THE EXPERIENCE OF SUFFERING AT THE END OF LIFE

By

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A Dissertation

Presented to
Oregon Health sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

November 15, 1999

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Issues related to pain and suffering at the end of life have captured the attention of researchers and clinicians in recent years, in particular the increasing interest in physician assisted suicide (PAS). However, the literature suggests that a critical issue embedded in PAS is the need to address the suffering at the end of life. This interpretative study, based on the philosophy of Heidegger, examined narrative accounts of six participants with Stage IV cancer and two participants with a contrast diagnosis of congestive heart failure to deepen the understanding of suffering with these illnesses. The primary thematic pattern that emerged was that of Not Being Heard. All participants told stories of how their words describing the physical and emotional suffering of their illnesses had been ignored or disregarded by the clinicians caring for them. Two secondary themes were identified. The first was Planning for Life Without Me, which captured participants' reports of their practical and pragmatic plans for the future care and safety of their children, fragile family members, their children's education, emotional comfort, and other issues such as funeral planning. Another theme was Searching for Understanding. While gathering information is a natural and expected part of living with a serious diagnosis, the participants revealed deeper reasons for obtaining information. They wanted not only to understand their disease and its treatments, but they also wanted to teach their loved ones about the disease in the hopes of preventing their children from contracting the disease.

Acknowledgments

The process of researching and writing a dissertation requires the concerted effort of numerous people and resources. This has certainly been true for this study. To express my gratitude to the people who helped me in this process, I would first like to thank my advisory committee. Christine Tanner, RN, Ph.D. was invaluable in her assistance and support while I learned the research method and more importantly, while I struggled with the snags and snares that occurred during this year. Sheila Kodadek, RN, Ph.D. was also invaluable as a committee member and consistently offered insightful and useful comments. Beverly Hoeffer, RN, DNSc, FAAN, was very helpful throughout the process because of her outstanding expertise in the content area and in her understanding of research. Without the wisdom and support of these women, this study would not have been possible.

In addition, I wish to acknowledge and sincerely thank the Department of Veteran's Affairs, Office of Academic Affairs for their financial assistance through their generous predoctoral fellowship award.

Finally, I wish to acknowledge the love and support from an amazing circle of friends who valiantly stood by me through this difficult process. I cannot list every person who has helped me during these long three years; however, I want to recognize the love, support, and faith of Keelin Anderson, Seiko Izumi, Napapron Wanitkun, Virapon Wirojratana, Lissi Hansen, and Janice Crist. Another important part of this circle is the Sisters of the Holy Names who taught me the importance of learning to delve deeply into the voice of suffering. As I lived besides these remarkable women, I was privileged to witness daily how their vows had led them to learn to love well. It was through loving well that the suffering of so many was relieved.

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Chapter 1

Introduction

Concerns related to pain and suffering have attained greater prominence as American voters are focusing attention on the complicated issues of physician assisted suicide (PAS), active and passive euthanasia, and the compassionate care of the dying. The underlying message from patients, families, and communities (particularly the voters of Oregon state who have now legalized physician assisted suicide for terminally ill Oregon residents) is that pain and suffering are intolerable conditions that must be promptly and carefully addressed (Scofield, 1995; Thomasma, 1996).

To further underscore this position, the American Medical Association, the American Nurses Association, the American Geriatrics Society, the National Hospice Organization, and the Veteran's Administration have all interpreted PAS as a public mandate to improve the physical, psychological, and spiritual care of dying patients, and have established end of life and palliative care as healthcare priorities (Byock, 1994; Caplan, 1997; Lee, Ganzini, & Brummel-Smith, 1996; Thomasma, 1996). Although much of the PAS debate has centered on issues of ethics, morality, medical integrity, and practice implications, the original purpose behind the PAS movement was to provide permanent relief of intractable pain and suffering (Bopp & Coleson, 1995; Bushong & Balmer, 1995; Campbell, Hare, & Matthews, 1995; Ferrell, Rhiner, Cohen, & Grant, 1991; Kamisar, 1996; Quill, 1991; Thomasma, 1996).

Although the death and dying movement began over thirty years ago with Elisabeth Kubler-Ross' seminal work (1969), the pain and suffering of dying are still not adequately addressed and palliative care is postponed frequently until physical pain is too far out of control. People are no longer willing to accept passively the severity of pain and suffering that can accompany the dying process, and as a result, physician assisted suicide (PAS) has become a pivotal issue in palliative care (Block, & Billings, 1998; Meier, Morrison, & Cassel, 1997; Quill, 1991; Tolle, 1998). However, the issues embedded in PAS debates are not just the legal and ethical implications of hastening the time of an expected death, but the more significant issues found within this debate are related to what constitutes and exacerbates the terminally ill patients' experience of suffering and what can be done to alleviate it..

To underscore this position, much of the PAS literature references pain and suffering as antecedents to the request for self-determined death, yet little attention has been directed to the actual lived experience of physical pain and even less to the complex phenomenon of suffering. Although pain may be a logical starting point to improve the care of the dying, suffering is cited more frequently as a rationale for PAS requests (Block & Billings, 1994; Byock, 1995; Campbell, Hare, & Matthews, 1995). In particular, many patients argue that the loss of dignity, autonomy, and the humiliation that may accompany dying are forms of suffering that warrant the option of self-determined suicide (McCormick & Conley, 1995; Thomasma, 1996). Unfortunately, suffering is challenging to investigate and even more challenging to treat. As a result, clinicians may not address the emotional issues of suffering with the same zeal as the pharmacology of pain or the biochemistry of disease (Cassell, 1991; Gregory, 1994).

Furthermore, the population most at risk for expected death and for pain and suffering is the older adult. In 1995, adults aged 50 years and older accounted for more than 80% of all deaths in Oregon (Oregon Department of Human Resources, 1998). This segment of the population is also expected to grow dramatically in the next 20 years, especially the 65+ age bracket. People aged 65+ represent the fastest growing segment of the U.S. population, projected to comprise over 16.4% of the total population by the year 2020 (Hobbs & Kamen, 1996). The older veteran population is expected to rise at an even faster rate than the national average (personal communication, Terri Harvath, June 4, 1998). In addition, many veterans have diagnoses of cancers of the lung, head, and neck which are strongly associated with intense physical and emotional suffering.

In light of the mandate to improve end-of-life care, coupled with the burgeoning elderly population, research into the experience of suffering and potential sources of relief for terminally ill patients warrants investigation.

The purpose of this study was to deepen our understanding and awareness of suffering at the end of life for terminally ill adults in order to improve palliative care options for this population. The specific aims were to:

1. Describe adult, terminally ill patients' experience of pain and suffering; and
2. Interpret these experiences of pain and suffering in the context of their life experiences and background meanings.

The following two chapters will explain and outline both the significance of this study and the methods that were used to complete it. Chapter 2 is the review of the literature. The intent of this chapter is to provide an overview of the literature on suffering and to synthesize the current literature in medicine, nursing, social work, and theology. The third chapter details the study methods. The first section of the methods chapter outlines the philosophical tenets and assumptions embedded in interpretive phenomenology and provides rationale for using this method for these research aims. The second section of the methods chapter explains the design framework used and relates this framework to both the overall study goals and the philosophical underpinnings. The fourth chapter presents the study results. The most prominent and compelling theme that emerged from the data was that of Not Being Heard. The first section of Chapter 4 presents the narrative findings and explains this predominant theme. The second section of Chapter 4 describes the secondary themes of Planning for Life Without Me and Searching for Understanding. Chapter 5 summarizes and concludes the study and will explicate some of the implications for future research and clinical practice.

