 8). My response was, “Of course it is a book about dying and death!” What I believe Siegel may have overlooked is that dying and death and living and life are not necessarily opposites. They can be complementary threads of the same cloth.

One of the reasons that issues of death and dying have become more prominent recently may be related to the fact that health care has changed so dramatically in the last thirty years. Research and technology have provided life-prolonging treatments and even cures for diseases that only a short time ago were invariably fatal. This progress, though, has not come without its dark underside. The cost of health care has risen so much it has become a serious political, social, and economic concern. Many of the “miraculous” life-saving technologies that have been developed are expensive and play a direct role in driving the cost of health care higher (Markman, 1992). Decisions regarding the care of patients with life-threatening illnesses are complex and have great impact on the cost of health care. In spite of increased desire for “death with dignity” and “peaceful death,”

eighty percent of all deaths still occur in a hospital or nursing home (Booth, 1991; Butler, 1991; Cassel & Omenn, 1995; Eddy, 1994). Although deaths in institutions can be peaceful and dignified, in institutions, people have less control over their surroundings. They are more likely to receive invasive treatments that increase costs yet do little to change the outcome. The treatments can also interfere with the limited time the patient has available to spend with family and other visitors. Furthermore, the family members often find daily trips to the institution burdensome, and while they are there, they may be considerably less comfortable than they would be at home. Enabling more patients to die at home with appropriate health care support could greatly increase the comfort of patients and families alike.

In health care literature, considerable attention has been paid to the topic of how to care for the dying. A recent computer search for death-related articles yielded 804 publications since 1991, but quantity has not yielded consensus. A review of many of those articles suggested that the patient's perspective is still absent (Jarrett, 1995). Instead the articles survey common practices in the care of the dying or instruct the caregiver in better ways to care for dying patients and their families. During my preparation for this study, I reviewed a grant proposal submitted to the Project on Death in America, a foundation seeking to improve care of the dying. The summary of the literature search for that proposal declared that "No study has tried to describe, from the patient's perspective, the elements of good care at the end of life and the interventions that might help ensure such care" (Emanuel, Emanuel, & Bergner, 1995). I found, however, a special edition of

the *Western Journal of Medicine*, titled *Caring for Patients at the End of Life* (1995). In that issue, McCormick and Conley reported a summary of interviews with six dying patients about their experiences and preferences for care. They found that participants sometimes “experience their gravest suffering from fears and anxieties that go unaddressed in conversations with their physician” (p. 236) and that “patients and physicians sometimes attach different meanings to words that are commonly used in discussing treatment” (p. 236). For example, one participant saw *terminal* and *incurable* as very different concepts—incurable meaning chronic and terminal meaning imminent—while the writers assumed (there was no report of interviewing the patient’s physicians) that the physicians used those terms interchangeably. The interviews stimulated McCormick and Conley to raise these thought-provoking questions:

How explicit should physicians be about the possibility of recurrence?  
What if a patient does not ask about recurrence? Is it better to allow patients to proceed through therapy with the highest level of hope? Can the power of suggesting that the cancer might return be a self-fulfilling prophecy by weakening the immune system of patients through the stress of worry and anxiety? (p. 240)

Unfortunately, McCormick and Conley did not return to their participants to elicit their perspectives on these important questions.

The difficulties in finding meaningful guidance for care of the dying were further illustrated in the recent report of the project funded by the Robert Wood Johnson Foundation (SUPPORT Principal Investigators, 1995). Over four years, a multidisciplinary team developed and implemented a program to increase communication between patients and their doctors in order to improve care of seriously ill hospitalized patients. The study

was conducted in five major teaching hospitals throughout the country--places where one would expect to receive "state of the art" care. Nevertheless, families of more than half of the patients who died reported that those patients were in moderate to severe pain at least half the time in the days before their deaths. Furthermore, in spite of what appeared to be a well-conceived study resulting in comprehensive and logical interventions, patients in the treatment group experienced no better outcomes than patients in the control group.

Clearly, something was missing in the care of those dying patients. Many explanations have been offered to explain these disappointing results (Armas, 1995; Berwick, 1995; Callahan, 1995b; Emanuel, 1995; Hardwig, 1995; Lo, 1995a, 1995b; Marshall, 1995; Moskowitz & Nelson, 1995; Solomon, 1995). Some have suggested that communication between the research team and attending physicians was ineffective. The study relied heavily on specially trained nurses to facilitate change, but some authors have suggested that nurses do not have enough institutional power to effect radical change. Furthermore, because the study focused only on hospitalized patients, patients who preferred palliative care at home were automatically excluded from the study. The study population was skewed toward critically ill patients who desired aggressive treatment. It could also be that the issues surrounding care of the dying are so deeply entwined with complex values and emotions that straightforward logical interventions are necessary, but insufficient.

Conflicting desires and fears may confound the logical choices of patients and health care professionals alike. As Pascal has said, "The heart has reasons that Reason knows not of" (The Columbia Dictionary of Quotations, 1993). I hope to uncover some of those reasons

of the heart. As I have reflected further on the report of the SUPPORT Principal Investigators, I have noted that patients and their families were not consulted regarding the development of interventions and I wonder what wisdom they could have offered. The SUPPORT study (1995) and the study by McCormick and Conley (1995) show that in spite of the preponderance of interest in how we care for dying patients, many of their needs are still going unmet. I began to believe that a sustained and thoughtful exploration of these issues could point the way toward effecting real change in the care of the dying.

Barriers to Communication about Dying: What's in a Name?

What tormented [the patient] most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result. (Tolstoy, 1886/1960, p. 137)

As I think back to several of my former patients, especially patients whose doctors or families wanted them to fight, I think the preceding passage could have been written about many of them, but contemporary as the description is, it was written by Tolstoy in 1886. The questions of what to say to a dying patient and what to allow a dying patient to say have been unanswered for a long time.

When Kubler-Ross (1969, 1971, 1975) began her study of dying patients in the late 1960's, she met resistance from physicians when she would ask to speak to their patients. At that time, it was common for physicians and families to withhold information from patients about their terminal condition, believing that such information would be psychologically devastating to the patient. Yet when Kubler-Ross would ask the patients directly, "How sick are you?" they would readily reply "I'm dying" whether they had been

given this information directly or not. Kubler-Ross concluded that dying patients know they are dying and that open communication among all parties enables essential preparation for death.

Kubler-Ross's (1969,1971,1975) work was published during a time of great social upheaval in this country--a time that saw War resistance, the Civil Rights movement, the Feminist movement, and an increased interest in consumer rights and the environment. One of the outcomes of that time was that people began to demand a more active role in their health care decisions. One expression of this demand was the beginning of the modern hospice movement, a movement that sought to provide better care for dying people (Wald, 1994). Death was acknowledged as a necessary part of life, rather than an enemy to be resisted and fought at every turn. Assisting a patient toward a "gentle death" was claimed as an appropriate goal; cure was not the only option; death was not a failure.

This has not yet become a universal view, however. Frequently, I have heard physicians or families resist referring patients for hospice care saying, "Oh, I would never take away hope," as if survival is the only thing one can hope for. Although they realize that hope is as essential to dying patients as it is to every other human, they seem not to realize that dying patients may need to change what it is they are hoping for. Hope for survival can be replaced with hope for an easy death, hope that one's grieving family will be well cared for, perhaps hope for being re-united with a loved one who has already died, or some other hope. Hospice workers are skilled in helping patients redirect their hope. Those who equate hospice care with having no hope lack a full understanding of what

hospice care can offer.

Thinking that hospice means hopelessness is one common misconception. Another, I believe, is the idea that characterizes palliative care as “passive euthanasia.” The implication seems to be that when a hospice patient is “allowed to die,” that means that appropriate interventions that would have prolonged life have been withheld. When we say that someone has been allowed to die, however, do we really mean that we have granted permission? Avoiding futile invasive medical technology is nothing more than good sense (Amenta & Shubert, 1995; Jecker, 1995; Lichter & Hunt, 1990; Longo, 1993; MacDonald, 1995; Management of symptoms, 1997; Ryder, 1992; Sampaio, 1992; Slomka, 1992; Taylor, 1995). Keeping a dying person as comfortable as possible requires considerable physical, emotional, and spiritual care from the family and the professional caregivers. There is nothing passive about it. To call such care passive euthanasia ignores the active care that is given and denies that death happens to all of us. One of my hospice colleagues has noted with dry irony, “The difference between dying in the hospital and dying at home is that in the hospital, one dies in perfect electrolyte balance.”

In current practice, many professionals cite Kubler-Ross (1969, 1971, 1975) when they advocate telling the patient the full extent of his or her diagnosis and prognosis. Such honesty is believed to help health care workers, families, and patients work together more effectively and openly. Therefore, it was with surprise that I re-read Kubler-Ross (1971) and found that although she believed that a patient should be told he or she has a serious illness, she did not think any patient should be *told* that he or she is dying. Instead, she

wrote, "He will tell you that when you dare to listen, when you are able to hear it" (p.56). Kubler-Ross implied that the question may not be "Should we be honest with the patient?" but rather "Dare we be honest with ourselves?" She seemed to suggest that the professional's personal comfort with death and dying has an important influence on that professional's ability to be helpful to the patient. If this is true, no wonder we are confused! Health professionals are trained to take in data, analyze it, and develop a treatment plan for the patient "out there." To suggest that the health care worker's awareness of his or her own feelings has impact on the quality of the care provided is a rather radical paradigm shift.<sup>5</sup>

The idea that the person of the health care worker makes a difference in the quality of the care given is still mentioned rarely in the professional literature. It is such a peculiar "unscientific" notion! Yet it is a common theme in the orientation programs for hospice staff and volunteers, and can be found in writings that are focused on hospice care or oncology (Amenta, 1991; Cunningham, 1993; Larson, 1993; Lev, 1994).

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<sup>5</sup> The paradigm shift required to turn one's attention inward is small combined to the shifts Kubler-Ross (1997) has taken in her own career. As she continued to pursue the care of the dying, she traveled far out of the main stream of medicine and academia. In her most recent publication--an autobiography--she tells of her experiences attempting to establish a home for children with AIDS in rural West Virginia. Her own home was burned to the ground during that time; she believes it was purposely set ablaze by neighbors who were threatened by the idea of AIDS coming so close to their own homes. She further tells in a very matter-of-fact manner of her encounters with patients after their deaths and with spiritual guides whom she believes to be the spirits of people who lived thousands of years ago. There is a part of me that wants to recall the idea that the problem with having an open mind is that it may become *too* open. There is another part that acknowledges that what happens after death is a mystery and that places accounts such as these in an imaginary mental box labeled "Awaiting Further Light."

Earlier in this chapter, I wrote of my concern for the patient who believes that he or she is dying and encounters a health professional who is reluctant to “talk much about death around here.” Though I would not want to negate the value of facing adversity, including death, with a strong positive outlook, I am concerned about those times when a positive outlook constrains the learning we may gain from examining the other side—the discouraging side. What is a person to do with despairing feelings? Where can that person openly express thoughts about his or her mortality? A report by Hendon and Epting (1989) illustrates this problem. They conducted a study comparing hospice patients to cancer patients in remission and to patients with a temporary illness. Dependent variables were *death threat*, *hopelessness*, and *depression*. The authors commented:

It would have been most helpful if we had been able to gain access to terminally ill persons who were being cared for in a standard hospital situation. This was not possible. We were denied permission by physicians in six hospitals. Doctors, as well as review committees, would not sanction the use of patients for this type of research. They called the research design bizarre and inappropriate. Several of the oncologists stated they would not allow their patients to fill out any of the questionnaires for fear that thinking about the content would produce an adverse reaction in the patients. The general concern of most doctors was that a project such as this could potentially bring out a barrage of emotions that would be very damaging for all concerned. Clearly much work is still needed to demonstrate to health care professionals in conventional hospitals that inquiry into death concerns for terminally ill patients can be a beneficial experience. (p. 576)

The authors clearly believed that it is beneficial for patients to inquire into death. Just as clearly, however, there were others who saw such inquiry as harmful. Uncertainty about the patient’s response may be one barrier that fuels the controversy. Nungusser (1988), writing about his own experiences as a person with AIDS, warned that diagnosis

and terminal illness can lead to an “overwhelming sense of loss in your own life’s purpose,” but he asserted, “A diagnosis is an event to be adapted to, not a death sentence to be compliant with” (p. 82). Thinking back to the barriers Hendon and Epting (1989) encountered in their efforts to study hospitalized dying patients, I suspect that Hendon and Epting anticipated the patients would see their diagnosis as an event to be adapted to, whereas opposing physicians feared patients would see a death sentence. What would the patients have seen?

As I continued my search for patient participants for this study, I began to realize that my use of the word *dying* was closing too many doors. I eventually decided to change the wording of my requests from *dying patients* to *patients with life-threatening illnesses*. I hoped that as I developed rapport with the participants, we could look together for guidance for approaching the subject of dying. As the study progressed, however, I began to believe that the distinction between life-threatening illness and dying was not critical. (This decision will be discussed in more detail in the section “The Research Question” on page 29.)

#### Philosophical Roots of the Inquiry

In my own practice, I was highly committed and attentive to the needs of my patients and their families, but nevertheless, I had failed to communicate well with Fred regarding Nancy’s care. For me, this was an experience of what Heidegger (1993) would term *breakdown*. The concept of breakdown is an integral part of the philosophy of interpretive phenomenology. In contrast to the idealists and realists who saw the world as

something outside of the person that could be studied objectively, Heidegger believed that there was no clear division between the world and the person living in and/or observing that world. Both the observed and the observer are so integrally shaped by the world that objectivity is impossible. The culture in which a person is raised provides a screen through which that person perceives the world. Because of that screen, much of what affects us is taken for granted and unnoticed. Van Manen (1990) wrote that we experience the world “pre-reflectively” (p. 9), a way Heidegger would call “ready-to-hand” (cited in Leonard, 1994, p. 48). For example, a child can learn to ride a bicycle without understanding anatomy, physiology, or physics. Considering the everyday use of a common tool like a hammer, Heidegger stated that a person using a hammer usually does not really notice the hammer itself at all. It is ready-to-hand, meaning he just picks it up and uses it for its designated task. Only if something goes wrong—that is, a situation of breakdown occurs—does the person examine the hammer carefully to discover its particular properties—weight, length, and so on—to analyze the hammer and its use. These situations of breakdown call us to study our world more carefully—to notice what we take for granted and to understand in a new way. It is as if something outside of ourselves in the world has come to life and called our attention to itself. As Heidegger said, “...some things make an appeal to us to give them thought, to turn toward them in thought: to think them” (p. 372). Gadamer (1960/1990) described this discord between expectations and experience as being “pulled up short” (p. 268). The experience is so surprising that it feels as if something outside of ourselves has acted. He asserted that that is why we often speak of

questions occurring to us or arising rather than always saying that we raise questions. He explained, “[We] have experiences when we are shocked by things that do not accord with our expectations. Thus questioning too is more a passion than an action. A question presses itself on us; we can no longer avoid it and persist in our accustomed opinion” (p. 366). Levinas (1996) also attended to this discord, calling it *disturbance*. He wrote:

[A disturbance] points to an order that is different from the one we thought we knew. The discordance that may be produced within this order *proposes itself* as an invitation to the search for a new order in which this first discord would be resolved: the discordance becomes a problem. When a disturbance occurs, it points to an order that is different from the one we thought we knew. (p. 68, italics added)

My experience in missed communication with Fred regarding Nancy’s care surprised me and called me to ponder what had happened. While I was caring for Nancy and her family, I believed myself to be a competent and sensitive nurse (albeit in a very challenging circumstance) who was open to the family’s needs and desires. I thought I was nudging them toward stopping the feedings that were, in my view, prolonging her dying. Her husband, however, completely missed my willingness to support him should he decide to discontinue feeding and treatment. Why? Was it something in me, something in him, something in the culture, or very likely, a combination of all those factors and more? This discord between what I thought I was communicating and what Nancy’s husband perceived pulled me up short. The experience called me to pursue the wonderings that have become my research questions.

### Turning to the Research Questions

Caring for Nancy and her family stimulated my interest in how patients make treatment decisions in the face of life-threatening illness. What information do they receive from their health care providers and what sense do they make of that information? How common is it that patients have concerns they dare not bring up for open discussion? To what extent do patients and health care providers consider quality of life in making decisions? And, after the decisions have been made and the patient has lived with the consequences of the decisions, what meanings does the patient make about those decisions? Would he or she make the same decisions if he or she could do it over again? These questions held a special urgency for me and I came to believe they could lead me through my dissertation.

I had been a long time coming to this place in my own journey. I entered nursing school intending to become a nurse midwife, but in the course of my education felt more strongly drawn to home health nursing. Visiting patients and their families in their own homes and helping them to adapt to their illnesses in the places where they lived held a particular appeal for me. Using my new nursing knowledge in the context of a home visit honored the patient as a whole person in a way that nursing in the hospital did not. Home health nursing also had an authenticity that I appreciated. As a student, I began to see that a health care worker's goals for a patient and the patient's own goals could differ greatly. Although patients in hospitals or doctors' offices may hear advice and seem to accept it,

once they are in their own homes, they are more likely to pick and choose among recommendations—to adapt those recommendations to accommodate their own preferences and goals. I found that I liked being a part of helping patients to examine their choices and the consequences of those choices and to choose the path that fit them best. This realization probably had a part in developing my interest in people's choices around terminal illness.

Over the course of the last semester of nursing school, several nurse specialists were invited to address my class. One nurse was part of a newly formed hospice team and I found her words to be of special interest to me. "What a wonderful service they provide," I thought, but I did not believe myself to be at all ready for that kind of work.

Twelve years later, I attended a luncheon at my church when the executive director of a local hospice spoke about the program. Again I was struck by how right and necessary that service was for people who were dying, but again, I did not believe myself to be called personally to that specialty in nursing. Two years after that luncheon, however, I was applying to graduate school in order to prepare myself to teach nursing. The application asked me to choose an intended specialty. Torn between medical-surgical nursing and psychiatric nursing, the two areas in which I had worked since graduation, I could not choose. A distant voice deep inside myself kept recalling the love I had had for home health nursing as a student and warned that if I did not explore that field, I would always wonder what I had missed. As I contemplated further, I recalled the draw that hospice nursing had had on me, and I decided that I would seek employment in a home

hospice agency when I began my graduate studies in nursing education. I was fearful that hospice nursing would be exhausting and depressing, but I also felt that I needed to heed that internal call to hospice. The following account of my first visit, written for a class assignment, shows that there was substance both to my fears and my call.

Oh, my Lord, what have I gotten myself into? I feel like I have just been kicked in the chest by a mule.

It is my first day visiting hospice patients and I am “shadowing” an experienced nurse for the day. We have driven to the patient’s home, been greeted at the door by the patient’s daughter Sarah and have now walked into the bedroom where the patient lies.

The hospital bed dominates the room which is cluttered with all the signs of illness. A bedpan, a bedside commode, piles of waterproof pads, linens, dressing supplies, and medicines cover every horizontal surface.

Although the day is bright outside, in here, the shades are drawn, the lights out. Nevertheless, I can make out James’s form in the bed. He is skin stretched tightly over a skeleton. Every bone in his head is clearly visible. Every rib evident even under the bedclothes. He is asleep (or is he already dead?) and his mouth hangs open as he breathes. Is this staleness the smell of death?

I am hanging back a little, trying to remain “professional” and show no one how horrified and repulsed I am. Sue, the experienced nurse, has already approached the bed. Gently, she touches his emaciated arm. “James, it’s Sue.” His eyes open and find her face. He smiles, saying, “Hi, Sue. Thanks for coming.” In that simple exchange, he has become a person to me, and I relax just a little. There has been a problem with his pain control, so Sue checks his morphine pump, showing me the equipment and explaining her thinking as she goes. Her manner is easy, quiet, and gentle. As she speaks, I begin to lose my horror and find my place as a nurse again. Soon, she has adjusted the dose, given him a brief physical exam, and positioned him for comfort. She takes his hand as she determines that he has no questions for her and doesn’t care to talk today. “Well, then, we’re just going to go into the living room and gossip for a little while with Sarah.” Again, he smiles and thanks her. We quietly leave the room.

In the living room, Sarah, still dressed in her robe, eases onto the floor. Sue and I find chairs. As Sarah begins to talk about caring for her dad, her tears begin to fall. Grief and exhaustion compete for her immediate attention. Sue listens, acknowledges that Sarah has taken on an incredibly demanding job, and reminds her that she is providing excellent care for her father. She also affirms Sarah’s suspicion that the end is likely

to come soon—James will probably die within the next day or two. Paradoxically, this prediction is a bittersweet comfort.

Turning her attention to Sarah herself, Sue asks several questions. “Are you eating all right? Can you get some rest later today when your cousin comes to help? Why don’t you avoid driving for the next few days while the strain is so great?” Sue’s concrete questions seem to make some space for Sarah’s needs in the house as well. I find a box of tissues and pass it to Sarah. She offers me a weak smile in thanks. We linger a few minutes more to make sure that Sarah has received what she needs from the visit. Promising to call tomorrow and visit again in a few days, we return to the car. As we go, I realize I am changed. “That visit was very satisfying,” I think. “Maybe coming to hospice was a good decision after all.” (Roop, 1995)

As I continued to work for the hospice, I soon began to feel that this work was a particularly good fit for me. Hospice nursing combined my interests in medical-surgical nursing, psychiatric nursing, and the spiritual dimension of life. On most days, I felt my work to be extremely meaningful and rewarding. In other nursing work, I had occasionally received notes of gratitude from patients’ families—maybe one or two notes a year. When I worked for the hospice, families expressed their gratitude at many of the visits, and I commonly received personal notes one or two times a month. The responses of the families and my own sense of personal satisfaction converged to make me believe that I was doing what I was meant to do. Thus, when I so completely “missed the boat” with Nancy’s family, I was strongly motivated to find out where I had gone wrong, and how I could be more effective the next time.

#### Preliminary Inquiry, Analysis, and Turning Again

Prompted by these thoughts and wonderings, I had beginning conversations with four different patients. Three were hospice patients and one was recovering from surgery

to remove a recurrent malignant tumor. My assumption was that many patients would say, "If I knew then what I know now, I would never have elected to (fill in the blank) have the surgery, have the feeding tube, or have the chemotherapy." Of these four patients, the first had chronic obstructive pulmonary disease. Her answers to my questions were brief and tended to focus on events rather than feelings or reflections, and she did not recall that she had made decisions regarding her health care. The next woman had made many decisions over the eight years of her illness and upon reflection felt that they had all been good decisions. The third man was having memory lapses, but his wife sat in on the conversation and "corrected" his memories. He essentially took the stance that his doctor wanted the best for him, so whatever his doctor suggested, he did. The fourth person was a woman with a cancer so non-aggressive that she was not really dying--her position was, "Fight with all you've got. Take every possible treatment! Go for the cure." Four people--four very different perspectives. What health care approaches will be most helpful for such very different people? What are the similarities and differences in their experiences? What approach(es) do they desire from health care workers?

As I journeyed with these four patients, I came to believe that my original questions about decision-making at the end-of-life were too limited and of secondary importance. Although the number of participants with whom I have met is small, none of them gave much attention to decision-making during the conversations. Decision-making was an issue that I chose; it did not emerge from the texts I collected even though I looked specifically for it. There was depth and richness in the conversations, but it came

from consideration of the experience of living with illness and from the personal interpretations of each person. I came away from these meetings believing that I knew less about the experience of living with a life-threatening illness than I knew when I started. At that point, then, I believed that I needed to start again and ask participants, "What is important to you as you live through this part of your life?" My assumption was that as health care workers learn more about the participant's perspectives, we would be better able to support their journeys.

### Purpose of the Study

The purpose of this study, then, became to examine the lived experience of having a life-threatening illness from the patients' perspectives. My hope was that a deep and thoughtful study of the people most affected, that is the patients themselves, would provide a valuable contribution to the body of knowledge and understanding about care of these patients. The ultimate aim of the inquiry was to inform the practice of nursing and to improve the care provided. Furthermore, people with life-threatening illnesses frequently confront the possibility of dying in a new and vivid way, and dying is a universal experience. Therefore, it was expected that the findings would have relevance beyond nursing's domain and would be informative for many settings and disciplines.

### Selection of Study Population

Life, of course, is a terminal condition. Any delineation separating those who are dying from those who are not is necessarily arbitrary. Even among those diagnosed with a terminal illness, there is great variety in length of survival. Hall (1990) reported that

patients in her cancer support group “collected” stories of dying patients who outlived all expectations of their time left. Recognizing the ambiguity of the terms *terminal* and *dying*, therefore, I initially decided to meet with adult patients who had been told by their physician that if their disease followed its normal course, the patient would live less than a year. I expected hospices to be obvious sources for referrals, but even among hospice patients, one cannot assume that the patient expects to die. In my practice as a hospice nurse, I have frequently encountered gravely ill patients who believe they will accept hospice services only for a little while until they feel better. Harold was such a patient.

Harold was in his early 50's when he was admitted to a home hospice program. His cancer was in an advanced state and his body so ravaged by the disease and the chemotherapy that his doctor determined that he was too weak to sustain further treatment. While Harold's understanding was that he could not have any more chemotherapy until his blood count improved, his wife understood that Harold was dying. Even as he continued to weaken and lose weight, Harold denied the finality of his prognosis. I was never certain exactly why Harold had consented to hospice services; I assumed it was because his insurance would cover more hospice services than home health services. Emaciated and yellow, he would drive himself to work. When he became too weak to drive himself, he insisted that his wife drive him to work, if only for a few hours. His wife was distressed by his behavior, believing that he was shortening the time he had left by exerting himself so much. As we talked it over, though, she began to believe that Harold was pursuing the course that would satisfy him most. He had always needed to be

active; lying around at home would have been very difficult for him. In fact, he continued to go in to work up until two weeks before he died. I was visiting just two days before he died. He was extremely weak and uncomfortable. He was unable even to get out of bed. In exasperation, he demanded, "When am I going to be strong enough to get my chemotherapy!" I drew a deep breath and said, "Harold, I don't think you are." He glared at me and then said, "Well, finally! Someone's being honest with me." Later when I spoke to his wife, she said many doctors had been honest with him about his prognosis, but for some reason, Harold had not heard that message. Was it denial on Harold's part? Was it that in their desire to be gentle or because of their own discomfort with dying, the doctors had been too subtle? Harold's wife and I came to believe that Harold was ultimately happier believing he would recover until the last few days. If that is true, what is it that needs to be understood in order to approach these conversations with someone who is gravely ill?

I have presented the rather lengthy story of Harold to illustrate some of the difficulties embedded in an inquiry into the lives of the very ill. I thought that if I stated at the outset that I intended to study dying patients, I would miss people like Harold who did not believe they were dying. Harold, however, was representative of one kind of hospice patient and probably many other dying patients who would not even accept hospice services. To structure the study in a way that discouraged the participation of patients like Harold would be to miss a perspective of patients in great need of sensitive care. Yet to avoid the use of the word dying risked missing the forthright conversation that was so

lacking in my care for Nancy and her family. Van Manen (1990) claimed that one of the aims of phenomenological studies is “[to humanize] human life and...human institutions to help human beings to become increasingly thoughtful and thus better prepared to act tactfully in situations” (p. 21). What approach would a patient like Harold consider tactful? Where was the balance between openness and tact? I held these questions open before me as I sought participants for the inquiry.

### Etymology as a Window to Understanding

In phenomenology, it is a common practice to examine the etymological roots of key words in order to open up the understanding of the phenomenon. Therefore, I turned to *The Oxford English Dictionary* (1992) to help me look more deeply into the meanings embedded in some of the words that were beginning to seem important to this study. When Nungusser (1988) explicated some of the difficulties embedded in telling the patient, he asserted that “A diagnosis is an event to be adapted to, not a death sentence to be compliant with” (p. 82). Two words in that sentence caught my attention. I wondered what shadows might be lying under the modern meanings of the word *event* and the phrase *death sentence*. As I continued my search, other words—*terminal illness* and *boundary* also emerged.

*The Oxford English Dictionary (OED)* gives little attention to the phrase death sentence except to note that death is frequently used in “general combinations of obvious meaning,” but a study of the individual words can help explain the aversion to a death sentence. *Death* has roots in Middle English, with Scottish, Swedish, Danish, and Norse

influences. It is, of course, “the act or fact of dying; the end of life” (*OED*) or “the state or condition of being without life, animation, or activity” (*OED*). Combining death with sentence creates even more ominous tones. Sentence, with roots in Spanish, Portuguese, and Latin is “an authoritative decision; a judgment pronounced by a tribunal” (*OED*). Further, it is “the judicial determination of the punishment to be inflicted on a convicted criminal. Hence, the punishment to which a criminal is sentenced” (*OED*). With its connotations of crime, punishment, and judgment, it is easy to see why a death sentence is something to be avoided. This may be one reason that people avoid open discussions of death.

What of event? What lies beneath the surface of that word? *The Oxford English Dictionary* (Simpson & Weiner, 1989) asserts that event is a word descended from Scottish, Latin, and Old French roots. It means “the (actual or contemplated) fact of anything happening; the occurrence of...an incident, occurrence” (Vol. V, p. 459). The *OED* goes on to say that in modern usage, event is “chiefly restricted to occurrences of some importance; hence, colloquial uses such as *quite an event*” (p. 459). Obsolete uses of the word event include use as a noun or an intransitive verb. The noun means “what ‘becomes of’ or befalls (a person or thing); fate” (p. 459); the verb means “to happen, take place; to come to pass” (p. 459). What does it mean, therefore to say that diagnosis (of a life-threatening illness) is an event to be adapted to? It is certainly an occurrence-- something that has happened--and it is of some importance. The word also brings along traces of meaning that point toward a fate that befalls a person. An event is something that

has come to pass. In a wispy kind of suggestion, an event could be a visitation from Some Thing--from Fate or Destiny--from something beyond the usual human experience.

What meanings might lie within the words *terminal illness*? Would an etymological search of those words help to illuminate the focus of this study? Terminal descends from the Latin *terminalis*, meaning *end* or *boundary*. Thus it refers to “the end of something (in time, or generally); forming the last member of a series or succession; closing, concluding, final, ultimate” (*OED*). A second meaning, specific for pathology, is “Applied to a morbid condition forming the final stage of a fatal disease; applied to a patient suffering from such a disease; or applied to an institution or ward in which such patients are nursed” (*OED*). Yet another meaning is “one suffering from a terminal illness” (*OED*). Though the first meaning of illness is “the quality or condition of being ill (in various senses),” (*OED*) obsolete meanings include “bad moral quality, condition, or character; wickedness, depravity; evil conduct; badness” (*OED*). Aspects of judgment, therefore, are missing from the word terminal, but when it is combined with illness, shades of evil and depravity appear. Again, a terminal illness carries with it shadows of negative connotations that may help to explain some of the avoidance of death in this culture.

Before I leave the discussion of the word terminal, I would like for a moment to return to the first definition offered: an end or boundary. Boundary is a word that means “That which serves to indicate the bounds or limits of anything whether material or immaterial; also the limit itself” (Simpson & Weiner, 1989, Vol. II, p. 443). It is also “a landmark indicating the limit of an estate or territory” (Simpson & Weiner, p. 441) and

“the limit or boundary beyond which soldiers, sailors, students, schoolchildren, etc....may not pass” (Simpson & Weiner, p. 442).

The word *bound* is embedded in the word boundary. It is both the past participle of the word *bind* and a verb itself. Bound means “made fast by a tie, confined; fastened down; bandaged...kept fast in bonds or in prison” (Simpson & Weiner, 1989, Vol. II, p. 442). It also means “to spring upwards, leap; to advance with leaps or springs” (p. 443). Thus, both boundary and bound are words with complex meanings. A boundary is a limit beyond which one *may not* pass, not a limit beyond which one *cannot* pass. A boundary marks the division between two distinct territories. It is not an end alone. Bound means both the action of springing and the ties that prevent movement. After all, one would not bind a tree or a rock to the ground. They are not going to go anywhere. If someone or something is bound, it is only because that entity has the potential to bound, and that potential is being thwarted.

What could bounds and boundaries signify regarding this study? The majority of people in America are descended from immigrants. We come from the people in our families who were adventurers or restless seekers--people who chose to cross boundaries both political and geographical. Perhaps one of our ancestors' legacies to us is that we do not like to come to the end of possibilities, and death appears at first glance to be terminal, that is, an end. As this dissertation proceeded, however, I wondered if we might find allusions to death as a boundary--a connotation that would suggest that there is something on the other side of death's boundary.

## The Research Question

My original research question centered around the treatment decisions that dying patients and their families made regarding end-of-life care. As I described in an earlier section of this chapter, however, my beginning conversations convinced me that that question was too narrow and of secondary importance. Instead, I turned my attention simply to the question “What is it like to be dying?” As I discussed in the previous section, there are many who advocate asking the question in this open forthright way. There are also many who see such a direct approach as brazen and insensitive. I have already described the hospice research director who claimed, “We don’t talk much about death around here.” In a subsequent meeting with other hospice personnel, three different staff persons suggested potential participants but warned that if I used the word *dying*, the participants would be very upset. It was difficult to find words to describe this study that balanced the honesty I sought, the sensitivity and tact that many dying patients might require, and the protective concerns of families and professional caregivers

The path I chose to begin this inquiry was to acknowledge in my writing and in my communication with professionals that my interest was in the lived experience of dying. With patient participants, however, I initially used the term life-threatening illness. I hoped that as I developed rapport with the participants, I would be able to glean some of their wisdom and guidance for determining when, if ever, one could speak openly about death.

Therefore, after seeking approval from the Internal Review Board at the University of Maryland, Baltimore, I sought participants who had a life-threatening illness, spoke

English, desired to reflect on their experiences with me, and were willing to have the conversations audiotaped. Because phenomenology values thoughtful depth rather than a broad synthesis, I expected my study would include fewer than 10 participants. The exact number could not be determined in advance. There is a sense in which a phenomenological study is never done, because there is always room for more contemplation and discovery. When I began the study, I believed that I would have enough participants when the participants and I believed that we had explored the phenomenon richly and fully, and I had come to a new understanding of patients and caregivers and the experience of having a life-threatening illness. Van Manen (1990) wrote that phenomenology is a “poetizing activity” (p. 13). It is an activity not of proving something or making a point, but of presenting something and revealing a new level of meaning—of seeing the world in a new way. I believed I would have a sufficient number of participants when I saw the world in a new and deeper way.

#### Approaching the Question

It was my intention to explore the phenomenon of having a life-threatening illness from the point of view of the patient. The patient’s personal subjective experience was my primary interest. Because of the exploratory nature of the research question, I elected to use an interpretive phenomenological approach to the study. Phenomenological studies require that the researcher approach the question with as few preconceived ideas as possible. Because the focus is the participant’s experience, the researcher imposes a minimum of structure on the inquiry, so as not to restrict the individual’s report of that

experience. Theoretical frameworks and exhaustive literature searches are postponed until after the text analysis. The intent is to allow the phenomenon under study to emerge wholly as it exists in “real life,” rather than to restrict the phenomenon by the researcher’s expectations. The researcher attends to the experience as a whole, instead of focusing on separate pieces of the experience (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). In phenomenological studies, the researcher’s responsibilities include being involved, interactive, and responsive (Oiler, 1982; Harvey, 1993; Omery, 1983; Stulginsky, 1993a, 1993b; Witherall & Noddings, 1991; van Manen, 1984, 1990). Initially, the purpose of the researcher is to facilitate the individual’s telling of his or her own story. It is believed that stories can help us understand ourselves and one another, and that stories can help the abstract become concrete, understandable, and accessible. Phenomenology is particularly well-suited to the study of people’s adaptation to critical life experiences, the ultimate focus of this study (Anzul, 1991; Denzin, 1984, 1989; Friedman, 1991; Garner, 1991; Polit & Hungler, 1991).

For this study, I identified people who met the inclusion criteria noted above. Although I was the initiator of this study, it was in no way a solitary effort. Its success, even its completion, depended on the patients’ willingness to engage in the inquiry in a deep and thoughtful manner. Their initial thoughts and their subsequent contributions to the emerging interpretation were crucial. Thus, throughout this study, I referred to the patients as *participants* to acknowledge their critical role in the inquiry. As a beginning phenomenologist, I intended to use language in a manner consistent with the

phenomenological perspective--that is, I attempted to recognize that language is informed by and informs our thinking. Etymological exploration of key words and concepts enhanced the understanding of the experience. These ideas about language are developed in more depth in Chapter Three.

A vital feature of the method was that interpretation occurred simultaneously with text generation. I had hoped to return to each participant several times to share the developing interpretation and to elicit the participant's evaluation of the emerging study. I believed the additional conversations would serve several purposes. They would increase trust between researcher and participants, and they would offer the opportunity to examine changing circumstances in the participants' lived experience. They would further allow for examination of reflections on earlier conversations and provide for participants' validation of the interpretation. As this inquiry began, however, I did not know how well I would be able to reach the ideal of repeated conversations. Patients with life-threatening illnesses can be a fragile population. Changing health status and frequent appointments for diagnosis or treatment can severely limit patient's time and energy for participation in research. Many phenomenological studies are sustained over several months so that the researchers can allow time for thoughts and interpretations to settle and ripen between research conversations. I believed that this study, because of the study participants' potential for rapid decline would need to be different. The deep and thoughtful analysis would need to be done quickly in order to maximize the possibility of meeting with participants at least twice. My aim was to be as deeply thoughtful as I could be within the

constraints of the fragile nature of the participants. I hoped I would discover meanings that the participants had not consciously known but that they recognized once they were expressed. Experiences explicated in this way, would approach what Merleau-Ponty (1964) calls *great prose*. “Great prose,” says Merleau-Ponty, “is the art of capturing a meaning which until then had never been objectified and of rendering it accessible to everyone who speaks the same language” (p. 9).

To develop this study, therefore, I invited potential participants to meet with me to explore their experiences of having a life-threatening illness and their interpretations of the meaning of that experience. Questions that were used to open the inquiry appear in Appendix A (p. 271). Each conversation took from forty minutes to three hours, depending on the participant’s energy and priorities. The conversations were audiotaped to generate a text that was analyzed for themes and interpretations. Eight participants ultimately contributed to this study. Two of them (Beth Marie and Doctor Magrisso) participated by sharing their writing with me. Three (Sarah, Mona, and Daniel) were able to meet with me just once. One participant (Hannah) shared her thoughts with me in one telephone conversation. Margaret met with me three times over several months. The last participant was my sister-in-law Linda. I walked with her and her husband, my brother Joel, through several months of her struggle with pancreatic cancer. Though Linda was not a formal participant, her experiences lent an invaluable depth to this inquiry. Because so few of the participants were able to meet with me repeatedly over time, I asked two other people to read and respond to the interpretation presented in this dissertation. Susan

is a friend whose husband died of a brain tumor a few years ago. She agreed to read this account and reported that the interpretation vividly matched her experience of caring for her husband. She particularly noted the discussion of the significance of eating; she told me that the interpretation helped her to make explicit her unarticulated understandings of the meanings of eating in life-threatening illness. The second person who read my work was Judy, a pastor at my church. Judy is responsible for pastoral care of the congregation. In that capacity, she interacts almost daily with people who are ill, and often meets over time with those who are living with a life-threatening illness. Judy has personal knowledge of life-threatening illness as well, for she developed breast cancer over eight years ago; thankfully, she is still disease free. Judy affirmed that the interpretation presented in this work is consistent with her personal and professional knowledge of the experience of life-threatening illness.

#### Assumptions, Biases, Experiences, and Intuitions

In phenomenology, the participants and the researcher form the framework of the study. It is through their interpretive screens that discovery and analysis take place. Therefore, the person of the researcher is of relevance to the study. Assumptions, biases, personal experiences, and intuition have great impact on the study. Phenomenologists believe that all research, quantitative and qualitative, is affected by researcher assumptions. For this reason, the researcher is counseled to identify and articulate these concerns prior to and throughout the study. Husserl believed that one should “bracket” these assumptions and set them aside in order to minimize their influence on the inquiry. Heidegger believed,

however, that bracketing and setting aside of assumptions was impossible. Rather, he believed that one should bring the assumptions to the forefront of one's awareness and try to keep them there. In that way, the researcher could acknowledge those assumptions and understand how they shape the developing study (van Manen, 1990). The researcher would also be able to observe how those assumptions change as the inquiry progresses. Consideration of the changing assumptions could help to shed light on the unfolding analysis. Therefore, as I began, I turned to my awareness of my own preunderstandings as I moved toward the inquiry. What follows is the text of my assumptions as I began the study.

I believe that dying is a critical life event with the potential for changing life views of both the patient and those around him or her. Dying can affect personal interpretations of ultimate questions about the character of the life that has been lived and the meaning of life in general.

I believe there is great value in being with other people in times of crisis. One of nursing's imperatives is to be with patients and, therefore, the very act of being with the study participants and dwelling with them in their experiences will be therapeutic for them and enriching for me.

I believe that the quality of dying has a profound effect on those close to the dying patient. Thus, the quality of dying has great potential to affect the grief process of the survivors and the hope with which they face their bereavement and ultimate adjustment to life without the deceased.

Dying is approached with a variety of awareness. Timing of that awareness is capricious, that is, there is no way of knowing when and how a person and/or family will accept that death is coming. Furthermore, both patient and family respond to the everyday changes in condition in many different ways. Sometimes people need to "live into" their grief and disappointment. At other times, people need to express their hope for the future. Patients and family members frequently have very different, even conflicting, needs at the same time. A perspective that one finds most comforting may be threatening to another. These personal differences can make the task of supporting one another far more difficult.

Dying is hard work for patient and family alike. It places great demands on a person's physical, spiritual, emotional, and social self. Nothing escapes. All aspects of life are affected.

Dying is paradoxically a social event and an isolating event. Many people may attend a dying person, and a death can have far-reaching effects on those surrounding people, but the fact remains that only the dying person is dying. Dying is his or her experience alone.

Paying attention to dying has the potential to change lives for the better—to motivate us to reorder priorities and to make life more meaningful and satisfying.

As a Christian, I believe in an afterlife in the presence of a loving creator, and I believe this experience is available to all who receive the offer whether before or after death. I think this is consistent with reports of near-death experiences and biblical text. I understand that many people, Christians and others, do not share this belief. It is my belief, however, and I firmly believe it to be true. This perspective renders me open to exploring the spiritual needs of patients and families. If we have similar beliefs, we can support and encourage each other through our shared faith. I am careful, however, to honor faith perspectives that differ or conflict with mine. In my interactions with patients of those differing perspectives, I try to explore their ideas about the meaning of life and death and support them where I can. Either way, I find that my faith protects me from despair and gives me hope as I stand with those who are suffering. In that way, I believe it enables me to work with dying patients and their families and sustains and nourishes me as I journey beside them.

### Methodological Assumptions

In addition to my assumptions about the subject matter of this inquiry, I had assumptions about the method—interpretive phenomenology. In the following section is the text of those assumptions at the beginning of the study.

We live life on the surface, but there is much that goes on under the surface. Diving deep into these pools of experience and meaning is a worthwhile endeavor. Heidegger (1993) believed that the characteristic that most makes humans human is language, for it is through language that humans try to make meaning out of their lives. As phenomenology is a method whose entire quest is a search for meaning, language plays a central role in the inquiry. Immersion in text and etymological searches of key words and concepts are central to the method.

I assume that participants will attempt to be truthful with me. Human understanding and motivation are extremely complex, however. When humans are in crisis, denial can serve to protect a person from devastating thoughts and emotions. People also have great variation in their

preferences for privacy and self-disclosure. I think it possible that some patients may knowingly avoid speaking their true thoughts from a combination of internal resistance and a need for privacy. I expect, however, that those who choose to work with me will be more likely to be self-disclosing. Because of the profound nature of the subject matter, however, we may all be surprised. As Gadamer (1960/1990) has suggested, if we give ourselves fully to a conversation, we are the followers of the conversation, not the leaders. It may not be possible to know in advance where the conversation will take us.

Words that we use every day sometimes have a rich history. Even if we are not instantly aware of that history, those ghosts of meaning come along with the word. I think of spirits being invoked by the saying of their names. In the same way, the spirit of the word may be invoked by speaking it. Examination of a word's past (etymological roots) can reveal meaning that enriches our understanding of who we are now.