Chapter 2

Review of Literature

Suffering as a Human Experience

Suffering is defined as a real or imagined threat to an individual's physical, psychological, emotional, or spiritual integrity, and encompasses alterations in meaning as it relates to health, physiology, mood, spirit, and future (Cassell, 1982; 1991; Kahn & Steeves, 1986; 1994; 1995; Steeves & Kahn, 1987; Younger, 1995).

Academicians and theologians further describe suffering as a common human experience that arises as a function of living in a fragile and finite body (Cassell, 1991; Hauerwas, 1986; Kahn & Steeves, 1986; 1995; Younger, 1995). As such, suffering is associated routinely with terminal illnesses and it is often believed that the suffering while dying arises from the physical pain of terminal diseases. However, suffering is not merely a physical phenomenon, but has strong emotional and spiritual components. While medicine has traditionally tried to alleviate suffering by treating the underlying physical conditions and symptoms, the nursing, theological, and psychiatric literature proposes that the experience of suffering is more accurately derived from patients' interpretations of living with illnesses, injuries, or situations (Cassell, 1991; Hauerwas, 1986; Steeves & Kahn, 1987). Although suffering may be precipitated by the failing body, the experience does not reside solely in the body. Suffering is a human experience that may be described more accurately as an embodied experience that resides in the deepest core of human existence.

It can be assumed safely that the finite nature of human physiology will lead inevitably to illnesses and death during the normal life span. Thus, all people will "suffer" death. As such, it may be assumed further that suffering is an ubiquitous, albeit negative human experience. While suffering may be a universal human experience, the manifestations, meanings, and interpretations are determined by each person and are influenced strongly by history, culture, family patterns, and language. Thus, the extent of suffering must be determined by the person experiencing the conditions that result in suffering (Kahn & Steeves, 1986; 1995; Steeves & Kahn, 1987; Younger, 1995). Pain, disability, and physical illnesses may hold the antecedents to suffering; however, the experience of suffering is driven by the meanings attached to the experience rather than the sheer intensity of physical symptoms. In this way, the degree of suffering rests on the internal interpretation that may be determined only through the person's sense of meaning, history, context, and future (Cassell, 1982; 1991; Kahn & Steeves, 1986; Steeves & Kahn, 1987).

Upon reflection, this position may seem quite obvious. Indeed, the internal nature of suffering may be viewed as an indisputable, embedded assumption of illness and death. However, it is important to note that because of the personal and internal nature of suffering, it becomes exceedingly difficult to treat. If the underlying problem cannot be cured or if symptoms cannot be managed, clinicians are confronted then with the inability to medically effect change or to improve the quality of life through traditional medical protocols.

Unfortunately, some patients may interpret clinicians' inability to offer measures to relieve the psychological and spiritual suffering as a form of professional abandonment. In particular, patients may feel the physicians' sense of helplessness given the lack of curative option and may interpret that helplessness as medical abandonment. In my clinical practice, I have repeatedly heard patients say that "the doctor gave up on my cancer and washed his hands of me. He doesn't want anything to do with me, so he referred me to hospice." Intentional abandonment would be a rare occurrence, yet without careful and compassionate discussion of symptoms, prognosis, suffering, and the limitations of treatments, the patient may perceive the physician's unconscious discomfort with the situation and misconstrue the motivation. More importantly, the physician assisted suicide (PAS) and palliative care literature strongly attests to medical abandonment as common rationales for PAS (Battin, 1994; Block & Billings, 1994; Byock, 1994; Emanuel, 1996; Thomasma, 1996).

The issue of patient abandonment is such a significant element in PAS that it must be addressed openly if the suffering of dying is to be relieved (Byock, 1997; Younger, 1995). By witnessing and understanding the deeper nature and dimensions of the experience of suffering, it may be possible to find creative ways to address suffering and to offer new hope to terminally ill patients. Without understanding the full nature of suffering which requires listening openly to the words, emotions, and experiences of suffering, healthcare professionals may remain helpless in the face of the suffering of death and incurable illnesses.

What Is Suffering?

To understand the antecedents to suffering, it is useful to begin by examining the world wisdom traditions, and in particular, Eastern religious philosophies. According to Buddhism and Hinduism, suffering is a largely unavoidable and recurring human experience that arises as a direct result of personal attachments and aversions (Easwaren, 1978; Epstein, 1995; Fox, 1991; Huston, 1958; James, 1982; Suzuki, 1983). These beliefs propose that all sentient beings are composed of constantly cycling episodes of attachment and aversions that become precursors to suffering. In simplest terms, this position states that we suffer when we are confronted with human likes and dislikes (Easwaren, 1978; Epstein, 1995; Johnston, 1970; Suzuki, 1983). Given these antecedents, suffering may arise when people are confronted with emotional attachments that are threatened by death, irrevocable change, or destruction. This structure may be recognized easily as feelings of grief and loss. The interaction between attachment, love, loss, and suffering is so extant that "to suffer loss" is a synonym for grief.

Aversion is just as readily apparent as an antecedent to suffering. Again, according to Eastern philosophy, suffering occurs when we are forced to accept things that we don't want or cannot avoid (Easwaren, 1978). Aversions to people, places, things, food, or activities may be relatively minor and lead to feelings of mild annoyance or irritation. However, when that aversion is to physical pain or when we are forced to experience a negative circumstance such as an amputation or life threatening illness, we can recognize easily that aversion can be a profound precursor to suffering.

In the medical and nursing cultures, and particularly in regard to the physician assisted suicide literature, suffering is linked also to aversive conditions, such as pain, incurable disease conditions, or terminal prognoses (Battin, 1994; Quill, et al, 1998; Scofield, 1995). Within this context, the physical component of the experience may be the initial cause of suffering, but the depth of suffering is a function of the depth of aversion to the changed physical state rather than solely the physical symptoms or outcomes. In this way, the personal interpretation or meaning of the physical condition is the crucial component of suffering.

Eric Cassell (1991) pioneered the investigation into the nature of suffering and identified many of its attributes. His classical definition of suffering is a "real or imagined threat to the person's sense of integrity" which may refer to an individual's physical, psychological, emotional, or spiritual integrity. Given that integrity is the operative component of the definition, it may be inferred that the person's interpreted meaning of integrity is essential to determining the intensity, severity, and direction of suffering. Thus, suffering can be described only by the meaning of the threat to integrity and generally cannot be assessed externally or evaluated through visual observation or biological measures. As stated, the fact that suffering is based on the experiencing person's perception speaks to the difficulty in treating the suffering of dying.

To illustrate the difficulty associated with assessing the degree of suffering, it is helpful to compare the subjective experience of suffering with the subjective experience of pain. It is well accepted that pain is a personal, subjective experience, yet it is possible to "measure" pain using standardized tests. Other pain scales use variations on visual analogue scales that may depict colors such as cold blue to a fiery red or may use varying facial expressions to represent the pain intensity. One of the most commonly used pain scales is the 1-10 scale in which 1 is the absence of pain and 10 is the most excruciating pain imaginable. These scales are employed routinely in medicine, nursing, physical therapy and other disciplines to quantify the experience of pain and evaluate the outcome of treatment (Emanuel, 1996; Kahn & Steeves, 1986; 1994; 1995; Meier, Morrison, & Cassel, 1997).

In sharp contrast, the suffering associated with pain is much more complex. One person may interpret the intensity of pain as suffering whereas another person may interpret the same pain intensity as merely sensation without positive or negative connotations. The classic illustration of this phenomenon is the difference between the pain of childbirth and the pain of tumor invasion. In both instances, the pain may be identical quantitatively, but the meaning of the experience is radically different. Childbirth may be excruciatingly painful, but mothers may not describe childbirth as an experience of suffering. Whereas patients with advanced cancer may rate their pain as severe as a mother in the transition phase of childbirth, cancer patients often suffer with their pain. Thus, the lived experience of suffering is dependent on the context, the history, the sense of future, the individual experience and most importantly, the meanings of the antecedent to the suffering.

These aspects of pain and suffering are well documented in medical, nursing, psychological, and social work literature (AHCPR, 1994; Byock, 1996; Cassell, 1991; Emanuel, 1996; Gregory, 1994). However, what is not adequately addressed is what is it that suffers? What is the process of suffering? Is it found totally in the mind? The body? The person's sense of future? Or is it an experience of fear? These questions may appear to be mere academic exercises, but these questions strike directly at the heart of living with disease, illness, and change.

Suffering and the Nature of Meaning

As stated above, the experience of suffering arises through perceived threats to an individual's sense of integrity (Cassell, 1982; 1991). Much of biomedical research has coupled physical pain with suffering and has sought to relieve physiological suffering through pharmacological measures. This approach has been criticized because it not only confuses the distinction between pain and suffering, but serves to limit suffering to perceived threats to bodily integrity rather than the broader, more comprehensive view that suffering can arise from any perceived threat. In addition, pharmacological control of suffering is in direct opposition to the definition of suffering which implies internal antecedents and causation (Gregory, 1994). In contrast to the biomedical model, Steeves and Kahn (1986; 1987; 1994; 1995) propose that the extent of suffering does not depend on the severity of physical pain, but rather on the changed interpretations and meanings of pain and circumstance. While suffering may arise as a consequence of living with physical pain or disease, it is the interpreted meaning of the perceived threat that determines the intensity and direction of suffering.

Although Steeves and Kahn describe suffering as a private and personal experience, they maintain that the meanings of suffering are shared by people with similar backgrounds, beliefs, and cultures. They propose further that suffering is a distinctly human experience and for this reason, suffering is dependent on the existential elements of being human. Given this position, suffering may be described further as an embodied experience that cannot be reduced readily or categorized because its meaning is dependent on physiology, psychology, culture, economics, time, and circumstances (Benner, 1994; Benner & Wrubel, 1989; Kahn & Steeves, 1986; 1994; 1995; Younger, 1995). As such, the interpretation of disease and illness is influenced strongly by the facets that compose life circumstances. Thus, suffering may be viewed as a noxious experience that is shaped by society, history, economics, culture, and affiliations (Easwaren, 1978; Epstein, 1995; Kahn & Steeves, 1986; Post, 1995; Younger, 1995).

Threats to Integrity: The Possible Root of Suffering

To understand the experience of suffering, it is important to reflect again on the stated definition of suffering. To reiterate, suffering is a real or imagined threat to the physical, psychological, or spiritual integrity of the person (Cassell, 1991). Thus, integrity may be viewed as the operative component within the definition. Given this, the parameters that define integrity are needed to determine the extent of the threat leading to suffering.

It may be that integrity is a colloquial and easily understood term whose meaning is readily apparent. We commonly use the term to describe trustworthiness and just as readily negate the word to describe its lack. However, if one is asked to define the word, we tend to falter after applying synonyms of honesty, wholeness, soundness, morality, responsibility, sincerity, and duty. Unfortunately, outside of wholeness and soundness, these synonyms have little to do with the actual lived experience of suffering and even less to do with physical illness or injury.

Curiously, although integrity plays a pivotal role in defining the experience of suffering and clearly is the object of the threat, most studies do not define or address integrity as it relates to suffering. As stated, it is possible that the absence is simply pragmatic. It may be assumed that the meaning of integrity is obvious and does not require further analysis. Much of the literature that incorporates integrity as the object of the threat uses the term within the context of physical illness or physiological processes (Cassell, 1991a; 1991b). Given this usage, threats to integrity may be assumed contextually to refer to threats to physical or physiological integrity.

In addition, integrity carries temporal as well as qualitative components. From one perspective, integrity refers to a timeless quality that moves with that individual from birth until death. Yet simultaneously, integrity is a dynamic and fluid dimension of human experience. While integrity may be influenced by history, it is subject to growth, change, and development (Beebe, 1992; Grudin, 1982). Consequently, physical, psychological, and spiritual healing are possible if integrity can be restored.

Grudin (1982) further expands the meaning of integrity by positing that it is a sustained psychological and ethical wholeness which "is not a painfully upheld standard so much as a prolonged and focused delight." Rarely is integrity described in terms of delight; however, in instances of contentment or joy, the sense of delight may be discernible by a lack of self-consciousness within the experience. According to Grudin, delight is one way to recognize the experience of integrity. Thus, if integrity is at the heart of joyful contentment, integrity as delight may be also synonymous with the sense of being at home with oneself, other people, family, or situations. Given these attributes, integrity may be described as the deepest essence of the self.

The Medical Meanings of Integrity

In contrast to Grudin's position, the medical model has maintained that integrity is limited necessarily to the physical integrity of the body. Traditionally, physicians have been trained to address the physical and biological aspects of integrity and suffering. Cassell (1991) states that physicians are trained to view patients' descriptions of symptoms as "soft" data and useful as preliminary diagnostic clues. Verbal reports of symptoms may provide direction for further investigation to obtain the "hard" data of laboratory and technological testing. As such, the medical model values the words of suffering to determine the direction of diagnosis, but traditionally, the actual narratives of suffering have been of limited interest to physicians as a distinct phenomenon. Besides psychiatry, most medical usage may infer physical integrity as synonymous with physiology and may limit contextually the meaning further to bodily integrity rather than to the broader psychological or spiritual dimensions (Cassell, 1991; Gregory, 1994).

The above position was substantiated firmly when I had the opportunity to speak to first year medical residents on the topic of ethics, suffering, and palliative care. The medical residents stated that they could comprehend the concept of threats to physical integrity as the antecedents to suffering, yet they could not understand any other dimension of integrity. Moreover, they did not see any medical rationale for investigating the psychological or spiritual dimensions of suffering. One resident stated that the issue of suffering wasn't important because his job was to treat symptoms and cure disease, whereas the broader issues of human nature were not his concern. He went on to state that he did not have time to pursue these issues with patients.

When viewed from the traditional medical perspective, integrity may be seen as synonymous with health or the absence of disease. This stance may imply further that the way to restore integrity is to restore health or physical wholeness. Unfortunately, the natural corollary to this position is that if health cannot be regained, integrity cannot be restored and thus, suffering cannot be relieved. More importantly, if integrity is limited to the restoration of health, the suffering associated with incurable illnesses may be perceived as irresolvable or hopeless.