Although I could not know what would emerge during the course of this inquiry, there were some words that had relevance as I began. *Hospital* is adopted from the medieval Latin *hospitale*, a place of reception for guests. *Hospice* is an adoption of the French *hospice*, itself adapted from the Latin *hospitium*, meaning “hospitality, entertainment, a lodging or inn” (*OED*, 1992). Both words have older connotations as places of rest and reception for pilgrims, travelers, or strangers. *Hospitality* is an adoption from the Old French *hospitalite*, which was adapted from the Latin *hospitalitas*. Its meaning, “The act or practice of being hospitable; the reception and entertainment of guests, visitors, or strangers, with liberality and goodwill” is embedded in both hospital and hospice (*OED*). In many discussions comparing hospice care to hospital care for dying patients, hospitals are seen as places where the patient and family lose control of the circumstances of dying. It is implied that patients are subjected to unwanted invasive treatments and diagnostic tests, and interactions with families and pets are restricted by

hospital policy. Hospices emphasize the comfort of staying home, or in the case of in-patient hospices, staying in a “homelike atmosphere.” This suggests that hospitals have lost touch with their roots as places of hospitality, and that patients and families hunger for those places of reception, rest, and entertainment. A goal of this inquiry was to discover insights that would lead to better hospitality for pilgrims passing through the last stages of their lives.

### Summary of the Journey So Far

In this chapter, I have described the story of how these research questions came to press themselves upon me. I have provided background information and an overview of the theoretical and methodological grounding for the study. In Chapter Two, I present a preliminary analysis of two beginning conversations, and consider how that analysis relates to existing literature about the care of patients with life-threatening illnesses. Further, I show how I expect this study to contribute to the present state of knowledge regarding the lived experience of having a life-threatening illness. Chapter Three is a fuller picture of the philosophical and theoretical legacies that supported and directed the study. In Chapter Four, I present the interpretation that was developed by the participants and me. In Chapter Five, I weave together my entering assumptions with the insights that emerged during the study to create a summary. Chapter Six, the epilogue, offers a concluding metaphor that summarizes the entire inquiry.

This chapter was not the beginning of my turning to the phenomenon. It would be

hard for me to locate the beginning with precision. Was it during the time when I cared for Nancy and her family? Was it years earlier when a hospice nurse spoke to my senior nursing class and first described this new (at that time) specialty in nursing? When it started was not really important. What was relevant was that it began. In this chapter, I described my understanding of the shape the journey would take. Remembering Gadamer's (1960/1990) counsel to open up possibilities and keep them open, I went forward prepared to change course when the inquiry took an unexpected turn. Like an explorer, I committed myself to the voyage, not the destination.

## **CHAPTER TWO**

### **EXPLORING THE PHENOMENON OF HAVING A LIFE-THREATENING ILLNESS**

In Chapter One, I described the thoughts, events, and wonderings that turned me toward an inquiry into the lived experience of having a life-threatening illness. In this chapter, I begin to explore that phenomenon by offering an analysis of two conversations. I offer further insights gleaned from professional, academic, personal, and artistic sources. Then, I suggest areas in which I expected the proposed study to enhance the knowledge and understanding of the human experience of having a life-threatening illness.

#### **Beginning Participants**

In order to continue the inquiry into the lived experience of having a life-threatening illness, I met with two participants to explore their experiences and perspectives. This preliminary analysis was a way to introduce patterns and theme clusters that began to emerge as the study developed.

Addie was a 49-year-old woman who was a patient in the home hospice program

where I was employed. She lived at home with her husband and four children who ranged in age from fifteen to eight. She had first been diagnosed with breast cancer eight years prior to our meeting. In the years since her diagnosis, she had undergone several courses of aggressive treatment, but shortly before our meeting, she had had seizures because of brain metastases. The seizures were one of several indications that her disease was finally winning the battle. Still, her claim on hope and courage remained strong. My sense of our conversation was that it was a time suffused with deep and rich meaning. Her body continued to decline, however, and she died three months after our meeting.

A mutual friend referred me to Alice, a 45-year-old woman who had recently had surgery for a metastatic tumor. It was not until my meeting with Alice began that I discovered that Alice was not terminal. She had had a hysterectomy for uterine cancer in 1978. Then, four months before our meeting, she had discovered a huge pelvic mass. Initially, she and her doctors thought she had advanced ovarian cancer, but pathology studies showed that the tumor was a metastases from the first cancer seventeen years ago. Although the diagnosis was metastatic cancer, it was a cancer that grew so slowly that Alice required only hormone therapy for treatment. Her prognosis was excellent. When the conversation began, I was dismayed thinking that the meeting would be irrelevant to the study.<sup>6</sup> Nevertheless, I chose not to end the meeting early, thinking that would be

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<sup>6</sup>Hospice nursing can have a peculiar effect on a person. It seems a bit twisted to be disappointed because someone is not dying.----Even at the time I wondered, what was happening to me? Who was I becoming that I was not glad that this vibrant woman was alive and well?

rude, and it quickly became apparent that Alice had much to offer. She had so recently lived through the experience of finding an ominous sign, enduring diagnostic tests and surgery, and then waiting for results, that her memory of that terrifying time was very fresh. She was able clearly to articulate the lived experience of “starting down the road.”

In many ways, Alice and Addie were “bookends”—one revealing the beginning time preceding diagnosis, and one revealing a life nearing its end. Although their paths quickly diverged when Alice was granted a reprieve from the threat of imminent death, both women offered glimpses into the phenomenon of having a life-threatening illness.

#### Emerging Themes and Patterns

Trying to sort the experiences of different people into discrete themes is a little like trying to analyze a plate of spaghetti. Each idea or theme twists and turns and is interwoven with several other themes. None of the ideas stands alone. Careful examination of one strand or theme affects the examination of other themes. Furthermore, the subject of this analysis was the experience of having a life-threatening illness—a subject that is intertwined with dying. It is logical to assume that much of the subject will remain veiled and confusing to us. Still, because we cannot know everything is no reason to think that we can know nothing. The point of this study was to examine what we do know and to search intently for what more could be uncovered by a thoughtful and careful attentiveness.

The analysis that appears here was seen as a glimpse of what might come. As I

lived into the texts of my meetings with Alice and Addie, some themes began to emerge.

In the following pages, I present those themes and my reflections about them.

### Family Involvement as a Double-Edged Sword

For me, one of the appeals of hospice nursing is that we are encouraged, even required, to attend to the needs of the family as well as the needs of the identified patient. It is an unexamined assumption that except in cases of extremely dysfunctional families, family support is of benefit to patient and family alike. Therefore, I was surprised to hear Alice explain that, although her family's support was invaluable to her, her family was a source of some of her most intense pain.

[My husband] was so wonderful through the whole thing. I knew he was just falling apart, but he never showed it...It hurt so much to see him. You know, if I had to go through this myself, it would have been easier...than if I had to see the look on his face and on my dad's face. That was just devastating. That's what I couldn't deal with...I really didn't want to tell my husband. Not that--I don't have any secrets from him and it wasn't that--it was just that I didn't want to see the hurt. I didn't want to watch that...I would have done anything if I could have just not told them. And just done it [the surgery]. I remember just watching my dad [after the first surgery 17 years before], and I felt like he was re-living my mother [who had died of cancer] all over again, and that was killing me. It was just killing me, to think that I was causing him that pain...So, I think that family involvement is important, but I think that it's a kind of a double-edged sword. At least it was for me.

When we discussed this double-edged sword more fully, Alice was very clear that her family was a great source of strength to her. She eloquently described, however, that seeing her family's pain was excruciatingly painful for her. Her words made me think about patients and families who have been reluctant to talk to each other. In the past, I have assumed their reluctance was an avoidance of intimacy. Perhaps it is, but I now have

a deeper understanding of what that intimacy may cost.

### The Divided Life/The Divided Self

Both Addie and Alice described feeling fragmented, but they described it in different ways. Addie said that her cancer was “very intrusive” and said, “I had another life before this, and I can’t seem to get back to it anymore.” I thought it was very interesting that Addie did not say that her life had changed, or that her life was different now, though that certainly was implied. She said that she couldn’t “get to” that other life. The implication was that that other life still existed and was going on, but she could not find her way to it. Perhaps that other life referred to the imagined future healthy self that she had to abandon when she developed breast cancer.

Alice’s fragmentation emerged in her conversation about different parts of herself.

Describing how she did not allow herself to voice or even think certain fears, she said:

There was something in my mind, that would not even allow me to think that it [the cancer] had spread to the point where it wasn’t treatable...it was like, once I would even think that, it made it possible...I would not allow my mouth to do that.

Later, when she explained why, even though she had overwhelming fear, she never really believed she was going to die, she said:

I kept telling my husband, I believe that, just based on my nursing experience, that people know when they’re gonna die. And people know inside when they are really really sick. They don’t have to be told that. *I think that there’s something in us that lets us know that, and I never had that feeling of impending doom. I believe there’s something in us that lets us know if our life is close. And I just never had that feeling (italics added).*

It seems that for both Addie and Alice, the experience of facing their own mortality

increased their awareness of differing parts of themselves or their lives. It is this “shaking up” of the familiar self that can make severe illness so threatening. The shaking of familiar patterns, though, may also present opportunities for self-growth and increased self-awareness (Kramer & Kramer, 1993). It is often noted that the Chinese character for crisis is a combination of the characters for danger and opportunity, signifying that a crisis brings both. The opportunity for growth and change in the face of threat is what O’Connor (1971) referred to when she wrote of suffering as our teacher and our friend. This is not to suggest that a person should wish for cancer in order to develop increased understanding. It does suggest that there is the possibility of growth in the midst of suffering, and the knowledge of that possibility may offer a route of hope. This theme is closely related to the theme of disguised blessings that follows.

#### Benefits of Illness and Disguised Blessings

When I asked Addie what had helped her during her illness, she answered in terms of benefits she had gained.

It’s given [my sisters and me] a chance to be closer, and I value that a lot. And the same with some friends that I really didn’t know all that well before, but know much better and come to love....I think Brian [her husband] and I have gotten more in touch with each other again...our relationship itself, I think, has improved a lot...now we talk things over more...cherish our times together...I just appreciate him so much.

Addie also described ways in which her illness had provided benefits for her children.

I think there are some benefits for the kids. The doing...for others and their mother. And for their brothers and sisters, too. And, getting through an ordeal, knowing that they’ll come out on the other side...And I think everybody will learn about caring more. Taking care of people from this experience. So I’m counting that as a plus.

Alice, too, talked about good things coming out of her illness, but the term she used was *blessings*.

When I look back, sometimes when something's happened that I thought was the absolute worst thing that would ever happen to me in my whole life, and I was devastated, fifteen years later, I'll look back and it turns out to be a blessing...It took me a long while to look at it that way! But God truly blessed me. I have nothing but gratitude.

When she reflected about the things that had helped her through her crisis, she said:

I think it was a combination of those things. The doctor who pulled me through the system, the doctor who did the surgery who was just so wonderful, and my husband, and my religion there to be the strength, I think were the things that helped the most. I wouldn't give any of them up and *sometimes I wonder how I got so lucky* (italics added).

What is this notion that having cancer and looking death in the face is a blessing—a lucky event? In the last chapter, I searched the roots of the word *event* and found that although it refers to an occurrence, it also brings suggestions of a visitation from Fate (Simpson & Weiner, 1989). In mythology, a visitation is often a mixed occurrence, bringing both desirable and undesirable effects. These texts from Addie and Alice and the texts of Nungusser and Kramer and Kramer that follow capture the complex notion of blessing descending in a disguise of illness. It is a paradoxical idea, but it is not an uncommon one. Nungusser (1988), dying of AIDS, wrote, “My diagnosis and illness have become simultaneously life-threatening and life-enhancing” (p. 64). Kay Kramer (Kramer & Kramer, 1993), writing in the time just prior to her husband's death stated, “It always seems amazing to find that there are things to be gained in the midst of such hideous loss” (p. 133). Remembering the time of his diagnosis, Herb Kramer wrote:

When the cancer was unmasked, I had no obvious symptoms, and so I

determined that everything in my life would continue as if nothing had happened. It was to be business as usual. Full speed ahead.

But Kay refused to let this happen. She persuaded me that by failing to acknowledge the presence of death, I was, in fact, denying it. And this denial could cost me an experience rich with meaning. It could keep me closed to insights and perceptions that could greatly expand my spiritual faculties. It could answer questions about life and death that 'business as usual' would reject until it was too late to receive them. (pp. 17-18)

What other blessings might be hidden in suffering? What can critically ill patients tell us about the joy woven into the sadness?

### Accepting Help

During the course of my conversation with Addie, she mentioned that she sometimes was "pampered." When I asked if it was hard to accept help, she answered "Yes." This was followed by a long silence. Although the conversation had been filled with long silences, this time, Addie became exasperated with me. In an irritated tone, she exclaimed, "I just can't talk! You have to ask me questions." As I looked back over the transcript, I realized that I dropped that subject immediately. I felt that I had received a clear, but unspoken message, "Don't go there." I felt I had received that message, but I did not check with Addie to see if my feeling reflected my own discomfort or a genuine message of hers.

Addie's (or my) reluctance to explore her feelings about needing and receiving help may have been related to the cultural norm that values activity and independence. Americans have a long tradition of "rugged individualism." Self-sufficiency and productivity are highly valued in our culture. For many ill people, the loss of independence makes them feel less valuable. If a person is not merely ill, but dying, the feeling can be

intensified. Exploring this notion, Ignatieff concluded:

Cultures that live by the values of self-realization and self-mastery are not especially good at dying, at submitting to those experiences where freedom ends and biological fate begins. Why should they be? Their strong side is Promethean ambition--the defiance and transcendence of fate, materials, and social limits. Their weak side is submitting to the inevitable. (as cited in Callahan, 1995a, p. 229)

What is it like to become so dependent in our self-sufficient society? What help is offered and what is it like to need help and to accept or reject it?

I turned to the roots of the words *dependent* and *independent* to see if I could discover hidden meaning there. Dependent is derived from the Old French word, *pendre* meaning "to hang" (*OED*, 1992). An early meaning is "to hang down, be suspended" (*OED*) but its current usage is closer to "To be connected with in a relation of subordination; to belong to as something subordinate; to be a dependent of" (*OED*). Other meanings include "To rest entirely...upon for maintenance, support, supply, or what is needed; to have to rely upon; to be a burden upon, to be sustained by; to be dependent on" (*OED*). The original idea of hanging down or being suspended provides a clue, perhaps, to Addie's aversion to dependency. It suggests a precarious, helpless hanging away from the comfort and security of solid ground. Current meanings also suggest subordination, being a dependent of someone, rather than a self-sufficient adult. Dependence further suggests that one is a burden to someone else--a load, an extra, perhaps, unwanted responsibility. Most of the meanings of the word *independent* can be summarized as *not dependent*, but the first meaning reveals some further connotations. Independent means "not depending upon the authority of another, not in a position of subordination or subjection; not subject

to external control or rule; self-governing, autonomous” (*OED*). It is easy to see how citizens of a country born of the values of self-governance and independence—citizens of America, the land of the free—would chafe at the notion of dependence.

#### Advice for Others

I asked both Addie and Alice what they thought they had learned from their experiences and what advice they would offer to someone else in the early stage of the same diagnosis. Addie had been receiving treatment for eight years at the time of our meeting and was within a few months of her death. Alice had been diagnosed with metastatic cancer just four months prior to our meeting. Her death, as far as we knew, was nowhere near the horizon. Given the differences in their circumstances, it was striking to me that they both offered similar advice. Addie responded to the question with focus and energy. Her message was, “Be as aggressive as possible.” She recommended trying to get a bone marrow transplant as early as possible, but expanded her advice beyond the physical realm. She suggested, “Get in a support group...or do psychotherapy if it would help. Do whatever you need to do to help yourself...and if your husband needs help, force him. Kick him...Maybe take the time to look at your spiritual side.”

Later on, she thought of more suggestions to add:

I think I would tell people not to stop their lives...but keep it going; stay in contact with everybody, and appreciate the gifts of love...But for example, I've had all these chairs covered and the drapes made, and all those were some things done since I've been sick, and I think it's important. It's given me something to do, and it's given me something to leave here...projects are important.

Like Addie, Alice also advocated fighting as hard as possible. She recommended

“getting as much information as you can” because “information is the power.” But she also indicated that there was a time to give up the fight--not give it up, exactly, but give it over.

But at one point, I just reached, I reached a point where, I mean, I remember, I was praying, and I said, You know, I have done absolutely all I can do. I’ve gotten to the doctors, I’ve done the tests. I’ve got the surgery scheduled. I can’t do anything more. And now it’s up to You [God]...and it was like at that point, I was okay. I couldn’t do anything else.

Alice asserted, “Fight with all you have and then give it up to a higher power.” Addie said, “Fight with all you have, but stay involved in life, too.” Clearly, to both women, the fight was important.

The call to fight struck a chord within me. It seemed to be an idea with deep roots in the culture and in the psyche. *The Oxford English Dictionary* (1992) offers tracings of *fight* as both a noun and a verb. Fight, the noun, is “the action of fighting...strife, conflict, struggle for victory” (*OED*). Fight, the verb, means “to contend in battle or single combat...to contend, strive for victory, struggle, engage in conflict...or of an animal, to struggle for freedom or mastery” (*OED*). What is this fight that Addie and Alice speak of? Who or what is the enemy? What is it like to fight? Are there alternatives to the fight? These questions deserve more exploration. In my clinical work, I have found that disagreements between patient, family, and health care workers over whether or not the patient should keep fighting can be the source of great pain and controversy. In a later section of this chapter, I consider the imperative to fight more fully.

As I reflected upon the imperative to fight, it led me to consider other issues that

may confound the ability to face death in a forthright manner. Attitudes about “realistic” and “unrealistic” hope are relevant. Also relevant are questions about “openness” in dying. A discussion of personal interpretation may help shed further light on these complicated issues. In the next section of this chapter, I explore these relevant ideas.

### How are We to Face Death?

Madan (1992) contended that “Western medicalization of death has stripped death of its potential as a cultural construct that sees death as a normal part of a full life, not a negation of it” (p. 428). Continuing, he said that this Western medicalization has “stripped patient and family of control” (p. 428). The social upheaval that began in the 1960’s has encouraged consumers to take back some of their participation in health care, but they may still find themselves caught between conflicting cultural expectations. Some of these conflicts are presented here.

### The Imperative to Fight

This desire to fight, no matter what, is very pervasive. One can almost see John Wayne or the Unsinkable Molly Brown hunkering down to do battle against overwhelming odds. It is commonly accepted that a fighting attitude can aid in recovery (Siegel, 1986), but this almost moral imperative to fight can constrain the patient who eventually “loses” to death. Patients who “choose” to accept death can find themselves judged negatively by others who may believe the lack of a desire to fight is a character flaw (Hunt, 1992). A consequence of this cultural resistance to death is that people can

avoid evaluating the quality of the life that is being lived. Hawkins (1990-91) described one patient who seemed to be limited by his need to fight, as he decided to continue with chemotherapy that did not seem to be effective.

At this time, both men [Dr. Goldman and the patient, Carl Lerner] are in *total accord, united in a single-minded though futile effort* which is not to reverse the illness, nor even to make Carl more comfortable in the death that *both see as inevitable*, but solely to fight the disease. As Carl observes of himself, "I've always been a fighter" and Goldman later echoes, "You are a fighter, Mr. Lerner...and I'm a fighter." (p. 313, italics added)

Both doctor and patient valued fighting, even futile fighting, over quality of life. Callahan (1995a) pointed out how public policy reflects this focus on quantity of life. He reported:

The National Institutes of Health carries out an unrelenting struggle against death, and for decades, the research budgets and priorities have given the primary place to those diseases that can cause death: cancer, heart disease and stroke, diabetes mellitus, and most recently, the acquired immunodeficiency syndrome (AIDS). Diseases that reduce or destroy the quality of life—deafness, blindness, the dementias, arthritis, osteoporosis, schizophrenia, and depression, for instance—receive considerably less research support. (p. 229)

It is worth noting that the relative lack of attention given to quality of life and compassionate care of the dying may be changing. In December of 1997, The National Institutes of Health announced that it is now seeking grant applications regarding the management of symptoms at the end of life. Quality of life was ranked third in a list of 91 research priorities in a survey of the Oncology Nursing Society in 1994 (Stetz, Haberman, Holcombe, & Jones, 1995). In 1995, the SUPPORT study conducted an extensive trial attempting to improve care of the dying. Though the results of that study were very disappointing, follow-up studies are continuing (personal communication, E. J. Emmanuel,

April 17, 1996). Furthermore, in 1995, the Open Society Institute initiated a "Project on Death in America" to improve care of the dying through multiple means (McCrary, 1996). These initiatives are encouraging, but we are still far from a cultural acceptance of death.

### "Realistic" and "Unrealistic" Hope

In 1989, five years after being diagnosed with breast cancer, Hall wrote an article entitled "The Struggle of the Diagnosed Terminally Ill Person to Maintain Hope." She discussed her own experiences and the experiences of other patients as they received treatment for cancer. The study participants said that often, health care professionals, would strongly insist that the patients be realistic. The patients perceived this insistence as a barrier to hope. Hall went on to ask, what, exactly, is realistic hope? Hope is an orientation toward the future, and that future is unknown both to patients and health care providers. Prognostic statistics are derived from aggregate data that rarely include social, contextual, or psychological facets, all or which are believed to have a strong influence on individual outcomes. Therefore, statistics cannot be applied with absolute certainty to an individual (Lynn & Teno, 1995). If a patient chooses to hope that he or she will be the 1 in 10,000 who survives a particular diagnosis, one can say that the likelihood of that survival is small, but who is to say it is unrealistic? In her interviews with the critically ill, Hall noted that patients collect stories of people who overcame a grim prognosis and outlived their expected survival time. Some accept poor prognostic statistics as a challenge to be overcome, and as such, those statistics become seeds of hope. Hall believed that health care providers' insistence on reality places unnecessary burdens on the medically

diagnosed, driving some of them to the alternative care systems, and forcing others to total hopelessness. As one of her participants put it, “Some of them just go ‘Eek!’ and die” (p. 180) when told they are dying. Hall asserted that health care workers must relate to all patients in a future oriented way, allowing each patient to maintain his or her interpretation of the probable or possible future. Hall’s analysis helps to shed light on some of the controversy surrounding care of the seriously ill. In my review of literature and my practice as a nurse, it has been rare to encounter anyone who advocates deceiving the patient about the diagnosis. There is far less consensus, however, on whether or not to reveal the prognosis and how exacting to be in the discussion of the prognosis. Because, as Hall says, the exact future is unknown to patient and practitioner alike, disagreements about what constitutes honesty about a prognosis are common. Different personal perspectives can yield different interpretations of the same circumstances. Therefore, I will turn my attention next to the concept of personal interpretation.

### Personal Interpretation

An issue that complicates the understanding of concepts like hope, optimism, and denial is the central role that personal interpretation plays. Although personal perspective and interpretation will be considered more fully in Chapter Three, it will be helpful to present a brief discussion here. The problem lies in the assumption that an external reality has the same meaning for all observers. Too often, the approach and internal world of the observer determines what is understood. People can be presented with the same situations and derive very different conclusions. While some may see a glass of water and say the

glass is half empty, another may say the glass is half full. Still another might say the glass is too big. Though in each case, it is the same glass, the interpretation could lead to very different actions.

### Language: A Bridge or a Chasm?

Language, too, can sometimes clarify understanding and sometimes confuse or distort understanding. Sampson (as cited in O'Connor, 1971) offered the following discussion of how language can be used to support differing views of the same situation.

Language...is rich in opportunities for masking and mistranslating reality according to inner psychic needs. It would not be difficult to compile a thesaurus of contrasting terms in common use: the one set to describe qualities of people belonging to one's own group, the other set to describe the same attributes when possessed by members of the group that is feared or hated: e.g.,

thrifty, stingy;  
generous, spendthrift;  
eager, grasping;  
determined, fanatical;  
brave, foolhardy;  
leisurely, idle;  
smart, flashy;  
statesman, political maneuverer. (pp. 76-77)

I began to see Samson's (as cited in O'Connor, 1971) analysis as important to the present inquiry when I began to try to sort ideas into categories of hope, optimism, realistic appraisals, and denial. I began to see that what I might call denial, another was calling optimism, or focusing on the positive. If a patient has 1 chance in 10,000 for survival, and that patient chooses to believe that he or she will survive, it is not an easy matter to determine if that patient is being strong and hopeful or if that patient is denying the severity of the disease. Patients, therefore, can consider the same prognostic indicators

and reach differing conclusions; so can health care professionals and families. Given that no one knows exactly what the future will bring for any one patient, it is not so surprising that agreement is so elusive a goal (Higginson, Priest, & McCarthy, 1994; Libbus & Russell, 1995; Seale, 1991).

### When Our Best Guess is Wrong

Another factor that complicates our approach to death and having a life-threatening illness is remembering a time when we felt certain that a patient was going to die, but, against all expectations, the patient lived. Though it is one thing to know abstractly that the future is uncertain, it is another thing to have one's "certainty" about a specific outcome proved wrong. It is an experience that can increase confusion and uncertainty when one confronts such a situation again. I will give two brief examples.

Recently I rented the movie *Lorenzo's Oil* (Mitchell & Miller, 1993). It is the story of a family in which the only child, Lorenzo, develops a rare disease when he is five years old. The disease is a progressive, debilitating syndrome that destroys the myelin surrounding nerve tissue. The child gradually loses all motor control, sight, speech, the ability to swallow. When the parents receive the diagnosis, they are told that the disease is always fatal, usually within two years. The parents initially accept the approach of the doctors, but after a time, they begin a quest to discover a treatment. They spend untold hours reading in research libraries and then searching for companies that can produce a particular extract of olive oil that might slow the progression of the disease. As Lorenzo becomes more and more compromised, his mother ruthlessly fires any assistants who

suggest the fight is not worth fighting. Lorenzo's suffering, in the meantime, is not confined to mere debilitation. He also endures frequent lengthy seizure-like attacks in which he screams and cries out in pain while his mother attempts to "talk him through" the episodes. This goes on for more than 5 years. I found myself watching the movie and shaking my head in horror and dismay. I have no doubt that had I been involved in Lorenzo's life, I would have advocated long and hard to end his suffering by allowing him to die. Finally, however, his parents, in cooperation with a manufacturer in England, discover and produce "Lorenzo's Oil." As the final credits of the movie rolled, an epilogue reported that Lorenzo was then 15 years old and was able to communicate with a specially adapted computer. That knowledge in itself was not enough to convince me that the fight was worth the suffering. But then, during the final credits, a procession of very short clips began in which boy after boy after boy, vibrant and healthy, would declare something like, "Hi, My name is Sam, (or Henry, or Mohammed). I've been taking Lorenzo's Oil for three years now. My favorite sports are hockey and basketball. This summer, I'm going to go camping with my family in the Rockies." I watched the credits in stunned silence. Had I been able to prevail upon Lorenzo's parents, all of those boys would have succumbed to that horrible disease. I wondered if Lorenzo's mother's astonishingly incomprehensible perseverance was really obedience to a holy call to persist until the treatment was found. I felt humbled. I believe that watching that movie changed me and made me more willing to entertain doubt about my own judgments.

Herman (1992) related a similar experience. He described his experience as a

physician caring for the siblings of an 11-year-old who was undergoing aggressive treatment for leukemia under the care of a different physician at a distant medical center. The family was stretched to the breaking point because of the demands of the illness, the grueling treatment, and the exhaustion of their resources. Once or twice, when the mother brought the siblings in for routine care, Herman almost asked her if she would like to quit treatment, but he could not quite bring himself to voice the question. Later, when the girl recovered, against all odds, he was glad he had had no part in encouraging the mother to quit. He would have felt remorse for his part in eroding the mother's hope and possibly jeopardizing the daughter's healing.

Where there is life, there is hope. After hearing stories such as these, how can we believe anything else? Yet where there is life, death will surely follow. What is it like to "be with" patients and their families when we cannot know what the future will hold? As I explore these questions more fully, it sometimes seems I am moving toward deeper confusion rather than toward deeper clarity.

### Summary of the Beginning Exploration

In this beginning exploration into the lived experience of having a life-threatening illness, I have examined the phenomenon in greater detail. A fuller picture of the experience has emerged from an examination of the lives of two participants, but many more questions have surfaced. What do patients and families desire when their very togetherness inflicts great pain even as they intensely need each other? What is it like to

tolerate fragmentation long enough to find the unexpected blessing that may be there?

What is it like to experience dependence in a culture that so values self-reliance? What is it like to navigate between the seemingly conflicting goals of embracing life and accepting death?

As I considered an expansion of the inquiry that would include more participants, I knew that it was possible that this investigation would not discover definitive answers to these difficult questions, but I believed it would be valuable to wrestle with those questions. Olson (1993) reported that “Reflecting on thematic difficulties in the text helped me to find questions that open up the way through the difficulty” (p. 175). Remembering van Manen’s (1990) description of phenomenology as a poetizing activity, I recalled that the goal of this study was not necessarily to find answers, but to illuminate what it means to be human. The beginning conversations had already begun to shed some light. I hoped that as more participants considered the phenomenon with me and helped shape the interpretation, I would come to understand the experience of having a life-threatening illness more deeply. I hoped that my increased understanding would contribute to better care of patients near the end of life.

In this chapter, I have examined more deeply the phenomenon of having a life-threatening illness. In Chapter Three, I present the methodology for the inquiry and the philosophical grounding from which that methodology arises.

**CHAPTER THREE**

**PHILOSOPHICAL AND THEOLOGICAL GROUNDING FOR THE  
EXPLORATION OF THE PHENOMENON OF HAVING A  
LIFE-THREATENING ILLNESS**

Chapter One described the circumstances that led to my interest in this study and Chapter Two presented an introductory analysis into the phenomenon of having a life-threatening illness. In this chapter I present the philosophical perspectives that ground the study and describe how I approached the inquiry. The study was proposed as an interpretive work, so it was important to examine the work of philosophers who developed interpretive phenomenology and to differentiate their work from that of earlier philosophers. Furthermore, because having a life-threatening illness often leads to an examination of ultimate meaning, some theological works that offer ethical perspectives were also of relevance.

Aristotle was the first to suggest that “a method of investigation must take into consideration the nature of the objects to be investigated” (Fjelland & Gjengedal, 1994, p. 8). Leonard (1994) has extended that idea, saying:

The issue is not what methodology is “best” or even necessarily what method is right for the question being asked because method acts as a theoretical screen and often determines the types of questions that are asked. Rather, the issue is, first, what it means to be a person; then, in light of our answer, how we ask our research question; and finally how we answer the questions we pose. Too often, researchers facilely seize on a method without considering the more profoundly important philosophical assumptions that undergird the method and whether those assumptions are consistent with the researcher’s own view of what it means to be a human being. (p. 44)

Thus, in order to build this inquiry on a firm foundation, I first had to examine the philosophical traditions that developed the phenomenological view of humanity.

### The Traditions of Nursing Science

As nursing has worked in the latter half of this century to define itself as a profession and an academic discipline, it has grappled with questions regarding the relationship between theory and practice. This concern did not originate with 20th century nursing, however. Dreyfus (1994) placed the question in the context of the ancient Greeks in whom Western philosophy has its roots. He related that as medicine, physics, astronomy, and geometry were dawning around 400 B.C.E., Socrates asked what it was that differentiated these new disciplines. Socrates concluded that they were revolutionary because they were based on theories. Thus, the mark of a true expert was his ability to articulate the theory undergirding his knowledge, and Socrates sought to discover those principles that would describe the world thoroughly and accurately. Aristotle, however, believed that emphasis on theory alone failed to account for other important sources of personal knowledge such as experience and intuition. In considering experts, Aristotle saw

that “Rather than being able to give reasons for their actions as the test of expertise, the immediate, unreasoned, intuitive response [was] characteristic of an expert craftsman” (Dreyfus, p. viii). This difference is illustrated in Plato’s account of Socrates’ encounter with the prophet Euthyphro. Socrates asked the prophet for a definition of piety and Euthyphro offered specific events and examples of his own intuition. Socrates rejected Euthyphro’s answer, however, because it did not provide a universal definition that was context free. Dreyfus (as cited in Dunlop, 1994) sided with Euthyphro believing that paradigm cases (examples) are more illuminating in the human sciences than universalizing theory, and concluded:

After 2000 years it seems clear we must give credit to Socrates and Plato for the vision of theory which has flourished in the natural sciences, but in the human sciences it might turn out that Euthyphro, who kept trying to give Socrates paradigm cases rather than abstract rules, was a true prophet after all. (p. 38)

Nursing science has found uses for both the natural sciences and the human sciences in its research. This study, with its focus on the meaning that humans make of their experiences, is grounded in the human science traditions.

Though this study clearly did not arise out of the natural science tradition, it is not really accurate to say that this study searched for paradigm cases. Bruner (1986) considered paradigm cases still to be within the realm of disembodied, abstract thinking. He claimed that the aim of paradigm cases was to discover a well-formed argument. Paradigms must be useful for prediction and seek to find words that are clear, definite, and literal. Narrative, or storied approaches seek a different end. They strive to call attention

to the “epiphanies of the ordinary” and to guide a search for the meaning that humans find in life. A narrative does not seek to proclaim a universal truth by which all can live. Instead, it seeks to illuminate a human experience in order to expand our understanding of ourselves. In the last chapter, I told the story of the movie, *Lorenzo’s Oil* (Mitchell & Miller, 1993), in which the parents of a child sought a treatment for their child’s fatal disease. Their perseverance caused great suffering for the child and for themselves, but it led to a thrilling outcome that benefited not only their child, but many other children. The movie touched me deeply, not because it illustrated principles by which parents of children with horrible diseases must live, but because it told a gripping dramatic story that enlarged my understanding of the possibilities of life. This study, in its search for the lived experience of a few individuals belongs in the realm of narrative inquiry. The aim of the study was not to find a paradigm that was applicable to all patients with life-threatening illnesses. Rather, this study aimed to illuminate and explicate the experiences of a few in order to explore more deeply one aspect of what it means to be human.

### Lived Experience and the Life World

In modern times, philosophers have worked to articulate epistemological concerns. Realists asserted that reality is something objective and “out there.” Idealists countered that we can not know objectively about reality, because all of our knowledge is derived through a human perceptual screen. We can know reality only as we perceive it and, therefore, are never really free of subjectivity. Both of these traditions gave foundation to

the natural science tradition with its emphasis on reduction, measurement, and observation.

Heidegger (1993) proposed a perspective that was radically different. Heidegger believed that philosophers from the ancient Greeks to the present were omitting the most important point of all which is that *the world exists*. He believed that this primordial fact of existence was of paramount importance for humans, and he asserted that existence precedes theoretical thinking. For example, a child learns to speak long before learning the rules of grammar and syntax. One can learn to walk without ever learning physics. This “pretheoretical” experience of the world is what phenomenologists call the *life world* or *lived experience*. This life world—this experience of the world as it is lived, not as it is thought about—this lived experience—is of great interest to phenomenologists (van Manen, 1990). The human experience of vision illustrates what is meant by the life world. We may know that we see because light waves stimulate our retinas thereby sending nerve impulses to our brains, so that seeing really happens in the brain, but that is not how we experience seeing. We experience seeing as perceiving objects “out there.” Perception of objects out there is one feature of the lived world (Fjelland & Gjengedal, 1994).

The life world is not merely an individualized perceptual experience, however. As Leonard (1994) described it, “The life world is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture” (p. 46). Heidegger believed that one could never separate a human from the historical context in which that human was living. Instead, he believed that humans are always born into a

historical and cultural context that shapes the way they look at the world. He called this condition *thrownness* because we are born or thrown into a particular culture at a particular time. This context provides a background from which humans perceive their world. It shapes their behavior and prescribes the limits of their behavior. As Logstrup (1956/1971) said, "We are born into a life that is already ordered in a very definite way, and this order lays claim upon us..." (p. 113). People learn to move and act and be in a culture long before they can articulate the culture's influence on them, and in many ways, the knowledge and ways of being in that culture remain tacit and unarticulated. Lemay and Pitts (1994) illustrated cultural influence in the following way. They point out that in Western culture, as a young person is contemplating a career choice, the person may consider thousands of alternatives. That person will most likely never consider becoming a witch doctor, though, because he or she has been thrown into a culture in which witch doctors have no role. Probably no one ever said, "Don't become a witch doctor," but through tacit and unarticulated means, he or she has internalized that part of the culture--the life world.

Heidegger (1993) proposed that a limitation to the perspective of the natural sciences and their emphasis on abstract theory is that it ignores the world, "the taken-for-granted, lived experience of our everydayness, and, concomitantly, it misses the meaning that is made intelligible through the linguistic and cultural skills and practices given by the world" (Leonard, 1994, p. 49). Fjelland and Gjengedal (1994) clarified that a difference between the life world and "the world of physics" is that the former refers to a world that

exists only because humans exist, but the world of physics studies aspects of the world that exist independent of human life and culture.

### Language, Understanding, and Interpretation

For Heidegger, attention to the world as humans experience it is critical to understanding what it is to be human. Further, the historical and cultural context in which a human lives is integrally a part of the life world. Much of what makes people human goes unnoticed in the everyday lived world. It may take careful attention to draw this unarticulated knowledge forth. For phenomenologists, it is important to study the life world, that is, the world as it is perceived by human beings--the world that would cease to exist if humans ceased to exist. It is also imperative to study the meaning that humans make of their world, for humans are self-interpreting beings--that is, they continually strive to make meaning out of their lives.

#### The Importance of Interpretation or Meaning

Plager (1994) offered a helpful example illustrating the importance of meaning for the human sciences. She described a scientist on a hill looking across a plain and studying clouds. For the study of clouds, the natural sciences such as physics and chemistry are well-developed tools for description and analysis. However, if the observer's gaze turns to particular cloud formations that are actually smoke signals, the smoke signals will still follow the laws of physics and chemistry, but understanding is required to capture their full meaning. In the same way, if I hear of a person who throws himself in front of a

moving train, I may conclude that the person committed suicide, probably out of a sense of despair. However, if I discover that a child had wandered onto the train tracks and the person pushed the child to safety by lunging in front of the train, I will have a completely different understanding of the event. We cannot fully understand another until we begin to explore the meanings that person is making of his or her life.

Some anecdotal examples may help to illustrate how self-interpretation and meaning can influence human behavior. Several years ago I was employed by a health service that specialized in helping clients lose weight. One client in her mid-30's had been severely obese since childhood, but was making excellent progress. Midway to her desired weight goal, however, she began to lose her motivation. She explained that for the first time in her life, men were noticing her and asking her for dates. This was a completely new experience for her. She was now contemplating dates with 30-year-old men when she herself had the social dating skills of a teenager. This made her very anxious, and she found herself longing to retreat to the "safety" of fat. An understanding of these issues was critical for helping her to re-evaluate her goals. A second example concerns the father of a colleague of mine who had a rare form of bladder cancer. My colleague related that her father always opted for treatment no matter how unpleasant the side effects nor how slim the chances that the treatment would help him. His family had trouble understanding his choices until he explained that he believed that because his cancer was so rare, he had an obligation to offer himself for clinical trials in order to increase the knowledge base about his cancer. Believing that his children were at increased risk for developing his form

of cancer, he also believed that his participation in clinical trials might be of benefit his children. His interpretation of the significance of his actions had a profound effect on his life choices.

### The Interplay of Language and Culture

According to Heidegger, language has a pivotal role in helping us come to understanding. Leonard (1994) stated “Language creates the possibility for particular ways of feeling and of relating that make sense within a culture” (p. 46). A familiar example is that English has but one word for *snow* whereas the language of the Inuit of the Arctic regions has many words for snow. There are, for example, different words to describe “snow falling, snow on the ground, snowdrift, drifting snow, and soft snow” (Boaz, 1963, p. 312). Because snow has such importance for survival among the Inuit, the language has found ways to name many different variations. For modern urban Americans, however, our life world is not as heavily influenced by snow, our language has not developed distinctions, and for the most part, we do not even notice differences in snow. It is not part of our life world. Yet if an urban American were to decide to learn the Inuit language, it is likely that as the American learned the many different words for snow, he or she would begin to notice the differences in snow. Language is shaped by culture, but language can also shape culture.

Wittgenstein claimed that “The meaning of a word is its use in the language” (Rogers & Baird, 1981, p. 206). Thus, he would limit the meaning of a word to its current common usage. Heidegger (1993), however, believed that words originally were suffused

with meaning, but through common usage, they have become trivialized, and we who use them do not notice the rich layers that are hidden in the words. If we pay attention to the words, though, and search for the original richness they once had, we will develop a fuller understanding of our world as we live it now. Our understanding will be fuller, but not complete, for language is always inadequate for the full expression of our lives. As Merleau-Ponty wrote, “The sorrow of language is that words cannot express all we want to say” (cited in Olson, 1993, p. 153). Still, I believe with Heidegger that etymology can deepen our understanding of our world.

#### Art and Literature as Additional Sources of Understanding

Art and literature can also help access the unarticulated meanings that fill our lives. Heidegger (1993) offered the example of Van Gogh’s painting of a pair of peasant shoes. Van Gogh’s careful treatment of his subject calls the viewer to look at the shoes in a new way. Instead of passing over the shoes and seeing them without noticing them, the viewer is called to ponder how important those shoes are to the everyday life of a peasant. In the play by Thornton Wilder, *Our Town* (1938/1985), a young woman who has died in childbirth returns to her life on an ordinary day and is distressed to see how casually the people in her family treat each other, now that she knows that life can end abruptly. Her observations call the audience to reflect on the significance of the other people in their lives. In Anne Tyler’s novel, *Searching for Caleb* (1983), the husband, Duncan, believes that the family of his wife, Justine, is overly involved in their lives, and that they continually try to interfere.

When [Duncan, reading a letter from her family] pointed out for her the

meaning beneath their words, the sharp edge beneath their sweet, trite phrases, Justine pointed out the meaning beneath *that* meaning, and he would have to admit some truth in what she said. She had the pathetic alertness of a child who has had to depend too much on adults; she picked up every inflection, every gesture and untied ribbon and wandering eye, and turned it over and over to study its significance. (pp. 153 -154)

Whatever Justine's other weaknesses, one suspects she might have become an accomplished phenomenologist. These meanings beneath *those* meanings can reveal much about the lived world.

There are times when fiction can be more "true" than biography. An unknown source has remarked on the difference between fiction and biography saying that a person who reads his or her own biography will smile and breathe a sigh of relief saying, "My secret is still safe," but if Natasha were to read about herself in Tolstoy's great novel, *War and Peace* (1865/1942), she would tear her hair and cry, "How did he know? How did he know?" In that sense, fiction can sometimes tap into deep springs that reveal the human heart.

### Embodiment, Life, and Death

An inquiry into the experience of dying or having a life-threatening illness naturally leads to a consideration of philosophical views of the body, mind, and soul. What is life and what is death and what can we know about them? A brief orienting discussion will be offered here.

Dreyfus (1994) credited the ancient Greeks with the initial development of the philosophy of the Western way of being human. A simplified explanation of the Greek

philosophy is that the soul was immaterial and immortal; body, mind, and spirit were different parts of this immortal soul. Spirit and mind were of primary importance. The body was seen not only as unimportant, but, because of its “appetites,” it was seen as a source of evil (Rogers & Baird, 1981; Niebuhr, 1941/1964). The goal of life was to perfect the soul, or the immortal part of the human. Descartes, a founder of modern science and philosophy, furthered the idea that mind and body were separate entities. Again, thought and reason were of primary importance: *Cogito, ergo sum* (I think; therefore, I am). For Descartes, humans were “thinking things.”

### Embodiment

Merleau-Ponty (1964) believed that it was neither necessary nor desirable to try to split the mind from the body. He held that our bodies are integrally related to our experience of and expression in the world. “For us, the body is much more than an instrument or a means; it is our expression in the world, the visible form of our intentions” (p. xvi). After all, he related, “The perceiving mind is an incarnated mind” (p. 3), and “It is through our bodies that we derive our point of view on the world” (p. 5). As Leonard (1994) explained, it is not that we *have* bodies that are separate from our essential selves; we *are* embodied beings.

Fjelland and Gjengedal (1994) offered an example of how our embodiment affects us. They reported that the moon appears much smaller when it is high in the sky than it does when it is near the horizon, even though the image on the human retina is the same size in both cases. They presented Koffka’s explanation of why this is so. Koffka, a

psychologist, theorized that horizontal distances are perceived by humans to be shorter than vertical distances because humans can move across horizontal ground but cannot move vertically. Therefore, because horizontal distances are more accessible to our bodies, our brains perceive them as closer. The fact that we are embodied affects our perceptions.

In the last 10 years, the field of psychoneuroimmunology has sought to develop a better understanding of how our minds, bodies, and emotions are interrelated. New research is describing ways in which thoughts and emotions are inextricably related to the body. These studies suggest that clear boundaries between mind and body do not seem to exist (Cerrato, 1998; N. Moore, 1996; Schotanus, 1997; Van Nguyen, 1991).