At this point, it is important to return again to the nursing, hospice, psychiatric, and theological literature on suffering. This body of literature emphasizes that suffering is not limited to distinct or discrete dimensions of bodily existence, but rather suffering is the embodied experience of living within the threatened body, mind, and spirit (Byock, 1996; Cassell, 1991; Kahn & Steeves, 1995; 1994; 1986; Steeves & Kahn, 1987). The body may hold the physical and biochemical antecedents to suffering, but the human spirit and soul holds the meaning. If this position is coupled with the more fluid and dynamic meaning of integrity as the essence of the self (Beebe, 1992; Grudin, 1982), the human core of integrity interprets the meaning of suffering and declares the depth and dimension of the experience. Consequently, the broadest definition of integrity may hold the clue to suffering's resolution.

Recognizing Integrity Through Violation

Although integrity may be embodied in experiences of "focused delight" or the essence of the self, integrity is more often recognized by its violation. Beebe (1992) states that integrity may even be defined as a condition or state of being that is of immeasurable value, yet may not be fully recognized until lost. This position emphasizes that integrity is such an embodied condition that it may not be consciously appreciated until some form of violation or threat has occurred.

As previously established, violations to integrity may be determined only by the experiencing person and may be found in the voices of crisis or in the descriptive words of suffering (Kahn & Steeves, 1994; 1995; Younger, 1995). Although chronic or terminal illnesses may result in pain or noxious symptoms, the more devastating forms of suffering rest in the experience of severe violations to the sense of identify, self-sufficiency, and pride. Not surprisingly, these non-physical forms of suffering are often at the heart of the physician assisted suicide arguments (Block & Billings, 1994; Byock, 1994; McCormick & Conley, 1995).

Shame as a Violation of Integrity

If the experience of integrity is most often recognized through its violations, the feelings associated with violations to integrity become crucial to understanding the experience of suffering. Again, Beebe (1992) provides insight. He states that shame is the most common and potent reaction to violations of integrity. In this way, the degree of shame may be viewed as a clue to both the intensity and the direction of the violation.

Erikson (1963) explicates both shame and integrity in his developmental theory. In his book, Childhood & Society, he describes the experience of shame versus autonomy as a critical crisis of childhood:

> Shame supposes that one is completely exposed and conscious of being looked at: in one word, self-conscious....Shame is early expressed in an impulse to bury one's face, or to sink into the ground. But this, I think is essentially rage turned against the self. He who is ashamed would like to force the world not to look at him, not to notice his exposure. He would like to destroy the eyes of the world. Instead he must wish for his own invisibility (p. 252-253).

Beebe further states that the greatest difficulty embedded in feelings of shame is not its correlation with the psychological shadow (Jung, 1979; Kaufman, 1985), nor in the angst contained in resolving the developmental task of autonomy versus shame (Erikson, 1963), but rather the difficulty lies within the belief that shame must be avoided at all costs. He proposes that avoiding shame actually maintains the suffering associated with threats to integrity and strengthens the negative hold that shame has on identity. As such, the shame of suffering blocks access to its resolution. Given Erikson's assertion that shame leads to the desire for invisibility, physician assisted suicide may be interpreted as the desire to become invisible permanently to escape the shame related to the indignities of dying. This position may become more apparent on reflection of the depth of shame associated with being a burden to others or becoming incontinent of stool. Thus, it should be no surprise that shame is implicated in many of the rationales for physician assisted suicide (Campbell, Hare, & Matthews, 1995; Quill, 1991).

I further suggest that shame is one of the root causes underlying clinicians' avoidance of the suffering of patients. As previously illustrated, doctors, nurses, and other clinicians often pull away from the voice of suffering when curative measures are non-existant, and attempt to insulate themselves by maintaining tight professional boundaries. It may be natural for clinicians to try to avoid feelings of helplessness when further treatment is contraindicated, but it may be that the professional helplessness associated with incurable diseases or intractable suffering are more accurately the shame of unrealistic professional expectations (Kahn & Steeves, 1994). Clinicians, too, have natural human responses and may also wish to become invisible if their patients' suffering cannot be alleviated.

It may be the unacknowledged shame on the part of both the physician and the patient that serves to exacerbate patients' suffering and may intensify the arguments for physician assisted suicide. If there is even a modicum of truth within this stance, I propose that the healthcare community must start to address not only the suffering and shame that patients may feel as a result of illnesses and injury, but must also confront the suffering and shame extant within medicine, nursing, and ancillary disciplines.

Resolving Shame, Restoring Integrity, Relieving Suffering

Given the position that understanding suffering lies in the meaning of the threat (Kahn & Steeves, 1986; 1994; 1995), the key to improved care for the dying lies in understandings the interactions among the meanings of suffering, integrity, and shame. If it can be assumed that violations to integrity are analogous to the perceived threat coupled with shame, and if the culture and society demand that shame be resolutely avoided, ameliorating suffering becomes profoundly complex. However, it is precisely this task that is required if the suffering of the dying is to be addressed. If this goal is to be accomplished, a deeper understanding of shame and its relationship to suffering is imperative.

The Interplay Between Suffering, Integrity, and Meaning

As stated, suffering may arise from an individual's experience of violation as a function of illness, pain, or negative life events and that these events hold the ascribed meanings embedded in the experience. Furthermore, the meanings associated with suffering influence its intensity, direction, and scope. Consequently, meanings become pivotal to the deeper understanding of suffering. Although some may argue that individual meanings are subjective, personal experiences that cannot be generalized to larger populations, meanings embedded within the experience of suffering more accurately reflect the public and culturally shaped meanings and concerns of people with similar backgrounds (Benner, 1994; Steeves & Kahn, 1987; van Manen, 1990). According to Benner & Wrubel (1989), shared background meanings represent the embodied understandings of the person's perceptions of the world that are acquired by virtue of being born into a family, community, and culture. The importance of shared meanings lies in the fact that people do not live in isolation, but rather are born, live, and die within families, communities, subcultures, and cultures that determine the meanings. Shared background meanings begin "with the private, inner world of personal experience and thereafter move toward the webs of interpersonal significance that bind a person to the social world" (Kleinman, p. 39, 1988). Thus, individuals interpret their experiences and events through the common, shared understandings of their larger cultural groups (Benner & Wrubel, 1989). As a result, the meaning (and potential resolution) of suffering can be understood only in relation to the shared background meanings of the group or culture.

The embodied nature of human existence, in conjunction with shared background meanings, can explain how an individual comes to understand the norms, mores, and meanings shared by the group, while it is the shared concerns that account for why something takes on special meaning (Benner & Wrubel, 1989). Thus, people become emotionally involved and connected in direct proportion to their degree of concern, and, as such, shared meanings and concerns reflect the intersubjective, shared significance of relationships, connections, and experiences.

Terminally Ill Patients' Experience of Suffering

The experience of suffering is influenced by the background meanings and concerns of the larger collective group. Steeves and Kahn's work with bone marrow transplant and with nursing home patients (1986; 1987; 1994; 1995), revealed that suffering is a fundamental human experience that can be understood only in relation to the essential aspects of humanity. According to Steeves and Kahn, the essential aspects of humanity and of suffering are the embodiment of body, mind, and spirit; the experience of time; the experience of relationships; and the experience of spatial relations. In this way, patients hold shared meanings and concerns regarding how illnesses and injuries change relationships, increase uncertainty of the future, and may intensify the challenges of disability.