### Embodiment and Death

Phenomenologists maintain that the life world is a world perceived by an embodied person. Humans experience the world through the senses of their bodies.

Phenomenologists reject the idea that mind and body are distinct entities, a view that is being supported by psychoneuroimmunology. Perhaps this is one reason why death can be so distressing, for what exactly is death if not a mind/body/soul split? After the moment of death, the body is still there--we can see it. If we choose, we can continue to monitor the body after death and can trace the manner in which it decomposes, but a dead body is very much separated from *something*. Kubler-Ross (1997) expressed this idea as she described the death of her father: "Whatever it was that had made my father him--energy, spirit and mind--was gone. His soul had taken flight from his physical body" (p. 124). That *something* is paramount. That critical substance is so absent that, although the body

clearly is still present, the *person* is definitely gone.

The questions of what exactly is gone and where it went are most often considered religious questions. A common, though by no means universal view is that humans have souls and the soul is immortal, ideas that will be explored later in this chapter. At this time, my concern is with the part of dying that occurs before the moment of physical death. There are, in the hospice literature, reports of dying people communicating with people who are not there in a physical sense. Callahan and Kelly (1992) reported that it is common for dying patients to see beings from “the other side.” These beings are people who have predeceased the dying patient, and the patients are rarely upset or concerned by these visitations. It is not my intention actively to explore, to support, or to deny such reports. I bring the topic up here because it complicates the phenomenological view of embodiment by suggesting that there is something in us that *can* separate from the body, at least after death. For the purposes of this dissertation, I assume that we are embodied creatures up until the moment of death. I address philosophical and theological ideas about what happens after death later in this chapter, and in Chapter Four, I address ideas that emerged from the participants. As I contemplate these mysteries, I stand with Voltaire, who, considering some of these questions wrote, “Doubt is not a very agreeable state, but certainty is a ridiculous one” (as cited in Durant, 1962, p. 177).

### Philosophical and Religious Perspectives on Death

A person who has a life-threatening illness is a person who may die. In order to

come to a fuller understanding of what that experience is like, it will be helpful to look at some philosophical and theological perspectives that have shaped our thinking about death.<sup>7</sup>

### Death and Contemporary Society

Kung (1991) has noted that modern society is at once brimming with death and death-denying. Twenty-five years ago, the combination of television and the war in Viet Nam had the unprecedented effect of bringing graphic visual accounts of killing and warfare into our living rooms. Today, news reports confirm that violent death is very much a part of modern life. Tales of crime and murder are so commonplace that they hardly seem like “news.” Recently, reports of children who kill have become chillingly familiar, and violence is commonplace in television shows and movies. At the same time, however, death is more removed from everyday life than it ever has been. In contemporary America, care of the dying is most often delegated to professional caregivers, and most people still die in institutions away from the immediate daily life of the family. Once the person has died, it is the funeral industry that prepares the corpse for burial or cremation. Living people are “protected” from all but the most sanitized exposure to the dead body. It may be that the current debate about physician-assisted suicide is partly motivated by a desire to approach a closer relatedness with death. These dual trends—increased exposure to death in the media and decreased exposure to death in personal life—may complicate

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<sup>7</sup> The reader will note that most of the philosophers and theologians consulted here wrote in a time when it was common to use masculine forms to refer to humans.

our ability to develop an integrated concept of death.

### What is Death?

Science and technology have provided astonishing changes in the world since primitive times. People have learned to divert rivers and move mountains. They have built skyscrapers and have moved from “the cave to the penthouse” (Wahl, 1959, p. 16).

Failing organs can be repaired or replaced. Advances in health care have all but eradicated many of the conditions that felled even our grandparents. In spite of all these advances, however, notes Wahl, we still die. Death remains unimpressed by our “astonishing” feats.

Wahl (1959) asserted that our inability to control or prevent death creates a fear that drives us to inconsistencies in our thinking. He claimed that we revert to “magic and irrationality” (p. 17) to relieve the anxiety. He continued:

... The vast majority of us identify ourselves with religious and philosophical systems of belief which asseverate that death is not death at all, but is rather a fictive experience, a brief transition between one more important existence and another....It is clear, however, that in this respect modern man has not advanced very far beyond his primitive ancestors. He shares with his skin-clad forebears the belief that death...does not truly exist. Furthermore, he maintains this in the face of the absence of any slightest shred of evidence of a type which he prefers to collect for the solution of his other problems. Here he remains obdurately immune to reality testing. (p. 18)

Wahl, committed to science and the scientific method, saw not one shred of evidence that life does not end at death. The question remains, however, what kind of evidence did he seek? Feifel (1959), confronting the same lack of evidence suggested, “It is conceivable that our science-conscious culture, which tends to measure all experiences within the bound of space and time, does not furnish us with all the necessary parameters for

investigating and understanding death” (p. xvii). Jackson (1959) would tend to agree saying, “The persistent effort in our science-conscious culture to measure all experience within the bounds of space and time prejudices us against that type of experience that is not so limited” (p. 221). Countless accounts of the way living people continue to wrestle with people who are deceased, either in memory or more rarely by “visitations,” point to the inadequacy of the idea that life ends completely at death. Whether death is simply an end or a doorway to another life (or both) will not be answered in these pages, but the viewpoint of those who see death as a doorway will be examined in more depth in a later section of this chapter. Before I turn to that discussion, however, I want to pick up another thread of Wahl’s argument and consider the concepts of *fear of death* and *anxiety*.

#### Anxiety and Being-Toward-Death

Wahl (1959) claimed that our fear of death caused anxiety. Fear of death and anxiety were themes of Heidegger’s (1993) writing as well. For Heidegger, the fact that the world exists was primordial. He called the fact of existence *Being* and he called those of us who pass through existence *beings*. Heidegger claimed that once we understood Being, we could begin to contemplate the possibility of its opposite--*Nothing*. For beings, even the idea that there could be Nothing reminds us that one day we will be nothing--we will die. When we awaken to that truth, said Heidegger, we experience anxiety. He continued:

The receding of beings as a whole that closes in on us in anxiety oppresses us. We can get no hold on things. In the slipping away of beings only this “no hold on things” comes over us and remains. Anxiety reveals the nothing. (p. 101)

Anxiety, asserted Heidegger, helps us to understand the Nothing. Anxiety, unlike fear, has no object; a person who fears knows what it is that he or she fears. Anxiety, however, is uneasiness that has no object--an anxious person is not able to articulate what it is that causes the anxiety (Freud, cited in Kaufmann, 1959). Thus, this nameless uneasiness reveals something of what Nothing is. Further, Heidegger noted, "Anxiety robs us of speech...That in the malaise of anxiety we often try to shatter the vacant stillness with compulsive talk only proves the presence of the nothing" (p. 101). Our restlessness and inability to find the words to describe what we are feeling are glimpses of the Nothing, and our poor efforts to conceal the Nothing through "mindless chatter" are ineffective. Even our words are nothing.

Heidegger (1993) believed that when a person, *being*, experienced the anxiety of the Nothing, that person could choose to withdraw from that anxiety or live into it--to become authentic. To become authentic was to acknowledge that one would one day become part of the Nothing through death, but authentic living also acknowledges that one still has a life right now. If one does one's best to live that life fully and responsibly and as truly to one's nature as possible, then one is living an authentic life. One who is living this authentic life is a *being-toward-death*.<sup>8</sup>

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<sup>8</sup>Heidegger clearly saw death as an end to existence. It is interesting, however, to note that his term *being-toward-death* has subtle similarity to beliefs that are common worldwide that being--life--is a preparation for life after death. To me, the term being-toward-death also suggests that life is but a preparation for death. I am certain that is not what Heidegger meant but it amuses me--a being who thinks some form of existence of life after death is likely--to wonder if a shred of the collective unconscious sneaked into Heidegger's thought.

For Heidegger (1993), death remained as being's most unique possibility. Beings were thrown into a culture that bound them in many predetermined ways. Even beings who lived authentic lives were limited by social conventions and expectations. A person could never truly escape from the culture into which he or she was thrown. Death, however, was uniquely one's own—one's most authentic possibility.

### Is Death a Doorway?

Wahl (1959) and Heidegger (1993) are representative of the philosophy that death can be completely summed up as an end to existence. Jung represents a different viewpoint: that death is a doorway to another kind of existence. *Doorway* is a word that descends from Old Teutonic and Old High German words that mean opening or gate (*OED*). Its meaning has changed little over time. It still means "an opening or passage into a building or room...a means of entrance or exit" (*OED*). If death as a doorway is an entrance or an exit, it suggests that death is a opening between life and something after death. It implies that death is a temporary passageway, not an end. Death as a doorway recalls the idea of death as a boundary, that is, a division between two distinct areas. If death is a doorway, it could be a means to bound across the boundary into something different from life, but not into Nothing.

Jung (1959) claimed that life was an energy process that, like all energy processes was directed toward a goal—a state of rest. For the energy process of life, the goal was death. He continued, "The curve of life is like the parabola of a projectile which, disturbed from its initial state of rest, rises and then returns to a state of repose" (p. 5). He asserted,

however, that we live as if this is not true--as if our lives will somehow go on forever.

Heidegger (1979/1985) expressed a similar idea, saying, "*Daesin* [humans] says, 'Everyone dies' because this means 'No one dies,' namely, not I myself" (p. 315).

Heidegger believed that human's incessant "cheering up" of the dying by asserting that they will soon feel better is another sign that humans really believe that no one dies.

Jung (1959) did not take a position on whether or not a form of existence continues beyond the grave. Instead he made two observations. First, he noted that the majority of the world's religions consider life to be a kind of preparation for existence after death. Secondly, he pointed to the persistent idea that the human psyche<sup>9</sup> somehow transcends time and space and participates in what is "inadequately described as eternity" (p. 14). Jung continued:

I am thinking of those spatial and temporal telepathic phenomena which as we know are much easier to ignore than to explain. In this regard science, with a few praiseworthy exceptions, has so far taken the easier path of ignoring them. (p. 15)

Jung asserted that one who believes that the psyche can transcend time and space "would have the inestimable advantage of agreeing with a trend of the human psyche which has existed from time immemorial and is universal in incidence" (p. 15). In the next two sections, I support Jung's assertion that many major religions see life as preparation for death. Following that, I return to the notion that the psyche might transcend time and

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<sup>9</sup> For Jung, the term *psyche* meant not only what is commonly called the soul, but also "the totality of all psychic processes, conscious as well as unconscious" (Jacobi, 1943, p. 5).

space.

### An Overview of World Religions

Jung (1959) asserted that most of the world's religions teach that life is a preparation for death. In a book entitled, *A Guide to the World's Religions*, Bradley (1963) agreed. Bradley noted that Zoroastrianism is an ancient religion that influenced both Judaism and Christianity. It conceived of dual forces of Good and Evil, predicted a coming of the kingdom of God, a future savior, and bodily resurrection. It taught that conduct in this life would be punished or rewarded in the next life (after death). Bradley noted the influence of Zoroastrianism on contemporary Judaism, particularly on the Jewish perspective of looking toward a Messianic Age, when God will bring an end to history and send God's Messiah to overthrow evil and reward the righteous. These beliefs are also central to Christianity and are explored in more depth in a later section of this paper. Islam, which also traces its roots to Judaism and Christianity, teaches as well that obedience to God's teachings in this life will be rewarded in the next life.

In Hinduism, a major religion of the Indian sub-continent, it is believed that life forms are re-incarnated after death. Allegiance to the truth about existence will lead to reincarnation into a higher life form; poor conduct will lead to re-incarnation into a lower life form. The ultimate goal is to end the cycle of rebirths. This will happen when the individual loses its "mistaken identity" (p. 93), that is, when the individual loses its idea that it has a real existence in this world at all. Humans' positive destiny is to achieve *nirvana*--a state where the human enters seamlessly into the "ocean of being" (p. 93).

Buddhism is a religion too vast and varied to have a unified teaching on what happens after death, but Buddhism teaches that to live is to suffer. Suffering is caused by craving, that is, by attachments to this world. The goal of the Buddhist is to achieve a state of detachment from all things. Bradley (1963) stated:

When Buddha was asked what happens after death to the monk who attains liberation, he answered that he had not attempted to answer this question ... He taught, "After death, the liberated being either exists or does not exist; if it exists, it is either conscious or unconscious." In the history of Buddhist thought, Buddhist philosophers have taken almost every conceivable position on that question. (pp. 114-115)

The Buddhist outlook stands in stark contrast to the Western outlook that "It is better to have loved and lost than never to have loved at all."

Taoism, one of several major religions in China and Japan sees death as "but a change into a new aspect, as fall merges into winter, as a leaf drops from a tree to become leaf mold" (Bradley, 1963, p. 138). Confucianism bears a similarity to Buddhism in that it is said that when Confucius was asked what happened after death, he answered, "Why do you ask me about death when you do not know how to live?" (p. 147). Bradley claimed that Confucianism does not formally oppose the traditional Chinese view that reveres ancestors and assumes some sort of survival of the spirit after death. Shintoism teaches that it is important to be remembered honorably by descendants. Bradley noted that the kamikaze pilots of World War II were Shintos who were showing ultimate loyalty to family and to the emperor by dying in service to them.

To say that the religions of China and Japan assume a life after death may be a distortion caused by a Western perspective. Perhaps it is only the *memory* of the deceased

that continues. Nevertheless, it appears that we can agree at least in part with Jung, for the religions originating in the Middle East and the Indian subcontinent clearly do assume that a form of life continues after death. Whether the assumption of life after death is a relic of primitive magic and superstition, or whether it persists because it is a revelation of truth will not be decided here. The critical point is that belief in a life after death is deeply ingrained in what Jung would call our psyches.

#### Christian Views of Life, Death and the Afterlife

Christianity teaches that all life was created by an eternal, omnipotent, omniscient God. Humans were created from dust and return to dust, yet they were created in the image of God and were given a spirit that shares with God the capacity for eternal life. Obedience to God in this life is of great importance and one's destiny in the life to come is determined in part by one's conduct in this life. For Christians, however, an even more important issue is one's commitment to Jesus Christ. Christ is seen as an incarnation of the living God who came to earth to save all people; Christ is believed to be wholly human and wholly divine. Christians believe that all people are sinners, and try as they might, they will fall into sin again and again. The person who casts herself upon Jesus, tries her best to love and follow him completely, and humbly begs his forgiveness when she inevitably fails, will be "saved" somehow by his death on the cross and will join him in heaven after death. Heaven and salvation are seen as a gift of grace that can only be received, not earned, yet one is commanded to demonstrate love and obedience to Christ by sacrificial love and service to others. Christians conceive that one who casts herself upon Jesus enters into

eternal life immediately and thus becomes a kind of dual citizen of two “worlds” simultaneously--the “here and now world” of time and space, and the “world of eternal life.” Berdyaev (1944) explained:

Human consciousness is subject to a variety of illusions in understanding the relation between this world in which man feels himself to be in a state of servitude and the other world in which he awaits his liberation. Man is the point of intersection of two worlds This world is the world of objectivization, of determinism, of alienation, of hostility, of law. While the other world is the world of spirituality, of freedom, love, kinship. (p. 254)

There is a certain folly in trying to explore infinite concepts with finite words and minds. Still, because of Christianity’s profound influence on Western culture, several concepts are relevant to the present study and will be examined. The concepts are broader than we can grasp and are intertwined perplexedly with each other, but perhaps a glimmer of clarity can be achieved.

### The Biblical View of Death

Niebuhr (1941/1964) declared that the Bible is inconsistent in its conceptualization of death. On one hand, the doctrine of creation declares that God initially proclaimed that all of creation was good. Thus Niebuhr explained, “The created world is a good world, for God created it” (p. 109). At the same time, in the influential writings of St. Paul, there is much to suggest that death is evil. Niebuhr believed that St. Paul and other New Testament writers were influenced by the Hellenistic view that dichotomized body and soul--body and its appetites were evil; the soul was pure. Thus, death, which is associated with the body, is evil. St. Paul’s assertion that “The wages of sin is death, but the free gift of God is eternal life in Christ Jesus our Lord” (*Romans 6:23*) illustrates both the

conception of death as evil and the conception of eternal life as good.<sup>10</sup>

### The Christian View of Humans

As suggested earlier in this chapter, Christians believe that humans are at once citizens of this world and the next. Berdyaev (1944) explained, “Man is not only spirit, he is of a complex make-up, he is also an animal, he is also a phenomenon of the material world, but man is spirit as well” (p. 247). In the words of Kierkegaard, (1949/1989), “A human being is a synthesis of the infinite and the finite, of the temporal and the eternal, of freedom and necessity (p. 43). Niebuhr (1941/1964), too, expressed the thought that humans are finite, yet self-transcending. He wrote that the concept of humans as “made in the image of God” is in tension with the concept of humans as creature. As illustration of this tension, Kung (1991) pointed to the poem by Erich Fried that follows:

A dog  
that dies  
and that knows  
that it dies  
like a dog  
and that can say  
that it knows  
that it dies  
like a dog  
is a man. (p. 162)

For humans, the experience of being both creature and spirit can feel like being caught between two worlds and belonging to neither. Niebuhr (1941/1964) claimed that

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<sup>10</sup> St. Paul's discussion of death is much broader than this. Niebuhr notes, for example, that it is not always clear when St. Paul is using the word *death* to mean death of the body and when he is using it to mean death of the spirit.

the tension that results is experienced as anxiety. He wrote, "Man, being both free and bound, both limited and limitless, is anxious. Anxiety is the inevitable concomitant of the paradox of freedom and finiteness in which man is involved" (p. 182). It is interesting to note that both philosophers and theologians seem to view anxiety as an important catalyst for human development. We have already seen that Wahl and Heidegger conceived of anxiety as a crisis that could turn humans toward magic and irrationality or toward authenticity and being-toward-death. In the immediately preceding passages, Kung and Niebuhr, theologians of great influence have also written of the importance of anxiety. In the next section, I will turn my attention to another theologian who has written extensively about the importance of anxiety.

#### Kierkegaard: Anxiety and Despair as a Way to God

Anxiety was a major theme of the "melancholy Dane" Soren Kierkegaard (F. Sontag, 1992, p. 369). Kierkegaard (1843/1985; 1849/1989) believed that humans found themselves living in a universe that contained mutually exclusive truths, and the task of the human was somehow to accept opposing views without rejecting either. Kierkegaard was concerned with prodding Christians who professed belief in a habitual way to recognize the fact that the manner in which they lived their lives did not measure up to the standards they professed. He believed that such recognition would lead to despair, but he saw despair, paradoxically, as a good and helpful state, for he believed despair to be the only avenue to truth and deliverance. He believed that the only cure for despair was to acknowledge totally one's complete dependence upon God, but in that acknowledgment

came true freedom. Thus, he asserted, “Is despair a merit or a defect? Purely dialectically it is both” (1849/1989, p. 44).

Kierkegaard’s thoughts are consistent with a long tradition in Christianity that purports that humans can find their true place in the universe only when they submit to God’s will. As Niebuhr (1941/1964) wrote:

The Biblical view is that the finiteness, dependence and insufficiency of man’s mortal life are facts which belong to God’s plan of creation and must be accepted with reverence and humility. [He then quotes *Isaiah 40:7-8*] “All flesh is grass and all the goodness thereof is as the flower of the field; The grass withereth, the flower fadeth...but the word of our God shall stand forever.” (p. 167)

Niebuhr concluded that it is not our finite natures, per se, that are evil. He continued, “Mortality, insecurity and dependence are not of themselves evil, but become the occasion of evil when man seeks in his pride to hide his mortality, to overcome his insecurity by his own power and to establish his independence” (p. 174). Thus, the source of evil is human’s denial of their dependence on God. A poetic rendering of the paradox of finding true freedom in submission is found in the words of George Matheson (1964):

Make me a captive, Lord, And then I shall be free;  
Force me to render up my sword, And I shall conqueror be.  
I sink in life’s alarms when by myself I stand;  
Imprison me within thine arms and strong shall be my hand.

My heart is weak and poor until it master find;  
It has no spring of action sure; it varies with the wind.  
It cannot freely move till Thou has wrought its chain;  
Enslave it with they matchless love and deathless it shall reign.

My power is faint and low till I have learned to serve;  
It wants the needed fire to glow; it wants the breeze to nerve;  
It cannot drive the world until itself be driven;  
Its flag can only be unfurled when thou shalt breathe from heaven.

My will is not my own till Thou hast made it thine;  
 If it would reach a monarch's throne, it must its crown resign;  
 It only stands unbent amid the clashing strife,  
 When on Thy bosom it has leant and found in Thee its life.  
 (Hymn 184)<sup>11</sup>

Threads of the paradoxical idea of finding freedom in submission rise up again in Chapter Four. There were many times when participants spoke of finding solace in knowing that they were totally dependent upon God. Additionally, Kierkegaard's (1849/1989) notion that despair is a necessary antecedent of hope or faith grounds the idea that blessings are found imbedded in suffering. That notion, too, surfaces again in Chapter Four.

#### Tillich: The Eternal Now

Throughout this section, I have discussed philosophical and theological perspectives on life and death. The concept of eternal life has risen time and again. At this time, I will turn to the work of Paul Tillich (1959) to consider what is meant by the concept of eternity.

Like Heidegger (1993), Tillich (1959) asserted that it is the destiny of all people and indeed all creation that one day everything in our world will come to an end. Like Heidegger, Tillich believed that "We come from the darkness of the 'not yet' and rush ahead towards the darkness of the 'no more...'" (p. 30). Unlike Heidegger, however, Tillich did imagine eternity. He did not envision eternity as an endless future, citing the

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<sup>11</sup> The hymnal does not number pages.

fact that the Bible does predict a future end. He reiterated that God said, "I am the Alpha and the Omega, the beginning and the end" (p. 32). Instead, Tillich wrote, "There is no time after time, but there is eternity *above* time" (p. 33). Tillich believed that humans can view time only because they are partly in time and partly outside of time (dual citizens). Were we entirely encased in time "like the animals" (p. 31) said Tillich, we would not be able to see time. "But as men," he continued, "we are aware of the eternal to which we belong and from which we are estranged by the bondage of time" (p. 31).

C. S. Lewis (1943) offered two illustrations that are helpful in understanding these matters. Lewis suggested that to understand the concept of eternity as time above time, or time outside of time, we can imagine that our human lives are lived along a "time-line" that is drawn upon a page of paper. We can follow the time-line to the right into what we call the future or we can look to the left to consider the past. In human form, however, we generally consider ourselves to be confined to the time-line. God, who is outside of time in eternity, said Lewis, is the piece of paper on which the line is drawn. God sees the past, the present, and the future all as one seamless "time." In the second illustration, Lewis (cited in Vanauken, 1977) wrote a letter to a friend explaining his reasons for believing that eternity is humans' true home. Lewis asked:

Do fish complain of the sea for being wet? Or if they did, would that fact itself not strongly suggest that they had not always been, or would not always be, purely aquatic creatures? Then, if we complain of time and take such joy in the seemingly timeless moment, what does that suggest?

It suggests that we have not always been or will not always be purely temporal creatures. It suggests that we were created for eternity. Not only are we harried by time, we seem unable, despite a thousand generations, even to get used to it. We are always amazed at it--how fast it goes, how slowly it goes, how much of it is gone .... We aren't adapted to

it, not at home in it. If that is so, it may appear as a proof, or at least a powerful suggestion, that eternity exists and is our home. (pp. 202-203)

Thus, in the view of Tillich and Lewis, eternity is *beyond* time, not *after* time, and humans, though they inhabit time, are strangers there, for they are creatures made for eternity.

Tillich (1959) believed that the surprising notion is that we have a present. This is surprising, he claimed, because time never really stops. He wrote:

In a sense, there is no “now” because it is a constant movement from the past to the future .... We accept the present and do not care that it is gone in the moment that we accept it. We live in it and it is renewed for us In every new “present.” This is possible because every moment of time reaches into the eternal. It is the eternal “now” which provides for us a temporal “now.” (p. 37)

Because the eternal now provides a temporal now, claimed Tillich, we not only *have* a present, we *have* a future because we anticipate it in the present, and we *have* a past because we remember it in the present.

#### The Meaning of the Past Being Present in Us

Tillich (1959) claimed that the past influences our present as both a blessing and a curse. He asserted, “In each human life, a struggle is going on with the past. Blessings fight with curses. Often we do not recognize what are blessings and what are curses” (p. 35). Further, he asserted that the past is always a blessing and a curse, not only for individuals, but for nations as well. Tillich then claimed that one way the past can become a blessing is when the meaning of the past changes. He noted that the past itself cannot be changed; what has happened has happened and will remain so for all eternity. He continued, though:

But the *meaning* of the facts can be changed by the eternal, and the name

of this change is the experience of “forgiveness.” If the meaning of the past is changed by forgiveness, its influence on the future is also changed. The character of curse is taken away from it. It has become a blessing by the transforming power of forgiveness. (p. 36)

Tillich’s thoughts offer a grounding of the experiences of Alice and Addie, first introduced in Chapter Two. Both spoke of finding blessings in their sufferings. In the next chapter, we will see that other participants experience blessing in suffering as well. For some of the participants, the blessings of their illness are abundant, obscuring the dichotomous distinction between blessing and curse.

#### Summary of Philosophical and Religious Perspectives on Death

Western culture in the late twentieth century has not yet developed an integrated perspective on death and the meaning of dying. Though violence and death are ubiquitous in society, people are generally “protected” from intimate contact with dying people and dead bodies. Though we say that we know that we will all die, we live as if we will live forever.

Life-threatening illness shakes the foundations of one’s life. Suddenly, a person must consider questions he or she may have always ignored: What happens to me when I die? Is there anything after death? Heidegger (1993) believed that death awareness drove one into anxiety. Death awareness forced beings to consider the possibility of the Nothing. A being who boldly acknowledged that one day he or she would be nothing could then proceed to live authentically as a being-toward-death. Kierkegaard, too, saw anxiety as a central problem for humanity. He believed, however, that anxiety was paradoxically a blessing that would force a human to recognize the truth of existence—that humans are

totally dependent on God.

In contrast to philosophers who see death as the end of existence stand Jung, Tillich, and Lewis. Jung asserted that the belief that life continues somehow after death is a view that is supported by cultures worldwide and by multicultural similarities in the human psyche. Tillich and Lewis provided conceptualizations of time that synthesize “the world of the here and now” with eternity. Tillich’s perspective illuminated facets of human’s experience as dual citizens of the present world and eternity. He purported that the past is always present within humans, yet the meaning of the past can be reinterpreted. Thus experience first interpreted as “cursed” can, through reinterpretation, spiritual growth, and forgiveness, become “blessed” instead.

Consideration of the work of these philosophers and theologians has provided a grounding for exploring the lifeworlds of the participants in this study. In the next section, I turn my attention to the context in which the study took place.

### The Meeting as Context for the Study

Up until this point in the dissertation, I have used the word *conversation* to describe the manner in which I began to explore the phenomenon of having a life-threatening illness. I visited patients in their homes, and had conversations with them about what it is like to have a life-threatening illness. There are times, however, when an encounter between two people is more than a conversation, and some of my encounters had this deeper quality. Buber (1958) referred to this deeper quality as a meeting of *I* and

*Thou.*

What is it that happens when I go to the house of a patient, pull a chair up to the bed, and wait in an alert attentive pose? What is it about that encounter that can seem so rich and full? As I contemplated and reflected upon my conversation with Addie, it came to me that I felt as though I had just spent two hours in prayer. What is it that can make these meetings feel sacred? Judeo-Christian tradition is steeped in the idea that when one meets another, one may be meeting God. Thus, it is important always to treat others with dignity and respect. In this section, I explore some of the sources of that thought.

According to Martin Buber (1958), it is in meeting others in a thoughtful attentive way that we can experience the holy. Levinas (1987/1993) explained, “The contact of the divine with the exalted instants is, for Buber, meeting, dialogue, opening to others but at the same time presence to self” (p. 10). Buber believed that authentic encounters between humans--meetings--were essential for discovering our true natures. He claimed that “The human *I* is the reuniting of the profane and the sacred,” (as cited in Levinas, p. 7) and said that “Man must act within the world as if God were present everywhere, even in the immediate and the sensible” (as cited in Levinas, p. 7). In his most famous work, *I and Thou*, Buber considered the ethical call to care for others in our encounters with them. Buber suggested that rather than considering others as objects--*Its*--what Heidegger (1993) would call *standing reserve* or resources that exist just to be used--we are to meet each other with an openness to the sacred in the other. Buber called the special relationship that follows, the *I-Thou*, and he linked the two words as one, calling I-Thou a

*primary word*. Buber said, “I do not experience the man to whom I say ‘Thou.’ But I take my stand in relation to him, in the sanctity of the primary word” (p. 9). He believed authentic meeting to be so important that he stated “All real living is meeting” (p. 11). His commitment to this idea is demonstrated in his autobiography, *Meetings* (1973) in which, rather than write about his life in narrative form, he described critical meetings with those who were important in his development. Considering the implications of Buber’s writing, Levinas remembered the teachings of Hasidism, saying, “...[O]ne must bring out the sparks from on high that are languid here below, and restore them to the original Ardor from which they have descended” (p. 7).

#### Meeting Others as Encounters with the Divine

Levinas (1987/1993) described meeting as “the welcome we prepare for one another”(p.1). Logstrup (1956/1971), too, believed that meetings between persons have great ethical significance. Citing Friedrich Gogarten, he claimed, “The individual’s relation to God is determined wholly at the point of his relation to the neighbor” (p. 4) and asserted that the character of one’s relationship to one’s neighbor determines one’s relationship with God. These ideas are firmly grounded in Judeo-Christian tradition. The author of the book of *Micah* wrote, “[W]hat does the Lord require of you but to do justice, and to love kindness, and to walk humbly with your God?” (*Micah* 6:8)—a passage that clearly links compassion and fairness to others with relationship to God.

In the late 20th century, religion no longer holds the prominence that it did even 50 years ago. Society has become much more secular, but the Judeo-Christian tradition has

had a marked influence on Western society. It is part of the context into which we have been thrown. Theological and ethical perspectives have relevance for secular scholars as well as religious scholars because these perspectives are embedded in our culture and exert influence over our view of the world. Even if one considers religion to be based on myth, it has shaped our ways of being in this culture. I suggest that the ethical imperative to treat others with dignity and respect has its roots in the religious idea that when we meet the other, we may meet God. As the writer of *Hebrews* said, "Let brotherly love continue. Do not neglect to show hospitality to strangers, for thereby some have entertained angels unawares" (*Hebrews* 13: 1-2). These traditions cast interactions with others--meetings--in a sacred light.

#### Meetings as Contexts for Trust

Logstrup (1956/1971) believed that another characteristic of human nature is that we long to trust one another. He claimed:

In its fundamental sense trust is essential to every conversation. In conversation as such, we deliver ourselves over into the hand of another .... That all speech takes place in such fundamental trust is evident in the fact that the most casual comment takes on a false note if one believes that it is not accepted in the sense that it is intended. (p. 15)

He added,

Regardless of how varied the communication between persons may be, it always involves the risk of one person approaching the other in the hope of a response. This is the essence of communication and the fundamental basis of ethical life. Trust is not of our own making, it is given. Life is so constituted that it cannot be lived except as one person surrenders something of himself to the other person either by trusting him or by asking him for his trust. (pp. 18-19)

Thus, the manner in which we approach one another has the potential to change the world in ways large or small. As Logstrup said:

By our attitude to the other person, we help to determine the scope and hue of his world; we make it large or small, bright or drab, rich or dull, threatening or secure. Herein lies the unarticulated and one might say anonymous demand that we take care of the life which trust has placed in our hands. (p. 19)

Logstrup asserted that we have an *ethical demand* to treat others with respect and dignity.

### Personal Examples of Others' Influence on My Life

There are numerous examples supporting Logstrup's assertion that small actions can have enormous influence on the lives of others. One of my own family's stories is a powerful reminder of this truth. I originally wrote this story for a class in narrative pedagogy; an abridged version is recounted here along with some of my subsequent reflections.

This story occurred after my father graduated from high school. His dad, my grandfather, was an inconsistent provider and they were very poor.

Dad was always very spirited and a stickler for fairness. His school was very repressive. It made for a difficult combination. This feisty, assertive kid, Dad, was being "educated" in a very repressive authoritarian environment. Somehow, Dad was able to maintain his grades and his self-respect and dignity. He became valedictorian of his graduating class. He had applied to the University of Pittsburgh (Pitt) and hoped to become a doctor. He was accepted but had no money for tuition, so he planned to work in the steel mills like all of his friends, neighbors, and family.

On or near the day of registration, an official at Pitt called Dad to chide him, "If you weren't going to use that scholarship, you should have let us know so that we could have given it to someone else."

"What scholarship?" Dad inquired. It turned out that because he was valedictorian of his class, Dad was entitled to a scholarship to Pitt, but his principal had never told him because he hated him.

And so, because someone at Pitt picked up the phone, I grew up as the child of a psychiatrist instead of the child of a steel-worker.

As I have pondered the meaning this story has for my life today, I

have found several interwoven strands. The first strand of the story is about the power one individual has to influence others and their future. I have always felt grateful to some nameless official at Pitt for taking the time to call Dad. No doubt, when he initiated the call, he expected to reprimand Dad; he had no notion that his call would be such a gift. I think that this story has been part of my motivation to “stick my neck out” and approach people when I feel an inner nudging. I have a respect for the power of the ordinary to be a pivotal piece in someone else’s history. I never know when something small of mine may be a gift to someone else. (Roop, 1994)

The “small” phone call of the officer at The University of Pittsburgh changed the course of my father’s life and the lives of others in his world.

Many years after this small event of the phone call, my father suffered a fatal heart attack at home. Though I lived only a few miles away, I did not arrive at the hospital until after he died. I had worked as a nurse at the hospital where he died, but I had never met the nurse who assumed primary nursing responsibility for him during the resuscitation attempt. I remember seeing that nurse leave well after the end of his shift that night. A few days later, my sisters and I returned to the hospital to pore over my father’s chart in an attempt to learn more about the circumstances of his death. We could tell that Dad had received every appropriate emergency treatment and concluded that the initial heart attack was simply not survivable. Because his “routine” care was attentive and thorough, however, and the documentation of that care so complete, I felt a little bit like I was with my father when he died. I still derive comfort and satisfaction from knowing that those who were with him cared for him very well. I suspect that the nurse who cared for Dad saw him as “just another code,” one of many in his long career. His documentation that night was probably no better or worse than on other nights. For my family and me, of

course, that code was a momentous event in our lives. We were immensely comforted by the thorough detailed account that the nurse wrote.

An official at Pitt took time to make a phone call. A nurse took time to document carefully the circumstances surrounding the death of a patient. These are just two small acts from strangers that have had immense influence for good in my life. When I interact as a hospice nurse with patients and their families, I know that I am entering into a very important time in the lives of those people. I want to be open and attentive to them so that if I become part of the memory of the dying of that loved one, it is because of my sensitive care, not because of my insensitivity. Meetings with others can have unexpected importance.

#### Conversation as Currency for Meeting

Although there can be times of deep and rich silence when we encounter the other in meeting, more often, we meet through the context of conversation and language. Gadamer (1960/1990) said, "Language is the medium in which substantive understanding and agreement take place between two people" (p. 384). When we are united in a common interest, the conversation takes on a quality that is different from ordinary discourse. In *Truth and Method*, Gadamer explained:

We say that we "conduct" a conversation, but the more genuine a conversation is, the less its conduct lies within the will of either partner. Thus a genuine conversation is never the one that we wanted to conduct. Rather, it is more correct to say that we fall into a conversation, or even that we become involved in it. The way one word follows another, with the conversation taking its own twists and reaching its own conclusion, may well be conducted in some way, but the partners conversing are far less the leaders of it than the led. No one knows in advance what will "come out" of a conversation. Understanding or its failure is like an event that happens

to us....All this shows that a conversation has a spirit of its own, and that the language in which it is conducted bears its own truth within it--i.e., that it allows something to "emerge" which henceforth exists. (p. 383)

Although, as Gadamer (1960/1990) said, we do not conduct a conversation, we can conduct ourselves in such a way that we are more likely to be led into a conversation. Approaching a meeting with others with openness and genuine interest in understanding that other's life world can help to prepare us to listen and hear. As Gadamer continued:

Conversation is a process of coming to an understanding. Thus it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid, and transposes himself into the other to such an extent that he understands not the particular individual but what he says. What is to be grasped is the substantive rightness of his opinion, so that we can be at one with each other on the subject. (p. 385)

I do not mean to suggest that each meeting I had with research participants had this numinous quality, but I sought ways to prepare to receive such a meeting if it should come.

### Approach to the Inquiry

Several years ago, I had the opportunity to hear Elie Wiesel, the human rights activist who survived incarceration in both Buchenwald and Auschwitz. I went expecting the evening to be very somber and depressing, but to my surprise, he was a delightful and charming speaker. One of his illustrations has stayed with me. He said that we are to live as if we have two pieces of paper in our pocket. On one paper, it says, "From dust you came, and to dust you will go." On the other, it says, "You have been fashioned in the image of the Creator of the Universe." The trick, said Wiesel, is figuring out when to bring

out which piece of paper. I thought of that advice as I prepared to meet with the research participants and asked, “Am I to approach this inquiry with the confidence of a doctoral candidate who has successfully completed her studies at a respected university, or am I to approach the inquiry in humility as a novice researcher who has much to learn from her participants?” A partial answer, I believed, was that both attitudes were relevant and appropriate.

At the end of the first chapter, I compared myself to an explorer, committed to the voyage, not the destination. The word *explorer* is derived from French and Latin sources. *Ex*, of course, means “out,” and *pluere* means “to flow or to make flow” (*OED*, 1992). One of the current meanings is “to go into or range over for the purpose of discovery” (*OED*). The word *voyage* derives from the Latin *viaticum* meaning “provision for a journey” (*OED*). Its common usage is now “An act of traveling, by which one goes from one place to another (especially at a considerable distance)” (*OED*). An older figurative meaning was “To denote the course of human life (or some part of it), or the fate of persons after death” (*OED*). *Destination* comes from the Latin *destinare*—to make fast or firm. It refers to “the fact of being...bound for a particular place; the intended end of a journey or course” (*OED*). The etymological roots of these words did not present a clear and precise picture, but they helped to open up an understanding of how I might approach this task. I certainly hoped to move from my place of understanding before the conversations to another one after the conversations, and I expected the distance to be considerable. I expected the ponderings and preliminary explorations to serve as my

provisions. I sought to open up the understanding so that the discoveries could flow out into the open. I could not know exactly what my destination was, because I did not want to presume that I knew where the journey would take me. As I continued to reflect upon the word destination, however, I saw that though a destination is “intended” there is no indication of who does the intending. Rather than thinking that I had chosen a destination, I attempted to give myself to the questions and then trust that the questions would lead me to the destination they had chosen.

The purpose of this inquiry was to discover, “What is it like to have a life-threatening illness?” The phenomenological task is to explore the life world of the study participants and to make tacit, unarticulated understandings explicit and available to the conscious mind. As van Manen (1990) explained, “...phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world” (p. 9). I intended this inquiry to explicate more fully the world of persons with life-threatening illnesses.

#### Finding Participants and Generating Texts

In order to find participants for this study, I contacted three hospices in the Chicago area. Eventually, the social worker in one hospice referred me to several patients. Two of them, Sarah and Mona, agreed to meet with me. On one of the visits to the agency to seek more participants, I met Dr. Magrisso, who referred me to two of his private patients, Daniel and Margaret. Daniel met with me once; Margaret met with me twice. All

of these meetings took place in the participants' homes. We met alone and I audiotaped the conversations. The questions that I used to open the conversations are found in Appendix A (page 274), but as the conversations unfolded, we did not restrict ourselves to the listed questions. Instead, we allowed the conversation to lead us.

Dr. Magrisso subsequently sent me pieces that he had written about his own experience of having a life-threatening illness. Beth Marie, a friend of mine, wrote a letter to me about her experience of having an abnormal mammogram. Their writing became part of the text for this study. Hannah was referred to me by a mutual friend. As she lived 1200 miles away from me, we conversed by telephone and I taped the conversation with her consent. Cheryl, a former classmate of mine, responded at length to an earlier draft of this paper. She added her experience of caring for her dying father to deepen my understanding of life-threatening illness. Linda, my sister-in-law, lived with me for three months as I was writing this dissertation. Though she was not a formal participant, her experiences with cancer and our reflections about those experiences lent depth to the developing interpretation.

I transcribed the tapes of the conversations to generate a text. I then analyzed the text for themes and insights. As I was writing the interpretation, I would sometimes suggest some of the emerging ideas to hospice patients I was visiting and I would note how they responded to the ideas I posed. I would also re-read the texts in light of the new experiences with hospice patients. Literature and film were used to further my understanding of the phenomenon.

Because Margaret was the only participant who was able to meet with me a second time to respond to the developing interpretation, I asked two other people to read the dissertation and offer their responses. Susan, a woman whose husband had died four years ago, read Chapters Four and Five and reported that my interpretation was consistent with her experiences caring for her husband. She made numerous marks and comments in the margins of her copy indicating that she was in full agreement with what I had written. Judy, the pastor for Pastoral Care at my church and herself a survivor of breast cancer also agreed to read the dissertation. She, too, reported that my interpretation corresponded to her experiences as a cancer patient and as a pastor.

As part of the research process, I began a research journal. The journal contained records of the contacts I made in developing this inquiry--hospices, researchers, and other agencies, for example. It also was the place where I developed my interpretation of the study. By definition, interpretive phenomenology demands a change in the thinking and understanding of the researcher. It was important that I write my thoughts and reflections in a journal as the inquiry developed. Careful attention to those times that surprised, changed, or touched me was critical for the development of the interpretation. As I began, I thought it likely that my view might change several times as the inquiry proceeded. A record of those changes would lend authenticity and understanding to the study.

I planned to analyze the texts looking for commonalities, themes, variations, similarities, inconsistencies and other characteristics with the goal of discovering tacit understandings. I used the computer software program *Martin* (Diekelmann, Lam, & Schuster, 1991) to

assist with this task. When the interpretation of the texts was underway, I returned to the participants again for further conversation when possible. Throughout the process, I kept written records of the twists and turns in the analysis in my research journal in order to attend to the journey (Sandelowski, 1986).

#### Plan for Evaluation of the Inquiry

There are numerous signs that an interpretive work has been done well, and as I began, I attempted to articulate the criteria I would use. I believed that the account should be plausible and should illuminate the “practices, meanings, concerns, and practical knowledge of the world it interpreted” (Dreyfus, 1994, p. xvii). The account should be believable to others who have been in similar situations—bereaved family members, or hospice workers, for example—but it should also be accessible and understandable to people who have not yet experienced a life-threatening illness in someone close to them. They should be able to learn about the world of a the patient simply by reading the account. Benner (1994) stated that “The ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown and opens up new possibilities for engaging the problem” (p. 60). I expected that when the study was completed, I would be able to describe how my understandings had changed since the beginning of the project. I expected also be able to say what was available to me at the end of the study that was opaque or hidden before the start of the study. I expected to be able to articulate how I had changed through the inquiry. I believed that consideration of all these questions would be important for the evaluation of this study.

In addition to the change in my understanding, it was hoped that this inquiry would be useful for the science and practice of nursing. What had been the experience of the participants in receiving health care? What have health care workers done that has been helpful, and what have the workers missed? While there was no assumption that the experiences of the participants would be “generalizable,” I did assume that by hearkening carefully to detailed experiences of a few, I could learn to become more attentive to many. I believed that knowing that some people experience life in a certain way could open my eyes to possibilities in others that I might otherwise have missed. I believed that clear communication of this study’s findings to other professionals would have the potential to improve the care that those professionals offer.

#### Summary of the Philosophical and Theological Grounding of the Inquiry

In this chapter, I have presented the philosophical and theological grounding for this inquiry. I have presented the perspective, derived from Heidegger (1993), that humans are inextricably bound in a historical and cultural context that shapes their interpretation of their existence. I have said that in order to understand a person’s life world, one must explore that person’s own interpretations and understandings of that world. I have examined the qualities of meaningful conversations and the central role of language in culture. I have explicated the idea of meeting the other person as *Thou*, and have suggested that our relationships with others and our relationship to God can be inextricably woven together. I have described how I intended to incorporate these

**perspectives in the study design and how I intended to evaluate the study.**

**In Chapter Four, I turn to the phenomenon itself, illuminating and articulating the life world of the study participants.**

## **CHAPTER FOUR**

### **UNCOVERING MEANINGS IN THE LIVED EXPERIENCE OF HAVING A LIFE-THREATENING ILLNESS**

For the participants in this study, discovering that they had a life-threatening illness was a life-changing experience. It caused them to reconsider the ways in which they were living their lives and to make many adjustments. It further changed their relationships with friends, families, and health professionals. The experience was suffused with suffering and loss, but surprisingly, blessing, gratitude, and humor were also woven into the fabric of this phase of their lives. In the pages that follow, I present the detailed interpretation that emerged when the research participants turned their attention to the phenomenon of having a life-threatening illness.