In particular, terminal illnesses, such as cancer, irrevocably change patients' relationship to their bodies, lives, and future and may be assumed to hold profoundly different meanings than the meanings of living with more curable diseases. Furthermore, the experience of elderly patients can be expected to reflect the historical, economic, and contextual culture specific to this segment of the population. This study, building on the work of Steeves and Kahn, will deepen our understanding of suffering through a closer examination of older adults living with terminal illnesses. It is hoped that this study may assist others in developing and testing non-pharmacological interventions to alleviate suffering.

From the investigator's clinical hospice practice and review of the thanatology, palliative care, oncology, and PAS literature, four aspects of suffering are associated commonly with terminal illnesses (Benner, 1994; Benner & Wrubel, 1989; Byock, 1997; 1994; Cassell, 1982; 1991; Ersek & Ferrell, 1994; Frank, 1995; Humphrey, 1991; Kahn & Steeves, 1995; McCormick & Conley, 1995; Quill, 1991; Reitman, 1995; Sulmasy & Lynn, 1997; Valente, Saunders, & Cohen, 1994; Younger, 1995). These four aspects are: (1) uncontrolled physical pain and physical symptoms, such as nausea, dyspnea, anxiety, and constipation; (2) depression, loss of self-concept, self-worth, and self-esteem as a result of the inability to maintain previous activities and social roles; (3) the loss of independence, loss of control, and the fear of becoming a financial, physical, emotional, or spiritual burden to family and friends; and (4) the existential loneliness, isolation, and abandonment associated with dying.

Although these aspects are listed and will be described separately, the actual experience of suffering cannot be easily delineated into distinct categories. As stated, suffering is an embodied experience; physical pain overlaps naturally with the experience of depression, vulnerability, loss of control, fear, and isolation.

The following is a brief review of the some of the current research associated with aspects of pain, depression, fears of being a burden, and existential loneliness. In addition, this section will identify some of the significant gaps in the medical, nursing, and psychological literature.

Uncontrolled Physical Pain and Symptoms

Pain is defined as "an unpleasant sensory and emotional experience associated with real or potential tissue damage or described in terms of such damage" (AHCPR, 1994). The pain associated with terminal illnesses can range from mild, to excruciating and demoralizing. Pain and pain management protocols have been studied extensively and have resulted in effective pharmacological relief for most forms of malignant pain and many forms of non-malignant pain (AHCPR, 1994; Emanuel, 1996; Ferrell, et al, 1991; Meier, Morrison, & Cassel, 1997). In particular, pain protocols and algorithms have been developed that address both assessment and treatment modalities (AHCPR, 1994; Byock, 1994; Emanuel, 1996; Ersek & Ferrel;, 1994; Ferrell, et al, 1991).

Yet, many physicians still maintain that opiates may result in the double effect of hastening death as a consequence of aggressive pain control (Bopp & Coleson, 1995; Preston, 1995; Reitman, 1995). In contrast, research and clinical practice has repeatedly shown that while strong analgesics may cause respiratory depression in high doses, its inherent lethality is unreliable (AHCPR, 1994; Byock, 1994; Emanuel, 1996). The hospice and palliative care literature has repeatedly refuted the concerns of lethality of opiates when prudently titrated. Yet many clinicians are still reluctant to administer adequate dosages to control severe pain (Byock, 1994; Emanuel, 1996; Enck, 1994).

In addition, many physicians and nurses lack knowledge of pain assessment and pharmacological techniques (Byock, 1994; Emanuel, 1996). Inadequate analgesia denies patients control over the physical consequences of disease and can cause unnecessary suffering (AHCPR, 1994; Cassell, 1982; 1991; Kahn & Steeves, 1986; 1994; 1995; Steeves & Kahn 1987). The literature provides a wealth of information regarding pain protocols, but dying patients are still frequently undermedicated (Bacom & Tolle, 1995; Byock, 1994; Chapman & Gavrin, 1993; Gregory, 1994; Meier, Morrison, & Cassel, 1997). In fact, as many as 50% of terminally ill patients may experience poor or inadequate relief of pain at the end of life (Emanuel, 1996; Meier, Morrison, & Cassel, 1997; Sulmasy & Lynn, 1997).

Depression, Loss of Self-Concept, Worth, and Esteem

Depression is strongly linked to living with terminal illnesses. Although depression is commonly associated with terminal prognoses, many terminal patients do not receive treatment for the condition. A diagnosis of clinical depression is difficult to delineate from depressive symptoms that may be normal, intense, and transient at the end of life (Block & Billings, 1994; 1995; Thomasma, 1996). While some depressive symtomatology may be normal, current research indicates that clinical depression is not a normal nor expected consequence of dying and should be treated actively as part of palliative care (Block &

Billings, 1994; 1995; Enck, 1994). Unfortunately, physicians are still not trained consistently in differential diagnoses of depression (Block & Billings, 1994; 1995).

Most depressive symptomatology is associated with fluctuations between intense periods of sadness and periods of relative contentment. In contrast, clinical depressions are differentiated by the absence of mood fluctuations and by persistent anhedonia or lack of positive mood (Block & Billings, 1994; 1995; Byock, 1994; Enck, 1994; Katz, 1994; Valente, et al, 1994). Clinical depressions are closely affiliated with intense suffering and must be carefully diagnosed and treated (Byock, 1994; Enck, 1994; Kleinman, 1988).

Embedded within the experience of clinical depression may be specific issues related to loss of self-concept and esteem (Cassell, 1982; 1991; Frank, 1995; Kleinman, 1988). Mainstream American culture is based heavily on productivity and the American work ethic. In fact, many people define human self-worth only in terms of personal and economic accomplishments (Benner, 1994; Kleinman, 1988). The angst associated with loss of productivity can be frequently seen with elderly dying patients who are no longer able to fulfill their responsibilities and roles. In contrast to the productivity of living, the dying process is an ontological experience rather than a series of distinct tasks to be mastered or accomplished. In this way, the dying process requires a paradigm shift from a "doing" to a "being" perspective (Benner, 1994; Ferrell, et al, 1991; Kleinman, 1988; McCormick & Conley, 1995). If this paradigmatic shift is not recognized and addressed, dying patients may quickly develop clinical depressions as a result of their interpretations of inactivity or non-productivity (Kahn & Steeves, 1995; McCormick & Conley, 1995).

Fears of Becoming a Burden

One of the more poignant forms of suffering arises from fears of becoming a burden to others. Besides cultural norms related to productivity, other culturally prized values are self-sufficiency, autonomy, and self-determination. The loss of autonomy and self-determination are very strongly linked to suffering and shame. It is no surprise that the cultural value of self-determination coupled with the potential loss of autonomy and shame of dying are found at the heart of the PAS debate. The PAS literature cites dramatic examples of agonizing suffering when patients lose the ability to physically care for themselves or become incontinent (Campbell, et al, 1995). PAS proponents state that people should have the autonomous right to end their lives if confronted with the indignity of dependency (Bushong & Balmer, 1995; Campbell, et al, 1995; Humphrey, 1991; Quill, 1991) and imply that this particular form of suffering is so intense that it can be impossible to ameliorate (Bushong & Balmer, 1995; Campbell, et al, 1995). The PAS literature often cites such dependency as “a physical condition that no longer warrants continuance” (Thomasma, 1996).

The hospice and palliative care literature counters this bleak position with moving anecdotal accounts of interpersonal and familial resolution of the suffering of dependency (Byock, 1997). These stories are equally as poignant and dramatic as the proponents' positions; however, neither position has substantive research findings to back their claims.

Existential Loneliness, Isolation, Abandonment

Loneliness, isolation, and abandonment are all associated with the loss of desired human relationships (Donaldson & Watson, 1996; Foxall & Ekberg, 1989; Frank, 1995; Frankl, 1963; James, 1982; Kokach, 1996; McCormick & Conley, 1995; Moustakas, 1961). Loneliness is generally defined in terms of deficits of social connections; however, the dying process involves a confrontation with the absolute existential loneliness of death. Besides being a profoundly unpleasant experience, existential loneliness may almost force the sufferer to acknowledge the fundamental and existential isolation of human life and death (James, 1982; Moustakas, 1961).

Younger (1995) expands on the impact of loneliness as an experience of suffering. She states that the severity of the isolation of suffering can be experienced as a process of alienation. Not only does the suffering of alienation involve the process of becoming more and more isolated from close, loving relationships, but the sufferer may also come to feel alienated from oneself. According to this perspective, pain and suffering may actually cause a break in the natural, smooth functioning of the sufferer's social and emotional relationships and this break may lead to severe isolation and an emotional and social disconnection with one's previous support networks. She states further that while alienation should not be perceived as a specific event, the experience of alienation is more accurately based on a continuum and as the suffering increases, the alienation or sense of disconnection from support may also increase. "Alienation is an experience of disconnectedness with one's self; with others; and with one's gods, nature, or a transcendent realm of being" (Younger, p. 57-58, 1995).

Although existential loneliness and alienation has been studied extensively in adolescent populations, limited research has analyzed the existential loneliness of dying. Existential loneliness is associated closely with the spiritual challenge of confronting the existential emptiness of being alive rather than the sadness of being alone or isolated (James, 1982; Moustakas, 1961; Younger, 1995). The resolution of existential loneliness may be related closely to spiritual beliefs and is also associated directly with the healthy acceptance of death (Kubler-Ross, 1970; McMillan, 1996). In addition, unresolved existential loneliness may well be implicated in the pain and sadness that can arise during the loneliness of the night.

Implications for Healthcare

Hospice programs are identified often as the preferred option for palliative care; however, less than 20% of patients currently receive palliative care through home-based or in-patient hospice programs (Miller, Miller, & Single, 1997). As a result, over 80% of patients die in acute care settings, in adult foster or nursing facilities, or at home without hospice services. Traditionally, health care settings have focused on aggressive treatment, health promotion, or health maintenance rather than palliation. According to one physician's account, many doctors may not recognize that someone is dying until the patient is within the last 24-48 hours of life (L. Ganzini, personal communication, September 21, 1999). For this reason, it may be inferred that an alarming number of people may not receive adequate palliation of symptoms, and thus, may experience intractable pain and suffering at the end of their lives.

Cancer is one example of an illness that commonly results in pain and suffering and is the leading cause of death in older adults (Oregon Department of Human Resources, 1998). Although heart disease and chronic obstructive pulmonary disease may cause enormous suffering, a cancer diagnosis in this culture is nearly synonymous with suffering. It is estimated that in the United States, in 1998, over 1.2 million people will be newly diagnosed with cancer and over 560,000 cancer patients will die (American Cancer

Society, 1997; Beresford, 1997). It is well accepted that the physical and psychological ramifications of cancer can be severe.

To illustrate, approximately 70% of cancer patients experience pain, 62% experience nausea, 58% experience depression, and 70% experience dyspnea (Enck, 1994). Within the VA patient population, lung cancer and head and neck cancers account for a disproportionately large percentage of all cancer diagnoses (personal communication, Terri Harvath, June 4, 1998). These two cancer diagnoses are frequently associated with intense suffering from pain, isolation, depression, and disfigurement. Given these cancer statistics, pain and suffering may be inferred as likely consequences of living with and dying from cancer (AHCPR, 1994; Block & Billings, 1994; 1995; Emanuel, 1996; Ferrell, et al, 1991).

Although effective pain management and palliation protocols exist and are accessible to most health care providers, many terminally ill patients fail to receive adequate relief of their pain and related symptoms (Bascom & Tolle, 1995; Byock, 1994; Emanuel, 1996; Meier, et al, 1997). Much of the suffering associated with the pain of dying may be a direct result of poor assessment and inadequate treatment (Bascom & Tolle, 1995; Meier, et al, 1997). However, uncontrolled pain is just one element of the suffering of dying.

The more challenging aspect rests within the individual's experience of emotional and spiritual suffering when nearing the end of life. Although suffering is often linked to pain, suffering is a distinct construct which has not been analyzed adequately to identify antecedents, exacerbating conditions, and ameliorating interventions for dying patients. Pioneers in medicine, nursing, psychology, and theology have begun to examine suffering and provided language and methodology to address and analyze the experience (Cassell, 1982; 1991; Frank, 1995; Frankl, 1963; Kahn & Steeves, 1986; 1994; 1995; Steeves & Kahn, 1987; Younger, 1995), yet little is known of the depth of this experience.

Ironically, as the debate over PAS and the humane treatment of dying patients has intensified in conjunction with the national emphasis on improving the care of the dying, the average length of stay for the hospice patients has fallen dramatically. In 1995, the average length of stay from hospice admission to the time of death was 63 days. In 1997, the average length of stay for the same population of patients fell to 37 days and 42% of those patients died within 14 days of admission and nearly 80% died in less than four weeks (personal communication, Janet Schaefer, June 4, 1998). The reasons for these dramatic changes are unclear; however, the critical impact of shortened length of hospice stays is reduced access to expert palliation and potentially greater suffering. Given its 25 year history in the U.S. and the political upheaval over PAS, it is curious that hospice programs are not accessed avidly by opponents of physician assisted suicide.

The proponents of physician assisted suicide clearly couch their arguments as a humane means of "self-deliverance" or "relief of suffering for the terminally ill." However, the PAS literature frequently reflects the voices of physicians, lawyers, and ethicists. It does not adequately reflect the range and diversity within the experience of dying. This gap in the literature is not only of concern from a scholarly and academic position, but concerns those individuals most intimately involved with the experience of suffering. Elisabeth Kubler-Ross, the founder of the death and dying movement in the United States, has voiced her own dismay at the quality of today's palliative care. Now that she, too, is dying, she stated that she feels that her 30+ years of research into the care of the dying has not significantly influenced the quality of the care she has received in American hospitals. She further states that she is shocked and distressed at the paternalism and callousness found in the medical and nursing professions (Kubler-Ross, 1997; O'Keefe, 1997).