#### **Introducing the Research Participants and Other Sources of Knowing**

Because this is an inquiry into the depth of the lives of a few, it is important to know something of those few. Therefore, I will introduce the participants who gave of their time and their effort to enter into this inquiry with me.

### Sarah

Sarah, 85 years old, lived alone in a subsidized apartment building. She had had a heart attack four years ago from which she had never fully recovered. Since that time, she had been a home hospice patient, her heart had been getting progressively weaker, and she had had many episodes of congestive heart failure. She required frequent admissions to the Hospice In-Patient Unit, but most of the time, she could stay at home with hospice support. Although she got out of bed and dressed each day, she tolerated activity poorly. Even with constant oxygen at home, she was frequently breathless. Fatigue was her constant companion.

### Mona

Mona was also a home hospice patient. Seventy-two years old, she had been diagnosed with lung cancer a few months before our meeting. She had had no symptoms, but her doctor had seen a spot on her lung on a routine x-ray. She agreed to have the spot biopsied, and that procedure led to surgery six weeks before our meeting. When I saw her, she was back at home with hospice care. Although she could walk around the first floor of her home, she, too, found activity very tiring. Her living room was dominated by the rented hospital bed in which she slept. Her children and friends were attentive and helpful in her care. One of her adult sons had several pet reptiles in cages in the living room. As my 12-year-old is a budding herpetologist, Mona and I had an instant connection through our sons' interests.

### Doctor Magrisso

During one of my trips to the hospice to seek patient participants, I met Doctor Magrisso. He, himself, had had a heart attack three years previously. While he was being treated in the emergency room, his heart had stopped. He had since become very interested in the experience of having a life-threatening illness. He gave me copies of some of the writing he had done about his own experience. He also referred me to two of his private patients—Margaret and Daniel.

### Margaret

Margaret was 52 years old. Four years ago she had suffered recurrent bouts of what her doctor told her was the flu. When it persisted for over a year, she consulted Doctor Magrisso for a second opinion. He immediately referred her to a surgeon who eventually diagnosed bowel cancer that had already metastasized to her liver. Since that time, Margaret had had 11 surgeries, chemotherapy and radiation. Her most recent surgery had occurred a few months prior to our first meeting. During that surgery, it was found that her cancer was once again proliferating. She was undergoing yet another course of chemotherapy, but the chances that it would slow her cancer were only about twenty percent. Margaret believed that she was going to die from the cancer this time, but she hoped that the chemotherapy would “buy her some time.”

### Daniel

Daniel, 55 years old, and I met for the first time in March at his home. He had been diagnosed with interstitial fibrosis of the lung fifteen years previously. The October before

our first meeting, he had had a total lung transplant. Daniel offered a unique perspective to the study. He had lived with a life-threatening illness for over a decade. He had then chosen to have a total lung transplant--surgery that carried the very real risk of death from the surgery itself or from acute or chronic complications post-operatively. Thus, he had both a long-term and short-term views on having a life-threatening illness. At the time of our meeting, he was recovering well. He was going into his office to work on Monday, Wednesday, and Friday, and worked at home the other two days of the work week. Still in his fifties, he was hoping to prove wrong the physician who had told him not to bother with a retirement plan because he would not live long enough to retire. He told me he had agreed to meet with me because he had once earned a Ph.D., and he knew doctoral students needed all the help they could get.

#### Hannah

A friend of mine mentioned that her parents in California were caring for a woman dying of cancer. Would I be open to a telephone conversation with her? Of course I was, so Hannah shared some of her life with me over the phone. She had been ill with ovarian cancer for about four years. Various treatments, including a stem cell transplant, had kept the cancer at bay, but now, treatments were no longer effective. Although Hannah sometimes would hope that a miracle cure could be found, most of the time, she believed that she was dying. My friend's parents, who were retired, had met her through their church, and the parents and Hannah had decided to "adopt" each other. The parents took Hannah into their home to care for her during the day while her own family worked. They

had become very fond of each other.

### Beth Marie

When my roommate from nursing school discovered that I was writing a dissertation about life-threatening illness, she sent me a letter with a vivid account of her own experience. Beth Marie, 45 years old, had had an abnormal mammogram ten years ago and for a few days until it was biopsied, she had believed that it was malignant (thankfully, it was not). She gave me permission to use her letter to help illuminate the experience of not knowing.

### Linda

In the last few months, circumstances in my own family arose that had direct relevance to this dissertation. In the midst of my attempts to find participants, my brother's wife Linda, 55 years old, was diagnosed with pancreatic cancer. After the initial diagnostic surgery in her home town of Cleveland, she underwent an aggressive regimen of simultaneous chemotherapy and radiation treatments. A second series of diagnostic tests convinced her doctors in Cleveland that the tumor was still inoperable, so she came to Illinois for a second opinion. The doctor in Evanston believed he could remove the tumor; therefore, she had surgery here on June 1st. She had several post-operative complications, some of which were indeed life-threatening, and she remained in the hospital for nine weeks. Her husband, Joel, who is my brother, lived at my house for the entire time, and her adult daughters visited whenever they could. Though she is not exactly a formal participant in this research, her story and my story as I have accompanied

her and her family through this difficult ordeal (that is not yet finished) have lent a vividness to the lens through which I have explored this phenomenon. They graciously agreed to let me include reflections about our experiences in this dissertation. My physical and emotional proximity to Linda and to Joel has drawn me closer to the lived experience of having a life-threatening illness than I have sometimes cared to go, and yet at the same time, I have regretted the hours I have spent at my computer during these nine weeks, because I wanted to be at their sides as they journeyed through that dark and scary land.

I am deeply indebted to all of the participants for their willingness to open their lives to me and let me walk a while with them.

#### Additional Sources of Knowing

During my graduate coursework, I took a class in phenomenology that helped to shape my thinking about this dissertation. My classmates and I wrote every week about our respective studies. We would then share writing with each other and write responses to each other's work. We exchanged our final papers as well. Several weeks after the semester ended, I received my classmate Cheryl's response to my final paper. She had undergone surgery herself and cared for her dying father in the interim. Her response to my paper was written after those very personal experiences, and she provided a thoughtful perspective on the phenomenon of having a life-threatening illness. Though I was never able to speak to Cheryl's parents themselves, Cheryl's interpretation of her parents' relationship to their doctor deepened my understanding of communication between doctor and patient.

The sources of knowing for this dissertation were not limited to people with whom I had personal contact. At times, I have used published accounts because they, too, have explicated a perspective on what it means to be a human in the context of life-threatening illness. I have also used pieces from film and literature, believing that art can help to open up our experiences of life.

### Awakening to Life

For the participants in this study, the experience of discovering that he or she had a life-threatening illness was a watershed event. It divided life into a time before the diagnosis and a time after the diagnosis. The division was very clear. For most of the participants, it changed radically the way they experienced “everyday life.” Van Manen (1984) states that phenomenology “makes us thoughtfully aware of the consequential in the inconsequential, the significant in the taken-for-granted” (p. 36). For the participants in this study, the experience of having a life-threatening illness placed the taken-for-granted into high relief.

There is a way in which, in order to answer, what is it like to have a life-threatening illness, we must first ask, what is it like *not* to have a life-threatening illness. What is “ordinary life” like? For most, it is experienced as a seemingly endless string of time, stretching off into a very distant future. People may occasionally be aware that parts of their lives are fleeting. A woman may realize her biological clock is running down. Joints and muscles that have always functioned smoothly may start to “answer back” after

exercise or on cold and rainy mornings. The scale may creep upwards; one's children may begin to win those parent-child tennis matches, or in other ways point out the contrast between their rising trajectories and a parent's waning vigor. Still, even as these signs of aging accumulate, we ordinarily do not consider the finiteness of our lives. Most of us live as if life is limitless. We know that at best we have a span of 80 to 100 years, but in our everyday lives, we live as if we are immortal. As Olson (1993) says, "When we are well, we are embodied in our plans for our future. We make plans as if tomorrow belonged to us, and we, to tomorrow. So our future is as familiar to us as our past and present" (p. 112). We keep busy at the ordinary activities that make our days so usual--work, food, sleep, paying bills, maybe reading or watching TV, studying, playing, or working in the community.

When an illness interrupts and is recognized as one that is not just a temporary nuisance, but one that may cause one's death, it is like a sudden awakening to a heretofore unnoticed reality. Suddenly, with shock and recognition, one realizes that life is not at all what it seems, and attention is drawn to matters that were of no interest before. One is called to attend to an entirely new host of thoughts, feelings, and experiences--concerns that may have always been there, but have rarely been acknowledged. Life is "broken."

Ten years after having an abnormal mammogram, Beth Marie can still vividly remember her feelings during the interminable time between finding out that her mammogram was abnormal and finding out that the abnormalities were benign (a period of only a few days by the calendar).

I was incredibly tense--physically and emotionally. It seemed that my whole

future--which I had of course assumed would happen--was now shattered. It was no longer a given which I could automatically expect. I prayed but I didn't "bargain" with God--I thought I had cancer. I was also mad, angry, envious of all the women on my street. It just didn't seem fair--their lives were not being shaken, challenged. We all had breasts--why was I the one whose future was being wrecked?

For Beth Marie, the threat of a terminal illness did not merely break her life, it shattered it.

It was like awakening *to* a nightmare. Her fears had physical, emotional, spiritual, and social consequences. Suddenly, Beth Marie was ripped from her life as she had known it. She had always imagined her future was a given--something she already possessed. Her abnormal mammogram placed her into an isolated spot, separate from her life as she had always known it, and separate from all the other women on her street. No longer just one of them, she alone was singled out for a wrecked future. It was a powerful and intensely unwelcome awakening.

For Alice, the threat of cancer resulted initially in one and only one emotion: fear. She told me, "I did hear the doctor say something about a large pelvic mass...then, my heart about beat out of my chest...I...I...I just cannot tell you the fear." Like Beth Marie, Alice awoke from her ordinary life into a new and frightening reality.

The difference between life before diagnosis and life after diagnosis is so remarkable that it is similar to the difference between being awake and asleep. The experience of being unaware of the finality of life--the comfort of being blissfully unaware of the possibility of one's own death--has been abruptly lost just as a dream is lost upon awakening. According to *The Oxford English Dictionary* (Simpson & Weiner, 1989), to be *awake* to anything is to be "fully conscious of it, to appreciate it fully" (Vol. I, p. 827).

Its figurative meaning is “to rise from a state resembling sleep, such as death, indifference, inaction; to become active or vigilant; to bestir oneself” (Simpson & Weiner, p. 828).

*Awaken* means “to arise or spring into existence, originate” (Simpson & Weiner, p. 828).

An *awakening* is “a rising from sleep, or (in modern use, more commonly) from sloth, inaction, or indifference” (Simpson & Weiner, p. 828). It is this modern use that seems most relevant here. Participants in the study have spent their lives in a state of inaction or indifference, essentially ignoring the fact that one day they will die. Diagnosis of a life-threatening illness, at least initially, rouses them from that state of indifference. As Bone (1996b) wrote, “Death has opened my eyes to life--literally” (p. 1931).

In his book about his final illness, Broyard (1992) wrote, “It sounds trite, yet I can only say that I realized for the first time that I don’t have forever” (pp. 3-4). Later he observed:

Freud said that every man is convinced of his own immortality. I certainly was. I had dawdled through life up to that point, and when the doctor told me I was ill it was like an immense electric shock. I felt galvanized. I was a new person. All of my old trivial selves fell away, and I was reduced to essence. (pp. 37-38)

“Dawdled through life.” It is a vivid image, immediately evoking the sense of living life as if it will go on forever--as if there is no “deadline.”

What is it about the way we live our lives that allows us to dawdle through life? What is it that causes us to feel surprise when life-threatening illness comes? If asked, we would probably not say that we believe ourselves invulnerable to disease and death, but our shock and outrage when illness is discovered suggests that we believe differently. If

we have known since childhood that someday we must die, what makes the experience so transforming when we learn that someday is now?

Shock and fear are not the only responses participants had to their awakening. In the moments after he was defibrillated, Doctor Magrisso experienced “a complex of thoughts and feelings” (1997a, p. 1). He elaborated, “The first was that I did not want to die. There was a feeling of incompleteness about my life, a sense of radical interruption. This is not how I thought it would end” (p.1)! As an internist, Doctor Magrisso was certainly aware that this is often how life ends; people in this country frequently die from sudden heart attacks. Yet for some reason, *his* brush with death caught him totally by surprise.

The experiences of these participants illustrate in a very vivid way that there is an enormous gulf between what we know and how we live. In spite of what these participants *knew*, their responses to the threat of their own death revealed that a very important part of themselves had never considered what they knew. It suggests that we are much more than what we know, and the part of us that is more than what we know has a very strong influence on our ordinary lives. I note with bemusement that even as I write these words, I myself am living as if I will have a long and prosperous future. If I should somehow discover that this is my last day or even my last year of life, I would be greatly astonished and dismayed. What I know is a very small part of me, too.

#### Responding to Awakened Life

For the participants, the knowledge that they were indeed mortal, came as an

unwelcome surprise. The participants needed to respond to that new knowledge, or rather to that tacit knowledge that had abruptly become explicit. Unspoken, but present in the responses of the participants was the notion that they had the ability to choose how they would respond, and in the pages that follow, we will see that participants did choose different routes.

Mona: Reluctant Acceptance

When I asked Mona what it was like to have a life-threatening illness, she replied,

Well, you have to accept it, number one. I mean there's no getting away from it. It's there. And I'm going to have to face it. That's it. I have a very strong faith. And I know that will carry me through...I'm not terrified of dying. Because there's a time for us to be born and a time to leave.

*Accept* is a word descended from the Latin *acceptare* which means "to receive" (Merriam-Webster Dictionary, 1998). Though one of its current meanings is "to receive willingly; to accept a gift" (Merriam-Webster Dictionary), that is clearly not the sense in which Mona is using the word here. Instead, her words indicate a different connotation found in an alternate definition, "to endure without protest or reaction" (Merriam-Webster Dictionary). When Mona says, "There's no getting away from it....And I'm going to have to face it," the implication is that she would get away from it if she could. She would gladly flee back to a time when her mortality was far from her mind if that were possible. Though Mona is accepting her illness and her impending death, there is no suggestion that she is receiving it willingly as a gift.

### Hannah: Resignation, Avoidance, and Gratitude

Hannah had been sick for four years when we spoke. Like Mona, Hannah did not receive the knowledge of her mortality willingly as a gift. Yet, perhaps because she had lived with her illness for years instead of months, she spoke about her illness with a combination of resignation, avoidance, and gratitude.

It isn't comfortable now to realize that my life is ending. Of course, we are all mortal and we all are going to pass on, but I have just decided that only God knows the number of my days. I'm not going to worry about anything else. The doctor doesn't have a clue and so it is God who is graciously giving me each day to take and enjoy to the best of my ability and that's precisely what I am going to do....I accept what is happening, and yet because I have been given--graciously given--each day--today's a beautiful day in California. The sun is shining. It's a blue sky. It's absolutely beautiful...I just feel that today is a gift to me, and it's up to me to take today and enjoy it to the best of my ability.

If we hold this small piece of Hannah's thought up to the light, it can show us many facets of her experience. Like Mona, she is not welcoming the coming end to her life, though she realizes it is coming. "It isn't comfortable now to realize my life is ending." In her words, however, is a subtle suggestion that she is doing her best to ignore that her life is ending. When she says that we are all mortal, she is blurring the distinction between herself, a very seriously ill person, and those of us who are well and have a higher probability of living a long time. Her comments that "only God knows the number of my days" and "the doctor doesn't have a clue" add to this notion that she is no different from anyone else. It implies that she is living as if she may still have a very long time. Some would consider this attitude unrealistic as Hannah had two cancer diagnoses and neither was responding to treatment. Though her doctor didn't know the day and the hour that she would die, it is

not accurate to say that the doctor didn't have a clue. Unlike many of us, however, Hannah is making a renewed effort to notice each day and receive it with gratitude. On the day that we spoke, it was a beautiful day in Illinois, too, yet I don't recall that I went outside at all that day. As I consider this, I ask myself, "Which one of us more 'realistically' accepting our mortality?"

#### Margaret: Gaining Perspective

Like Hannah, Margaret had been sick for four years when we first spoke. She told me that she had told her story many times in those four years, and she found that the telling and the re-telling helped her to put her illness into perspective.

I've told it so many times. It actually does help to talk about it because it does put it into perspective for me. And I think one of the things that has been helpful for me in putting it into perspective is to really understand what parts of it make me get sad, what parts of it make me feel angry, and I have a friend who constantly says to me, "I don't understand why you're not angry! Why aren't you angry?" And I'm not angry. Well, I guess, I sort of feel like, what makes me any different from anybody else, and anything can happen to anybody. Bad things do happen to people. And so I don't feel unlucky. I don't feel like this was a really unfair thing. Unless you look at all the unfair things and say, every bad thing that happens is unfair. I don't feel any more or less in a position to have unfair things happen to me than anybody else. It happens.

Margaret did not say "Bad things happen to good people," as the title of a popular book suggests. To her, it seemed irrelevant whether the people were bad or good. Bad things just happen to people in the course of living. Margaret's perspective is unusual in Western culture. A more common Western view of life is illustrated in the film *Beyond Rangoon* (Spikings, Pleskow, & Boorman, 1995). In that film, an American doctor travels to Burma in an attempt to recover from the horrible shock of coming home one day to find her

husband and young son had been murdered. On her trip, she becomes aware of the political oppression in that country and spends time with a professor and some students who are in hiding because of their dissident ideas. As she learns that all of them have suffered greatly, too, she says, "I was brought up to believe that if I were good--if I worked hard--than I had a right to happiness. I was a fool, wasn't I?" The Buddhist professor replies, "We are taught that suffering is the one promise that Life always keeps, so that if happiness comes, we know it is a precious gift which is ours only for a brief time." The notion that suffering is the only universal experience of life struck me as a brand new thought that I knew to be profoundly true. What is it about Western life that keeps that truth so hidden and unacknowledged? What would our lives be like--what would be different if we incorporated that truth into our daily lives? It seemed to me that the Buddhist perspective had something important to say to us.

#### Discovering Life Anew

Once participants "woke up" and found themselves in a new and unfamiliar life, they began to explore what that new life was like. As might be expected, suffering and loss were a part of that new life, but there were many other parts as well. Participants who continued to live into their new lives found other more welcome elements stirred into those new lives: faith, or spiritual experiences; even good luck, blessings and humor. Initially, it was the blessings and the notion of being lucky or grateful that surprised me most.

### Blessings, Luck, and Gratitude

The idea that blessings and suffering are intermingled is an idea with deep roots in Judeo-Christian tradition. One of the early examples of blessings intertwined with suffering is found in the following Biblical story of Joseph and his brothers, a story that Biblical scholars believe dates to 1500 to 1200 B.C.E. (Metzger & Murphy, 1991). Of the 12 sons of Jacob, Joseph was the most favored one. He was young, arrogant, and insensitive to his brothers' jealousy. Therefore, one day his brothers kidnapped him and sold him into slavery. They bloodied his cloak with the blood of a slain animal and told their father that he was dead. Many years later, Joseph had risen to a position of power in the Egyptian Pharaoh's government, and because of his station, he was able to save his family from starvation. In the scene where Joseph and his brothers recognize and forgive each other, he tells them, "It was not really you who sent me here, but God" (*Genesis* 45:8). He continues, "[You] meant evil against me; but God meant it for good" (*Genesis* 50:20).<sup>12</sup> I retell this story now, because of the strange and wonderful way that some of the patients talked about their experiences of having a life-threatening illness. Though sorrow and regret and grief abound in their experiences since diagnosis, words like *lucky*, *blessed* and *fortunate* find their way into conversations as well. For some, there have been precious gifts woven into the midst of their experiences. Remen (1996), writing of her feelings about her illness when she was in her late teens said, "I remember thinking that

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<sup>12</sup> For a wonderful tale of drama, intrigue, and redemption, the reader is referred to the complete story of Joseph and his brothers in *Genesis*, Chapters 39-46.

this disease had robbed me of my youth. I did not yet know what it had given me in exchange” (p. 30).

In a hymn by Isaac Watts (1964), he imagined the suffering Jesus on the cross and saw, “sorrow and love flow mingled down” (Hymn 435). As I have struggled to capture what it was like for the participants in this study, that hymn has come to mind again and again. Some of the participants described not only sorrow and love, but also blessing, luck, and gratitude flowing mingled down in their lives since diagnosis. To focus only on the love, or only on the sorrow, or only on the blessing, or only on any other one aspect would be to fail to appreciate the totality of the experience. All are there. All are real. All are important. Still, it was the words *lucky* and *blessing* that surprised me most.

Listen to the words of Margaret:

One of the things that I’m amazed about—I feel incredibly lucky—is that I’ve been able to experience how much people care for me. And most people never get that opportunity. Most people die without ever knowing—I mean, they have a circle of friends, and they have a family around them, and they can feel supported, but they have no idea how supported they really are and how much people really care about them, and Oh, my God! It’s just been—it’s been overwhelming—totally overwhelming. There isn’t a day that goes by that I don’t get several phone calls. And this is—I mean I’ve had this disease since 1995! There is not a day that goes by! And I have a wonderful family. And I’ve been able to experience that. So that definitely goes in the ‘pro’ column. A very very strong pro. In addition to the handicap card [for parking her car] (laughs). But it really is, I mean, that far outweighs any of the bad things that have happened as a result of the disease....It does. And I may feel differently the day I die, but—it even outweighs the day I die. It really does. I just feel incredibly lucky.

*Overwhelm* is a Scottish word that originally meant “to overturn, overthrow, upset; to turn upside down” (Simpson & Weiner, 1989, Vol. X, p. 1137). Another

meaning is “to throw (something) over in a heap upon something else” (Simpson & Weiner, p.1137). Overwhelming, therefore, means “That overwhelms, overthrows, overturns, or submerges utterly: so powerful as to overcome utterly by strength of numbers, influence, etc.” (Simpson & Weiner, p. 1137). What is it that is submerging Margaret so utterly, and what of Margaret is being submerged? It would seem that her diagnosis and the threat of her death has awakened the love of her friends and family, and has awakened Margaret to that love. The power and force of that love has completely overwhelmed Margaret’s former relatively shallow experience of their love for her. Their love has been deeper and stronger and wider than she had ever imagined. Her reception of that love has been precious enough even to outweigh the day she dies.

Margaret also used the word *lucky* to describe herself. *Luck* is a word that dates to the 15th century. It derives from the Middle English and Dutch words meaning *fortune* and from Indo-European words meaning *to bend*. Thus, luck is good fortune resulting from circumstances that “bend together” (Webster, 1966, p. 871). For Margaret, her illness and her experience of receiving the love of her family and friends are circumstances that have bent together--that have joined to change the quality of her life for the better.

It was not Margaret alone who benefited from the bending together of her fortune. Her cancer has also protected her family in an unexpected way. Colon cancer is unique in that it always arises from polyps that can be found on colonoscopy. If the polyps are removed before they become cancerous, or in the very early cancerous stages, the person is cured. Margaret realized that her disease had served as a poignant warning to her

siblings. Because of her diagnosis, they had all had colonoscopies, had been found to be cancer free, and were now planning to undergo frequent focused cancer screening. She concluded, "They will be fine....I'm grateful for that."

The word *grateful* casts Margaret's experience in a somewhat different light from that cast by the word *lucky*. Grateful is a word derived from Latin words meaning "pleasing" (Webster, 1966, p. 632). One who is grateful is "feeling or expressing gratitude; thankful; appreciative" (Webster, 1966, p. 632; Agnes & Laird, 1996, p. 268). Thus, Margaret is appreciative of what has been given. Unlike the word *lucky*, which implies that benefits are the result of chance or fortune, the word *grateful* implies that there is a giver, even when the giver is not named. Margaret feels grateful--thankful. She sees herself as a receiver but she did not explore the question of who or what the giver was.

Sometimes, it is change in others that is seen as good. Margaret reported that her illness had pushed her younger sister to grow in some important ways.

She's grown up a lot....It's very interesting. She was pretty protected. And my sister's grown up a lot in the last couple years. She's done things that she'd never done before....She's developed a circle of friends, which was very hard for her to do. She's a very quiet person. Never did a lot socially. And now, she's got this circle of friends that she does things with on a regular basis...and she's doing more for herself than she has before....She's taken trips. I mean, in all the time I've lived in Chicago, she's been here--before I've been sick--I think she's been here once. And I've lived here for 24 years. But since I've been sick, she's been here, three or four times. So, I mean, those are things she never would have done before--get in the car and drive here. So, she's grown a lot. Gotten more self-confident. Than she ever was before. [I responded, "That's a plus."] Yeah! Yeah. Goes in the pro column. (Both of us laughed).

It seems that Margaret's sister has awakened as well. Perhaps, she, too, realized she had been dawdling through life. Margaret believed that in response to her illness, her sister had found the motivation to seek a wider circle of friends and to make the effort to visit more often. The emerging growth in Margaret's sister was a positive outcome of Margaret's illness.

Daniel, too, looked back over his illness and found gifts within the experience.

Reflecting on the changes in his life since that time, he remarked:

And I'd have to say. To look at it over a much larger perspective, I'd have to say that the illness was a real blessing. Would I have searched for God? Probably not. Would I still have gone on perhaps living a self-destructive life? Probably...very definitely. And to tell people that and they say, "You're nuts." Would I do it this way again? I'd wonder, maybe I'd say, "Yes." Did the Lord give me this? Because otherwise, I ain't gonna go. Things ain't gonna change. And when I think of the way things could've been, I can say, you know, they could've been a whole lot worse....I think would've been self-destructive. Certainly would've destroyed the family. And yet, because of this, a complete change in the way I live. In my life. So I'd have to say, "Yeah, I think I'd take this [the illness]." Which is a real weird thing to say.

Daniel believed that the blessings embedded in his illness were so great that, given a choice, he would choose to have the illness again in order to receive the blessings again. His evaluation turns the idea that illness is bad and undesirable upon its head.

*Blessing* is a word with a long etymological history. Originating in Old English and Old Teutonic, it originally arose from words meaning *blood, to be mild or show pity, to rule, and ruler or king* (Simpson & Weiner, 1989, Vol. II, p. 281). *The Oxford English Dictionary* remarks that "It has a long and varied series of associations, heathen, Jewish, and Christian" (Simpson & Weiner, p. 281). It originally referred to marking something

with blood for a sacrifice in order to invoke beneficence from a god. To bless something, was “to make ‘sacred’ or ‘holy’ with blood; to consecrate by some sacrificial rite which was held to render a thing inviolable from profane use of men and evil influence of men or demons” (Simpson & Weiner, p. 281). To bless someone was to “confer well-being upon...to make happy, prosperous, or successful” (Simpson & Weiner, p. 281). To bless is also “to make happy with some gift, originally a gift with God as the giver” (Simpson & Weiner, p. 281). The word *blessings* refers to the benefits themselves. Thus a blessing is “the bestowal of divine favour and prospering influence...a beneficent gift of God...a favor bestowed, a present” (Simpson & Weiner, p. 282). Though blessing usually has religious connotations, a blessing can also be “a beneficent gift of...nature, etc.; anything that makes happy or prosperous” (Simpson & Weiner, p. 282) and “a gift or favour bestowed, a present” (Simpson & Weiner, p. 282). Like the word grateful, blessing implies a giver and a receiver.

It is humbling to note that the gifts or blessings the participants have received were not created by their illnesses. Instead, their illnesses opened their eyes to see what had always been there. Consideration of their experiences can call all of us to ask, “What are the gifts in our lives that we are too busy to see? Is there a way that we can appreciate the blessings that surround us every day? What is it in our lives that prevents us from claiming the richness we have been given?”

### Suffering and Loss

The participants were able easily to name the benefits or blessings in their lives, yet

as the Buddhist professor in *Beyond Rangoon* declared, “Suffering is the one promise that Life always keeps” (Spikings, Pleskow, & Boorman, 1995). The participants in this study had all experienced suffering because of their illnesses. The very reciprocal involvement in the lives of others that gave them so much satisfaction and joy also gave them sadness and pain. The illness had deepened relationships with others, but it had also intensified the loss that will occur if and when the participant dies. In the flurry of thoughts and emotions that Doctor Magrisso experienced in the moments after his resuscitation, he felt “an enormous sense of impending loneliness and separation from everyone and everything I knew and loved—grief.” The depth of his grief mirrored the depth of his love.

Doctor Magrisso described the pain of his own separation from his loved ones. Other participants were saddened by the knowledge of the pain their loved ones were feeling over losing them. Mona, a woman given to understatement, said, “I’m unhappy that it’s been such a drain on my family...Because you see someone you love going downhill. And that is not pleasant.” Mona was concerned that for her family, the experience of seeing her health decline was an unpleasant experience.

Margaret, too, suffered for the loss her family was experiencing and would continue to experience. She said,

My sadness about this whole thing really has to do with people that I love. I really don’t regret anything....But one of the things that makes me cry very easily is when I think of how sad they are about it.

She did not regret her illness; she regretted its effect on her family. Margaret had thought that her most recent surgery was going to be very simple—the removal of a very small

tumor. Compared to the extremely difficult surgeries she had had in the past, this one should have been “nothing.” She told her family not even to bother coming to be with her this time because she didn’t think she would need them. However, when the surgeon began the operation, he found countless tumors throughout her abdomen, meaning that her cancer was back and was probably terminal. Telling me about that time, Margaret said:

My sister, for some reason, insisted on coming [to be with me during the surgery]. She said, “I don’t care. I just don’t want you to do this alone.” And she and two of my friends were there while I was having the surgery. And of course, my surgeon had to come out and tell them, even before I was awake, what he had found. Now, they were all devastated. Because, none of us expected it....So they--I mean--it was total--totally awful for all three of them, and when I think about that, I get very sad. I mean, I never would have wanted her to have that sadness. I am very sad about the fact that they’re going to lose a sister. My sister won’t have a sister. I think that’s really sad. She’s been very important to me....I was glad my friends were with her, but I feel bad about them, too! You know, it’s not only my family. It’s my friends. I feel horrible for them.

In this reflection, Margaret speaks eloquently of the entanglement of love and suffering. As Alice expressed in Chapter Two, love of friends and families is a “double-edged sword.” Love of friends and family is one of life’s greatest joys, but it opens us to great suffering. In the preceding passage, Margaret’s pain is not for herself--it is for the pain that her sister and friends experience because of their love for her. Their pain over losing her, in turn, causes Margaret to suffer. Margaret knows that her dying will inflict pain upon the ones she loves most, yet she is helpless to stop her dying. She cannot protect her family and her friends from the pain they will experience *because of* their love for her.

When Margaret considered more deeply the fact that her cancer had protected her

siblings, she continued, "If it had to be one of us, I'm glad it was me. I'm glad I didn't have to watch one of them go." What is Margaret revealing about the experience of human loving, living and dying? What is this gladness Margaret speaks of? Is the pain of dying so great that she wants to protect her loved ones by taking the pain upon herself, and is she glad she can do that? Or is the pain of watching a loved one die so great that she is glad she does not have to experience it? What is it to suffer in someone else's stead?

*Suffer* is descended from Anglo-French, Old French, Spanish, and Portuguese words that mean "to bear" (Simpson & Weiner, 1989, Vol. XVII, p. 122). It means "to have something painful, distressing, or injurious inflicted or imposed upon one; to submit to with pain, distress, or grief" (Simpson & Weiner, p. 122). A variation of the meaning of suffer captures the idea of time passing, or even a journey, for suffer also means "to go or pass through, be subjected to, undergo, experience (now usually something evil or painful), to submit patiently to" (Simpson & Weiner, p. 123). It carries the meaning of "to resist the weight, stress, or painfulness of; to endure, bear, stand" (Simpson & Weiner, p. 123) and also "to allow (a thing) to be done, exist, or take place; to allow to go on without interference or objection, put up with, tolerate" (Simpson & Weiner, p. 123). Thus, to suffer something is to endure it but also to prevail. Doctor Magrisso, Mona, and Margaret were all undergoing experiences that were painful, yet all were enduring or prevailing as well. While one is suffering, the trial is not finished; the outcome is not known. Because the outcome is not known, participants found different ways of enduring or addressing the suffering.

Hannah told how she acknowledged her sadness without being overwhelmed by it.

She said,

There have been days that I have been depressed and been unhappy and I have cried—cried for fifteen minutes, and I feel better after that. And then I'm just, "Well, now, that's over with. Now let's just get on with it and see what we can do to make today a nice day." And I think that that is a gained perspective that you are able to utilize. I have decided that I'm not going to just do nothing besides be depressed and sit in a hole and cry the whole time. God has given me this time, and he is giving me this time to enjoy, and that is how I'm going to use it.

Here we see that Hannah has found a way to make room for the sadness in her life. She is not avoiding it or shutting it out. She is not attempting to pretend it isn't there. But after a brief time of feeling her sad feelings, she makes a conscious effort to set them aside and experience the equally true experience of gratitude to God for the enjoyment that is still possible. One wonders if Kierkegaard (1849/1989) would be proud of Hannah for the way she has found to recognize two opposite "truths"—that life is sad and life is enjoyable—and to hold on to both of them.

Margaret believed that, in spite of his sadness, one of her brothers was doing well at working through his adjustment to her impending death, in large part because of his children. She believed that the forthrightness of her young nieces and nephews prevented her brother from "hiding" in denial and prodded him to continue to confront and work through his feelings.

Some of it is—you know, they've talked about a lot of hard stuff! And the kids are just, like, right out there with it. They're asking questions of me, and they don't get a respite from it. There's no denial going around with little kids. If you tell them something, they're right there with it. They want to know all about it. And so, he's had to deal with it pretty openly. And actually, I think he's probably doing better than the others. Maybe because

of it. Maybe he's lucky he's got those kids. So he has to keep explaining it to them.

Here is another conundrum. Margaret's nieces and nephews have not yet learned that death is a topic about which one must be careful. They have not learned the sensitivity of wondering if the time is "right" to talk openly about such matters. This openness both deprives the children and their parents of protection from painful feelings and propels them through the painful process to a better place. Again, though, although the openness of the children was helpful, it also had its deeply painful side. Margaret said:

But my five-year-old niece, she'll come right out and say to me, "I love you. Please don't die." You know, she just comes right out with it. Umm, and I keep telling her, that I hope that I don't, but....and I love her, too. And that's enough.

What is it like to endure the sorrow of leaving children and seeing their sorrow? What is it like to have a child give voice to thoughts and feelings one is trying to repress? As I listened to Margaret's account, I became aware that it was hard, even for me, to hear about the tender feelings of her niece. I found myself wanting to avoid the painful feelings in myself. I responded, "Yeah. Wow...I...I'm wanting to be in denial about this!" As we both burst out laughing, Margaret cried, "Me, too! Me, too!"

Margaret also related that her father found himself caught in a very difficult place. He was a surgeon, and although he was in his eighties, he was still only "semi-retired." The irony of his daughter dying of a disease a surgeon "should have" been able to cure was particularly painful for him.

Anyway, he's this remarkable guy who has had an extremely difficult time with my illness...he's taken this particularly hard--very hard. And again, he can't do anything about it, and it's in his field, and oh my god, oh my god.

It's in his field. What a strange picture! His field, of course, is surgery and early surgery would have given Margaret a complete cure. Yet a field is also a piece of land that one cultivates for crops or grazing--for providing for oneself and one's family. Arising from the source, then, of his family's sustenance is the cancer that will kill his daughter. The enemy is not an outside intruder; it is an inside betrayer--just like a cell that becomes cancerous. What a difficult situation to accept. It is no wonder Margaret's father is having a difficult time.

Hannah reported that she had made peace with most of the aspects of her dying, yet for her, too, the love she and her husband have for each other leads them to difficulty. She said:

With my husband, I am having trouble still with the issue of leaving my husband, and not being here for him, and with him...[You] always expect that you are going to be married until you are a little gray-haired couple, and the fact that we are not is--is difficult at times.

Hannah speaks not of dying and not of loss, but of *leaving*. Why leaving? Leave has many meanings, but the ones that Hannah is using are "to go away from, to abandon, and to forsake" (*Merriam-Webster Dictionary*, 1998). *Abandon* and *forsake* are words that carry heavy moral implications. They are words that do not belong in a marriage relationship. In fact, a phrase of a common wedding vow has each partner promise to forsake all others. Leaving suggests that the separation is a matter of will. Certainly, that is not what Hannah believes. It is not her will to die. Her choice of the word leave, however, reveals that she does feel remorse about "abandoning" her husband; she does feel at some level that she is

leaving. What would be different if Hannah saw herself as someone who was being taken instead of someone who is leaving?

Though none of the participants believed he or she was truly “responsible” for the pain of their loved ones, nevertheless, they still *felt* responsible. They felt as if, somehow they were the cause of their loved one’s pain—as indeed they were! Though they were helpless to change that, they still wished that they could. They wished that somehow it would be within their power to relieve the burden of care that had fallen onto their loved one—wished that they were greater than human. For being human meant that they were mortal—that they were going to die, and that they were powerless to change that, and powerless to protect their loved ones from the loss. Confronting the threat of death showed participants how small their human capabilities were.

As I continued to reflect on the painful experiences of the participants, I began to remember Tillich’s (1959) work. He asserted that as we live in the eternal Now, we do not always know which of our experiences are blessings and which are curses. These excerpts from the texts of Daniel and Hannah seem to illustrate Tillich’s claim. Daniel knew that he received his lungs from a man in his twenties who had been killed by an accidental gunshot. He reflected:

And I’ve thought about that more from the standpoint of the parents, and the horrible grief—the shock—the horror of it all. Losing a child. I mean, I’ve tried to think about it, and all I can think of is being so horribly sick to your stomach, that you’re just totally devastated. And yet, for whatever reasons, somebody approached them or they’d already thought about it and said, “Use...” that they gave a gift of life. I mean, it’s just, I don’t know...a phenomenal thing....And that’s something that I’ve thought about too when I’m on Second Wind [an internet community of people with lung diseases], you know, you wish somebody gets their--wish little Jessica gets her lungs.

Yeah, that means somebody's gotta die--in this case a child's gotta die--in order for somebody to get a new set of lungs. And you begin to feel, there's something not quite right about that.

Daniel was acutely aware that the experience of transplant combined the joy and gratitude of one group of people very closely with the pain and suffering of another group. In this next excerpt from Hannah, the suffering and blessing are intertwined within Hannah herself.

Originally when you first said to me, "What is it like having a life-threatening illness,"...my first instinct was to say, "It's the pits." And then secondly, it came to me in some ways, this past four years has been some of the most rewarding times that I have ever had...I've come to know God and the Holy Spirit and Jesus on a quite intense level which got me extreme peace and beauty, but I've had interactions with just wonderful, wonderful people, who have, I feel, enriched my life.

Suffering and blessing are wrapped up in the same cloth--or perhaps, packed in the same box. As I noted at the beginning of the section on blessings, the idea of suffering and blessing being intermingled has roots in Judeo-Christian tradition (Kennedy, 1974). It is found in other traditions as well (Hawthorne, 1986). In Hawthorne's retelling of the ancient story of Pandora, all of the world's troubles were released when Pandora lifted the lid of an ornate box for a forbidden peek inside. Finally, she was able to shut the lid again, but it was too late; a great cloud of troubles, portrayed by Hawthorne as an enormous swarm of stinging insects, had escaped and were already infesting the whole world. Realizing the enormity of her horrid deed, she lay sobbing on the box. After a time, she became aware of the tapping of another being still inside the box. Pandora was at last persuaded to open the box once more, and Hope emerged. Hope promised that she would

help them endure the suffering that was now inescapable. Thus, hope--so essential to the human spirit--is inextricably connected to suffering. In the myth, suffering even necessarily precedes hope. Some research studies have found that paradoxically, hope is often stronger under threat than it is when things are going well (Herth, 1989, 1990a, 1990b, 1993; McGee, 1984; Mickley, Soeken, & Belcher, 1992). Perhaps hope is strongest when it is most needed.

Doctor Magrisso pointed me toward a song of Leonard Cohen's (cited in Magrisso, 1997b) that suggests a variation of the same theme in its refrain:

Ring the bells that still can ring.  
 Forget your perfect offering.  
 There is a crack, a crack in everything.  
 That's how the light gets in.  
 That's how the light gets in. (p. 12)

In the myth, and in the studies, suffering precedes or strengthens hope. In the song, a crack in perfection--a flaw or a weakness--lets light, a symbol of goodness and revelation in. Goodness, blessing, and suffering are inextricably intertwined.

#### Faith and Spiritual Experiences

In recent years, there has been increased interest in spirituality. Doctor Magrisso(1997b) noted that the writings of Bone (1995a, 1995b, 1996a, 1996b) and Cardinal Joseph Bernadin (1997) were part of a growing collection of "reflections of a people coming to grips with death and *growing* from it" (p.1). He added that for most of us the idea of our own deaths is unthinkable, but continued:

When we let in the "unthinkable," is that not also an expansion of consciousness? Is that not what spiritual unfolding is all about? Is this not "growth" of the soul?...The real dangers and real fears of illness can defeat

our souls or they can be a catalyst to the inner chemistry of the unfolding of the soul. And the soul, even in illness and death, can flourish and triumph. In fact, I would propose that in the openness that life-threatening illness can bring, we may be more open than at most other times in our life to receiving a spiritual teaching. (pp. 2, 9)

Magrisso suggests that life-threatening illness can open us to receive teachings we would not be ready for otherwise.

For the participants in this study, illness did indeed turn them to consider the spiritual aspects of their natures. Some connected their experiences to formal religious traditions; others spoke in more general terms. Some were drawn to consider the ultimate meaning or purpose of their lives. Others found in their faith or spiritual experiences strength to endure the challenges that confronted them in their experience of illness. Two participants, Margaret and Daniel, told me of spiritual experiences that were uniquely personal. In the sections that follow, I will consider these perspectives.

#### Faith as a Window on the Meaning of Life

Daniel began his response to my questions by turning to his faith. He said, “What comes to my mind first is the issue of spirituality. When you develop a life-threatening illness, the big question is “Why? Who am I? What’s it all about? All those things....And as I go down these questions here, it’s the issue of spirituality that comes up. Because, I look at, what would life be without a faith?” For Daniel, life without faith would be meaningless. The experience of illness turned him toward questions of faith.

Doctor Magrisso (1997a), too, found that illness turned him toward faith. In the moments after resuscitation he recalls feeling “a clear-headed sense of utter helplessness,

being completely under the power of a Divine Will, and a feeling of submission to that Will.” (p.1). In the days that followed, he re-read a book of sermons by Meister Eckhart (cited in Magrisso, 1997a). Magrisso wrote:

[In a sermon about one of Jesus’ sayings, “Blessed are the poor in spirit, for theirs is the Kingdom of Heaven,” Eckhart claimed that it was in] “having nothing, knowing nothing, wanting nothing and being nothing” that we recognize the extent to which we live by God’s grace. And while [Doctor Magrisso’s experience] could have been just good luck, or good medical care, it had a different feeling to it as well, another dimension, orthogonal to the others, and it was that of being blessed by God’s grace. Which, of course, despite our chronic complaining of how bad things are, is there, unrecognized, all the time. (pp. 11-12)

Eckhart, like Heidegger (1993), turned his eye upon the nothing. He, like Heidegger, believed that it was important and necessary to acknowledge the nothing, but there the similarity ceases. Eckhart found that only when all of our “possessions” are stripped away do we find the truth of our lives--that we live by God’s grace. Magrisso says that God’s grace is there, unrecognized, all the time, but it is covered up by the commotion of the everyday. When the false security of the everyday is stripped away, we find our true place, which is a place of utter helplessness and total dependence on God. This is a clear description of discovering the essential that is under the surface. The breakdown in Magrisso’s life re-emphasized his fundamental relationship to the Divine. The crack in his life let the light in. These experiences recall Kierkegaard’s (1848/1989) assertion that despair is a good and helpful state because it forces us to recognize our dependence on God.

The notion that the Divine is present in everyday occurrences was echoed by one

of Daniel's doctors. He had told Daniel that he had been at a meeting where someone asked him if he ever saw divine intervention. The doctor replied, "Every time I do surgery." That doctor saw the "miracle" of surgery and healing as evidence of the divine in everyday life.

### Faith and Spirituality as a Source of Strength and Comfort

In addition to guiding participants toward questions of ultimate meaning and reclaiming what was important to them in life, faith and spirituality also provided participants with a source of strength and comfort as they endured the experience of being ill.

For Sarah, her faith was so much a part of her everyday experience that she spoke of it naturally; words of faith laced her conversation. I commented on her habit of always saying "God bless" whenever she hung up the phone. When I had called her to make arrangements for our meetings, I had been the recipient of several of those spontaneous blessings and it had felt very nice. I told Sarah that when she would say that to me, I felt like somebody had given me a blessing. She replied, "I do too, when they say, 'You, too.'" Her habit was a way of keeping her faith in the forefront of her mind. That faith was an important part of her everyday coping. When I asked what kept Sarah going in spite of her severe fatigue, she replied:

I don't know...maybe God wants me to stay a little longer...And you get so tired that you can't do anything. You think, again, why am I here? There must be a reason, though...I think there's a reason, but I don't know the reason...I don't know why I'm living this long...because I'm ready to go any time, but it seems that...there's a purpose in life for everyone, being here.

Sarah did not know the reason why she was living this long. Her faith did not give her reasons. *Reason* comes from the Middle English *raison* and the Old French *reson* and *raisun*, words that mean “a reckoning, reason, plan” (Webster, 1966, p. 1211). Its Indo-European bases *re* and *ar* indicate “to fit or join” (Webster, 1966, p. 1211). Sarah’s faith did not give her ordered plans that fit her understandings, but her belief that there was a reason known to a benevolent God helped her to endure.

Daniel found in his spiritual growth, not reasons, but strength.

And I would have to say that it’s because of that swell, that development of spiritual growth that has given me the strength to get through this....It’s kind of a spiritual relationship that keeps me going. And gives me the strength.

What is implicit in his words is the idea that being ill is an exhausting and weakening experience. One who becomes ill is one who will need strength derived from a source that is different from and more abundant than the everyday source. People speak of finding an inner strength they did not know was there or of receiving strength from something outside themselves. Faith may be seen as both an inner and an outer source.

Hannah found in her faith a resource to help her reframe her experience of receiving a stem cell transplant. She said:

I had a stem cell transplant...three years ago...and what other people considered just a horrendous, a horrendous experience, I can’t look at it like that because every day brought--I went in with the attitude that it was going to help me, and that I was going to go on a spiritual retreat....I never looked at it as a horrendous experience.

*Attitude* is derived from the Latin *aptis* meaning “to see” (Webster, 1966, p. 95).

Hannah’s words speak of the human ability to choose to see events from different

perspectives. In preparing for her stem cell transplant, Hannah chose to look at the required isolation, not as an episode of loneliness to endure, but as an opportunity to retreat from the cares of the world and attend to her spirit. Thus, the experience became a good event that would nourish her spiritual nature.

### Uniquely Personal Spiritual Experiences

Both Daniel and Margaret had stories to tell of spiritual experiences that were uniquely personal in nature. Daniel's was rooted in his developing understanding of God; Margaret's was of a more general spirituality. Both believed that they had had encounters that transcended everyday life.

For Daniel, his spiritual journey was an important part of his story. Events that had happened years ago grounded his understanding of meanings in his life today. He had not been raised in a religious tradition, and had been a teenager when he first realized that Jesus Christ had been a historical person rather than a fictional character. Several years later, his wife became interested in church and Daniel would go occasionally "to keep the family happy." One evening, he took his wife to a meeting at the church, and while she was in the meeting, he waited for her in the sanctuary. He was thinking about their own son, who was 12 at the time and experiencing some of the turbulence of adolescence.

Daniel said:

So I was sitting in the sanctuary, killing time while she was in a meeting. And it was going through my head, too, my relationship with my son. He was 12 years old, his teenage years, you know, [and I was thinking] Why can't my son understand how much I love him, and how I don't want him to have to go through the problems I had when I was a kid, and you know, I just want the best for him, and so forth. When I heard a voice, literally, that I turned [to see who was speaking], that said, "Now, Daniel, you

know how I feel about you.” And at that point I knew there was a God.

Daniel’s new realization remained dormant for many more years, however, until he went on a spiritual retreat with his church. He told me that while he was there, he had the following experience:

I had an experience there, that basically I would say, I was at the crucifixion. And I knew, that He [Jesus] did that for me. If I had been the only person in the history of Man to sin, that He would have done it just for me. And it was an experience that was overwhelming, overpowering... And that also changed my life, and it becomes part of the spiritual aspect of what it’s all about.

In a bemused way, Daniel admitted that in spite of the vivid nature of some of his spiritual experiences, he would still sometimes forget to think about them. He likened his forgetting to the Israelites in the book of Exodus who forgot again and again how much God had done for them and would complain as they traversed the wilderness. Yet his spiritual perspective continued to color the way he told his story.

In the fall of 1997, Daniel’s wife made arrangements to go visit her sister who was very ill with cancer. Daniel related:

Martha told me, “I’m leaving on the 17th [of October].” And immediately, I had the feeling, I was going to get a call on the 17th or 18th of October while she was gone. And honestly, too, it was like God was telling me, “Daniel, it’s just going to be you and me on this one.”

It may be no accident that Daniel used the phrase *get a call*. Though of course, he was referring to a phone call, receiving a call is a notion that has deep spiritual undertones. In the Bible, there are specific stories of the call of prophets like Isaiah (*Isaiah 6*) and Jeremiah (*Jeremiah 1*). Those stories relate the story of God coming to those men and

singling them out for a specific task of obedience--a call. Today, this meaning of the word call persists as "a strong inner urge or prompting; a vocation: a call to the priesthood."(*American Heritage Dictionary*, 1995). In the context of my own husband's career as a Presbyterian pastor, he has never had a "job;" he has been "called to serve" various congregations. In fact a Presbyterian cannot be ordained as a pastor until he or she receives a call--a position that is recognized by the greater church as a form of service to God.<sup>13</sup>

Daniel did receive a call from the transplant team on October 18th. Like all patients awaiting transplants, he wore a beeper. It had sounded a few times before, but those alerts had been wrong numbers. This time when he called the transplant office, the secretary affirmed that they had summoned him, and she would connect his call to the physician. Daniel relates, "The first thought out of my mind was 'God have mercy on me.'" His wife was out-of-town, but his daughter came quickly to be at his side. They each drove to the hospital, but on the way, his daughter's car broke down, so Daniel went ahead without her. Therefore, Daniel told me, "I walked into the hospital, and as God [had] said, 'It's just gonna be me and you.'" Daniel laughed as he told me that the hospital staff "had a little trouble believing that this guy--except that I did have an oxygen tank on my shoulder--that somebody walks in completely alone and says, 'I'm here for my lungs.'"

For Daniel, the series of spiritual experiences that were uniquely his helped him to

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<sup>13</sup> Service to God can be interpreted rather broadly. For example, Fred Rogers, the Mr. Rogers of children's television, is an ordained Presbyterian pastor. His work is seen as a call of ministry to children and families.

believe that God was with him during his surgery. I asked Daniel if, while he was waiting for surgery to begin, he thought about the risk that his new lungs could fail and they would not be able to put his old lungs back. Daniel told me that he is in a group on the internet called “Second Wind,” and some of the people in that network have had the experience of getting as far as the operating room and then being told that the donor lungs were no longer suitable for transplant. One person has had five false alarms! Daniel continued, “But! I got there, and it never entered my mind. This was gonna happen. And I honestly believe that I was given a sense of peace that, as it says, peace that passes all understanding.<sup>14</sup> I don’t understand it.”

Daniel’s experiences led him to believe that God had been guiding and caring from him for many years. It enabled him to face critical surgery with a sense not of fear and anxiety, but of peace.

Margaret, too, had a story of finding unique resources in a spiritual experience. Margaret described herself as coming from a big Irish Catholic family, but she did not talk about her religious faith during our conversations. She did, however, tell me that she got “spiritual help” at a time when she was in need. When her bowel cancer was finally diagnosed, it was already at the most serious stage. Her doctor recommended that she have surgery to have the tumors removed. He was confident that he could remove the tumors, thereby, lengthening her survival time, but there was a risk that she would bleed to

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<sup>14</sup> This is a reference to the Bible verse, *Philippians 4:7*, that promises that God will give “peace that passes all understanding” to believers who call upon God.

death on the operating room table. She told me:

That was a hard decision to make. I was terrified of surgery. I'd had a bad experience...I was terrified out of my mind, and I actually got some spiritual help with that.

Margaret's first husband had died of leukemia almost thirty years before in the first few years of their marriage. Margaret said:

This is going to sound really odd, but I've always sort of maintained contact with Bill--whoever or whatever that spirit is. He was my best friend, and we never stopped loving each other. So I knew that--I sort of--I don't know how to explain this. When you talk about this kind of thing, it's really odd, but I've talked to him at times--one-sided, very one-sided--about things, and one of the things that I said to him, was that I'd never asked him for anything, but I needed his help now. I was terrified out of my mind. I didn't know what I was going to do about this surgery. I thought it was the best thing, and I had already told the surgeons that I would do it, but I wasn't sure that I could actually go through it. And, what he--what happened was, I had this dream. I was awake, but I had this dream. And the dream was very simple. Bill was this very big guy. He was a football player...So he was a very big guy. And the dream was that he was lying on the hospital bed, and that I lay down on top of him, my back to his front, and I just went into his body, so that his strength became my strength. His muscles became my muscles. It was this really short, like two-minute dream, but it was more than a mental image. It was....and then I totally relaxed. And went through the surgery.

When I wrote my comprehensive exams, I discussed the commonly held "knowledge" that life and death are relatively straightforward concepts. Modern technology has blurred the lines a bit through life support and brain wave monitoring, but, I said, "By and large, there is not a lot of confusion. Life has a beginning and an end. That's it, and it's clear."

Why then, I asked, is there in literature, poetry, art, drama, and folk tales a plethora of suggestions that the separation is not so clear? I cited many examples from

literature, art, and dreams that support the idea that death is not the end of existence—that the living and the dead continue to influence each other. The idea that life could continue in some form after death does not fit into a scientific model that is easy to demonstrate, but it is an idea that arises again and again. Margaret’s experience is an example of the dead influencing the living in a good way.

### Humor

Rich and humbling spiritual experiences were part of the illness journey of the participants in this study. Yet all was not somber and serious. Participants found that there were times of light-heartedness as well—and humor. When Margaret was telling me about some of the surprises she had had since she had been diagnosed, she said,

My sense of humor was a surprise. I didn’t think I had one, but I do, and it’s really pretty funny....I was also surprised by the fact that we could still have a good time. That it wasn’t going to be so devastatingly awful that we couldn’t still party together as a family, and get together with friends, and we could still have a good party...We still could do the things we used to do without it being a black pall hanging over everything. So that was a very nice surprise....My family is a great Irish party family. And we deal with a lot of things with humor—a lot of it has been black humor—but for example, my sister and I talk about the pros and cons of cancer, and one of the pros is you get a handicap sticker for your car, so you can park close to the store.

Other participants, too, had not lost their ability to be humorous. When I met with Mona, she was still very weak from the surgery. She could get up and walk around the house, but she was too weak to be left alone, and too weak to get into the bathtub without help. When I asked her what her days were like, however, she replied, “I don’t bungee jump or anything like that!” Daniel told me that after his surgery, his sister came “to take

care of her sick brother in bed, but I just drove the poor lady ragged. 'You can drive, I can't. Let's go.' And she said she was glad to get home!" When he told me about the powerful experience he had of hearing God speak to him, he told me that he that after it happened, "That was the end of that. And I went on for [years]; I was shocked that I never really did anything with it. I tell people, I'm not stupid...slow, maybe...but not stupid." Even Sarah, who was so weak that it tired her just to talk to me, made some quips to the tape-recorder during our conversations. Speaking of her niece, whom she called "Sis," Sarah said, "She's not a spring chicken, anymore, either." Then, to the tape recorder, "I hope you don't ever hear this, Sis." Laughing, I replied that I had promised to keep the tape confidential, so Sarah went on, "I think she's 68--I'm sorry, Sis!" Hannah told me the story of her ovarian cancer, its diagnosis, treatment, response, and recurrence. She told me that now, her cancer markers were going up, and she kept collecting fluid in her abdomen that was becoming harder to treat. Further, her doctor had recently diagnosed breast cancer, but planned no treatment because she was not strong enough. She concluded, "Other than those few little things, I'm doing fine."

In my first job as a nurse, I worked on a psychiatric unit. A young woman was admitted who would become so fragmented that she could not speak in sentences. Even in that stressed state, she could sometimes crack a joke. When I expressed surprise that she could still make jokes, she would reply, "Not dead yet." There is a sense in which humor is an affirmation of life. During my sister-in-law's recent illness, she spent sixteen days in the Intensive Care Unit. As the staff began to lighten her sedation so that she could

respond a bit, we would talk to her and tell her about our days. She would mouth words around the breathing tube, and sometimes we could figure out what she was trying to say. One night, we were telling of our escapades that day recapturing one of my son's pet lizards that had escaped. Linda's daughter was able to decipher that Linda was repeating lines from a current television advertisement where a tiny Chihuahua dog tries to trap an enormous lizard-like monster. She was saying, "Here, leezard, leezard, leezard." I was amazed at the relief I felt. We began to believe that Linda might recover.

What is it about humor that is so important to life? Research studies claim that laughing and humor can reduce pain and promote healing (Abel, 1998; Beck, 1997; Richman, 1995; Sheldon, 1996). It provides a refuge from the serious concerns of life, and it stimulates thought. Humor requires that one grasp two ideas that have not been linked before. The surprising connection results in humor or "getting the joke." The quick turn of mental perspective is a little bit like a ride at an amusement park with its quick dips and turns that delight.

#### Adjusting to Life Anew

Once the participants had awoken to the reality of their illness and explored some of the meanings of that experience, they found that they needed to re-consider how they were living their lives, or perhaps more accurately, how they were filling their thoughts and their time. Suddenly concerns that seemed urgent could be dropped and matters that were given little time and thought moved into the foreground of their lives. Bone (1996b),

a physician and scholar who developed renal cancer wrote, "One of the things I have learned from the process of my dying is that the most important things in the process of my living were not what I--and most others--usually think are important" (p. 1931). The *present* (current time) does indeed become a *present* (gift) and takes on great significance and importance. After all, the present is all we ever have, but we usually take it for granted. Life-threatening illness changes that. It motivates us to *see* the present and want to unwrap the gift of everyday.

#### Changes in the Present Tense

One of the gifts in the experience of illness was a renewed awareness of the fleeting nature of life. Participants were more alert to the limited nature of life and they were determined not to squander any life they had left. They reordered their priorities and tried to be thoughtful about how they spent their time and energy. They paid attention to their "everydays." One effect for Margaret was that she found she was able to make decisions more easily now that her priorities were in better order.

I actually thought decision making would be harder. And in fact, it's actually easier, because it's like, "Don't sweat the small stuff and it's all small stuff"--that book? It's been kind of like that. It really does put life into perspective. What is truly important here? I don't get stuck in a lot of small decisions. It's very easy to clean my refrigerator now.

Margaret was expressing a paradoxical kind of freedom that comes with serious illness.

The threat of a shortened life freed her to pay less attention to the trivial concerns that had consumed too much of her time in the days when she was "well."

For Margaret, her focus changed from tasks and accomplishments to the people in

her life.

Those are the important--the people in my life are the things that are most important to me, not the things that I never accomplished--it's really the people. Since 1995, when I was originally diagnosed, I've made it a point to say things to people I thought were important to say. And be in contact with people that I thought were important to be in contact with....I never hang up the phone with anybody without telling them that I love them. I never do anymore. And another example is the conversations that I have with people, in general, just with anybody--I don't let something go by if there's something that is upsetting to me or I think I've upset them in some way, or that there's something that needs to be asked, I do it right then. I don't put off at all anything that I can't take care of right then.

In this text, Margaret has expressed not only that the people are important but also that she has ceased to be embodied in her future (Olson, 1993, p.112). Her changed perspective on her future has motivated her to live differently in her present.

A way that Daniel's present had changed through his experience of having a transplant was that he was more careful to limit the time that he spent feeling angry. He told me that he noticed that things bother him less. He described a time recently after an argument at work.

So I'm driving home, and it starts going through my head, "Wait a minute! [What am I doing?]" And I look around me, and the sky is blue, and I just say to myself, "Smile." And I smile, and it's like, everything lifts....I've also learned some things, relating to the relationship which my wife and I have...there are things I've struggled with for 34 years, and finally, just the other day, I realized, "Wait a minute, Daniel. You shouldn't worry about this. Ain't gonna change. This is the way it is. And all it's gonna do is mess up your immune system. Could cause you to go into rejection, and that's pretty stupid! Ain't worth it!"

Daniel's experience with life-threatening illness has changed his evaluation of what is worth worrying about. It has further changed his perspective on an ongoing problem with

his wife. He has re-evaluated what the disagreement could cost him and has chosen to set aside the issue.

Another way that Daniel's life had changed was that he found that he was more aware of pleasures in the world around him.

Another example [of how my life has changed since my transplant], is I'll be out walking. I've got a walk through the neighborhood, and I'll maybe smell some pine, or I'll see a tree, see, because I got training as a botanist, and it will bring back not only memories of going out into the field as a student, but it brings back the sensory perception as well. It's like re-living the experience, not just the thoughts of it, but also what you sensed. The sights, the sounds, the smells, and I'm not sure where that comes from...And it's really a strange feeling. And very nice. Because you can bring back those pleasant memories, but then they're more than memories--it's like re-living it.

Daniel has learned to see the forest and the trees--he notices what earlier he would have simply passed by. And his noticing is not limited to seeing--the smells and the sounds are now present to him in a way they were not before. It's not really learning--it's more an awakening--a seeing where once he was not exactly blind, but inattentive--a noticing where before he would not have noticed.

As I began to work on this analysis, I began to wonder about the words *present* and *gift* sharing a common meaning. I discovered they do not share common etymological roots. Of the five entries in *The Oxford English Dictionary* (Simpson & Weiner, 1989) for the word present, two are relevant to this discussion. The first entry traces the word present to the Old French and Latin word *praesens*. It is an adjective meaning "immediate...prompt" (Simpson & Weiner, Vol. XII, p. 395). Its meaning can relate to both the "present place" (p. 395) and the "present time" (p. 395). Thus, its current usage

to mean the immediate time and place is evident. The second entry of interest traces the word's roots to the Old French phrase *en present*, meaning "in or into the presence" (Simpson & Weiner, p. 396). It also is derived from other Romantic languages, namely, Italian, Spanish, and Portuguese, and its meaning in those languages is "an offering or a gift; a thing that is offered, presented, or given" (Simpson & Weiner, p. 396). Thus, a present is a gift that is brought into the presence of another.

The roots of *gift* are more surprising. It is an Old Teutonic word that originally referred to a *payment for a wife* or a *wedding* (Simpson & Weiner, 1989). (As it moved into Dutch and Old High German, it picked up an additional meaning--*poison*--an association that has completely befuddled this happily married writer.) One of its modern meanings is "something, the possession of which is transferred to another without the expectation or receipt of an equivalent; a donation, present" (Simpson & Weiner, Vol. VI, p. 503). It can also be "an offering to God or to a heathen deity" (Simpson & Weiner, p. 503) and it can mean "a natural endowment, faculty, ability or talent as in a natural gift, a gift of God or nature" (Simpson & Weiner, p. 503).

It would seem that for the participants in this study, there is a sense in which they have rediscovered the present. Rather than living as if, as Olson (1993) said, they belonged to the future and the future to them, they are noticing the present and experiencing it as a precious gift. Doctor Magrisso (1997b) wrote:

It is 95 days since my heart attack and cardiac arrest. I see this as a "second life," one I almost did not have. This part of my life feels like a gift. It also give life a "borrowed" quality. We are all living on "borrowed time," though it is rare to think of it that way. Mostly we feel ownership of our time, of our lives. We own them. This is certainly better than to feel we are

living as if someone else owned them...But, neither do we really own our lives either: We have been created. The first part of my life was a gift, too, but I never really saw it quite that way (p. 13).

Can that be true? Are our whole lives gifts? From whom? Magrisso (1997b)

suggests that even to call our lives *ours* is a distortion, because we do not *own* our lives.

What is it that makes us believe that our lives are ours and that we own them? Is illness a kind of poisonous gift that wakes us to see our lives in a new and clearer light? What would be different about our everydayness if we truly believed our lives were a precious gift?

In Alice Walker's novel, *The Color Purple* (1982) a colorful character named Shug suggests that in a cyclical kind of way, noticing and appreciating the present can be a way to give a gift to God—an offering or a way to say, “Thank you.” She tells her friend, “You can...praise God by liking what you like. [God's] not vain, just wanting to share a good thing. I think it [annoys] God if you walk by the color purple in a field somewhere and don't notice it” (p. 178). Shug casts the act of appreciating the present into a spiritual realm.

Daniel made a connection between God and the rich blessings he had received through his illness. It was difficult for him to find the words to express his thoughts. He said:

When you can see it from the perspective of looking back...God in His wisdom sees things, and says--because I've almost come to the belief that life is not--is not that important....There are other things that are a whole lot more important. And that's difficult to explain to some people. Because I don't want to say that life is unimportant, because it is [important]. And that's where I fall apart in trying to explain something....But to try even to say that life is important, but it isn't important, is difficult to explain.

For Daniel, there were things more important than life itself. Why should that be an easy thought to explain? Life is all we know, so of course it is important, but faith suggests something even more important than life. Yet that more important value is something we do not see clearly. We take its existence and its importance--on faith!

Campolo (1986) has written a book called *Who Switched the Price Tags?* The title refers to a prank he imagined as a child. He and a friend imagined what confusion they could cause if they sneaked into the local dime store and switched around the pricetags so that inexpensive items were marked with high prices and expensive items were marked with low ones. He suggests that prank as a metaphor for modern life. Someone has switched the price tags so we chase after fame, wealth, and material possessions, and we ignore things of lasting value. We rarely stop to notice and appreciate the extravagant but priceless blessings we encounter every day--loved ones, time with children and family, sunshine, health, the color purple. Illness can call us to attend to the irreplaceable taken-for-granted--to *spend* our time cherishing what we love most.

The effort to resist the cultural emphasis on material wealth and fame and to turn again toward things of lasting value echoes Heidegger's (1993) call to live an authentic life. One who strives to look inward to personal values rather than outward for social approval is moving toward becoming a being-toward-death, an authentic person.

Still, it would be a mistake to suggest that the present is always a desirable gift. Sarah's present was characterized by overwhelming fatigue.

What is the most important? Well, the most important thing is for me right now, I hope God's listening, so that He takes me soon, because I'm getting

very tired. Very very tired of getting up every morning and taking a shower, and trying to, Oh, I don't know.

For Sarah, even trying to describe her daily life was a chore. Sarah's present was a time to be endured, not cherished. She longed for death as a welcome rest.

### Adjusting to Illness

Though there were ways in which illness brought gifts and blessings, participants did not in any way suggest that illness was unequivocally good. The word *ill*, after all, derives from Indo-European words that mean "bad" (*OED*, 1992) and "evil" (*OED*). The very fact that blessings come within illness and suffering suggests a kind of reverse Trojan horse, for unlike the Trojan Horse that brought harm within the form of a gift, illness sometimes brings good within an evil form--illness. For most of us, evil is too strong a word, but it is a universal assumption that illness is bad. In this section, I will turn my attention to facets of the experience of illness that were seen not as gifts but as intrusions.

After one has "awakened to a new life" of life-threatening illness, this new life must be adjusted to--made room for--gotten acquainted with. One has a new roommate--an unwelcome new roommate--who is here to stay. Adjustments must be made and made again. Like a roommate, an illness is seen as something that is not part of oneself. It is an "outsider"--something that has come from elsewhere--yet it lives in close proximity. Like a roommate, it demands adjustments to its presence. Roommates may play loud music or leave wet clothes on the bathroom floor or dirty dishes in the sink. These intrusions require adjustments in one's everyday life. Getting up and getting ready in the morning take longer. Perhaps one cannot be gone from home as long. Everyday activities are

interrupted. This roommate's arrival may be sudden, as when illness is discovered on a routine examination, or it can be a gradual dawning awareness. Susan Sontag (1977) compared the experience of cancer with the experience of tuberculosis in the era before effective medications could treat tuberculosis, saying, "Now it is cancer's turn to be the disease that doesn't knock before it enters, cancer that fills the role of...a ruthless, secret invasion" (p. 5). Broyard described this adjustment as a journey, saying, "I saw my illness as a visit to a disturbed country, rather like contemporary China" (1992, p. 21). When I asked Addie what it was like to have a life-threatening illness, she replied with marked understatement, "Well, it's not a lot of fun. Sometimes it's scary. It's very intrusive. I had another life before this, and I can't seem to get to [it] anymore." For Addie, illness was scary and intrusive.

*Intrude* derives from the Latin *intrudere* meaning "to thrust or push" (OED, 1992). An intruder is an unwanted visitor. It is not an invited guest. It has thrust or pushed itself into one's life, and adjustments must be made. Of course, some of the adjustments relate simply to changes in the physical body--symptoms are now present that were not there before. There are also changes in how one views oneself, and there are adaptations made to accommodate the physical changes. Medications must be taken because they are essential for maintaining what health is left or for treating symptoms, but they may also have unwelcome side effects that must be endured or accommodated. In the following section, some of these issues will be addressed.

## Eating

Eating is one of the ordinary experiences that is cast in an extraordinary light though life-threatening illness. Eating took on heightened importance for many of the participants. It has such a central role in our lives. Of course, food and water are essential for survival, but food represents much more than that. Obtaining, preparing, and consuming food are fundamental human activities. Meals are social events--a time when families or friends may gather together for a little while before or after they scatter to their individual activities. Eating, and the tasks that surround it are part of every single ordinary day. Whenever participants had a disruption in their ability to eat, therefore, it was troublesome. Eating became a symbol of health--If a person could eat, she was doing all right. If a person could not eat, she was doing poorly and if she didn't start eating soon, she would die. Eating provided a daily reminder of the connection between bodies and life. Eating well was seen as an indicator of good health and vitality. For families, getting the patient to eat was a primary concern. If the patient was not eating, the family generally intensified efforts to get the patient to eat. It was hard for them to believe that they were giving their loved one good care, if they could not even get her to eat! Providing nutrition is a fundamental part of providing love. In my hospice practice, I have found that most patients do stop eating and drinking in the days before they die. At that time, it was always very important to help the caregivers separate the giving of love from the giving of food and help them to see the many ways in which they were still demonstrating their love now that the patient was not eating. So weighted with meaning was the issue of eating that, if

the participants expressed concerns about not being able to eat, I did not have to wonder why. Mona told me:

Well, I was on some rather strong...and it was also causing a *major* problem. Number one, constipation, number two, all you want to do is sleep all the time....lose your appetite completely. I couldn't even look at food. Well, now, I'm tapering off that. But the sooner I get off that, the better it'll be. And I've noticed, my appetite has increased. I can taste food. The taste wasn't there. It was just..."You better eat this, Mom, or you're not going to be able to walk around." [I remarked, "Yes, that's dreary to eat because you're supposed to, instead of because you enjoy it."] Yes, and everybody's concerned and after a while, you think, "Leave me alone. Just leave." Because it wouldn't go down. [I added, "And sometimes if you force it at a time like that, it just comes back up and you feel even worse."] Yes, yes, I've had that problem, too.

As Mona expressed, disturbances in the ability to eat could also cause disturbances in the relationships with families. Families became frustrated with the patient because she "wouldn't try harder" to eat, and the patient became frustrated with the family because they continued to push the patient to do something she believed she really could not do. The conflict became one more problem for patient and family alike.

### Medications

Most people who are ill take medications. In *The Oxford English Dictionary* (Simpson & Weiner, 1989), discussions of the word *medicine* provide clues to the meaning of the experience of taking medicine for those who are ill. Medicine is "any substance or preparation used in the treatment of disease...now commonly restricted to medicaments taken internally" (Simpson & Weiner, Vol. IX, p. 549). This relatively straightforward definition is not the only sense of the word, however. Though medicine can be "an effectual remedy, a cure" (Simpson & Weiner, p. 549), it also has less pleasant

connotations. To *take one's medicine* is "to submit to or endure something disagreeable; to learn a lesson;...a dose, taste, etc. of one's own (kind of) medicine...is repayment or retaliation in kind: 'tit for tat'" (Simpson & Weiner, p. 549). Thus, we see that taking medicine is not always neutral or good. The suggestion of deserved unpleasant punishment lurks under the meaning of the word. One can see why resistance to medicine could be psychological as well as physical.

Someone who is ill may not have the luxury of avoiding medication, however. Medications can be critical for maximizing one's health during illness. Commonly, medications will have both desirable and undesirable effects, and it is a continuing challenge to find the combination that will maximize the former and minimize the latter. Nevertheless, taking medication becomes a part of the day. In the following excerpts from Sarah, she expressed the trade-offs she made with her medications.

I don't take that [MSIR--short acting Morphine] too often. Only when I absolutely have to. When the two don't work, when the two Nitrostat don't work, then I take the MSIR.

In this passage, one can see that medications are not a straightforward experience for Sarah. She takes MSIR only when she absolutely has to. The unspoken message is that she would prefer never to take it. She takes it only when she believes that she has no choice.

But I also take MS-Contin, and I think that's the one that clouds your mind because I take that in the morning when I get up at 8 o'clock, I take that. And that clouds your mind....But when you take this certain pill, it's a pain pill, and it does cloud your mind I want you to know. It really does. And it keeps you from thinking like you should. I know that, very definitely. In the morning, I'm bright and cheery, and when I take that pill, oh boy. Then, of course, I have to take other pills for heart and blood pressure, et cetera,

et cetera.

Notice that in this passage, Sarah does not mention any benefits of her medications. We can infer that the medication helps with her pain, but she does not tell us that the medications help her in any way. What she is mindful of is what her medications cost her in her everyday life. What is it like willfully to take a medication every morning that “clouds your mind?” Before the medication, Sarah feels bright and cheery. The medication takes that from her. In this passage, it appears that for Sarah, it is the medications as much as the illness that have thrust themselves into her life.

Daniel also had many medications to take. Because he had had a transplant, he was at constant risk for rejection. He believed a strictly followed schedule would increase his chances for health. He experienced his need for frequent medications in a very different way from Sarah’s experience.

...taking my pills reminds me. Taking pills must become almost like a devotion. You know, you’re doing something on a regular basis like the desert fathers did, you know, and of course, with me, I constantly feel the tightness [in his chest] sometimes there’s pain, whatever--feels like sometimes a rubber band, a steel band. So there’s a physical reminder of what’s happened.

Rather than resent their intrusion into his day, however, he had found a way to welcome the frequent interruptions. He chose to see his symptoms and the interruptions as a spiritual discipline that nourished his body and his spirit.

My husband has a friend who contracted Parkinson’s disease at age 34. Six or seven years later, I attended a group where he told the story of his spiritual journey since developing the disease. He, like Daniel, had found a way to conceptualize his illness in a

way that fed his spiritual side. As the symptoms and medications were never far from his conscious mind, he said, “God keeps me on a short tether, and that’s not all bad.” Like Daniel, he had found a way to construct a deep and powerful positive interpretation of circumstances that he could not change.

### Body Image

In Chapter Three, I introduced the phenomenological view that we are embodied persons--that up until the moment of death, we experience the lifeworld through the senses of our bodies. When we are healthy, we may pay little attention to our bodies, using them almost as “tools” that take us where we want to go. In illness, however, the everyday experience of the body is altered, and we are forced to experience our bodies in a new and unfamiliar way. Daniel spoke of his almost constant chest tightness as a “physical reminder” of his transplant. Mona and Margaret also described what it is like to adapt to this “new” body. Margaret said:

It’s been hard. I mean, and the hardest thing has been coping with the things that were probably the least threatening. Hair loss was one. Colostomy was another one. And I was surprised at that. You know, I made the decision that they would go ahead with the surgery knowing that they were going to do a colostomy. I thought, okay, no big deal. I could be dead, so that’s not a big deal. So I was surprised at how hard that was....That was real--that was *hard*! It’s really hard to figure out what you need to do to maintain on a daily basis, and I mean, it is just unrelenting. I mean it’s just there to deal with all the time.

According to *The Oxford English Dictionary* (Simpson & Weiner, 1989)

*unrelenting* means “not softening or yielding; especially not giving way to feelings of kindness or compassion” (Simpson & Weiner, Vol. XIX, p. 165). For Margaret, the

presence of her colostomy was a constant reminder of all she had been through. Because it was so visible, it was unrelenting--never yielding nor giving her a respite from the harsh reality of her illness. For Margaret, this was particularly surprising, because she did not expect her adjustment to be difficult. Yet her response to the experience of having a colostomy was very very different from the way in which she imagined it before her surgery. *Lived* experience can be dramatically different from expected experience.

Margaret continued:

And the other thing was hair loss. I didn't think the hair loss would bother me. But it did the first go-round. The second go-round, it hit me really hard. This time. Because, what I realized was that when I lost my hair, I wasn't going to have time for it to grow back again. When I stop the medication, I will have, maybe, three months...That's just not enough time for it to grow back....That was a surprise. I was surprised at how much that affected me.

Again, Margaret had not expected the experience of hair loss to be hard, but it was. The second time it was even more difficult. Hair is a principle "fashion accessory." Particularly for women, hair is an important piece of body image. When Margaret lost her hair the second time, it was a loss, not only of a physical trait; it was a loss of the self that appeared in her mirror--of the self that she presented to the world. It was particularly difficult because Margaret believed it to be an irrevocable loss.

Both Margaret and Mona were also affected by other changes in their bodies.

Margaret said:

I've been surprised at the way my body looks now. (laughs) I mean, it's incredible. I have so many scars on my stomach. I have--oh, it's just an unbelievable thing. And I guess the surprise is that you can survive something like that. That surprises the hell out of me.

Margaret's body is so changed that she does not recognize it as her own. Whose body is this! Where did it come from! How is it possible that anyone could survive this much surgery! Margaret's body is hers and it is not hers. Her embodiment is altered.

Mona also had numerous scars. Notice how she describes herself.

I had a biopsy. I had about a million tests. Eight, actually. Then I had another biopsy. Then I had all--all this was supposed to be was a biopsy, then it wound up going further and further, and I had one surgery on Monday, and then I had another biopsy on Thursday. Which my doctor did not understand. So I am cut up like a--a chicken really.

When Mona says that she had a million tests, she is telling us that the tests seemed unending in number. They went on and on and on. She found herself on a road she had not intended to go down. It was supposed to be only a biopsy, but the treatments took on a life of their own. In the process, Mona lost the sense that her body was treated with the dignity it deserved

*Unrelenting. Surprised that a person could survive that. Cut up like a chicken.*

These phrases speak to the dramatic changes in the lives of the participants.

Mona's and Margaret's descriptions also open a window onto how intrusive multiple surgeries can be. Every time Margaret sees her unclothed abdomen, she is surprised that a person could survive so many extensive surgeries. She is surprised that a body can withstand so much invasion and yet prevail. Mona describes herself as "cut up like a chicken"--like an inhuman object that is slaughtered for food. These are momentous changes in the ways they experience their bodies.

Broyard (1992) has described in a very vivid way how his illness awoke in him a

new appreciation for the every day functions of his body. It is an exemplary description of the concept of breakdown and of how a breakdown calls to our consciousness parts of our everyday world that we did not previously notice because we took them for granted.

In the first stages of my illness, I couldn't sleep, urinate, or defecate--the word "ordeal" comes to mind. Then, when my doctor changed all this and everything worked again, what a voluptuous pleasure it was! With a cry of joy I realized how marvelous it is simply to function. My body, which in the last decade or two had become a familiar, no-longer-thrilling old flame, was reborn as a brand-new infatuation. (p. 7)

How marvelous it is simply to function! Function is a mechanical kind of word. It implies unnoticed ordinariness. In Broyard's writing, however, we see how very important functioning is. Broyard's illness woke him up to the thrill of the everyday functions of his body.

Broyard (1992), infatuated by his body, had some unique suggestions for physicians to ease the pain of a patient's changed body image. He wrote:

I wish my doctor could somehow repersonalize [my illness] for me. It would be more satisfying to me, it would allow me to feel that I *owned* my illness, if my urologist were to say, "You know, you've worked this prostate of yours pretty hard. It looks like a worn-out baseball."

It is only natural for a patient to feel some disgust at the changes brought about in his body by illness, and I wonder whether an innovative doctor couldn't find a way to reconceptualize this situation...The doctor could use almost anything: "Art burned up your body with beauty and truth." Or, "You've spent yourself like a philanthropist who gives all his money away." (pp. 47-48)

Broyard admits that his suggestions are half playful, but suggests that playful thinking can sometimes lead to new and helpful ideas. Broyard's words suggest that a person is comforted by thinking he or she had some part in developing his or her illness, and that

part was not all bad. If illness is the consequence of a life well-lived, it could be less anonymous. The unknown intruder might be seen somehow less as a stranger and more perhaps like a dysfunctional cousin.

For Mona, Margaret, and Broyard, illness has “made the familiar strange.” They saw their bodies in a different light.

### Fatigue and the Importance of Doing

For some participants, fatigue was a particularly oppressive problem. Being alive usually means being “up and around”--able to do things. As the saying goes, we are raised to be “human doings” rather than “human beings.” When illness caused fatigue, the resulting inactivity was problematic.

For Sarah, fatigue was especially difficult to tolerate--so difficult that she said, “I want to curl up in a ball many times.” Sarah’s fatigue and weakness were caused by progressive heart disease. Her ability to perform what nurses call “the activities of daily living” was compromised. It is extremely unlikely that Sarah’s fatigue will improve; instead, she is likely to become more fatigued with each passing day. As she speaks she makes clear that the fatigue, for her, is a physical kind of suffering, saying, “Oh, yeah, my body is so worn out, Janna. And I ache all over.” It is also difficult, though, because it inhibits her ability to do things and, therefore, her ability to feel useful.

Every day, you think, wow, you’re so miserable. It’s so hard for me to get out of bed, and I fight with myself in the morning--getting out of bed. It’s so hard for me to get out of bed because my body is just--I’m so tired all the time. Tired...oh, I don’t know what to tell you about that. I just don’t have the energy. You can’t explain to another person, you can’t, what this lack of energy, because it’s like...it’s an effort to walk. It’s an effort to go and make a meal. And mostly, now, I did a lot of cooking and that, I

always cooked a lot. But now, I...TV dinners, or Healthy Request, or things like that, or....that's it. And I used to be able to go out to lunch...go out to dinner once in a while. And it was wonderful. And the family got together every year here. Christmastime, Eastertime, Fourth of July, et cetera. Christmas. New Years. All of those things are gone.

Sarah depicts every day as a struggle. She “fights with herself” every morning. In the phrases “fight with myself” and “My body is just...I'm so tired” Sarah reveals that there are parts of herself that are in conflict. She does not experience herself as “One.” The Sarah who wants to stay in bed fights with the Sarah who wants to get up, yet both are Sarah. She starts to say “my body is tired,” but changes that to “I'm so tired.” Underneath her words is the suggestion that there are parts of her will that are no longer embodied. The tired body that she has can no longer accommodate her willful, motivated desire. Ordinary activities like walking and preparing a meal are not fluid movements any more. They are efforts.

Sarah speaks also of the isolation and loss that her fatigue has brought. She does not believe that another can understand the way that she feels. She is alone in her weariness. She grieves the loss of the outings and holiday celebrations that were so important to her. Her fatigue prevents her participation in those social events.

*Fatigue* is descended from French and Spanish words. It means “Lassitude or weariness resulting from either bodily or mental exertion” (Simpson & Weiner, 1989, Vol. V, p. 763). It is also “a condition of muscles, organs, or cells characterized by a temporary reduction in power or sensitivity following a period of prolonged activity or stimulation” (Simpson & Weiner, p. 763). Fatigue, as a verb, means “to tire, weary; to harass with toil;

to exhaust with labour” (Simpson & Weiner, p. 764). Although Sarah’s fatigue has been caused by illness, not by work, she feels exhausted with labour. The physical weariness of fatigue leads to mental and emotional weariness as well.

Margaret also experienced fatigue, but it was not nearly as severe. Even on her worst days, she was still able to get up and move around. One can see, embedded in her words, however, the importance of being able to *do* things. Doing--being active--like eating, was another sign that things were going well. Not being able to do, like not being able to eat, was an ominous sign.

I’ve found that I have a [chemotherapy] treatment on Wednesday, and Wednesday, Thursday, and Friday are pretty much the pits. But I can do some things. I can still do some things. I can run a couple errands with some help. So I still get out. I still get to see people. The rest of the week is really very good. I can manage on my own. Driving my own car.

Though some days are “the pits,” they are tolerable because Margaret can still *do* things.

Just how important doing is is illustrated in the following text from Sarah:

[I think, in this country, we tend to kind of value somebody by the work that they do, and if you can’t do work, then ...] How true, how true. What you’re saying is very true. And even the menial tasks that people do should be respected, I think. Very much so. [But that leaves someone like you who has trouble doing any work. Then it sort of leaves you wondering....] Yeah, I know what....That you’re nothing. That you’re really nothing.

Sarah felt that if she could not *do*, she had no worth. The work ethic, so deeply embedded in our collective consciousness, erodes the self esteem of those who cannot be active.

*Do* is a word descended from Indo-European and Sanskrit bases meaning “to put, set, place...to set down, ground, establish” (Webster, 1966, p. 428). In the context of this discussion, it means “to perform; carry out; fulfill...to finish; bring to completion...to be

active, as in ‘do, don’t talk’” Webster, p. 428). When Margaret and Sarah are too fatigued to do anything, they feel ungrounded, unfulfilled, and inactive. An insidious sense of incompleteness and frustration mars their days.

Margaret found a creative way to interpret her own inability to work. She disliked thinking of herself as disabled and said:

It took me a long time [to recover from surgery and chemotherapy]. I wasn’t working full time until almost the end of December. I went back part time to begin with. It really socked me. Socked me. And then I only worked six months before I had a recurrence. Then I went on permanent disability. I consider myself retired! (laughs).

Retirement holds the image of closure and completion that disability does not.

The issues of activity and self-care were very important to the participants. When they could not care for themselves, that inability opened a whole new area of concern: their own dependency and the burden that dependency put upon caregivers. While they were very grateful for the help they received, they also felt diminished by their need for help, and they worried about the added work that their caregivers took on to care for them. These issues will be explored in more depth in the discussion about the role of community that begins on page 175.

#### The Need for Closure and the Desire for a Legacy

Two closely related ideas have emerged in my study of the experiences of people with life-threatening illness. One of those ideas is the need for closure--that is, the feeling that one cannot die until one’s life is “finished,” or until some necessary work is done. In hospice literature, it is common to read of patients who seem to hang on to life until some

special milestone is reached—a daughter’s wedding, the birth of a grandchild, or resolution of a family problem, for example (Byock, 1997; Callahan & Kelley, 1992). Broyard (1992) referred to the work of Lisl Goodman, who together with her students, interviewed over seven hundred people on the subject of death. She wrote, “I don’t think people are afraid of death. What they are afraid of is the incompleteness of their life” (cited in Broyard, p. 78). Broyard tied Goodman’s work to the experience of a friend of his who was a professional writer. This friend, a young man of forty-seven, had published stories, articles, and reviews, and had co-authored a book on architecture. Still, he felt that unless he finished his novel before he died, his life would have been a failure. He took a minimum of pain medication and rigged up a fancy contraption so that he could type while lying down. Broyard suggested, “Perhaps he pretended to himself that so long as he was still inventing he couldn’t die” (p. 87).

There is a story by O. Henry (1953) that has much the same theme. Two young women share an apartment and become friends with an elderly artist who lives downstairs. The artist is struggling to create a masterpiece, but has not been able to do it. One autumn, one of the young women becomes very ill. As the weather worsens towards winter, so does her health. She becomes discouraged and begins to consider an ivy vine on the brick wall just outside her window. Resplendent with the dying colors of autumn, the vine loses more leaves each day. To her roommate’s dismay, she becomes convinced that when that last leaf falls, she, too, will die. One night, there is a terrible cold, windy rainstorm. The woman is sure that the last leaf will fall that night and that she will, therefore, die the next

day, but in the morning the leaf is still there--as it is the next morning and the morning after that. The crisis passes and the woman, never having received the closure she sought, recovers. She discovers that the "leaf" that held her to this earthly life was not a real leaf at all, but a masterful painting created on the wall outside her window by their neighbor the night of the storm. Because the story is by O. Henry, however, there is a twist at the end. The artist becomes ill from his exposure during the storm, and he dies. But then, he dies satisfied because he has finally completed his masterpiece. It would be cruel to suggest that death never cuts a life short until the liver of that life is ready to leave, but these accounts in the literature reflect a common and powerful human motive.