The issue is not only the compassionate care of dying patients, but more importantly, it is an issue of enhancing the humanity of both dying patients and the healthcare community (Block & Billings, 1995; Fields & Cassel, 1997; Lee, Ganzini, & Brummel-Smith, 1996; Meier, Morrison, & Cassel, 1997; Scofield, 1995; Tomasma, 1996). The answer to the public mandate for compassionate care of the dying lies in amplifying our concern, commitment, and intelligence toward improving palliative care. Almost by definition, the voice of suffering demands time to express the full story. If healthcare is to enhance the care of dying patients, it clearly must find the means to hear, understand, and act upon the narratives of suffering.

Implications for This Study

The suffering of dying is clearly a complex phenomenon, involving alterations in the meaning of health, bodies, relationships, and the uncertainty of the future. Yet, the suffering of dying patients has not been addressed adequately at this time. Furthermore, they state that it is the responsibility of healthcare professionals to expand their understanding of the processes associated with suffering and to explore methods to alleviate the suffering of dying. However, outside of Steeves & Kahn's extensive work on suffering in bone marrow transplant and in nursing home patients, little research has concentrated on the experience of suffering (not solely pain) for elderly patients at the end of life. This gap in the literature is significant particularly when evaluated in light of the current emphasis on improving end of life care and the expected growth in the elderly population in the near future. Moreover, presenters at the Harvard Medical School conference on palliative care (Toward Excellence in Palliative Care, June 17-20, 1998) repeatedly emphasized that research into the nature of suffering must become a significant focus of future palliative care research.

The results from this study provide an opportunity to view the experience of suffering through the narrative accounts of terminally patients with advanced cancer and congestive heart failure. The next chapter explores the match between this study's research questions and the philosophical underpinnings of the method, interpretive phenomenology. In addition, Chapter 3 describes the method used in this study and explains the process of data collection and the subsequent analysis.

Chapter 3

Methods and Methodological Issues

> "......Our words are wiser than we are .... Language used truly, not mere talk, neither propaganda, nor chatter, has real power. It's words are allowed to be themselves, to bless or curse, wound or heal."
> (Norris, p. 9, 1998).

Suffering is dependent on the individual's meaning of the antecedents and experience. Yet, while people may experience suffering as distinct individuals, understanding the experience of suffering can emerge from within the descriptive, everyday language spoken by homogenous groups of people with similar histories, contexts, and cultures. Each individual may describe personal accounts of the experience, but those accounts will reflect naturally the shared background meanings and concerns that are socially and culturally determined (Dreyfus, 1992). Thus, to understand the experience of suffering, the investigator must apply methods that will explicate these shared background meanings and concerns. I have chosen interpretative phenomenology as the design for this study because it is a scientific method uniquely suited to this type of investigation (Benner, 1994; Benner, & Wrubel, 1989; Dreyfus, 1992; Lauer, 1958; Moustakas, 1994).

As in any scientific endeavor, the philosophical assumptions and tenets will influence the research design. Philosophical principles and assumptions provide the foundation for any study's methodological consideration. This next section of this chapter will explain the most pertinent principles and assumptions of Heideggerian interpretative phenomenology. The second section will focus on the specific details of this study's design features.

Philosophical Principles and Assumptions

The traditional empiric-analytic philosophy of science maintains that the goals of inquiry are to explicate truth through a systematic process of quantifying and measuring discrete dimensions of observable phenomenon. Within the empiric-analytic paradigm, the goals of inquiry are to predict outcomes and explain causation rather than to deepen understanding. In contrast, the philosopher Martin Heidegger proposed an alternative approach that emphasized understanding as the primary purpose and goal of scientific inquiry. In addition, while the traditional empiric-analytic philosophy of science has sought to explicate the nature of phenomenon by reducing it to smaller, quantifiable dimensions, Heidegger proposed that phenomenon could be understood from within the context of that experience and that meaning could be explicated by investigating the human, lived experience of that phenomenon. Furthermore, understanding will naturally emerge from the words that are used to describe the experience (Dreyfus, 1992; Lauer, 1958; Heidegger, 1962).

Heidegger opposed the traditional empiric-analytic assumption that phenomenon could be defined by central, defining truths. In contrast, he proposed that the purpose of phenomenological investigation was to explicate and understand the meanings embedded within the experience (Dreyfus, 1992; Heidegger, 1962). Although the experience of phenomenon may be intensely personal, the meaning of the lived experience of phenomenon is shaped by the shared background meanings and concerns embedded within the experiencing person's context, language, history, and culture. Given this position, Heidegger posited that the understanding of phenomenon will emerge naturally from the embedded meanings within the experience. Thus, the phenomenon may be explicated and understood through interpreting the shared meanings and concerns common to individuals who have experienced the phenomenon (Dreyfus, 1992; Heidegger, 1962; 1971).

In addition, Heidegger further stated that shared meanings are naturally fluid and dynamic and will change and evolve as history, context, culture, and society evolve (Benner, 1994; Dreyfus, 1992). Within this perspective, he described phenomenology as an ever changing hermeneutic or interpretive process that seeks to uncover the meaning of experience rather than to determine the truth or essence of the identified phenomenon. Heidegger affirmed that the key to understanding humanity lay in how people make sense of and interpret their everyday worlds. Thus, Heidegger proposed that it is through analyzing the everyday, ordinary words people use to describe experience that can lead to extraordinary insight into the nature of humanity and it is through this insight that the phenomenon may be understood.

Ontology of Experience

The most central concept within Heidegger's philosophy is that of *Dasein*, or being-ness. Rather than re-define existing philosophical terms to fit his philosophical ideas, Heidegger invented the term, *Dasein,* to refer to multiple concepts. First, he used, *Dasein,* to refer to the ontology (or study of being) of humanity, but *Dasein* also means the experience of being or being-in-the-world. Furthermore, Heidegger used *Dasein* to refer to the person who experiences the state of being. While his use of multiple definitions of the word *Dasein,* may appear confusing, the most important meaning of *Dasein* is that of a fully embodied, integrated state that may be glimpsed by analyzing the words used to describe everyday, lived experiences (Dreyfus, 1992; Heidegger, 1962).

Heidegger further suggested that because humans interact directly with their world, the words describing *Dasein* or being-in-the-world can become the vehicle to understand the experience (Dreyfus, 1992; Heidegger, 1971). The basic assumption underlying this position is that the meanings of everyday words are not derived randomly from meaningless abstractions or by mere chance, but rather the meanings of words develop intentionally and evolve through shared practices, beliefs, and values. In this way, the meaning of words are not artificially determined, but arise from the shared contexts that are already meaningful. Therefore, everyday language is understood to hold contextually bound meanings of phenomenon (Dreyfus, 1992). As such, the everyday culturally grounded words used to describe experience become the focus of study. Thus, the words used to describe experiences will naturally reflect the cultural, social, and contextually shared meanings embedded in the experience.

Heidegger asserted that people live in the world in three distinct ways. The first mode of engagement, or way of being, is referred to as ready-to-hand and implies unconscious, effortless, skilled interaction with the world. Heidegger cited the use of a hammer as illustrative of the ready-to-hand mode of engagement. He stated that the effortless use of a hammer is generally not bounded by conscious thought, but rather, easy, fully-engaged hammering typifies the natural, everyday actions that represent the unconscious, skilled interaction between the human, the hammer, the nail, and the wood.