A closely related idea--the need for a legacy--was expressed only by Margaret.

Speaking of a recent visit with her brother, she said:

And so we walked, every night after dinner, we'd go out for a walk. And some of the walks were longer than other nights. And one of the things that I told him was that initially when I was diagnosed, I thought, "Oh, I can't, not yet! I haven't done anything significant." And I really hadn't. I had nothing. I had just bought his house, but I never owned a house before. I thought, "I can't die thinking that my greatest accomplishment was that I finally bought a house." But what I've realized through this is something that you just said about calling everybody you love and making sure that they know is that so many of my friends and my family have made it a point, too, to do those same things, because of what's happened, and I thought, "Well, you know, that is not a bad legacy. That is not bad. I can live with that."

Margaret said, "I can live with that," but she also meant, "I can die satisfied with that." She had identified her legacy.

*Legacy* is a word descended from the Latin word *legatus* itself a form of the Latin word *legare*, which means "to send as ambassador." When in its modern form, *legacy*, it

means anything handed down from an ancestor to a descendant. Of all the participants, Margaret may have been most interested in identifying her legacy because she was young (in her early fifties), she was very likely to die from her illness, and she had no children of her own. Perhaps for her, sending something as an ambassador to those who will outlive her, even though they are not direct descendants, took on particular importance.

During our second conversation, Margaret spoke more about this legacy. She believes that her life could have been spared if her gynecologist had performed a fecal exam for occult blood (she called it “the little poop test”) during any of her routine examinations. She had written to him to tell him of the consequences of his omission and had received a thoughtful letter in return, but it did not have the assurances of action she had hoped for. With help from friends, she was preparing an open letter to physicians that she planned to submit to several medical journals. The letter exhorts physicians to “spread the word” to be sure that many more people received this important cancer screening. She had further been in touch with friends at a local university hospital who were changing the routine forms to prompt clinicians to perform the test. Other friends were addressing envelopes and engaging in a physician-awareness campaign as a way to support Margaret. I remarked that even if she does nothing more, it sounded as if she had moved the cause of cancer screening forward. I said, “It’s more of your legacy, too. You had talked about needing a legacy.” She replied, “The poop test will be my legacy!” and burst into laughter.

Another more personal attempt to define her legacy was not as merry, however. Her brother had called her in tears one night and asked her (for reasons she could not fully

understand) to re-write her will to give his portion to their sister. She said,

And I tried to talk to him about it, because what he hadn't realized was what he was asking me to do, which was, you know--most of the time I'm pretty strong, but when we were doing that will and putting my affairs in order was one of the hardest things I've ever had to do. We just don't want to think about it. And I think it's easier when you're well than when you're sick, because you know that all of this stuff is going to come to pass. So I thought, "Oh, no. I'm not doing that!"

Writing her will, planning in a concrete way for her death and for her belongings to pass on to others, was one of the hardest things she had ever done, and she had endured some very hard things! She had had 11 surgeries, one of which removed two-thirds of her liver. For Margaret, she wanted to have her affairs in order, and she had accomplished that task, but it was not a task she wanted to do again--in spite of her brother's tears.

Some intriguing questions arise out of this examination of Margaret's experience.

What does it mean to do something significant? What marks an accomplishment as significant? What is the quest to have one's life amount to something? What does it mean to have one's affairs in order or not in order? What is important to understand in order to bring closure or satisfaction to a life?

### Living in the Shadow

All of the participants were living in an "in-between" kind of time. They had contracted a life-threatening illness, but they weren't dead yet. They had left behind a life that felt ordinary and had entered a life that felt extraordinary. Although no one, healthy or ill, knows what tomorrow may bring, the participants lived in the shadow of a threat that felt more "real." There was a sense in which they were "waiting for the other shoe to

drop.”

Of all the participants, Daniel was in the most robust state of health. He was recovering well from his lung transplant, and was working three days a week at his office, and two more days at home. Still, in the back of his mind, he knew his illness could worsen again. He wondered if it was sensible to begin an ambitious remodeling project in his house. Would he live long enough to enjoy it? In an earlier section of this chapter, I related that Daniel thought of his frequent medications and his physical symptoms as a kind of spiritual discipline. Here, I present a continuation of his thoughts.

So there's a physical reminder of what's happened. And as a consequence, it's never still far from your thoughts. Man, this is still a serious issue! And there are times when I stop and think, when I go in for the next bronchoscopy, they're going to find rejection. It's going to be chronic. Chronic rejection is tough to deal with, and they really can't do much about it. So, it's still in the back of your mind that you have a life-threatening illness.

Though he was doing well, he always carried the knowledge that any day his health could begin to decline.

Margaret, too, was living in a waiting, unknowing time. She knew she had cancer. She was undergoing a course of chemotherapy, but she did not know if her tumors would respond to the therapy. Her doctor had told her the chemotherapy was effective in only twenty percent of the patients who received it. She was tolerating the chemotherapy fairly well, though her fatigue was increasing. As she considered whether or not to continue with treatment, she said:

Without this chemotherapy, they gave me an estimate--you know how they are about estimates--they don't know--It could be tomorrow, it could be whatever....I guess I'll keep on plugging if I can keep on having this

particular experience [meaning, if the side effects get no worse]. Maybe we're about at the point where we're at the maximum accumulation [of side effects]. I don't know. Hope so. I'm afraid to ask...And then, I'll have a CAT scan on the 14th, and then we'll know if it's having an effect.<sup>15</sup> Basically, I think it is, but I'm not as sure about that, because I'm having more pain. Than I was having. It's not constant. It's intermittent. It's not anything I take anything for, because it may be misinterpreted, but it's more. So that makes me wonder, but then there's some other stuff that's gone away totally, so I don't know. [The bleeding] stopped. Hasn't come back...so who knows? It'll be a surprise!

In this passage, Margaret suggests that not knowing is sometimes desirable. She is wondering if the chemotherapy has had an effect, but beneath her words is the suggestion that she is in no hurry to find out. While she yet does not know, she can continue to live her life as it is, and she can continue to hope for the best. She is afraid to ask because she does not want to hurry the known. Living in the shadow of what could be very disappointing news, Margaret has chosen to live awhile with the unknown. What is it like to want to approach one's unknown future and yet want to avoid it? What is it that simultaneously draws us in and intimidates?

In the preceding passage, the tape recording illuminated a detail that is hidden in the written word. For most of that discussion, Margaret had spoken in a serious contemplative tone. At the end, however, her demeanor abruptly became playful as she suggested, "It'll be a surprise!" *Surprise*, of course, placed a rather festive air on what could be very ominous news. It was a way of softening the threat of what may be in

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<sup>15</sup> The CAT scan on the 14th showed that indeed, the tumors were responding to the chemotherapy. She was in the "lucky" 20 per cent who responded to that medicine. On the day that I called and heard the good news, I was the second person to suggest she should buy a lottery ticket!

Margaret's very near future.

Thinking of this time in their lives as *living in the shadow* calls up several images and associations. There is, of course, the association with "The Twenty-third Psalm," a scripture verse that is widely quoted by Christians in times of trouble (*Psalms*). The psalm presents the image of God as shepherd and God's people as sheep. The psalmist wrote, "Even though I walk through the valley of the shadow of death, I fear no evil; for Thou art with me" (verse 4). In truth, however, this verse is usually quoted when a person does indeed fear evil. It is used as a reassurance against evil—a reminder that God will care for and sustain God's people in all circumstances. *The Merriam-Webster Dictionary* (1998) traces the word shadow to Middle and Old English words from before the 12th century that meant *shade*. A shadow is "the dark figure cast upon a surface by a body intercepting the rays from a source of light" (*Merriam-Webster Dictionary*). Though a shadow can be "shelter from danger or observation" (*Merriam-Webster Dictionary*), it can also be "a source of gloom or unhappiness or a state of ignominy or obscurity" (*Merriam-Webster Dictionary*). It is these latter associations that apply to illness. Light is a ubiquitous symbol for knowledge, understanding and goodness. Dark, of which a shadow is a part, is a symbol of separation from all that is good and is seen as a source of evil. Participants experiencing life-threatening illness felt themselves to be somewhat threatened with separation from life and light, and menaced by threats of the dark.

In earlier sections of this chapter, we saw how life-threatening illness could bring blessings and a new awareness of the sanctity of the present. Could it be that encountering

and living into the shadow of the threat of life-threatening illness can be a path to growth and wholeness? Herb Kramer (Kramer & Kramer, 1993) would answer, "Yes." He and his wife, Kay, wrote a book about their final earthly journey together. Reflecting on his experience of having terminal prostate cancer, he wrote, "Since there is no escaping death's company, doesn't it make sense to call it out of the shadows and make its acquaintance?" (p. 30). With Kay's help, he continued to try to make death's acquaintance. He believed that while his body got smaller and more diseased, his spirit grew. He claimed that "the smaller his body got, the bigger he felt" (p. 225). He became more aware of nature and his own spirit and his relationships to others. He also experienced increasing "numinous dreams and visions" (p. 225). There is no denying that death carries with it the promise of pain, suffering, and loss. Is there a way, however, in which death also offers what Kubler-Ross (1975) has called "the final stage of growth" (p. 145)?

### The Dance of Family, Friends, and Community

The experience of having a life-threatening illness affects an individual in many ways. Because individuals live in community, however, the illness affects others within that person's social circle as well. In the late part of the twentieth century, many people spend less time socializing than did the people of a generation ago. Two career families, scattered extended families, or perhaps just the hours spent watching television make us less available for casual social gathering. Rarely do we sit on front porches and chat with

neighbors as they pass by or go to each other's homes for a leisurely cup of coffee. Yet, for the participants in this study, when they found themselves in need, the community rose to the occasion and was available to help. Daniel said, "People took my wife down to the hospital, in the morning, came and picked her up in the evening, and when we came back, they brought meals over." Margaret was overwhelmed that her friends had not let her be alone for a single night for months.

### Family and Friends are Essential

Earlier in this chapter, I presented the important place of family in both the blessings and the suffering of participants. There is an additional aspect to family, however, and that is the role the family and friends play in the participant's survival. Perhaps not survival in the literal sense, but the participants left no doubt that the presence (presents?) of a community had a tremendously positive effect on the quality of their lives.

I have beautiful people with me--my children, my friends. Just beautiful people. Who are supportive, who have, you know, been there for me, and that's so important. Not just important. Vital. It's absolutely vital. (Mona)

*Vital* is a word derived from the Latin word *vita* meaning *life*. Mona's use of it here is in the sense of "essential to the existence of something;...absolutely indispensable, necessary, or requisite. Also, of supreme importance" (Simpson & Weiner, 1989, Vol. XIX, p. 701-702). I knew that Mona was not telling me that she would literally die if she were deprived of the people who love her. Her life would not end in the same way it would end if she were deprived of water or oxygen, but her friends and family brought an essential quality to the life she was living now. If she were isolated, the life she would lead in isolation

would be so different, it would seem not even to be the same life. Her friends and family were vital to the life that she was living now. Though it is hard to describe, the support Mona received from her family and friends transcended the realm of emotional support. When she described support of friends and family as vital--essential to existence, she moved that support into the physical realm as well.

Margaret, too, talked of friends and family as having strong positive effects on her, both physical and emotional, after her surgery.

Hearing from people has been very helpful. Even if it's just a little note. People that I haven't talked to for years. A woman I went to high school with...sent me a card with maybe one or two lines on it, and it's not what they say. It's the fact that they took the time to sit down and put a stamp on an envelope. And send it to me, that they were thinking about me. I have found that to be so powerful. I have told people. It's not as evident now, because I'm doing so much better, but those times when I was feeling horrible, when I was in the hospital recovering from liver surgery. I actually picked up strength from that. I mean, physical strength. From getting a card in the mail from somebody who was thinking about me. It just helped me feel...stronger. It's the only word I can think of. But physically, it had an effect on me. Not just emotionally...somehow that got translated you know, into my muscles. I don't know. But I found that I would have a little more energy, say maybe to walk a little longer, or eat a little more, which is really difficult after liver surgery. Eating is really really hard.

Margaret is saying a remarkable thing here. She is saying that emotional support from people who are not physically present supported not only her emotions, but her physical strength. Perhaps it happened through the mediator of her emotions, but the message is still the same--that emotional support is also a kind of physical support. Hidden beneath Margaret's words is a comment about the gift of time. The fact that a friend took the *time* to choose a card, write a message, and put a stamp on the envelope was a

meaningful gift to Margaret. It is an example of a small but personal gesture that had deep significance--the extraordinary in the ordinary.

There were other ways that Margaret received support from others. Friends helped her gain a sense of mastery over her own story by listening to her, and she derived particular joy over celebrating holidays with her family.

People asking me about it has been helpful. Like I used to tell clients, you've been essentially in a car crash. And the more often you tell the story, the more powerful you'll feel about it. Now, I don't feel like I can burden people with my story, but luckily people ask me about it....And I'm lucky I'm in an age group where people are pretty comfortable with those kinds of questions, and boy, if I'm asked, I talk! I do. And that's enormously helpful!! And we have--sometimes people in the store--people you just bump into--sort of get into it--a thing--where it might not be about the fact that I have cancer and I'm dying, but it might be something related to not working or disability, which I also have strong feelings about. I don't want to be disabled. Especially when I was a runner! You know, I was running, and I'm suddenly disabled. So, you know, sometimes, I'll hang up that sticker on the car, and somebody'll just walk by and make a comment about it--a nice comment about it--and maybe they have a sticker, too. And so we'll just talk about how different life is. Having those stickers on our car. So that's been helpful....So, you know, those kind of things really help. And then, of course, my family and my friends. I have one friend who called me every day. You know, it's really just, "Hi, how's your day?" Kind of thing. But she'd call every day! And that's been--I can't--I don't even know where to begin with how helpful those kinds of things--my family does for me. My whole family came for Easter. (laughs) You know, I had, well not the whole family--almost all my family came. We had twenty people in this little tiny place! Twenty people! Now we didn't have dinner here. I have another friend who loaned us her house. She was going to be in Florida, so we went there and made dinner. It was a much bigger place. But there were times when we were all here. In this little tiny place. Now, it wouldn't have been my idea of a good time, had I been going to one of my siblings'--knowing how small it was and that we were going to be nineteen other people there. I don't think I'd want to do that. But they all did that. And it was--it was great! We had a great time. It was a great party. So that was helpful, too--to do the things that you would normally do. Easter is a big deal. Easter isn't as big a deal as Christmas, but Easter is a big deal, and it's a family time, and we got together.

Margaret's friends and family--even kind strangers--have a tremendous and vital influence on the life she is living now. What is it about human interactions that can have such a deep and profound effect? Sometimes gestures large or small--acts as simple and profound as daily phone calls--can point toward the sacred in the everyday. What is the depth that is being plumbed by the kind gestures or Margaret's friends and family?

### Caregiver Burden

The participants were deeply grateful for the help they were receiving. At the same time, however, the fact that they needed help was troubling to them. Not only did their self-esteem suffer from their need for help, but they were concerned about the burden of care that fell on others because of them. As Mona said:

In all my life, the one thought that bothered me more, and my husband also, and I think, most people who are getting up in age, is that you're going to be a burden to your family. And I said, the one day, I said, "You know, this has happened to me. I've become a burden." And they all jumped down my (laughs). They said, "Mom, you are not a burden!" We all need help somewhere along the line, and I'm fortunate that I'm getting it. Now that my family has told me, "Mom, you're not a burden, that's it." So, that's helpful. It's life-saving, really. Whatever period of life you have left. It really is. Well, it makes your life a lot better....I'm unhappy that it's been such a drain on my family, although they assure me that it hasn't been, but I know it has.

In this text, we see that in spite of Mona's family's reassurances, she still worried about the burden that they carried. They have tried to reassure her and she does feel better for their efforts. Still, she knows that caring for her is a burden, and she will not be fooled by their kind-hearted denials of what she knows to be true. What is it like to be dependent upon the care of others especially when one knows that the necessary care is increased

work for loved ones?

Daniel, too, was aware that his needs added to his wife's responsibilities and stress. Daniel spoke of his concern for his wife, saying,

And yet. With Martha, I could sense that she was upset about having to take time off from work. And that becomes another issue. When one of the spouses, the caregiver, has to be away from work, and they begin to feel insecure about their job, and so on. And so that created another issue of stress between us. Although, she'd say, "Hey, I got to take off? I'll take off." But I knew she was upset about having to take off and using up sick leave, and eventually getting into her vacation time. And like now, even when I go down for my bronchoscopies, I can't drive back. I can't take public transportation or limo. You have to have somebody, caregiver, bring you home, and then they have to watch you. Because you get sleepy and they have to wake you up every hour. They can't wake you up, then they call 911. So she ended up having to take the whole day off. Unless, of course, I can schedule it late in the day. And then try to do something like that, or whatever. So there's that stress.

Daniel's experience is similar to Mona's. His wife has assured him that if she needs to take time off from work to care for him, she will, but for Daniel, the issue is not really resolved. He knows that caring for him imposes obligations on Martha that interfere with her own work. He is uneasy knowing that she must sometimes assume responsibilities for his care. He tries to schedule his tests later in the day to accommodate her professional obligations, but he cannot always do that. Daniel's concerns point to an enormous gap in the care that is provided to the seriously ill and their families. When Daniel goes for follow-up studies regarding his life-threatening illness, Daniel's wife must choose between earning a living and caring for her husband who is at risk for respiratory arrest. What kind of health care system and what kind of society would require such excruciating choices from its citizens?

Both Mona and Daniel raised concerns about the burden of care that had fallen on their loved ones. In the professional literature, this “caregiver burden” has received considerable attention (Bascom, & Tolle, 1995; Boland & Sims, 1996; Gaynor, 1990; Hileman, Lackey, & Hassanein, 1992; Holing, 1986; Hull, 1992; Jassak, 1992; McMillan & Mahon, 1994). Why caregiver burden? What could those words mean? *The Oxford English Dictionary* (1992) traces the word *burden* in many different forms to Old English *byrden*, Old Saxon *burthinnia*, and Old High German *burdin*. Although it can mean simply, “a load, that which is borne,” (*OED*), it can also mean “a load of labour, duty, responsibility, blame, sin, or sorrow” (*OED*). Further, it can mean “an obligatory expense...often with the additional notion of pressing heavily upon industry and restraining freedom of action” (*OED*). A *caregiver*, of course, is one who gives care. In common usage, *care* can mean “to have regard, fondness, or attachment for (a person); to take care of, guard, preserve with care” (Simpson & Weiner, 1989, Vol. II, pp. 893-894). Those meanings are late in the history of the word, however. Early meanings connect the word *care* with *sorrow*. *Care* refers to “mental suffering, sorrow, grief, trouble...utterance of sorrow, lamentation, mourning” (Simpson & Weiner, p. 893). For the participants in this study, their caregivers were people they loved. Of course, they were loathe to lead their loved ones into restraining obligations, sorrows, and lamentations. They regretted the burden that they had become to the people they loved. Yet, the words of Mona and Daniel have also pointed to a different side of the experience. What are Mona and Daniel telling us about the burden of *receiving* care?

### Need to Give as Well as Receive

For Daniel and Mona, receiving care was also burdensome. In this next text from Daniel, he explained that it was uncomfortable always to be receiving help and support.

I have found that it really helps me if I can give to Martha, because she has something going wrong. She has some needs, and I tell her, Martha, if you need something, let me know so I can do it for you. Otherwise, and that's an interesting thought, because you're constantly receiving, receiving. There's something that doesn't feel right about that. And it, in itself, is almost a sick feeling. So, it's good if you can turn it around and give as well.

Always receiving is "almost a sick feeling." It erodes one's self-respect and self-esteem.

Daniel needed to know that sometimes he could still be a help-mate to his wife. In what ways can someone who is very sick continue to give to others?

### Uncovering Hidden Meanings in Care-giving

Byock (1997), a hospice physician and writer, presents a side of dependency and caregiver burden that is rarely shown. He counsels his patients to think of themselves as contributing to the community by receiving the care of others. Speaking to one of his patients whose progressive degenerative nerve disease made self-care impossible, Byock said:

Interactions just like this, caring and being cared for, are the way in which community is created. I believe that community, like the word *family*, is really more of a verb than a noun. Community comes about in the process of caring for those in need among us. It's unfortunate now that you're getting to see that side of it, but in allowing yourself to be cared for, and being a willing recipient of care, you're contributing in a remarkably valuable way to the community. In a real sense, we need to care for you. Not just those of us in hospice, but the community we represent, the community that funds us and supports us." (p. 98-97 italics in the original; underlining added)

Byock wrote that his patients are comforted by these words. I tried them out on Mona, who responded simply, "Oh, that's beautiful." Byock's view echoed Addie's. She commented that a good thing about her illness was that it had taught her children to care for others--to care for her and to care for each other. As Byock saw, an essential part of learning to care for others is having a someone to care for.

Margaret heard the same message from one of her doctors. She told me:

One of my doctors had this long talk with me when I was in the hospital, and he said... "The one thing I want you to do--because this doesn't come easy for you--is to let your friends help you. It will help them.

Byock (1997) and Margaret's doctor suggested that receiving is an important role for the building of community. Lingis (1994) helped to explain that view. He noted that a community is usually thought of as a group of individuals who have something in common (language or interests or neighborhood) and who are creating something in common (a nation, culture, or institution). As he worked with dying people in hospitals, however, he began to see that the act of dying also created a community, sometimes among people who had nothing in common save their humanity. He recalled Heidegger's notion that every person dies alone, but Lingis's work in hospitals opened his awareness of the living who feel a commitment to accompany the dying as far as they can. He wrote:

Not only is this true of the doctors and nurses, who do all they can, but of the one who goes to stay with the dying one to the end and who stays when there is no longer any healing possible--who knows in his or her heart he or she has to stay. It is the hardest thing there is, but one knows it is what one has to do. Not only because it is a parent or lover who is dying, someone with whom one has lived one's life; one will stay when, in the next bed or the next room, there is someone one never knew, dying alone. ...I came to think that a society that would forsake the dying to die alone,

whether in hospitals or in the gutters, undermines itself radically. (pp. x-xi)

Lingis suggests that care of the sick and dying is a critical task for humans. Those who ignore or deny that task erode a part of the grounding of their humanity. Seen in this light, does the meaning of being dependent change? Can it be that by receiving care, we give to the giver?

It is very true that caring for one who is dying is an extremely demanding task. In my hospice practice, I often see families stretched to the breaking point by the demands of caring for someone twenty-four hours a day. Yet, when that someone is a beloved relative or friend, the physical demands of the task pale in comparison to the emotional grief work that must be done. Caring for someone who is dying is indeed an enormous burden. But what else might it be? After Ira Byock's (1997) father was diagnosed with pancreatic cancer, he came to visit his son. He became severely ill during the visit and it became evident that he was going to die. Though his father had previously expressed a desire to return to his home and die in the hospital and it would have been possible for Byock to get his father back home, Byock began to realize that he really wanted to care for his father himself. When his father agreed to stay, Byock wept with relief and sadness. Reflecting on that time, Byock wrote, "[Dad's] decision to allow himself to be totally care for--dressed and undressed, toileted and turned--by his family was his final gift to us" (p. 23).

Remembering the hours before his father died peacefully in his home, Byock wrote:

There was little for us to do, and none of us wanted to leave his side. This time felt sacred, but not in the way that scripture, liturgy, or chants are sacred. There was a luminous--or numinous--quality to the moment. A great man was passing. So much was being lost, but oh, what a treasure he was. What a privilege to have known him, to have loved and been loved by

him and to have been raised by him. (p. 23)

Clearly, for Byock and his family, the burdens of care—dressing, toileting, and so on—were present in their experience. But to characterize their experience as caregiver burden casts far too narrow a gaze. The care was indeed burdensome, but it was a sacred privilege as well.

### The Dance of Community

People need to give and they need to receive. They also need to be honest, but they need to refrain from pressuring others to do their will. This can be complicated, uncharted territory. In a previous passage, Daniel described his wife's simultaneous frustration and willingness to take time off from work to care for him. In the following passage, Margaret describes her attempts to take her loved ones' desires into consideration when she decided whether or not to undergo another course of chemotherapy. The process of revealing and concealing thoughts and feelings to each other struck me as a dance. A dance is not spontaneous. It is not (at least initially) natural and thoughtless movement. It is "a rhythmical skipping and stepping, with regular turnings and movements of the limbs and body, usually to the accompaniment of music" (Simpson & Weiner, 1989, Vol. IV, p. 235). A dance must be learned, and dancers must move in unison. If one is out of step, one can interfere with the movements of all the other dancers. As Margaret spoke of the efforts of her friends and herself simultaneously to reveal and conceal their thoughts and feelings, the metaphor of the dance was uncovered. "Dancers" would make a statement and wait for the other's response before deciding to go forward

or to retreat. This differs from the give and take of “normal” conversation in that the dancers are much more guarded because of their perception of the other as vulnerable.

What music or rhythm do the dancers hear? The music of hope or the music of “realistic” appraisal? The rhythm of connected community or the rhythm of individual living? What is it like for the dancers trying to dance with each other when each may be responding to different music or hearing a different drummer? Listen, as Margaret describes her attempts:

I try to take people’s feelings into consideration, too. One of the things that I did before I made the decision about chemotherapy was to talk to all my brothers, my sister, my dad, my friends about, how do they feel? I said what I was really leaning toward was not doing it. If they had really strong feelings about me doing it, I might have made a different decision, but they all were supportive of whatever I wanted to do. Now, when I decided to do it, they all said, “Thank you.” (Both of us laughed.) Gosh, darn you all anyway, you weren’t honest! (I responded, “It’s hard.”) Very hard. (I continued, “I mean it’s hard for them, sorting out supporting you, and having their own feelings, and you know, ‘How honest do we be, without pressuring her to make us happy?’ Makes me tired just to think about it!”)

We laughed again, and Margaret responded, “Now I know why I sleep so much!”

Margaret seemed to be mildly frustrated that her family and friends were not totally forthright with her when she asked them their preferences. Daniel, however, described a different dance step in which he intentionally concealed his true feelings, and yet, believed the effect was beneficial to others and to himself.

You talk more and more and these other insights come out. And then having to deal with that. And sometimes, having to say to yourself, “Well, I’m not going to be sad. I’m not going to be down today. I’m not going to get depressed. Because I don’t want the family to get depressed unnecessarily.” And so, to a large extent, a lot of times, you put on a mask, if you will. For others, and for the people you care about. But at the same time, I think it also changes how you then feel. If you put on--you know

the typical, “Oh, how ya doing, Daniel?” “Oh, I’m doing fine.” Instead of, “Oh, geez, my chest hurts and da da da da da” You with me? You know, pretty soon, people are going out of their way to go around you. So, you know, there’s a way of doing things for social reasons, as well as for the benefit of not hurting other people. And then ultimately, in the end, by not hurting others, you do yourself a favor. You make yourself feel better, because you’re not dwelling on the negative. You know there’s an old story about this concept, of putting on a mask for someone else, and it becomes that other person. And I’ve found that that’s very true. And I do that, and I mentioned earlier about just smiling, and then suddenly, my whole spirit is just lifted. Everything else is gone. And it really does work.

Daniel found that, at times, if he hid his discomfort or discouragement from others--if he tried to stay in the dance--he would start to feel better, too.

Hannah talked about times when she and her daughter had conflicting assumptions about Hannah’s illness. She said:

It has been hard--it’s hard to talk to my daughter about the fact that I am dying or that I will be dying because she refuses to want to hear it. [She says, “Oh, Mom, you’re going to get better. Mom, you are going to get better.”] And I have finally said to her, “Eventually, Rebecca, whether it is from this cancer or from whatever, I am going to die, and you are just going to have to accept that. And none of us know the time when we will die.”

For Hannah and Rebecca, the dance was not always in step.

Broyard (1992) described still a different dance step. Diagnosed with terminal prostate cancer, he became fascinated-- “intoxicated” --by this new life experience. He related,

I can’t help thinking there’s something comical about my friends’ behavior--all these witty men suddenly saying pious, inspirational things. They are not intoxicated as I am by my illness, but sobered. Since I refuse to, they’ve taken on the responsibility of being serious. (p.5)

We all have heard of friends helping ill people with tasks they cannot do--tasks like

laundering clothes or shopping for groceries or driving to doctors' appointments. Broyard has captured the idea that friends can help with intangible "duties" as well—in this case, the "obligation" to be somber and serious about one's illness. In Broyard's case, it is help that is not exactly welcome. He continued:

[My friends are] being so nice to me. I don't know whether they really mean what they say or whether they're accommodating me. It's as though they're talking to a child, and I want them to stop that. I can't find them anymore. (p. 23)

What a strange idea! What is this dance? He implies that these new sober people are not the friends he has always known. He wants the cheerful, fun-loving friends back instead of these dour serious ones. His words are reminiscent of Addie saying, "I used to have a life, but I can't get there anymore." Addie's life and Broyard's friends are so different from the way they used to be, that they seem like different entities altogether. They are familiar and strange at the same time; it makes for a disconcerting dance.

Broyard described a way in which one can even dance with oneself. In his memoir about his father's fatal illness, he tells of the moment after his father's doctor told him that his father was dying.

[As the doctor walked away, he said, "Your father is a nice man."] My mother's nice husband was not doing so nicely, and it was my job to tell her. After that, someday when she was through crying, I would try to tell myself. Not now, though, there was too much else to do. (p. 99)

"I would try to tell myself," says Broyard. Alice had said, "I would not even let my mouth say that [that she might be dying]." Earlier, I suggested that finding out one has a life-threatening illness makes one feel as if life is broken. These words of Alice and

Broyard clearly describe a person who is broken into fragments, and at times, the fragments may “hide” information from each other...in a kind of dance.

### Between Doctor and Patient

Life-threatening illness affects the community of patient, family, and friends. There is another community that is affected as well--the community of doctor and patient. In this section, I will turn my attention to the experiences participants had as they journeyed through illness with their doctors.

In the United States health care system, the doctor is commonly referred to as a gatekeeper. Though patients have autonomy regarding the health care they may accept, it has traditionally been the doctor who decides what care will be offered. Insurance companies are making sweeping changes in the dynamics of the health care system, but for the participants in this study, the doctor was still the most influential member of the health care team. Thus, the way that the doctor and patient communicated with each other had great influence on the patient's experience of illness. What was it like for the participants in this study to communicate with their doctors? There were noticeable differences. In the following pages, I will present some of their experiences.

#### Mona: A Relationship Unresolved

Many of the participants in this study were content with the information they had received from their doctors. Mona, however, was not. She said, “The doctors have got to take a little time with their patients. We're entitled to--we're not only entitled to that, we

have an absolute right to that.” She continued:

I think they lost touch with the human side of medicine. The doctors. I think it’s an abomination, really. There’s no explanation...Sit down, explain it to them for heaven’s sakes! These people are terrified. They’ve been told something that means the end of their life, doesn’t it? It also means pain and agony in the future. And they can’t take, what? Ten, fifteen minutes to sit there? To say something comforting. To say something--”Now we’re here for you”? Just a little booster there. That’s all. [How did your doctors talk to you about it?] Oh, he was very good...BUT. He has not once called in the time I’ve been home. To say, you know? “How are you doing?” I was his patient for 10 years.

Mona expressed a variety of concerns in those few words. At first, she seemed to be complaining about all doctors, including her own, regarding the lack of time and attention patients receive when bad news is given. However, when pressed for details, she said that her own doctor was very “good.” Her disappointment in him was due to her perception of his lack of follow-up concern for her now that she was too weak to go to see him. She expected him to show his respect and care for her by taking the initiative to contact her at home. His silence felt like disinterest to her.

Mona, further, had deep regrets about having had surgery at all. Her surgery had been a response to a tumor seen on x-ray. Prior to having surgery, she had not had any symptoms, however. She had gained weight, was independent and active, and had no pain. The surgery had taken away her energy and independence, and had not improved her prognosis. She told me:

I should’ve gotten a second opinion. I should definitely have gotten a second opinion...I don’t know why. I just went along with this.... We’re intimidated by the doctors, aren’t we? We all are. Everyone I’ve ever spoken to has said that.

It seems that before surgery, Mona had been content to follow her doctor's recommendation without question. In the aftermath of that choice, she believed she had made the wrong decision. When it was time for Mona to decide whether or not to have chemotherapy, she had recovered some of her ability to choose for herself. She said:

I knew I didn't want chemo. Because what chemo had to offer would in no way make any difference for...I opted not to have it done. I mean, both my doctor and the surgeon thought it would be...but if I have from three to six months, and they're going to do six months of chemo, and I'm going to be vomiting my brains out for six...that's a coarse way of putting it. I'm sorry. But where is the percentage? They're not going to cure this. I mean, that's it. Pure and simple.....I know they were disappointed. They thought, you know, I should, but you do have a choice here.

When I met with Mona, she had very little energy and elected to end the conversation after a half hour. That was unfortunate for my purposes, because I had many questions about the previous passages. Did she ever talk over her reasons with her doctors? Did she express her concerns about nausea and vomiting? Did they know why she refused chemotherapy? I know that many patients do not experience severe nausea and vomiting with chemotherapy, and that there are new drugs available for those who do, though of course, they may not be effective for all patients. Did Mona base her decision on outdated ideas of what it is like to have chemotherapy? If her doctors did discuss these issues with her, were they still disappointed after the discussion or did they understand her point of view? It seemed that Mona had unresolved feelings about her treatment and about her doctors. She indicated, however, that she was not intending to make efforts to resolve those feelings. Whether that was because of a reluctance to confront her doctors or her own feelings, or a combination of both remains unknown.

### Margaret and Daniel: Resolution through Persistence

Both Daniel and Margaret explained that sometimes the relationships with their doctors changed for the better as they came to know each other better. Margaret said that for her, confronting physicians did not come easily.

[Something] that was really difficult for me to do--is working out the relationships with the different health professionals. I have a surgeon. When we started, he was very clinical. Not at all personable. Things have changed drastically. And he's probably become overly involved, which is not necessarily bad for me, but it may be bad for him. I'm sorry to say. But when we started out, it was very difficult.

Margaret went on to tell that after her first surgery, she felt so terrible that she could not concentrate and remember details of her daily conversations with her surgeon. Her elderly father, who was also a physician, would spend most of the day with her, but leave at sunset because he was not comfortable driving at night.

So [my father] would come, and every day, he'd see me in the hospital, and he would leave as the sun was setting, and shortly after he'd leave, my doctor would walk in and tell me what was happening, and the next day, my father would ask me. I had not a clue! I had not a clue. About what was happening to me. What was--I would even try to write things down, and I had such a limited attention span, that I would get only a few words down, and it wouldn't mean anything to me when I'd look at it the next day. And one of the things that I had to do was to confront the surgeon, and tell him about the difficulties I was having...And it was a very difficult conversation. It was very difficult. I ended up in tears, and he got angry, but darn! The next day he showed up with my parents there. So, it worked, and ever since then, we've had a really good working relationship, but it was extremely difficult, because he was that kind of personality. And I was a very different personality.

Daniel, too, had come to a good relationship with his physician. He told me:

I've become a compliant patient, but I also--I have questions. I want to know. But in the end, I have to decide, do I trust these doctors to tell me the right thing to do--to keep me alive?

Daniel has found a comfortable balance between questioning and trusting his doctors. He wants answers to his questions, but he also trusts these doctors literally with his life. He has found a way to be a partner in his own health care.

It was also important for Daniel to develop a relationship with his doctors that transcended the merely professional. He wanted to know something of his doctors as persons, too.

It's hard to get to know the doctors a little bit...the guy I had down at [hospital] until he left and went back to Pennsylvania...took quite a few visits before he started to smile and laugh with me, and you know, get to know each other....This doctor's [at local hospital] sort of reserved...but I talk to him and I said, "Well, you know, if I go into rejection after three months and die, well, it's been the best three months." He says, "You're not gonna die. I wouldn't be doing this if I couldn't give you another five or ten years."

And he's saying things like, "You know, I get to know you people better than your own family...It's like I'm adopting you, and when my patients die because they either didn't get a transplant or they did, but it didn't work, it's really like getting hit in the back of the head with a baseball bat." It really affected him.

Clearly, Daniel's doctor has developed an attachment to Daniel and his other patients, and Daniel appreciates that attachment. Still, the doctor uses some unusual images in his speech. He talks about "giving" Daniel more survival time, and he states, "You're not gonna die." Both of these phrases suggest superhuman abilities. Can one person give time to another person? Is time an entity that can be given? On what basis does he assert that Daniel is not going to die? Perhaps he means his words as reassurance, but his words imply that he can see the future. His use of the phrase *adopt you* suggests a paternalistic parent-child relationship, complete with deep concern for the "child's"

welfare. A clue to the doctor's outlook may lie in his choice of words regarding how it feels when a patient dies. "It's like getting hit in the back of the head with a baseball bat." It's like being attacked from behind without warning. The doctor experiences the loss, not as a loss, but as an attack that can cause serious bodily harm. If that is how he feels, (and of course, all we have is Daniel's interpretation of how his doctor feels), we can understand that he might wish for superhuman powers to avoid the loss. In any case, the doctor has clearly communicated to Daniel that Daniel matters to him personally. It is important to note that Daniel is content with the tone of the relationship.

#### Doctor Magrisso: A Friend

Margaret had a very different kind of relationship with Doctor Magrisso. Speaking about him, she said:

I mean one of the things I've really appreciated is Doctor Magrisso's style. I mean, he would come into the hospital, just as an example, he'd go for a walk with me. You know, I had to do it anyway. We'd walk around the floor a couple of times, and we'd just sort of chat about, you know, how your day was, and what I was thinking about, what I was worried about. Any questions I had. Any thoughts I had about what might be happening in the future, that I needed to know about. It was just...talking. And that was extremely helpful for me, not only from the point of view of being able to talk with somebody about what I was going through, but he helped me problem solve things that I didn't know there were solutions to. Like, I've been extremely worried about traveling and having another bowel obstruction, because that's imminent. That's always gonna be there. Well, come to find out, that there's a medication I can take with me that would maybe stem the tide of the symptoms enough for me to get home to my own doctors. And I wouldn't have known that had we not had this little chat while we were walking. And so that was enormously helpful! Because now I feel like, I mean, it not only helped me medically, but it--now I feel like, I've got some independence! I can get a drug. I can put it in my suitcase. I can get on a plane, you know? Which I didn't think I'd be able to do. And I feel much better about that.

I responded, "That's a great idea--to go walking with patients," and Margaret replied, "Wonderful. Activity therapy" She laughed. "You don't have to make eye contact. You can, be a little bit diverted by your surroundings, and you still--yeah, it was great. He's just--he's just my friend. I really like it." For Margaret, her relationship with Doctor Magrisso is like a friendship. He is helpful to her medically, but their relationship has far transcended the professional. Broyard (1992) writes about doctors giving up some of their authority in exchange for their humanity. It seems that Doctor Magrisso is clearly in touch with his own humanity and with Margaret's. It is hard to see that he has given up anything at all. Doctor Magrisso has found a way to meet Margaret in a whole and healing way.

#### Differing Desires and Expectations

One of the difficulties inherent in communication between professional and patient is that different patients have different preferences and expectations. Doctors also vary in their expectations. It can take some time and effort to discover how much information a patient really wants to hear. Martocchio (1982) has addressed this concern stating that people generally face illness in much the same way that they face life. She continued:

Some individuals are very private--they characteristically keep their thoughts, feelings, and desires to themselves. Subjecting these persons to prying questions, thus stripping them of their right to remain private especially when death is imminent, is both insensitive and cruel. On the other hand, it is insensitive and cruel to deny more outwardly expressive persons the opportunity to share their thoughts openly and to make their desires known to those about them. (p. 131)

Margaret's thoughts echoed Martocchio's. She said:

I think that health professionals need to get to know their patients--which kind of patient they are. I am definitely the kind of person who does better the more information I have. I have a friend who says I'm very controlling.

Well, I am controlling. She says, "You even want to control your side effects. You want to go to Florida and do it at a time when you know you're going to be feeling good." Well, yeah, I do. I mean, I do.

Margaret knew, however, that not every patient shared her preference.

I was surprised that I had a discussion with another patient in the waiting room when we were doing radiation therapy, and she was telling me that she didn't want to know. And that surprised me. I knew it intellectually, being a therapist, but a lot of stuff just goes out of your head when you're a patient. You're really concerned much in your own world. So it surprised me, and then I remembered, oh, yes, some people are like that. Well, I hope, the important thing for the health professional is to find out what kind of patient you have. Who does better under what circumstances? And try and work with that.

Margaret claims that each patient is "in [his or her] own little world" and she asserts that it is important for the health professional to find out what kind of person the patient is. In her words is a call for professionals to notice that the world of the patient--the world of each patient--is different from the world of the professional. An important part of meeting the other in what Buber (1958) would call the *I-Thou* relationship is to try to enter the world of the patient and see the world from that perspective.

#### Margaret: A Give and Take

Margaret described a way in which her doctors attempted to accommodate her view of the world. They generally took their time and gave her information at a rate that allowed her to assimilate it.

I don't know of any of my doctors who have given too much [information]. Most of them...give me what I need to know, and then wait for me to ask questions, and if there's something I haven't asked about, they say, "You might have a question about such and such. And if I say, "No," they say, "Okay. That's fine."...and they sort of think about holding back on things. And that's an okay way to handle it, I guess, but knowing your own comfort level, and then finding out who they've got for a patient.

They have certain things that they want to communicate to me, that I need to know. You know, 100 per cent of the people get nauseated when they take a particular drug. They will tell me that. But they may not tell me everything about that. Every single little detail all the way down the line. And then they ask me if I have questions. What do I want to know? And sometimes they will give me additional information after my questions seem to be exhausted. Things that I haven't asked that they think I might have a question about. [I said, "So they take some--I almost see it as a dance a little bit."] Yeah, it is a dance. It is a dance....and I don't know how to get around that. I know that more and more health care professionals are taking less time with their patients because they have to see more patients to be able to maintain a practice. They just have to if they're going to stay in managed care. And the only way that you can really have a significant relationship with the patient is to take time....And I don't know what to do about that. I don't know if there's any easy or fast way to do it.

I think that would be really hard to do for specialists who get called in to do specific things, like my surgeon certainly is one. He came in when I had the liver metastases. He didn't know me. He had one conversation with me before I had surgery. So, I don't really know the answer on how they do that. [I'm a patient who wants all the information]...but some people, I'm sure, want none. They don't even want to know they have cancer....Some people really don't want to know. And that would be sad, if they got too much information. So, I don't know. I really think it must be very hard.

As Margaret considered her own experiences, she realized that communication with physicians is a complicated dance. Could giving too much information be a form of stepping on the other's toes?

#### Linda: I Didn't Ask the Right Questions

The doctors of my brother's wife, Linda, were not as skilled at leading Linda and Joel to the right questions. Linda had surgery in January for pancreatic cancer. She told me that after she decided to come to Evanston for surgery to remove the tumor, the radiologist in Cleveland called to inquire why she had canceled her appointments. She told him she had decided to come here to have the tumor removed. He said he had not known

that was what she wanted. If she had told him, he could have referred her to surgeons in Cleveland who would have performed that surgery for her. Linda said to me, "I guess we did not ask the right questions in Cleveland." I suppose that is part of the truth, but when Linda expressed that thought, I remembered immediately the words of the lawyer on my hospice's ethics committee who told me emphatically that I needed to initiate conversation with Nancy about her right to refuse treatment. I remembered clearly his assertions that when health professionals wait for patients to bring up the questions, only the most assertive patients receive complete information. Linda's experience leads me to ask how the dance of communication gets started. Who starts the music? Who should? Whose job is it to take the first steps? Who leads? Who follows?

#### Cheryl's Parents: Following Doctor's "Orders"

Cheryl's parents, in contrast, learned a different kind of dance. They were reluctant to ask any questions at all. For Cheryl's parents, informed consent and choosing treatment options were almost irrelevant issues. She tells that when her father was first diagnosed with cancer, his internist referred him to a surgeon for a surgical opinion. Cheryl believed that the internist thought he was presenting an option, but her parents assumed he was prescribing surgery. When her father spoke to her on a Thursday, he said, "Well, Doctor Smith sent us to the surgeon, so I'm going to have my stomach removed on Saturday." When Cheryl herself investigated the treatment options and encouraged her father to explore those options more fully, he decided not to have the surgery, a decision that he and Cheryl both felt had a positive impact on the quality of life in his final months.

Nevertheless, Cheryl said throughout her father's illness, whenever she would suggest a treatment plan that differed from Doctor Smith's, her parents would say, "We'll ask him about that, but he's the doctor, you know, and we don't want to get him mad. He's so good to us--we wouldn't want to have to change doctors." This was in spite of Cheryl's experience of Doctor Smith, which was that he was very "relaxed, flexible, and easy going." She believed that her parents' attitude about Doctor Smith was rooted in their upbringing during a time when doctors were absolute authorities rather than in an assessment of who Doctor Smith was as a person.

Cheryl also related that for her parents, when they were presented with the option of having her father given feedings through a jejunostomy tube, the information from the doctor focused on the reasons for having tube feedings (to increase calorie intake, and therefore to increase energy) and the ultimate goal of tube feedings (more energy for beloved activities like fishing). The day-to-day lived experience of having and using a jejunostomy tube was given almost no attention. Once the tube was in, her father had great difficulty tolerating feedings and had to be connected to the feeding pump 24 hours a day. He told Cheryl, "If I had only known *what this was going to be like*--I would have never done it" (italics added). In spite of that message, Cheryl said that her mother never complained to her and said simply that the tube was doctor's orders.

What is markedly important to me in Cheryl's story is the distinction she makes between information about what a treatment's goals and purposes are and information about what it is like to undergo that treatment. It seems to me that it is of utmost

importance to inform patients in both areas. Goals and purposes are essential, but understanding what day to day life will be like with the new treatment is also crucial for making an informed choice. Health care professionals cannot wait for patients to ask the right questions.

### When Questions Don't Help

While communication can be difficult in any situation, it was even more difficult for Margaret with one of her doctors who, in her words, “lies to me.”<sup>16</sup>

One thing that happens with one of my doctors is he doesn't tell me the truth. He consistently does not tell me the truth! And I'm bright enough, that I've gotten a lot of information about my disease, so I know when he's not telling me the truth....He out and out lied to me this last time about this drug that I'm on now--he told me that I wouldn't lose my hair....And I have a friend who was with me when we were talking with him, and we were both a little surprised, because we had read the studies that talked about alopecia, so we were both a little surprised, but we thought, “Well, you, know, they were all the research studies--maybe they've got it down now, so that this doesn't happen.” Well, the nurse, the first time I went in for treatment said, “Now, the doctor's told you that you're going to lose your hair, right?” And I said, “No.” And she just kind of rolled her eyes, because she obviously knows him. She said, “You will lose your hair. So you might want to think about getting a wig”...but when I told my friend about it, he just--“My God! He lied to us! He out and out lied!” That's really hard for me.

Margaret and her friend believe that the doctor is lying, but could there be another interpretation of his behavior? Is the doctor uninformed or incompetent? Did he misunderstand Margaret's question or did she misunderstand his answer? What has led to

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<sup>16</sup> I want to emphasize that the ethically loaded word ‘lie’ is Margaret's word. There could certainly be other interpretations of the physician's communication. See, for example, the discussion about Harold and his physician on page 24. I will concede, however, that Margaret's account sounded very plausible.

this “mis-meeting” between Margaret and her doctor?

Margaret told me of an earlier episode with the same physician. She said:

I got neurologic problems. I thought I was losing my mind! I couldn't stand up. And he said, “Oh, no, that's one of the side effects.” And I said, “Well, why didn't you tell me!” I thought I had a brain tumor. I wasn't sure what was going on. And it terrified me, absolutely terrified me. And he said, “Well, I don't like to tell people all the symptoms, because I don't want to give them any ideas.”

As she continues to reflect on his behavior, she said:

[His lying] is really hard for me. I mean, I'm not really sure what purpose it serves. Now that's what he said to me. I also suspect that's one reason, and then the other reason is that he doesn't--he knows that [patients] won't choose what he would choose if he told them all the bad things that could happen. He did not say that, but I have a feeling that--just from, you know, having worked with him for a while--I know that that's another thing that's probably operating.

Explaining why she did not continue to confront him about his behavior, Margaret said:

He's not going to really change his mind, and I'm really frankly afraid of alienating him. I think he's a good technician. And that's what I really need. Now you've got that on tape! But I really have a lot of confidence in his skill. I know that he's an excellent doctor. I'm just wishing he had a different bedside manner. That's very hard for me.

Margaret's reluctance to confront her doctor points to a legacy of the socialization of doctors and patients, a characteristic Bledstein (1976) has called “the culture of professionalism” (p. ix). Bledstein traced this culture to the middle of the nineteenth century when many of the professions in America began to emerge. He claimed that as specialized training and licensing advanced, people began to put their trust in professionals and to defer to them in their areas of expertise. Bledstein asserted that as regard for professionals increased, “people [believed] the voices of authority unquestioningly,

thereby undermining self-confidence and discouraging independent evaluation” (p. xi). A person would not question a doctor’s judgment, for example, because he was “unqualified” to do so. As Broyard (1992) remarked, “You don’t really know that you’re ill until the doctor tells you so” (p. 37). In other words, even though the sickness is in one’s own body, the doctor is better qualified to recognize it. It is this tradition that may have contributed to Margaret’s waiting for a year to get a second opinion even when she had four episodes of “the worst flu I’d ever had” in a year. Her doctor told her she was not seriously ill, and she took him at his word. Margaret’s reluctance to confront her doctor even though she believes he is clearly in the wrong may be a remnant of the belief that the doctor should be the unquestioned expert.

There is another issue underlying Margaret’s texts, though, and that is that Margaret does not feel safe confronting her doctor about his lying. She must therefore guess about his reasons for his “lying” because to ask him directly would risk losing his care. What does it mean to feel unsafe with a person one needs to protect one’s life? It is an impossible bind—a dance with severe consequences. One false step and Margaret could lose the care of a physician she believes she needs. False step? The doctor frequently makes *false* steps. Margaret, however, must follow if she is to stay in the dance.

At our second meeting, Margaret felt that the doctor was continuing to withhold information from her. She said she had been experiencing severe fatigue and she thought, “Oh, my God, I’m doing something wrong! Or I’m lazy.” When she mentioned it to her doctor, he said, “Oh, yeah, that’s just the chemotherapy.” She laughed, and said, “I

wanted to strangle him!" I noticed she used her sense of humor to make a kind of peace with the situation. She told me she thought she was about at a point of maximum accumulation of side effects from the current chemotherapy regime. She said, "Hope so. I'm afraid to ask. He's probably going to lie to me," and she laughed again.

As Margaret reflected further on her doctor's reasons for lying, she repeated that she believed doctors needed to get to know their patients and their preferences for information. She added:

[Doctors should] know themselves, too. Because, I guess the one thing I think about with the one particular doctor who is not giving his patients too much information is that *he* can't handle it. It's not them that can't handle it. He can't handle it.

Whether her assertion is true of her own doctor or not, it is an interesting question. What is the effect of a physician's personal needs for avoidance or denial on the quality and completeness of information given to the patient or family or both?

### Patient Ambivalence

Another factor that may impede communication between doctor and patient is that patients may have conflicting desires within themselves. Daniel illustrated the ambivalence patients can have about receiving information. They may want to hear and not want to hear at the same time. Reflecting upon the time when he first learned his diagnosis, he remembered:

They said there was really no treatment for it, but they really didn't tell me what the prognosis was either. I have since found out, they think, normally they figure two to five years on the average....And just that one comment about they really didn't tell me what the prognosis was, I think is one of the problems in the medical profession. Is they really don't give you all the information that you need in order to determine how you're going to live

your life. Whatever is left of it...But on the other hand, I realize, well, if they tell you you only have two to five years, and I went fifteen, by telling you as they often do, the down side, are they telling you a self-fulfilling prophecy?

Daniel's words recall Hall's (1990) description of patients who, finding out they have a terminal illness "just go 'Eek!' and die" (p. 190). Daniel had more to say about the practice of carefully presenting the possible risks of treatment, an essential element of informed consent.

When you go in for your evaluation, they tell you the hard facts. And that's another problem, I think that they have. Is that they go through all of the down sides of a transplant process. They really don't tell you about the up side. You need to get that from the support groups, who had it, and you see the live person 5 years later, and you say, "Oh, this really does work." I'm not sure why they do that. I know they need to do it because they need to inform you of your rights or what could happen. They don't want to get sued because you didn't tell them, "Oh, I might die." But at the same time, they should also be pointing out, "Here's what life might be like afterwards—You'll be able to run your snowblower, clear your driveway out." Things like that.

Daniel wants the information to include the possibilities for good as well as the possibilities for harm. He knows that health care professionals have an obligation to inform him of the potential risks of treatment. He understands that they do that not only to inform the patient, but to protect themselves. But for Daniel, information about risks is clearly not enough. He also wants hope. He wants his doctors to tell him of all the good effects that might come, too. Where is the balance between hope and reality?

#### Reporting Symptoms or Complaining?

In addition to the variety of personal styles that can affect the way in which doctors and patients relate to each other, there are cultural norms that can "muddy the

waters.” In Chapter Three, I noted how the same behaviors can be given different names according to whether or not the observer is sympathetic to the actor. For example, the words *thrifty* and *stingy* can be used to describe the same behavior. In the same way, people can experience confusion about how to evaluate their own behavior. For an ill person, whether she interprets her own behavior as complaining or reporting can have a strong influence on her communication with her doctor. Sarah and Margaret spoke to this problem. When I asked Sarah if there was any thing that was hard for her to talk about with her family or her health care team, she responded:

Yeah, how I feel. How terrible I feel. I’m not a complainer. I hate to complain. And yet I think, Oh, God, every part of my body, and my eyes, and my...and then years ago, I had a hip operation. And I was very very steady on my feet and that. But I fell on Chicago sidewalks, they were all broken up. And, uh, so I have my left hip that bothers me. I lay on that side. I can’t lay on that side. I turn around and I can’t lay on that side. And every part of my body aches, and I think to myself, I can’t tell them. God. They’re tired of listening to me after all these years. And I believe that, although they don’t act like it at all. I’m positive, they don’t.

What is it that keeps Sarah from telling others how she feels? What is it that imposes itself between patient and health care worker? Is it that health care workers no longer want to hear of the chronic pain that stays in spite of our best efforts? Is it that people are taught that it’s somehow wrong to feel badly all the time? What is needed for patients, families, and health care workers to acknowledge the suffering that is part of their lives?

Margaret, too was concerned about differentiating between reporting and complaining. She said:

This is real—really really subjective. I don’t know how many people have trouble with this, but I’ve always minimized my symptoms. You know, whenever I had a headache, I’d, you know, it’s just a headache. If you

weren't a lazy son-of-a-gun, you would just get up and go do. Which is part of the reason, I feel partly responsible for going a whole year, and having eleven bowel obstructions [her doctor had told her it was 'the flu']. I mean anybody else probably would've gone to see another doctor. But when somebody says to me, "You only have this," I think, "Oh, I'm just being hypochondriachal," or "Whew! I thought it was something terrible, and it's really not." So sometimes it's hard for me to talk about symptoms and really tell them what things are problems, and it's been a learning experience for me, because, consistently, I've been right on the money. There hasn't been a single thing that has been hypochondriachal. I had this funny little pain on my right side. Funny little pain--That's exactly where this little tumor is. Exactly where it is....I didn't mention it, and then I should've been mentioning little aches and pains I wasn't mentioning. I thought they were just little aches and pains.

I am really learning a lot about things that are okay for me to say, and that it's not complaining, which I'm always designating as complaining. It's helping them tell what's going on with me. I'm the only reporter. That's hard. That's very hard. That's also been a surprise. I thought once I ever had a life-threatening illness, I wouldn't be learning anything. Except maybe, how to die, or how to take care of.....but this is something that I have to learn to do, that's been really hard for me to do. It's been a challenge. To even learn to tell them how I feel.

For Margaret, it is in her dying that she is learning to take care of herself.

Previously, she has not really lived in her body. She has worked to ignore the "funny little pains" that have been clues regarding her health. She has worked to minimize the fact of her embodiment. "It's just a headache....You're just being hypochondriachal." It is new learning for her to accept her body's messages as they come.

Sarah and Margaret have avoided reporting symptoms because they do not want to be seen as complainers. There is another dynamic operating in the process of reporting symptoms, however. Before one can report a symptom to another, one must first report it to oneself. Remember Broyard (1992) remarking that sometime after his mother stopped crying, he would have to tell himself that his father wasn't doing well? Sometimes,

patients do not allow themselves to acknowledge symptoms because, on some level, they may not want to admit that the symptom is there. The symptom may mean that he or she is getting worse. On a primitive level, the patient may hope that if he or she ignores the symptom, it may go away. Alice said, "I would not let my mouth say that," for fear that speaking would make it so. A patient's reluctance to report symptoms, however, can have dire effects on the course of the illness, because it may interfere with early diagnosis, which is so often critical for the patient's recovery.

Can we speak our fears into existence? Is a spoken fear more "real" than an unspoken one? Or does speaking a fear paradoxically weaken its power? For the patients in this study, the dilemma felt powerful and frightening.

An examination of the etymological roots of the words *report* and *complain* may help to open up an understanding of this difficulty. Report descends from the Latin word *reportare* which is a combination of the word *portare*, meaning "to carry" (Webster, 1966, p. 1234) and *re*, meaning "back" (Webster, p. 1234). Thus, report descends from a phrase that means, "to carry back" (Webster, p. 1234). Forms of *reportare* are found both in Middle English and Old French. Complain also traces its roots to the Late Latin words *com*, meaning "with" (*Merriam-Webster Dictionary*, 1988) and *plangere*, meaning "to strike" (*Merriam-Webster Dictionary*). It has also descended through Middle English and Old French where its common meaning was "to beat the breast" (*Merriam-Webster Dictionary*). As the breast was considered to be the seat of emotions, one can perhaps understand a modern American's reluctance for the emotional excess associated with

beating one's breast. It makes sense that the distinction between reporting and complaining would be important to patients.

### Communicating in an Atmosphere of High Emotion

For me, my "front row seat" in my sister-in-law's illness has illuminated the complexities of communication about health care information in an atmosphere of highly charged and painful emotions. In this context, is the dance a Jitterbug, or do fears and indecision turn the dance into a motionless tableau?

My brother was broken apart by the diagnosis of Linda's pancreatic cancer and would frequently burst into shaking sobs. The morning after her surgery one doctor had come to Linda and told her that she had cancer that was inoperable, but her cancer might respond to treatment. I was present in Linda's hospital room the evening after her surgery when her primary surgeon came to see her. After he explained what he had done during surgery, Linda said, "Do you want to give me a prognosis?" He smiled sadly, shook his head and said, "No." And there the subject dropped. I stood there frozen, thinking, "Well, wait a minute! Who cares if he doesn't *want* to give her a prognosis? It's his job to answer her question!" But I was reluctant to push him because I knew that my brother was so fragile at the moment and Linda was exhausted after grueling surgery. I did not know which would be more helpful to Joel and Linda--to receive clear information right then or to be protected from hearing what I knew was a very grim prognosis when they were both so vulnerable. Later, as their doctor outlined his treatment plan (simultaneous chemotherapy and radiation followed by another surgery), Linda asked, "And then you'll

take out the tumor?" He replied, "We will do surgery again and it will be our intention to take out the tumor." In that phrase of his, the word *intention* meant to me that he was not at all certain he could do it. I don't believe Linda and Joel heard any hesitancy in his message. A few days later, moments before I was leaving to come back to Chicago, Linda asked me if there were any other questions she should be asking. Joel had been privately telling me that he knew he needed to raise with Linda the question of changing the date of their daughter's wedding that was scheduled for eleven months hence. "Here's my chance," I thought. "Let me leap through this window of opportunity." I said, "Well, you might want to think about rescheduling the wedding," and Linda began to cry. I am a hospice nurse. I have experience in psychiatric nursing. I *know* that it is not necessarily bad if someone starts to cry—in fact, sometimes it is helpful, but I *felt* like an opportunistic, insensitive bully. I re-tell this story now, not because I have any answers or conclusions about the questions raised, but because I believe it illustrates the complicated issues of what to tell and when to tell. In the language of the metaphor of the dance, I did not know the steps and my movements felt like awkward blunders.

After Linda's surgery on June 1st, she had complications and was in the Intensive Care Unit for sixteen days. She was attached to a ventilator, sedated to unresponsiveness, and she gained almost one hundred pounds of water weight. It was a scary time for my brother and me. We both clung to assurances from her doctor that she was really doing okay and he fully expected her to recover. That Sunday in church, I saw his wife (both doctor and wife are friends of mine) and she asked how Linda was doing. I told her and

she replied, "I get a much better picture when I hear it from you than when I hear it from him. He's 'Mr. Optimism.'" My heart sank to the floor as I wondered if the doctor's assurances to which I was clinging so fiercely were "merely" an overly optimistic assessment of Linda's prognosis. I realized that as much as I believe that patients (or their families) ought to be partners in the management of their care, at that particular time in Linda's illness, I really wanted the doctor to be the all-knowing, all-powerful expert. I did not want him to be an ordinary human, subject to the distortions of denial or over-optimism.

The evening after I wrote the preceding passage, I changed the dressing on Linda's abdominal wound. It was drenched with bile-stained drainage—much more so than on previous days. Linda was very discouraged, believing probably rightly, that the increased drainage is an indication that her bile duct is not yet healing. If it is not yet healing, that means there is no time soon when she will be able to eat. She believes she cannot go back to her home in Cleveland until she can tolerate regular food again, and if the duct does not heal, she will need further surgery. It wasn't until I went to bed that night and was falling asleep that it occurred to me, that the whole time Linda was expressing her dismay, I was searching for the most positive interpretation I could put on the evidence. "Oh, maybe it's old drainage that is just finding its way out," I said. "Let's ask the doctor if he, too, thinks it's a discouraging sign. Remember when Joel and I were so worried about your kidneys because your urine output was so low? And those fears turned out to be unfounded altogether. Maybe this isn't so bad." My hope or denial or compassion—my desire to

protect her from further disappointment--was certainly coloring my ability to look objectively at the evidence in front of me. Is it not likely to assume that the same dynamic happens between doctor and patient?

### Through a Glass Darkly: The Illusion of Choice

As I have journeyed with the participants in this research, I have been struck time and time again by how arduous the task of choosing treatment options is. When we speak of choosing a treatment option, or deciding which course a patient wants to take, it sounds like a fairly straightforward affair. Find out what the facts are, weigh the pros and the cons, and then choose the path that is most consistent with one's personality or life preferences.

Siegel (1986) often writes as if it is this easy. He tells of a patient with cancer who resisted every suggestion his doctor offered for treatment. When Siegel suggested to the man that he did not really want to get well, the man realized Siegel was right. He said, "My father's ninety and senile and in a nursing home, and I never want to be like my father, so it's perfectly all right if I die of cancer now" (p. 23). Siegel responded, "It became a matter of getting him to feel that he could be in control of his life and death, to realize that he didn't have to give up many good years just to avoid the possibility of an unpleasant end" (p. 23). Perhaps Siegel was able to get the man to *feel* that he was in control of his life and death, but I would argue that that doesn't mean he *was* in control of his life and death. The feeling of control was an illusion. What is it about us that causes us

to yearn so deeply for control that we do not have. What is it about control that is so appealing? For the participants in this study, deciding did not feel like controlling a choice between two clear options. It felt much more like peering through a murky fog to get a better glimpse of what the future might hold.

When Daniel was first diagnosed with interstitial fibrosis, transplant was not yet a viable option. Several years later, when he had already outlived the life expectancy of a person with his disease, his doctor told him that transplant would be the only option for him. Because transplant was still fairly new, Daniel told me his doctor suggested he “try to hold off for as long as we can. And I’m sure that he was thinking the same thing that I think now, that the longer you put it off, the better. Because they’re constantly making improvements.” So Daniel knew that eventually he would need a transplant. The question became “When?” He wanted to choose a time when he was still fairly “strong and healthy” so that he could tolerate the surgery well, but if he went too soon and the transplant failed, he would have prematurely ended his life. To me, this is not a *choice*. A choice is, do I want lemon pie or lime for dinner tonight. Daniel’s choice was far more serious, and the outcome of his choice could not be known ahead of time.

[That’s] another very difficult issue and question...When they said, “It’s time to consider transplant” and you’re on the list--well, do you really need it now? Should you really do it? If you didn’t do it now, how much longer would you live? And, would you live another 15 years?...So, I just had to make that decision. To go for it then. Whether I’d still be alive [if I hadn’t had the transplant then]?--probably still be alive today if I hadn’t gotten it five months ago, but I’d be schlepping around the oxygen.

As Daniel evaluated his decision to have the transplant, he believed that he had made the

right choice. It may be more accurate to say that he “guessed right.”

Mona felt differently about her situation. She had surgery because of a spot on her lung, but she had not yet become symptomatic. She had been alert, active, and able to climb stairs without becoming short of breath. Now, however, she told me, “The surgery was done, and now I am going down hill...In retrospect, I should not have gone ahead with it.” When I asked, “But part of you worried that the surgery shortened the time that you have?” she replied, “I firmly believe that. I really and truly do.”

Margaret told me that her first decision to have chemotherapy was relatively easy, however, as she lived into her decision, her experience had little to do with her choice. She had chosen to have chemotherapy believing that it would not interfere with her ability to work. She had severe side effects, however, that prevented her from working at all. What she “chose” was not at all what she received. In spite of her unexpected response to chemotherapy, though, Margaret believed that she had made the right choice.

Making the decision about chemotherapy was relatively easy. What they told me was that I could work while I was (starts to laugh)—again, this was the doctor who doesn’t tell me all the truth. “Oh, this’ll be fine,” he said. “You’ll be on a pump. You’ll get it every day, but it’ll be such a small dose. You won’t have any side effects.” (laughs) “You can work.” And they thought the two in combination made it a much more significant bet that I would be in that 25 per cent [who respond favorably to the chemotherapy].

So, I went through the chemo, and I was into it about halfway when I had such severe symptoms that I couldn’t continue to work. In fact, I couldn’t continue to do anything. I spent most of the time lying on the floor in my living room, because I felt like everything was spinning out of control. They gave me all kinds of things for side effects. Well, I managed to get through that six months, and I thought afterwards, it was a good decision again. I had good disability at work. Had I not had that, I might have made a different decision. But I could stay, pretty much independent, with the support of my friends. My family and my friends in the Chicago

area. I could manage it, and I returned to relatively good health. It took me a long time. I wasn't working full time until almost the end of December. I went back part-time to begin with. It really socked me. Socked me. And then I only worked six months before I had a recurrence. Then I went on permanent disability.

Margaret related that her most recent decision, to have this current course of chemotherapy was particularly difficult. She knew that she wanted to maximize the time that she had to spend with people she loved, but she didn't know if chemotherapy would add to her "quality time," or foreshorten it. She told me:

Those were hard ones [decisions], I mean, they've all been hard all the way along. This one, the most recent one, has been the most difficult one. For most of the time I was thinking about it, I had decided not to do chemotherapy. It wasn't until the last minute that I decided that I would try it. That if I could be well enough while I was taking it to make the time beneficial that I'm with people, then it didn't matter. My fear was that, if I was going to get into trouble in three months, and if I happened to fall into that eighty per cent that didn't respond to this drug, I was going to get in trouble in three months. Even if I went through whatever effect the chemotherapy had on me--balding, nausea, and all that kind of stuff. Do I really want to do this? Well, this was really hard. That was hard. Because I didn't want to waste any time if I only had three months. I wanted to spend it with people I cared about. So. That one was difficult, but I decided that I would start it, and see how bad it was. And I got through 4 weeks of it, and if it doesn't get any worse, then I made the best decision. (laughs) That one was very difficult.

For Margaret, she knew what she wanted; she just had no idea which choice would get her there.

My sister-in-law, Linda, has also lived into consequences of her choice that no one foresaw. One of her doctors told her that pancreatic cancer is the cancer that gives *Cancer* its bad name. Most people with pancreatic cancer die within five to twelve months of diagnosis, and the 5-year survival rate varies from 5 per cent to less than 1 per cent

depending on the source consulted (Baird, McCorkle, & Grant, 1991; Groenwald, Frogge, Goodman, & Yarbrow, 1993; Lewis, Collier, & Heitkemper, 1996). In marked contrast to these statistics is the story of another friend of mine. Hearing of Linda's illness, she wrote a letter of support and concern. In her letter, she told of her journey with a friend who refused to believe grim prognostic statistics. She wrote:

My friend, 54 years old, was told last July she'd be dead in 3 months because her stomach cancer had metastasized throughout her body. Her doctors told her she was beyond medical hope, and she should go from the hospital to a hospice and prepare to die. She fired those doctors [whom she called Drs. Doom and Gloom], hired a new one [Doctor Sunshine], and started chemo, along with reiki, acupuncture, and Chinese herbs. She also asked everyone to pray for her. She fought every single day just to eat. Just this March, after six months of an intense struggle [as she put it, damn hard work], she was told--miracle of miracles--that she is in total remission. Go figure.

This friend and I learned a lot about fighting to stay alive balanced with accepting what God has sent our way. It seemed to us the key might be in setting the intention (in this case, to recover), working toward that end, and all the while accepting what is. Since we cannot know what the outcome will be, our intentions can set our direction.

What is it like to decide when one has no idea what the future will bring? With anecdotal accounts of outcomes far more hopeful than could "reasonably" be expected, what guidance can one find? When Linda's first "decision," which was to have chemotherapy and radiation, failed to shrink her tumor, her doctors in her hometown of Cleveland told her the tumor was still inoperable. At my suggestion, she came to Evanston for a second opinion. The doctor here had trained at a different institution from the one in which the doctors in Cleveland had trained. He told Linda that the tumor could be removed. He said that Cleveland doctors' concern that she would bleed to death during

surgery was simply not consistent with the capabilities of medicine in 1998. He told her she would be in the hospital post-operatively for 10 to 14 days, she would come to my house to recuperate for a few days more, and then she could return home to Cleveland. Well, Linda did not bleed to death on the operating room table. She lost eight pints of blood in about 10 minutes, but she survived. The tumor is out, and her margins are clear. Still she stayed in the hospital for nine weeks and will be at “home” in my house for at least four more weeks. Her infected wound is slowly healing, but her bile duct is leaking, so she continues to receive all her nutrition through an intravenous line, and she may not eat. She is very weak, requiring a walker to walk around my house. We don’t know how long it will be until she is strong enough to climb stairs to take a real bath. Linda’s day to day lived experience bears little resemblance to the choice she made over two months ago.

In the meantime, I who “got her into this” ask myself: How long will she survive now that the cancer is out? How long will she feel well before the cancer returns? Will she be in the minority in whom the cancer does not return? Will she at least have a long period of wellness to “balance” this very difficult ordeal she has endured? Did she choose the right thing? What would have happened if she had elected not to have surgery? How on earth can we know?

How on earth can we know? Exactly. We *on earth* can never know. As Feifel (1959) remarked with marked understatement, “It is conceivable that our science-conscious culture, which tends to measure all experiences within the bounds of space and time, does not furnish us with all the necessary parameters for investigating and

understanding death” (p. xvii). There are some questions for which we do not and perhaps can not have answers. Hannah wrestled with these issues of “unknowing” and concluded,

I have just decided that only God knows the number of my days. I’m not going to worry about anything else. The doctor doesn’t have a clue and so it is God who is graciously giving me each day to take and enjoy to the best of my ability, and it’s precisely what I am going to do.

Hannah has chosen to “know” that she doesn’t know. Unknowing is her knowing.

The title of this section is an allusion to a phrase in the Biblical book of *First Corinthians*. Comparing our lives on earth to our lives to come in heaven, the writer asserts, “For now we see through a glass, darkly; but then face to face” (*I Corinthians* 13:12). Our struggles to use our knowledge and wisdom to determine which path will lead to the most favored future can be like trying to see through a glass darkly--like trying to see our reflections in a dark, distorted mirror. We may see glimpses of consequences of our choices, but we cannot see the image in full....at least not while we live on this earth.

#### Summary: From Experience to Understanding

In the first three chapters of this dissertation, I laid the groundwork for beginning to inquire what it is like to have a life-threatening illness. Through a variety of paths, I found participants who agreed to help me enter into the question and dwell there awhile. There have been many times in these last few months when a participant has opened his or her life and heart to me and I have felt a bit like Moses encountering the burning bush. Like Moses, I have felt that I should take off my shoes for I was standing on holy ground. What does it mean that I have walked a while with these participants? What can we as

**people learn from their experiences? And how have we changed through the inquiry?**

**In the next chapter, I shall stand back and consider what it is that has been revealed.**

**CHAPTER FIVE**  
**LIVING THE GIFT OF THE PRESENT**

The scene was the hospital's Central Registration Department. A woman stood at the counter conferring with a secretary who was sitting at a computer terminal. Though the woman had called ahead and had given her "vital statistics," in this case the details of her health insurance coverage, the secretary seemed stymied. The information on the computer screen did not match the needs of the woman standing before her. The computer would not accept the information the secretary was trying to enter. The secretary was confused; the woman was wearily patient. Both the secretary and the patient had encountered this situation many many times before. In fact, all of us have encountered this situation many times. It was an unremarkable, tediously usual, ordinary event. As the word *ordinary* means, it was customary, usual, regular, normal, familiar, unexceptional, and common (Webster, 1966). It was just another one of those events of the everyday.

What a lie! What a misrepresentation of the situation! The weary patient standing at the counter was my brother's wife Linda. She was trying to make arrangements for

surgery that would determine whether she would soon die of her cancer or live for many more years. Whether or not she would be able to attend her daughter's wedding or see her granddaughter's first day of preschool was hanging on the outcome of that surgery.

Whether my brother might enjoy thirty more years of companionship with the partner he loved or become a widower in his early fifties would be determined perhaps in the next few days. A powerful and vital drama was being enacted before our eyes. Who knew?

Where were the banners and the attendants who would shield Linda from as much harm as possible so that she could conserve her strength for the ordeal that lay ahead? A person facing such a critical life challenge should be receiving ministrations and elixirs to strengthen and protect her, not standing at a counter enduring the most ordinary and tedious of tasks!

Yet Linda's drama was probably only one of many dramas that unfolded at that counter that day. If the walls of hospitals could speak, those of us who work there day after day might be crushed in the emotions that would pour forth. Tales of joy, sadness, fear, anger, grief, and elation might overwhelm us utterly. We would have to be like Ulysses' sailors who stopped up their ears with paraffin so that they would not hear the songs of the Sirens; we would have to make ourselves deaf to the cries. Perhaps we already have.

This study began five years ago when I realized that I had not heard the cries of a family in my care. It has been that long since I was "pulled up short"--since I failed in an important way to communicate with Fred about Nancy's care. At that time, I suddenly

realized that my “everyday nursing care” by which I mean not only the physical care and teaching that I provided, but also my way of being, of attending to my patients and their families--my usual nursing care was not enough. I had let down my guard. My ears had been stopped up. I had not questioned enough. I had not *reached* the concerns that Fred and I both shared. This research has been a response to that awakening. It has been a call to *see* beneath the surface of the every day--to attend to the extraordinary that dwells beneath that surface.

In response to the breakdown I encountered in my care of Nancy and her family, I turned my attention to the phenomenon of life-threatening illness. I began to ask: What is it like to have a life-threatening illness? Heidegger (1993) noted that the word *phenomenon* is derived from the Greek word *phainomenon*, itself a form of the verb *phainesthai*. *Phainesthai* means “to show itself” (p. 73), and my quest was to attend to the phenomenon of life-threatening illness in order to see what might show itself within that experience.

#### Summary of Themes That Emerged

For the participants in this study, the discovery that they had a life-threatening illness was like a rude awakening. No longer could they, like the rest of us, live as if life would go on forever. Although, intellectually, they had all known that someday they would die, the realization that “someday” was fast approaching was a shocking revelation. Their experiences illuminated the enormous gulf between what we know and how we live.

Paradoxically, the discovery that they were likely to die soon motivated the participants to “wake up” to life. In waking up to life, they began to examine more closely what was filling their lives, their thoughts, and their time. Though suffering was an inevitable part of their experiences, participants were surprised to find other gifts embedded in their everyday lives. Sometimes the gifts were new to their lives, but often the gift was simply a recognition of something that had always been there. Participants spoke of gratitude and of feeling blessed or lucky. Some found new meanings in faith or spiritual experiences, and several were surprised and delighted to find that humor could still find its way into their lives. Nevertheless, advancing disease required many adaptations. Physical symptoms, declining energy, necessary medications, health care appointments, and treatments demanded considerable adjustments in the ways in which they lived their everyday lives.

The changes wrought by life-threatening illness extended into the relationships between participants and the others in their lives. They needed help from others, but they still needed to be of help to their loved ones. Although, family and friends provided vital support and sustenance for participants, they were sometimes the source of the participants’ deepest grief. Participants suffered not only because they might soon be forced to leave the ones they loved, but they suffered in seeing the pain their loved ones felt. The depth of their love for each other was echoed by the depth of their grief.

As participants lived into their illnesses, they struggled with the tension between wanting to be open and honest with the other people in their lives and wanting to be gentle

and sensitive. As the participants and I considered together the nature of these changed relationships, the metaphor of the dance emerged. The tension created by the desire to approach each other in honesty without “stepping on one another’s toes” felt sometimes like a new and unfamiliar dance.

As might be expected, communication with physicians took on renewed importance in the lives of the participants. Participants desired both fullness of information from their doctors and tact and concern in the delivery of what often was very bad news. Ambivalence about wanting to know versus wanting to remain in the relative safety of not knowing complicated the interchanges that took place. Not wanting to be “complainers,” participants struggled to discern the difference between reporting symptoms and complaining. Further, because communication often took place in an atmosphere of high emotion, misunderstandings were common.

Journeying with participants in this study often illuminated how incomplete our understandings are. Though policies of “informed consent” require that patients are informed of the potential risks and benefits of treatment, there are still enormous gaps in what can be known about the course of any individual. Modern science can make fairly accurate prognostications about groups of people with common diagnoses, but predictions about an individual’s illness trajectory take on the character of educated guesses at best. Participants forced to make treatment decisions keenly felt the lack of guidance for their personal decisions. Trying to see which choice would be best for them was like trying to “see through a glass darkly,” that is, to see through a dark and hazy mirror. Facing life-

threatening illness forced participants to acknowledge how little of our lives is subject to human control. In an age of astonishing scientific and technical advances, life-threatening illness was an encounter with the Unknown. It cast the everyday in a new and unfamiliar light and threw open a window upon wonder.

### The Wonder of the Everyday

What is it that anesthetizes us to the wonder of our every days? What is it about the ordinary that blinds us to its depth? We numbly plod or madly race along the surface of our lives, forgetting that great mysteries surround us, above, below, and within. Children frequently ask, “Where did I come from?” or “Where did Grampa go when he died?” As adults, however, we forget that we don’t know. More surprisingly, we forget to wonder. My brother-in-law was employed for several years as a chaplain in a home for retarded children and adults. When the “normal” sibling of one of the residents died, the family was disinclined to take the resident child to the funeral. “He won’t understand it,” they explained. My brother-in-law responded in surprise, “Do you understand it?” We forget to be surprised--to wonder--about the mysteries of the everyday.

Phenomenologists believe that experiences of discord, disturbance, or breakdown can be calls to attend to the wonder of the everyday (Heidegger, 1993; Levinas, 1996; van Manen, 1990). Something unexpected happens and we realize that our conception of life was incomplete. Levinas claimed that the discord “proposes itself as an invitation to search for a new order...The science of yesterday, before the new facts of today, thus makes its

way toward the science of tomorrow” (p. 68). Levinas understood, however, that there are some thoughts and experiences that are even beyond understanding. Levinas believed that a fundamental problem inherent in Western philosophy was that it failed to consider that there are some thoughts that are so totally *other* that they defy the confines of language, thought, and understanding. Using the language of religion to express himself, he wrote,

Once come into a correlation, the divinity of God dissipates, like the clouds that served to describe his presence. All that could have attested to his holiness, that is, to his transcendence, in the light of experience would immediately belie its own witness already by its very presence and intelligibility, by its chain of significations, which constitute the world. To appear, to seem, is forthwith to resemble terms of an already familiar order, to compromise oneself with them, to be assimilated to them...If a formal description of such a disturbance could be attempted, it would have us speak of a time, a plot, and norms that are not reducible to the understanding of being, which is allegedly the alpha and the omega of philosophy. (pp. 67, 68)

Levinas used the term *The Infinite* to describe the idea of thoughts beyond thought as well. He said, “The idea of the Infinite would contain more than it is capable of containing, more than its capacity as a *cogito*. The idea of the Infinite would somehow think beyond what it thinks” (p. 156). Though this wording is confusing, that is exactly Levinas’s point. If we could clearly describe and understand the Infinite, it would not be infinite.

Heidegger (1959/1966) has approached this dilemma from a philosophical rather than a theological perspective. In his work, *Discourse on Thinking* (1959/1966) he considered the distinctions between what he called *calculative thinking* and *meditative thinking*. Calculative thinking is thinking that proceeds in an orderly fashion from one

thought to another. It is the kind of thinking that is used to solve problems. It is thinking that happens when the thinker knows what she wants to think about. Meditative thinking is a very different activity (though *activity* is not an accurate word). Though meditative thinking is not mindless, it is an emptying of thought in order to consider what might be perceived beyond thought. As Anderson (1966), one of his translators, explained, “Meditative thinking involves an awareness of the horizon of the field of awareness. [It is] open to the field beyond knowing” (p. 29). Thus, it is a kind of Sisyphean task. When we try to think of what Levinas (1996) called *The Infinite* and Heidegger called *that-which-regions*, we find ourselves in an experience Heidegger called “*coming-into-the-nearness of distance*” (p. 68). He meant that when we try to “think beyond thought,” as soon as we begin to grasp something of its “beyondness,” we diminish it, so our thinking simultaneously reveals and conceals that which it wants to apprehend. Explaining why he had not published the third part of his work *Being and Time* with the earlier parts, he wrote, “...[The piece] in question was held back because thinking failed in adequately articulating this [question of the meaning of Being], and did not achieve its goal by means of the language of metaphysics” (p. 18).

The writings of Levinas (1996) and Heidegger (1959/1966) apply to this study at a very deep level. Participants in this study were shaken out of their normal everyday experience by the diagnosis of life-threatening illness. Against their will and desire, they were forced to confront the possibility of non-being, of being no more. It was an experience of the Infinite breaking in upon their lives. The discord that they felt was a call

or a demand to reconsider their own lives. In that reassessment, many of them “found” understandings and perspectives that greatly enriched their everyday. Surprisingly, what they found was often merely a recognition of what had always been there. Their brush with the Infinite opened their eyes to the wonders of their everyday. It called them to expand their vision beyond the surface of their lives.

### Discovery as Remembering the Forgotten

It probably should not be surprising that participants in this study often “found” what had always been there. Phenomenology is a philosophy that arose out of forgetting. It seeks to rediscover the rich meaning that lies hidden beneath the surface of the everyday. The quest of phenomenology is to coax that which has been concealed out into the light. In his introduction to *Being and Time*, Heidegger (1993) wrote that the very question of Being had been forgotten. Referring to the work of philosophers who had preceded him, he wrote:

It is said that “Being” is the most universal and the emptiest concept....Nor does this most universal and thus undefinable concept need any definition. Everybody uses it constantly and also already understands what they [sic] mean by it...[But] if one says accordingly that “Being” is the most universal concept, that cannot mean that it is the clearest and that it needs no further discussion. The concept of “Being” is rather the most obscure of all. (pp. 42-43)

For Heidegger, existence itself--Being--the most fundamental aspect of the universe--was so ubiquitous it had become invisible. He lamented what he saw as the loss of meditative thinking in the modern world, believing that the advance of science had focused Western thought on calculative thinking instead. Further, he claimed that people were losing

themselves, in a very literal sense, to pursuits such as television, radio, and frivolous film. This loss of thinking--meditative thinking--was a loss of a fundamental part of our selves, for thinking is constitutive of humans. He noted, "Thoughtlessness is an uncanny visitor who comes and goes everywhere in today's world" (1959/1966, p. 45). He added that the very fact that we can be *thought-less* points to our capacity for thought. The task of phenomenology was to reawaken our destiny as thinkers and to rediscover Being. It is important to note that the task is not to *discover*, but to *re-dis-cover*. The task, in a sense, is to find again what had once been known, but had become overlooked or forgotten. Hillman (1967) has noted, "Forgetting and remembering show us that the mind can lose something and yet not lose it; the mind simply stores it somewhere, and then brings it out again" (p. 51). The "discoveries" within this dissertation had the character of forgotten knowledge brought once again into the light. Through the experience of life-threatening illness, some participants rediscovered and reclaimed what was most important to them.

#### The Relevance of Attending and Waiting

As I began to write this chapter, the word *attend* began to rise to the surface of my thinking. As I began to notice the word attend, I began to understand why it might be an important word for this interpretation. William James has said, "My experience is what I agree to attend to" (cited in Kurtz & Ketcham, 1994, p. 78). Attend means "to pay attention or to give heed" (*Merriam-Webster Dictionary*, 1998). It also means "to take care of, to wait upon" (*Merriam-Webster Dictionary*). It arose from Old French and Latin words that mean *to stretch*, and it developed to mean "to direct the mind or observant

faculties to listen, to watch over, to wait upon.” An *attendant* is one who “follows, escorts or accompanies for the purpose of rendering service, usually to royal personages” (*OED*). Thus, one who attends is one who accompanies another or one who waits in readiness to serve another. I began to see myself as one who *attended* to the phenomenon, that is, as one who accompanied participants, willing to stretch myself toward them, but also as one who waited in readiness to receive whatever the phenomenon had to say to me. The participants, too, *attended* to their lives in new and more thoughtful ways.

The waiting in readiness of which I speak is what Heidegger (1959/1966) called *waiting upon*. Anderson (1966) explained the difference between waiting upon and *waiting for*. He said that normally when we wait, we wait for something that is an expression of our desires, goals, or needs—entities that arise from within ourselves. Waiting upon, on the other hand, is waiting “without knowing for what we wait....for something that cannot be grasped and expressed in subjective human terms” (p. 23). In the words of Heidegger, “In waiting [upon] we leave open what we are waiting for” (p. 68). It was in waiting upon the phenomenon of having a life-threatening illness that I hoped to discover what would be revealed.

#### Discovery as a Dangerous Journey

The discovery that one has a life-threatening illness is an unwelcome shock. It abruptly tears away the familiar fabric of life and plunges a person into the unknown. Nothing is as it was before. And yet, almost everything is as it was before. What is profoundly different is one’s perspective on the every day. Merleau-Ponty (1964) has

noted that because we are living in the present, we lack distance from it and can see only one side of life. A diagnosis of life-threatening illness abruptly reveals a side of life that has been unnoticed or unacknowledged before the diagnosis.

When confronted with a life-threatening illness, participants felt that their lives were profoundly shaken. Life felt very, very broken. My journey with the participants has suggested, however, that the irony may be that we are more broken when we are blissfully unaware. The pain and brokenness of illness can be catalysts that lead us to awareness and healing. Bolen (1996) likened life-threatening illness to a mythic journey to the underground world--a journey full of danger, but also a world of transformation and possibility. Hillman (1967), too, used the metaphor of a downward journey. He wrote:

If we discover the place of the soul...to be darkly within and below, we must reckon with a perilous voyage. The lower positions (the dark, the down, and the deep) are the realm of the devil and his horde of demons. The way of descent means the way through the labyrinth, and even theological tradition tells us that the descending path means a confrontation with all things which have been put down through the ages... (pp. 49-50)

This is a journey fraught with danger. Loss, suffering, and disability may await those who enter here, but treasure and blessing may also be found.

Hillman (1967) described a place "darkly within and below" (p. 49). Sanford (1968) and Jung (1959) gave this notion a different form; they called it the shadow. Sanford explained that people are made up of far more than their conscious, known selves. Personality also consists of a hidden and unknown, unconscious self. Within the unconscious part of self that we do not want to face or recognize is the shadow. As each person develops unique characteristics of his or her psyche, other characteristics are

repressed or left without expression. The sum of this unacknowledged self is the shadow. It sometimes is encountered as an enemy in our dreams--an enemy that seeks to do us harm. Yet Sanford, a Jungian analyst, maintained that if we will explore our shadows and allow them to speak to us, we will move toward greater wholeness. It is not that the shadow is not threatening--it is. It will very likely transform our familiar selves and lives. Still, the shadow influences us whether we acknowledge it or not. In befriending our shadows, we can develop into more integrated whole people. An encounter with the shadow, like a crisis, can be a danger and an opportunity. It can be the start of a journey that expands our spirits (Magrisso, 1997b). Hillman (1967) asserted that healing can come from the shadow side. He wrote, "Healing comes from our unguarded side, from where we are foolish and vulnerable" (p. 22). By attending to those parts of us that are unacknowledged and unintegrated, we can become more whole. Thomas Moore (1992) extended this idea to suggest that suffering can also be a messenger. He cautioned against moving to alleviate suffering too quickly before its message has been heard. He wrote, "The basic intention in any caring, physical or psychological, is to alleviate suffering. But in relation to the symptom itself, observance means first of all listening and looking carefully at what is being revealed in the suffering" (p. 10).

Susan Sontag (1989) called illness the "night-side of life" (p. 3). She said:

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (p. 3)

For the participants in this study, encounter with a life-threatening illness propelled

them into a journey that none would have chosen. It forced them to use their “passports to that other place.” It illuminated their weakness and mortality. It brought suffering on many levels. At the same time, however, for some, the encounter with illness—with the shadow side of health—provided deep and meaningful experiences.

### The Central Place of Community

When the participants in this study re-examined their lives through the experience of life-threatening illness, they attended to the other people in their lives—family and friends—in a deeper way. The discovery of the inestimable value of the other people in their lives was one of the treasures hidden within their illness. As Margaret so vividly noted, “Most people die without ever knowing how much people care about them...The good things that have happened to me since I have become ill outweigh even the day that I die.” She and the people in her life began to see each other as precious gifts.

Human beings are creatures who live in relation to each other. Logstrup (1956/1971) and Levinas (1996) believed that living in community with others evoked an ethical demand to care for the other. Levinas claimed that we have an ultimate responsibility to our neighbor. In Levinas’s view, so strong was this call to the other that it was impossible to evade. Peperzak (1996) summarized Levinas’s assertion by writing “To encounter another is to discover that I am under a basic obligation: the human other’s infinity reveals itself as a command” (p. xi). Logstrup claimed that because we can influence another so easily, we are obligated to influence the other for good. He wrote:

By our attitude to the other person, we help to determine the scope and

hue of his world; we make it large or small, bright or drab, rich or dull, threatening or secure....Herein lies the unarticulated and one might say anonymous demand that we take care of the life which trust has placed in our hands. (p. 19)

We so often see others in terms of what they can do for us. We look for clients or customers. We go to meetings to “network” in order to meet people who may be able to further us along our career paths. We recruit others for causes we want to advance. When we see others solely in utilitarian terms, we are viewing them as *standing reserve* (Heidegger, 1993)--as helpers and resources for us. We are engaged with them in a relationship Buber (1958) would call *I-It*, rather than *I-Thou*. Hidden from our view is a sense of the other as *person*. Even those who are closest and most important to us can be pushed into the background until some future day when we will have time to spend with them. When life-threatening illness comes, however, our lives change. Life-threatening illness casts our lives into an unfamiliar light, and it reframes our view of the others in our lives. We become aware of how much we value those closest to us. We become aware of their intrinsic value as other. Participants in this study felt a renewed call to notice and appreciate the friends and family in their lives--to *attend* to others in a more thoughtful way.

The call to attend to others was a complicated demand. For the participants in this study, the people who made up their communities were the source of their deepest joy and their deepest pain. Time and again, they told of the richness they experienced in the love of friends and family, but at the same time, the connection to their loved ones caused them their deepest grief. The participants were loathe to leave the ones they loved; they also felt

helpless to protect their loved ones from the grief that those loved ones would experience if and when the participant died. Like the arrow of Eros, love wounded as it blessed (Hillman, 1967).

### Receiving as Constitutive of Community

A community is usually thought of as a body that shares life in common with each other. Members of a community are exhorted to give to one another. The emphasis on giving, however, conceals an equally important role--the role of receiving. As Hillman (1967) wrote:

My needs are never absent. I could not do this work [psychotherapy] did I not need to do this work. But my needs are not mine alone...Just as the person who comes to me needs me for help, I need him to express my ability to give help. The helper and the needy, the social worker and the social case, the lost and the found, always go together.

However, we have been brought up to deny our needs. To need is to be dependent, weak; needing implies submission to another. (p. 17)

Lingis (1994) claimed that care of the sick and dying is a critical task for humans--that a society that forsakes the dying to die alone is a society that "undermines itself radically" (p. xi). He maintained that the sick and dying are inherently valuable to a society *because* of their dependency. The idea that the weak have a unique gift that a community needs is a perspective that is usually lost in Western society. It is a costly loss for those who have a life-threatening illness and must cast themselves upon the care of others (Byock, 1997). Participants in this study struggled fiercely with their need to lean on others. Their need for help from others often eroded their self-esteem. They worried about being a burden to those they loved. The conception that those who receive from others build community by

their very act of receiving can lend self-respect to people who are wholly dependent on the care of others.

*Logos: The Fire that Warms, Illuminates, and Burns*

Philosophers claim that language is at the core of community (Levinas, 1996). It is our capacity for language that most makes us human (Heidegger, 1993). Our ability to bring concepts forth into words shapes us into the *beings* that we are. Heidegger saw the concept of *logos* as central to this understanding. *Logos* means *speech*, but it means considerably more than that. *Logos* has been used to mean “reason, judgment, concept, definition, ground, relation” (Heidegger, p. 78). Heidegger believed those definitions clouded the true meaning of *logos*. Instead, he claimed, *logos’s* meaning is *deloun*, a word that means “to make manifest ‘what is being talked about’ in speech....*Logos* lets something be seen (*phainesthai*), namely what is being talked about, and indeed *for* the speaker...Speech ‘let’s us see’...what is being talked about” (p. 78). Merleau-Ponty (cited in van Manen, 1990) expressed this idea in a slightly different way. He wrote, “When I speak, I discover what it is that I wished to say” (p. 32). Speaking and thinking are very difficult to separate. The act of bringing forth speech is an act of making thoughts visible. It can bring forth the speaker’s perspective on the world. Gilligan (1982) asserted that the central assumption of her research was “that the way people talk about their lives is of significance, that the language they use and the connections they make reveal the world that they see and in which they act” (p. 2). Belenky, Clinchy, Goldberger, and Tarule (1986) have illuminated the ways in which speech and voice are integral aspects of the

development of mind and self. Thus, speech, thought, revelation, and perspective are woven together in *logos*.

*Logos*, speaking and listening, are so fundamental to community that the ancient Greeks used the word *logos* to describe the hearth-fire that provided warmth, protection, and togetherness for a family (Olson, 1993). To care for the hearth-fire was to care for the community, and to speak and listen carefully to one another was to heed to one another in the light of *logos*.

The relationship between community and communication is visible in the similarity of the words. Both derive from the Latin *communis* which means common (Webster, 1966, p. 296). *Communicate* means literally “to make common” (Webster, p. 296). It is used to mean “to impart; pass along...to make known” (Webster, p. 296). *Community* in its earliest meanings meant “fellowship” (Webster, p. 296). It still means “the quality of appertaining to or being held by all in common...common character, agreement, identity...social fellowship...life in association with others, society” (Simpson & Weiner, 1989, Vol. III, pp. 581-582). The sense of these ideas is further revealed when *communis* descends into the word *communion*. The Christian sacrament of Holy Communion is a sacrament in which believers are made one with all believers, those who are alive now and those who have died, and with the risen Christ. Communication, community, and communion are words with deep and profound histories.

What is lost in the philosophical and theoretical discussions of communication is the realization of how difficult that communication is. Speaking and listening are not

straightforward acts. Apprehending one another is a very difficult task. In the flickering light of *logos* we see the side that faces the light, yet in the shadows looms a side unknown, unspoken. Our attempts to communicate with one another are continually thwarted by the limits of our energy and understanding. We can never bring the whole of ourselves out into the light; we can never see the whole of another.

The work of David Levin (1989) has opened up my understanding of some of the difficulties embedded in speaking and listening. Levin asserted that hearing is a gift of nature. Like all such gifts, it is freely received, but it places an implicit demand upon the receiver. That demand is to develop one's capacity to use the gift. In the case of hearing, the receiver is called to develop the gift of hearing into the gift of hearkening. Harkening is the highest (or perhaps deepest) level of listening. It arises out of skillful listening in which we commit ourselves to the other in an attitude of compassion, but it has an even more contemplative flavor. Harkening is a process of "letting-go and letting-be" (p. 257). It is a focusing and attending to the other. It involves removing attention from oneself in order to make room for the fullness of the other. Hillman (1967) described this listening as "allowing the other to come through in his own way....On the human level, withdrawal of myself aids the other to come into being" (pp. 22, 31). In the words of Lame Deer, a Lakota medicine man, it requires wrapping a cloak of inner silence around oneself like a blanket (cited in Levin, 1989). Gadamer, too, spoke of opening ourselves to the other in conversation. He wrote:

Thus it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid, and transposed himself into the other to such an extent that he understands not the particular

individual but what he says. (p. 382)

Because hearkening in this way is such intense demanding work, requiring time, energy and focus, it is not surprising that failures to communicate may be as ubiquitous as successes. An archer who sends an arrow toward a target sees immediately if the arrow misses its mark. For speakers and listeners, however, indications of failed communication may be far less visible. Both may leave the interchange believing that understanding has been achieved only to learn later that it was not. No bell rings to indicate that the intended message and the received message differed. This elusive nature of communication has emerged over and over again in the stories of the study participants. From Harold who never apprehended the terminal nature of his disease until a few days before he died to my experience with Nancy and her family, to Margaret's doctor who "lies," the words speakers used to try to unite themselves with others have divided them instead. After one of Linda's post-surgical CT scans, the radiologist began his interpretation by saying, "At the very least, we have bought you some more time." He meant that the efforts they had made so far had stabilized Linda so that if surgery were needed in the future, it could be postponed until she were stronger, and thus, surgery would be less risky. His phrase "bought you some more time," however, closed Linda to his message. That phrase, to her, consisted of "cancer words." As she later explained, she thought he meant that they had bought her more time until her inevitable death from cancer. She was so devastated she was not able to listen any more, to ask any questions, or to explain why she had closed down. The radiologist's words, intended as reassurance, were received instead as a

horrible blow. It was not until several days had passed, however, that he found out how his message had been received.

As logos illuminates some areas, it throws others into shadow. It warms, but it can also burn without warning. Logos--the heart of communication--can wound and heal, reveal and conceal.

### Implications for Practice, Research, and Education

The aim of phenomenology is not to come to a point or a conclusion about the world but to enlarge our understanding about ourselves and our lived world (van Manen, 1990). Thus, what follows is not a summation of results, but more an opening of questions to consider in practice, research, and education.

#### Implications for Practice and Research

Phenomenology strives to uncover meanings and make them visible. Therefore, the question that presents itself now is: What has been discovered that has application to practice? Several themes have emerged that are relevant for the practice setting. The first theme concerns the idea that blessing and suffering are inextricably intertwined. So often, nurses encounter patients who are suffering. Sometimes that suffering is relatively mild and transient, but sometimes it is overwhelming. Though it is important that nurses do not minimize the suffering of their patients, I would suggest that nurses should remain alert for opportunities to ask patients if there have been any blessings or messages or teachings hidden within the suffering? In what way might the illness be a crack in perfection that lets

the light in (Cohen, cited in Magrisso, 1997b)? Perhaps there is a way that nurses can help patients to consider what else there is in their experiences besides suffering. Have there been ways in which their illness has shed light on mutually exclusive truths (Kierkegaard, 1843/1983; 1849/1989)?

A second consideration that relates to the practice setting concerns the word *blessing* itself. Within the discussion of the word blessing was the observation that blessing originally referred to marking something with blood in order to invoke beneficence from a god (Simpson & Weiner, 1989). To bless something was “to make...holy with blood...to render a thing inviolable from profane use...” (Simpson & Weiner, Vol. II, p. 281). The nature of nursing practice means that we are frequently intimately involved in both sacred and profane aspects of patient’s care. Our care often requires poking, prodding, and manipulating tender or private places of another’s body. Mona said that she had been “cut up like a chicken,” a phrase that suggested her body had been treated in a most profane way. Yet, is there a way in which nursing care can have a sacred quality? Nurses commonly draw blood samples, interpret the blood’s messages (lab values), and administer blood transfusions. Nurses are present at pivotal times in the lives of patients--births, rescues, life-saving treatments, and death. What would happen if nurses and patients perceived their treatments as sanctified?

Another implication for practice concerns the themes of knowing and unknowing. During my second conversation with Margaret, she explained that she was in no hurry to discover the efficacy of her chemotherapy. She described herself as “afraid to ask” because

she did not want to hurry what might be bad news. Margaret's viewpoint recalled Hall's (1990) discussion of the difficulties of maintaining hope in an era of aggressive informing. There is a delicate balance between "informing" a patient of his or her diagnosis and allowing a patient to linger awhile in the unknown. The examination of communication between doctors and patients in this inquiry shows that health professionals and patients are often at cross purposes regarding how much information a patient desires at any one time. Further, understanding is an elusive goal. The experiences of participants in this study suggest that health care professionals must be vigilant in the attention they pay to communication. Checking and re-checking the intended message against the received message should be a high priority. Careful sensitivity to the patient's desire for pacing of information is also required. As *logos* is a fire that can both warm and burn, we need to be cognizant of which effect our communication is having on our patients. Simply asking patients to repeat their understandings of what has been said could help to make communication more visible.

A further consideration for practice raised by this inquiry is the need for a legacy. As Margaret was nearing her death, she found that she needed to begin to identify the ways in which the world was a better place for her passing through it. Though Margaret was the only participant who spoke of this issue, Callahan and Kelly (1992) suggest that it is an almost universal need. They wrote, "Most people, as they're dying, want to feel that their having been alive has been significant, that they made some difference in this world and in the lives of those around them" (p. 170). An implication for practice is that nurses

can invite patients to begin to take inventory of their lives. Asking the patient to tell about some of the accomplishments of which he is proud or about something important that he has learned from his experience can open discussion of the meaning of an individual's life and of his legacy.

A more general theme that has emerged from this inquiry concerns the conceptualization of human encounters as meetings within the space of the primary word *I-Thou* (Buber, 1958). It raises the question: "What can health care workers and patients do to engage each other more fully when we meet in the practice setting?" Broyard (1992) pondered what he wanted in a physician and wrote:

I would like a doctor who is not only a talented physician, but a bit of a metaphysician, too. Someone who can treat body and soul. There's a physical self who's ill, and there's a metaphysical self who's ill....So I want a metaphysical man to keep me company. To get to my body, my doctor has to get to my character. He has to go through my soul. (p. 40)

Broyard's words recall the thoughts of Buber (1958) who suggested that when we meet others, we are to give ourselves over to them. We are to make room for them to *be* in our presence. We are to open ourselves to encounter them in the holy space of the *I-Thou*, the *primary word*. What would our nursing care be like if we endeavored to approach each patient as if that person might be a holy one in need of our ministrations? What are the ways that practitioners attempt to meet patients in the space of the *primary word*? Buber wrote:

Primary words do not signify things, but they intimate relations. Primary words do not describe something that might exist independently of them, but being spoken they bring about existence. Primary words are spoken from the being....The primary word *I-Thou* can only be spoken with the whole being. The primary word *I-It* can never be spoken with the whole

being. (p. 3)

Thus, for Buber, the primary word was a space that is made, not a sound that is spoken. This is akin to Vendryes's observation that language is "in the air *between* the speaking subjects but never fully realized in any of them" (cited in Merleau-Ponty, 1964, p. 81). It recalls Gadamer's (1960/1990) description of a conversation as something that draws us in, not something that we conduct.

These conceptions of human interaction stand in stark contrast to the health care environment of today. In the context of managed health care, of understaffing and the pressure to generate income, what can we do to acknowledge the *Thou* in the patients we meet and the *I* within ourselves? What questions must be addressed to reveal the metaphysical person who seeks our help? What must we do to balance the human needs of the patients and staff with the business needs of the institution that provides the structure for care?

The first step would be an honest appraisal of the values of the institutions for which we work. Tethered as they are to financial indicators, institutional structures can easily focus on economics. Clinical excellence is valued, but excellence is usually conceptualized as something that can be measured with objective outcomes. Mission statements and advertising campaigns are more likely to speak of caring for the whole person, but day to day operations must be examined in that light. In what way do the structures of the institution create room for workers and patients to meet each other in an attentive holy interpersonal space? What are the ways in which the space of the primary

word can be made visible? I believe that the very act of asking the question will create possibilities for more authentic meeting. What is the experience of a patient who first enters the institution? How much weary “standing at the counter” does the patient endure? What is the character of initial encounters with nurses? Is the patient welcomed and valued as a central person in the healing process (Chinn, 1989)? In initial meetings with nurses, is the emphasis placed on completing comprehensive paperwork or on making space for the patient to express his or her needs, desires, or fears? When authentic meeting does take place, in what way can that meeting be made visible to others? Is sitting and talking to a patient or sitting in silence with a patient a valued use of the professional’s time? In what ways can the professional who meets another in a deep and nurturing way be recognized? What are the ways that audits can capture provisions of care that cannot be counted? Do continuing education curricula provide space for engaging with the dilemma of persons caring for persons within a corporate business culture? We need to take Gadamer’s (1960/1990) suggestion to open ourselves to these questions and hold them open as we practice, so that we might *dis-cover* ways of being that approach the ideal we seek.

Research questions could include: What happens in a health care institution when practitioners begin to examine the meetings that take place within the institution? What do patients experience when their health care workers make a conscious attempt to open themselves for a meeting? What do the health care workers themselves experience? Do they perceive any differences in their practice?

### Implications for Education and Research

My experience is in nursing education, first and seemingly forever as a student, and most recently as a clinical instructor. Though I suspect my observations are not unique to nursing education, it is the context I know best, so my focus will be directed to that discipline.

Nursing education is a demanding endeavor. The explosion of information and the rapidly changing health care field continue to add to the “knowledge burden” that students must attempt to master in a narrowing time frame. Limited clinical opportunities make it extremely difficult for students to gain the practical experience they need to synthesize their classroom learning. Additionally, the student who can devote him or herself to studies full-time is becoming the exception rather than the rule. Many students must find employment in order to meet the expenses of education and living (Sullivan, 1997). Those who are fortunate enough to find employment in a health care environment have two advantages. They are able to supplement their incomes and they are able to supplement their “book and lecture learning” with learning by doing and seeing. In my own clinical groups, students who were not employed in health care settings had difficulty gaining the knowledge and skills that were required to advance in the curriculum. Most of my students felt stretched to the breaking point by the demands of their studies and their work. What is the effect of this sustained pressure on the person who will soon be a graduate nurse? Within the pressures of an academic calendar, where is the balance between time for the synthesis of knowledge and experience and time for attending to the

inner person?

The clinical site is a setting in which people interact with each other almost continuously. Almost every moment of a nurse's day is meeting. From change of shift report to rounds to consultations with other health care professionals and families, the day is full of encounters with others. Are any of these encounters meetings within the holy space of the primary word (Buber, 1958)? Listening hearkening, and emptying oneself to meet the other fully are activities that require care, attention, and time. When we teach students to prepare themselves before they go to a patient's room, we usually mean, "Gather all the supplies and paper forms that are needed. Think about the order in which you will carry out your tasks." What would change if we also taught students to take a moment to center their thoughts and feelings and open themselves to the meeting that is about to occur?

If we want students to become nurses who care about the patients they meet--who attend to the unexpressed messages as well as the spoken messages, we need to attend to ourselves and the person inside the student as he or she moves through the curriculum. What is required to assist students to attend to the experiences they most need? Curricula must make space for the inner life of students. Students could be engaged in small "reflection groups" during their curriculum. Within these groups, they could examine their own responses to their academic and clinical experiences. What has called to them and what ways have they found to answer that call? What impedes their ability to meet authentically with patients, faculty, and each other? What encourages that ability?

Consideration of literature, film, and art could open additional avenues to knowing about themselves and their patients.

Another area of questioning concerns the pedagogy of “not knowing.” Nursing education demands that the student master a wealth of concrete knowledge. Students must be taught to make a plethora of observations and measurements and then to synthesize those observations into a plan of care for the patient. When a student spends years honing those observational skills and adapting those skills to the formalized structure of the multiple choice test--an adaptation that is crucial for passing computerized qualifying exams--what happens to wonder? What happens to the mystery of *Being*? Where in curricula is the space for pondering the meaning that lies beneath the surface of our lives? What needs to happen to encourage the student along the path of “not knowing?” Is there a way to balance a nurse’s need for knowing with a human’s need for wonder? Where is there space for “not knowing” in pedagogy? Does the quest for knowledge drive wonder underground?

Wonder and “not knowing” are not skills that can be taught in the way that listening to breath sounds and interpreting laboratory values can be taught. Wonder is more like a window on the world that needs to be thrown open. “Not knowing” can be an omnipresent but unacknowledged presence in every setting. Sometimes, simply acknowledging its presence can revive wonder. For example, one teacher of basic statistics occasionally started class by asking each student to complete the sentence, “One thing I do not know is...” By making space for each student to acknowledge and claim a part of

“unknowing” the teacher made space for the unknowing part of each student. In similar ways, occasional turnings to the wonders that are present in the lives of students, faculty and patients could nourish a student’s (person’s) sense of wonder in the midst of overwhelming knowledge. Students could be invited to keep “wonder journals” in which they could attend to the dramas they encounter in the lives of patients. They could be invited to ponder what the walls of their clinical areas could tell them. They should be encouraged to notice the clinical situations that do not illustrate learned principles as well as those that do. What are the situations that do not make sense? What calls forth their unknowing? The research question(s) is what is the experience of the faculty and the students who pursue quests of wondering and unknowing? Is there a way in which wonder and unknowing can be made visible in curricula?

#### Evaluation of the Study

When I return to the assumptions I laid out at the beginning of this study and the criteria by which I intended to evaluate the study, I am given pause. Leonard (1994) believed that a measure of the success of a study is the degree to which the study has resolved the breakdown and opened up new possibilities for engaging the problem. At this point in the study, however, I find that I am less interested in “resolving” breakdown than I am in listening to the message of the breakdown. I no longer expect that a breakdown can be resolved; instead, I believe it should be heard. This dissertation is a response to the message of the initial breakdown.

### Meanings That Have Emerged

Leonard (1994) further suggested that an interpretive study can be evaluated by asking “What does the account make available to the clinician that did not exist before except as concealed and baffling? What kind of new access do the study’s findings give to the clinical phenomenon?” (p. 60). Here, I stand on firmer ground. The study has turned my attention to the depth that exists beneath the surface of our everyday lives. It is not that I didn’t know that it was there before I began this inquiry, it was that too often I did not take the time to hearken to what was there. For me, this study has been a re-calling to attend to my life and the lives of the people around me. When Margaret said that most people die without ever really knowing how much other people love them, it awoke in me a desire to attend to the others in my life in a new way. I left that first meeting with Margaret feeling jealous of the depth of her experience. I wanted to receive the love that others have for me and I wanted to express my love for others more openly. My response is very definitely a work in progress, but I am re-called to attend to life in a new way.

The study has further opened my eyes to the wonders and mysteries of life. A firm believer in the concept of “informed consent” at the beginning of this study, I have come to appreciate how complex that concept is. As Linda’s story illustrates, what we consent to may bear little resemblance to what we receive. While it is true that we can make choices that will influence our futures, it is equally true that we cannot choose our futures. The clause in consent forms that notes that “medicine is not an exact science” does not begin to plumb the depth of what is unknown. As Levinas (1996) has said, “We still

reason as though the ego had been present at the creation of the world and as though the world, henceforth in its charge, had issued from an act of free will" (p. 93). In matters of health, life, and death, we have some knowledge, but we have much more unknowing (Chamorro & Appelbaum, 1988; Orentlicher, 1992; Quintana, Nevarez, Rogers, Murata, & Tzamaloukas, 1991; Siminoff & Fetting, 1991).

This study further offers a new illumination on the limits of interpersonal communication and understanding. The quest to improve understanding has been framed as a cyclical rather than a linear journey. Breakdown and discord may open our awareness of missed communication, but after thoroughly exploring and clarifying the miscommunication, it is likely to return again, perhaps in a different form. A repeated question may not be a sign that no progress has been made, but rather an indication that questions, like onions, have many layers, and can be addressed repeatedly with increasing depth.

When I began this study, an experience of breakdown had called me realize that a client and I had failed to communicate about an important aspect of a patient's care. As I was writing this summary chapter, Linda and I discovered that we had had a new episode of missed communication about an issue that was very important to her. Does that mean that I am in the same place as when I began? Not at all. I have a deeper, fuller, richer understanding of the phenomenon of life-threatening illness. Perhaps, having spun through one round of the dance, I have come again to the beginning. My journey through the first rotation of the dance will inform my journey through the second one. I also have come to

believe that miscommunication will continue to be a part of all relationships. What this account has made more available to me is the knowledge that communication is likely always to be an elusive goal and will require my continued vigilance. At the same time, I have witnessed expressions of a wealth of human experience that have enlarged my vision. My assumptions listed in the first chapter have not changed, but they have deepened and matured. For example, before the study began, I believed that it was important for nurses to *be* with their patients. The philosophical writings that grounded the study as well as my experiences with participants have expanded my understanding of what it means to be with a patient. Attending to the other as a *Thou* and trying meet in the space of the primary word are goals that have been articulated through this inquiry.

Further, I knew before this study began that paying attention to dying had the potential to change lives for the better. Because of the difficulties in defining exactly who was dying and who was not and the difficulties of gaining access to “dying” patients, I changed the focus of the inquiry to patients with life-threatening illness. As I expected, attention to that phenomenon was a worthwhile endeavor. What was unexpected, was the depth of the experience for participants and for me.

#### Limitations

This study did not seek to create universal meanings that would be applicable to all who face life-threatening illness. Rather than seek common understandings that undergird the phenomenon, this study sought to consider the depth of the experiences of a few to illuminate a possibility of what it means to be human. The number of participants was

necessarily small. Some of them were geographically distant from me, which limited our ability to spend lengthy times together. Of the ones who were geographically close, their re-ordered priorities limited the time they chose to give to the study. More than most of us, they realized that time given away was precious. Frequent meetings and conversations with me were more than they could afford, and I am deeply grateful for the time they did give.

It should be further noted that all of the participants in this study were privileged. They all had friends, families, and neighbors who were willing and able to accompany them on this part of their journeys. They all had the financial resources to acquire the health care they needed as well as the basic needs for food and shelter. Most had resources that provided much more than that. This study does not examine, therefore, what it is like to have a life-threatening illness when one is alone and poor.

Additionally, none of the participants had yet entered their “final decline.” Daniel was experiencing a time of recovery. Sarah was the weakest, the one whose tasks of daily living were most tiring, yet even she was able to get up and dressed with help each day. The phase of life that demands dependence on others for every need--eating, drinking, bathing, toileting, moving in bed--that phase is not represented in this study.

What this study offers is a careful attending to a time in the lives of the participants when they all considered what it was like to have a life-threatening illness. I trust that I have captured some of that life and presented a view upon their worlds.

### Summary

The questions remain: What has been discovered? What has been revealed? What follows is not my answer, but my response.

Throughout the journey of this inquiry, I have been called to attend to the sanctity of the present moment. As Tillich (1959) declared, it is in the present that we have access to the eternal. The gift of the present is all we ever have. Though this continues to be an elusive call--the stuff of everyday life continually threatens to bury the treasure of the present tense, it is a call that reaches me more often than it did before.

This study has also reminded me of the depth that resides within each individual. Patients, families, and colleagues are *Thou-s*. Encounters with others bear the potential of becoming meetings within what Buber (1958) calls the sanctity of the primary word, *I-Thou*. The study has been a reminder that sparks from the divine may glow within the others in my everyday.

The study has been a call to attend to the complications of communication. Missed messages and confused interactions have emerged from the beginning of the study through to the end. There is no reason to believe that communication will be any different in the future. Part of the call of *logos*, the ethical demand to care for the center of community is the call to *attend* to the complexities of communication. In order to meet the other fully, we must engage our continued vigilance in our attempts to reach each other.

One of the hearkenings of this study has been to consider the attitude in which we engage in life. Are our lives ours to choose and control or are our lives something that we

receive? Are we creators of our lives or are our lives created? Here, Kierkegaard (1849/1989) has been instructive, claiming that life consists of mutually exclusive truths that we must somehow learn to apprehend simultaneously. We must approach our lives with confidence, but humbly. We are both creators and created. We are both helpless and able. We are called to tolerate and embrace unknowing as well as knowing.

This study was an inquiry into the experience of having a life-threatening illness. Through a sustained journey with the participants, the experience was revealed as an awakening to life and an uncovering of meaning hidden beneath the surface of life. What is the role of the health professional who accompanies a patient through this dangerous land? What can be called forth from the underground of the patient and the professional? What encouragement and sustenance is there for those who are led or driven into that shadowland? What does it mean to attend to those patients in the spirit of *logos*? These questions offer a perspective that may enlarge our understanding of what it means to be human. Perhaps the most important question of all is “What signs and wonders exist in our lives today?” This study is a call to attend to the mystery that is unnoticed beneath the familiar of our everyday lives. It is a call to *attend* to our lives and each other in a renascent way.

**CHAPTER SIX, THE EPILOGUE:  
DIVING DEEP AND RESURFACING<sup>17</sup>**

It has been two years since my comprehensive examinations, the rite of passage that found me ready to begin an “independent” research project. Still, as I wrote in Chapter One, the true beginning of the journey cannot really be identified; I know it was much earlier. As I begin this, the final chapter of my dissertation, again I am planning for rites of passage--my dissertation defense and graduation. Again, I know that the ceremony will not be the true end. The changes within me, my participants, and perhaps my readers will move into the future as we do. Yet, my tenure as a doctoral candidate is coming to an end, and at this time I am claiming one kind of closure to my research. In this chapter, I will speak to the research process as a whole, and to the insights that have revealed themselves along the way.

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<sup>17</sup> The title of this chapter is adapted from a book by Carol Christ, *Diving Deep and Surfacing: Women Writers on a Spiritual Quest* (1980).

In Chapter One, I wrote, “We live life on the surface, but there is much that goes on under the surface. Diving deep into these pools of experience and meaning is a worthwhile endeavor.” As I think about this research project as a whole, I believe it has indeed been an underwater journey. In the language of dreams, water is a symbol for the subconscious (Sanford, 1968). A dreamer who finds herself swimming underwater is a person who may well be exploring areas of herself that are not easily accessible to her waking self. In modern life, we usually travel along the surface of life. Work, play, and family life demand our constant attention. Turning from the urgent to attend to the important--that is, questions of ultimate meaning--can feel indeed like a dive into deep water. Like divers, we must take a deep breath of preparation. Like divers, we must turn ourselves upside down and use strong effort to overcome the natural buoyancy that keeps us on the surface. Like divers, we cannot stay down too long, for the need for oxygen--the concerns of the everyday--demand that we return to the surface again. But while we are down under the water, we may encounter realities and perspectives that are usually hidden from our view. We reach understandings that change the way we live our lives on the surface. Strange life forms or beautiful coral reefs or dangerous wildlife alter our perspective on what it means to be human.

DiBartolomeo (1998) wrote a memoir about traveling as an adult to the seaside with a beloved teacher from his youth. As they stood gazing at the people playing in the surf, she spoke.

“Look at it,” she said, gesturing to what she called the “majestic mystery” of the sea. “It’s all surface to our eyes now. But beneath it are great depths and life of all kinds. That’s what people are when we first meet them. But

we only have to go below the surface a bit to see one another's hearts." (p. 105)

Yes, people are like the sea, with life teeming underneath. So is life itself like the sea, teeming with life underneath.

As I began to reflect on the metaphor of research as an underwater dive, I found myself thinking about the common loon, a water bird that dives for food. In our more carefree years before the birth of our children, who have both confined us and opened us to more life than we could ever have imagined, my husband and I used to camp in the Canadian wilderness parks. In those parks, the loon is commonly found. It has two vocalizations that can be heard for up to a mile through the wilderness: One is an eerie, pensive, two-toned lament; the other is a wild, cackling burst of noise that sounds like maniacal laughter. A person who hears that second sound instantly understands the colloquial term that describes insanity as *loony*. The loon is a pretty bird with black and white feathers, but it is awkward both on land and in the air. Its wings are just barely large enough to sustain flight--take-offs and landings are almost comical in their clumsiness. It is underwater where the loon excels. As a guidebook explains:

Their stream-lined bodies and powerful, webbed feet, set at the rear of the body, make for maximum efficiency. They are capable of astonishing speed and lightning-quick, underwater pivots in their quest for fish, which are seized by equally quick thrusts of the bill. (Ministry of Natural Resources, 1977, p. 2)

There is something quirkily perfect about seeing myself as a loon in these last two years. I am told I have a sense of humor that abruptly alters the contexts in which I engage with others. Sometimes the humor is welcome. Sometimes it strikes others as a bit weird--

out of place and *loony*. Because I have moved 800 miles away from my nurturing academic community, and because I live in a house with four lively children, a husband, a dog, and a variety of lizards, my efforts at sustained scholarship have no doubt resembled a loon's lumbering land waddle. My take-offs and landings from my research and writing have been awkward indeed. But my dives! When I have entered that underwater place of reflection and revelation, either alone or in the company of my research participants, I have encountered a deep, meaningful, fluid beauty.

Returning to the surface, I find I do not want to leave. I hope to stay awhile and watch the water and the setting sun as I cherish the underwater journey that has come to a close.

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## **APPENDIX A**

### **QUESTIONS TO OPEN THE INQUIRY**

1. **What is it like to have a life-threatening illness? You might want to start by telling me the story of your illness.**
2. **What would you say to someone else just starting down the road you have come?**
3. **As you look back over your illness, tell me about some of the things that have helped you.**
4. **Have you had to make any decisions about your health care? What were they? What do you think of those decisions now?**
5. **Over the course of your illness, have there been any topics that have been hard to talk about with your health care team? With your family?**
6. **As you look back over the course of the illness, is there anything you would change?**
7. **What do you consider to be most important for others to know about people with life-threatening illness?**

## **APPENDIX B**

### **APPLICATION TO INTERNAL REVIEW BOARD**

#### **Research Plan Summary The Lived Experience of Having a Life-Threatening Illness**

**Investigator:** Dr. Maggie T. Neal  
**Co-Investigator:** Janna C. Roop, RN, MS, PhD Candidate

#### **Research Question**

What is it like to have a life-threatening illness?

#### **Rationale**

During the last thirty years, health care has changed dramatically. Research and technology have provided life-prolonging treatments and even cures for diseases that only a short time ago were invariably fatal. This progress, though, has given birth to a whole new set of conundrums. Decisions regarding the care of patients with life-threatening illnesses are complicated and have great impact on the cost of health care. Deciding when to implement and when to withhold life-extending technology can be exceedingly complex. There are many who recognize a theoretical difference between prolonging life and prolonging having a life-threatening illness, but in the realities of clinical practice, discerning which is operating for an individual patient can be a daunting task (Brescia, 1988; Markman, 1992). The difficulties in finding guidance for these decisions were recently illustrated in the report of the project funded by the Robert Wood Johnson Foundation (The SUPPORT Principal Investigators, 1995). Over four years, a multidisciplinary team developed and implemented a program to increase communication between patients and their doctors in order to improve care of seriously ill hospitalized patients. In spite of what appeared to be a well-conceived study resulting in

comprehensive and logical interventions, patients in the treatment group experienced no better outcomes than patients in the control group experienced. I suggest that it could be that the issues surrounding care of the having a life-threatening illness are so deeply entwined with complex values and emotions that straightforward logical interventions are necessary, but insufficient. Conflicting desires and fears may confound the 'logical' choices of patients and health care professionals alike; exploration of these issues may be an essential step in effecting real change in the care of the having a life-threatening illness in America. As I have reflected on the report of the SUPPORT Principal Investigators, I have noted that patients and their families were not consulted regarding the development of interventions and I wonder what wisdom they could have offered. My hope is that my research, by exploring the perspectives of the patients, will shed light on these critical issues. As Pascal has said, "The heart has reasons that Reason knows not of." I hope to uncover some of those "reasons of the heart."

### **Procedures**

I intend to meet with adult participants who have a prognosis of 12 months or less to explore the phenomenon of having a life-threatening from their perspectives. I will ask health care providers to refer me to prospective participants by phone or letter. A copy of the letter of invitation is included in this research plan summary. Throughout the inquiry, I plan to be particularly alert for experiences and perspectives that are important to participants, recognizing that things may come up that have not occurred to me. For that reason, the enclosed questions are seen as a guide to the conversation, not an exhaustive list of topics for discussion. The conversations will be audiotaped and transcribed to generate a text. I will then analyze the text using an interpretive phenomenological approach in order to identify themes and issues that better explicate the experience of having a life-threatening illness from the patient's perspective. As I begin to identify themes and insight, I will meet with the participants again to confirm that my interpretations are faithful renderings of their experiences. A copy of the questions to open the inquiry is included in this research plan summary.

### **Audio Tapes**

At the time that I obtain consent from the participant, I will request permission to keep the audio tapes until the study is completed

### **Risks or Benefits**

The risks to the participants would be minimal. Exploration of these topics could conceivably elicit a strong emotional response, and if either the participant or I believed that the response required health care intervention, I would notify the participant's health care provider. It should be noted that the questions would be appropriate during any routine nursing visit, and many people find it beneficial and satisfying to reflect upon and

share their personal experiences and feelings. Participation in the study will require the expenditure of participants' time and energy with no monetary compensation. If a participant desires a copy of the audio tape(s) or the transcript(s) of his or her own conversation(s), one will be provided at no cost to the participant.

### **Consent Procedures**

I will obtain two original signed written consent forms from all study participants prior to the first conversation. I will give one original signed copy to the participant and will retain one original signed copy. A copy of the signed consent will be forwarded to the participant's chart if applicable.

Dear

I am seeking your help in my research. I am a hospice nurse and a doctoral student in nursing. In the past few years, as I have read about the care of patients who have life-threatening illnesses, I have noticed that there is very little written about the views of the patients themselves. I believe that it is important to listen to what patients have to say about their own experiences. Would you be willing to talk to me about your experiences?

If you agree, I would like to meet with you and have a conversation about what it is like to have a life-threatening illness. What is important to you at this time in your life? What has worked well? What has been difficult? I would like to tape the conversation so that I could study your views and the views of other patients in more depth at home. After I have met with a few patients, I might ask to come back to meet with you a few more times to see if my understanding is accurate and to see if you have had any more thoughts since we last met. You would be under no obligation to agree to these additional meetings, however. I know that your time and energy are limited.

I would like to call you to see if you have any questions for me and to find out if you are willing to meet with me. In the meantime, I thank you very much for your consideration.

**Sincerely,  
Janna C. Roop, RN, MS  
Doctoral Candidate  
University of Maryland, Baltimore, School of Nursing  
phone: [REDACTED]**

**APPENDIX C**  
**INTERNAL REVIEW BOARD APPROVAL**

UNIVERSITY OF MARYLAND  
BALTIMORE  
INSTITUTIONAL REVIEW BOARD

655 W. Baltimore Street  
Room 14-016 BEE  
Baltimore, MD 21201-1339

email: ORS@schmed01.ab.umd.edu  
voice: (410) 706-5037  
Assurance Number: M1174-01NR

TO: MAGGIE NEAL, PHD, RN  
PSYCHIATRIC, COMMUNITY HEALTH  
515 W. LOMBARD STREET, RM. 459

FROM: INSTITUTIONAL REVIEW BOARD

DATE: August 05, 1998

RE: IRB PROTOCOL #0498212

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"THE LIVED EXPERIENCE OF HAVING A LIFE-THREATENING ILLNESS"

Expires: 08/05/01

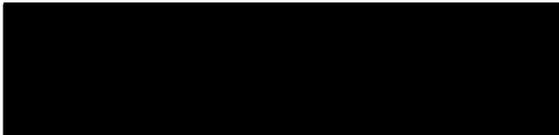
Report required Once yearly

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Response to correspondence dated: July 17, 1998

This is to certify that the Institutional Review Board has reviewed your response to their queries and fully approved your protocol. The enclosed stamped consent form and/or protocol is valid from August 05, 1998 to August 04, 1999.

*You must notify the IRB if the project is altered in any way (change in location, personnel, number of subjects, age of subjects, or any change in research protocol). If you have any questions, please do not hesitate to contact the Office for Research Subjects by email (ORS@schmed01.ab.umd.edu) or by phone (at 706-5037).*



Paul Fishman, M.D., Ph.D.  
Chairman, IRB

SCHOOL OF NURSING

DEPARTMENT OF PSYCHIATRIC  
AND COMMUNITY HEALTH

UNIVERSITY OF MARYLAND

**CONSENT FORM, PAGE 1 OF 5**

**Title of Research Project:** The Lived Experience of Having  
a Life-Limiting Illness

**Principle Investigator:** Dr. Maggie T. Neal  
Phone: [REDACTED]

**Co-Investigator:** Janna C. Roop, RN, MS  
Phone: [REDACTED]

**PURPOSE OF THE STUDY**

The purpose of this study is to explore the patient's view of what it is like to have a life-limiting illness. I hope to use the information I learn to improve the care of patients.

**PROCEDURES**

If you agree to participate in this study, I will meet with you and tape record our conversation using the enclosed list of questions to start our discussion. We may turn to other topics if we want to during the conversation. Meetings would take place at your home or another location of your choosing. I will then type the conversation and study it for deeper understanding. After I have



## CONSENT FORM, PAGE 2 OF 5

studied our conversation and the conversations of a few other patients, I may request follow-up meetings so that you can comment on the things I am learning or on thoughts you have had since our earlier meeting. A few meetings may be necessary for a complete study; the exact number cannot be determined in advance. As an estimate, I expect that each meeting would last about an hour and that two or three meetings would be sufficient. Therefore, your total time investment would be about 3 hours. Because your time and energy are very valuable, however, you could request fewer or shorter meetings. Even if you agree to the first meeting, you are under no obligation to meet with me again.

### CONSENT FOR AUDIOTAPES

I understand that the conversations will be audiotaped and that the audiotapes will be confidential. I understand that the investigator will keep the audiotapes until the completion of the study. At that time, the audiotapes will be destroyed.

### RISKS AND BENEFITS

It is possible that you could have a strong emotional response to this discussion. If you or I believed that your response required immediate health care, I would notify your health care provider. It should be noted that all of the beginning questions could be appropriate during a routine nursing visit. You will also be in charge of the conversation, meaning that you may choose what you want to talk about and you may choose not to talk about anything. You may also end the meeting any time you want to.



**CONSENT FORM, PAGE 3 OF 5**

Many people find it beneficial and satisfying to think about their personal experiences and tell someone else about them. You may find it satisfying to know that by participating in this inquiry, you are contributing to the improvement of care of future patients.

**COSTS AND COMPENSATION**

You will not be paid for your participation in this study. If you would like a copy of the tape(s) or a copy of the written transcript(s) of your own conversation(s), I will give them to you at no charge.

**CONFIDENTIALITY**

I will change your name when I type up the conversations. I will ask other doctoral students and faculty to read all or some of the conversations to help me discover insights. I may publish findings or present findings at professional meetings or to community service groups in order to teach people how to take better care of patients, but I will keep your name and personal details confidential.

**RIGHT TO WITHDRAW**

Participation in this study is voluntary. You are not obligated to participate in this research. You are free to withdraw your consent at anytime. Refusal to participate will not affect your current or future medical care in any way.



**CONSENT FORM PAGE 4 OF 5****UNIVERSITY STATEMENT**

The University is committed to providing subjects of its research all rights due them under State and federal law. You give up none of your legal rights by signing this consent form or by participating in the research project. Please call the Institutional Review Board (IRB) if you have questions about your rights as a research subject.

The research described in this consent form has been classified as minimal risk by the University of Maryland Institutional Review Board (IRB), a group of scientists, physicians, and other experts. The Board's membership includes persons who are not affiliated with the University and persons who do not conduct research projects. The Board's decision that the research is minimal risk does not mean that the research is risk-free, however. Generally speaking, you are assuming the risks of research participation, as discussed in the consent form. But, if you are harmed as a result of the negligence of a researcher, you can make a claim for compensation. If you believe you have been harmed through participation in this research study as a result of researcher negligence, you can contact the IRB for more information about claims procedures.

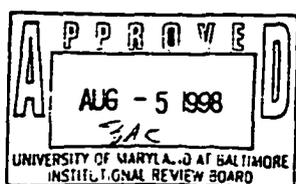
Institutional Review Board  
University of Maryland, Baltimore  
655 West Baltimore Street  
Baltimore, Maryland 21201



### CONSENT FORM, PAGE 5 OF 5

If you agree to join this study, please sign your name below.

NOT VALID WITHOUT THE  
IRB STAMP OF  
CERTIFICATION



\_\_\_\_\_  
Participant's signature/Date

\_\_\_\_ I have read and understand the information on this form.

\_\_\_\_ I have had the information on this form explained to me.

\_\_\_\_\_  
Witness to Consent procedures (Optional unless participant is illiterate, or unable to sign)

VALID FROM 2-5-98 TO 8-6-99

\_\_\_\_\_  
Janna C. Roop, RN, MS.  
Investigator/Date

RPN NO. 3-14-98