He described the second mode of engagement as unready-to-hand. This reflects periods in which the easy and effortless approach is hampered. It may be that the ready-to-hand situation has changed and now requires new skills, or the situation may have changed necessitating a novel approach to old skills or the context or situation may require close and intentional concentration. An example of this may be using a hammer in an awkward position or using it in the non-dominant hand that requires more conscious and thoughtful consideration. The third way of being is the present-to-hand mode which implies a theoretical, reflective way of being which is uninvolved and detached such as considering abstract properties of hammers (Dreyfus, 1992).

The Hermeneutic Circle

Another important principle of the interpretative phenomenological method is the hermeneutic circle. This conceptual arc or circle represents metaphorically the dynamic and fluid process of hermeneutic investigation. The hermeneutic circle begins with the study conceptualization and moves quickly forward along the perimeter of the circle through analyzing the narrative data and the nascent interpretations. The first layers of understandings are then challenged by the arc-like movement backward to review and expand the investigator's level of understanding and to re-examine and revise the initial lines of inquiry. Each and every time the investigator enters the hermeneutic circle, the understanding moves forward along the arc and then moves backward to achieve greater clarification of the first layers of understandings; however, the backward movement never totally returns to the first point of entry. As the conceptual arc moves forward toward the phenomenon and backward for necessary reflection, the investigator is able to deepen and develop the understanding of the embodied phenomenon (Dreyfus, 1992; Packer & Addison, 1989; van Manen, 1990). In this way, the investigator enters the circle time and time again to continually explore and evaluate the provisional findings.

The movement on the hermeneutic circle continues until the investigator believes that the understanding of the phenomenon is as complete as possible given the boundaries of the study. Although the arc-like movement may be slow, it is the methodical and consistent movement forward for insight and back for reflection that eventually leads to a full circle of understanding.

The hermeneutic circle is closely related to developing lines of inquiry. Lines of inquiry are defined as an evolving series of questions that fulfilled the specific aims of the study and broaden the early understandings of the phenomenon. While some qualitative methods recommend interview guides to direct and focus the interviews (Miles & Huberman, 1994), interpretative phenomenology is grounded in broader lines of inquiry. These lines of inquiry are not structured interview questions posed to each participant, nor are they outlined as a formal interview guide. Within the perspective of the interpretative method, lines of inquiry direct the investigator's thinking regarding both the interpretation and the future direction of questioning (Benner, 1994; Packer & Addison, 1989; Seidman, 1991).

The lines of inquiry should reasonably match the specific aims as outlined in the study proposal. Cohesion between the aims and lines of inquiry assure logical consistency within the study and cohesion is fundamental to the research process (Benner, 1994). However, while the specific aims of research studies should remain stable within the study design, the lines of inquiry will naturally adapt, change, and evolve as the investigator uncovers deeper and deeper meanings embedded within the understanding of the phenomenon and as that understanding deepens through data collection, analysis, and interpretation (Benner, 1994; Dreyfus, 1992; van Manen, 1990).

The interpretative phenomenology literature states that the first movement along the forward arc of the hermeneutic circle is to fully immerse oneself in the phenomenon

(Benner, 1994; Dreyfus, 1992; Lauer, 1958; Moustakas, 1994; Packer & Addison, 1989). The basis of this assertion is that without *a priori* understanding or preunderstandings of the phenomenon, the initial lines of inquiry and interpretations may be inappropriate or naïve. Although *a priori* knowledge and understanding provide opportunities to develop greater awareness, there are hazards to immersion in a phenomenon.

The *a priori* and pre-understandings the investigator holds regarding the specific phenomenon constitute what Heidegger termed the forestructure. While forestructure may enhance the ability to understand and explicate phenomena, it will also hold the roots of assumptions, prejudices, and biases. As such, forestructure is a double edged sword. Although the forestructure can serve to focus the interview process and can result in uncovering rich interpreted meanings, these natural biases can simultaneously threaten both the trustworthiness of the data and may unwittingly blind the investigator to new or possibly conflicting themes.

According to Heidegger, investigator biases and prejudices are not necessarily limitations of the method. The investigator's forestructure provides the foundation for the initial lines of inquiry, besides offering a framework for theme recognition. Heidegger did not believe it was possible to bracket or control assumptions and biases as the more quantitative philosophers proposed; however, he proposed that the forestructure is a natural part of the context of the experience. The forestructure may be identified and examined, but need not be eradicated (Dreyfus, 1992; Heidegger, 1962).

There are several techniques that may be used to examine one's forestructure or pre-understandings. By using a process of continual reading, writing, and discussion with colleagues and consultants, the investigator will come to deepen awareness of unconscious assumptions and prejudices. In addition, investigators may find that writing, editing, discussing, and revising thematic interpretations will not only uncover unconscious assumptions, but will strengthen the understanding of the phenomenon.

Study Design and Methods

The purpose of this study was to deepen the understanding of suffering at the end of life for patients with cancer and congestive heart disease. A series of non-structured interviews were conducted, recorded, and transcribed. The transcribed texts were then used as the data source to analyze and interpret the narrative accounts to ascertain the emerging thematic patterns that would become the understanding of the phenomenon.

Study Inspiration

My clinical experience and educational background are in hospice and palliative care. The research questions arose directly from my experience working with dying patients. For many years, I had witnessed patients experience tremendous psychological, emotional, and spiritual suffering which appeared nearly impossible to relieve. Patient suffering was a persistent and difficult problem that I wanted to understand more fully. In addition, the issue of physician assisted suicide had become an important issue in Oregon state. Thus, my own clinical experience and the current issue of physician assisted suicide were the source of inspiration for this study.

Narrative Accounts as Data

Suffering is believed generally to arise from negatively changed states of being, suffering. As such, suffering will reflect the unready-to-hand mode of engagement. However, the human experience of suffering is also influenced by the common language, shared meanings, and cultural norms and mores. In this way, suffering may also encompass the ready-to-hand mode of engagement embedded within the changed body, mind, or situation. Thus, the everyday language can be used to uncover the individual meanings the person attributes to the experience and the shared meanings found within a homogenous group. Given these aspects of suffering, I selected interpretative phenomenology as the study method and non-structured interviews as the source of data.

Sampling Strategy

The purpose of phenomenological research is to explicate the common meanings embedded within shared experiences, in contrast to quantitative studies which seek to explain variance within diverse samples. Most qualitative studies use quite small samples. According to Patton, "the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the analytical capabilities of the researcher than with the sample size" (Patton, p. 185, 1990). To assure information-rich data, I chose an in-depth approach to provide the necessary depth of narrative to fully explicate the meanings associated with suffering. In addition, small samples are not only acceptable within this paradigm, but are exceedingly pragmatic (Benner, 1994; Dreyfus, 1992).

Given Patton's recommendation of information-rich cases, a small homogeneous sample was used. This study broadly defined homogeneity by terminal diagnosis and by age. To explain in greater detail, an interpretative phenomenological sample must reflect adequate homogeneity to ensure that adequate shared meanings and concerns will be uncovered within the narratives. Thus, by establishing inclusion criteria that may be interpreted and understood to be strongly associated with suffering, the probability of finding participants with similar background meanings and concerns was heightened.

Investigator pre-understandings or forestructure also influenced my decisions regarding inclusion criteria. My clinical experience and education in hospice care was weighted heavily toward cancer patients. Because cancer is believed to be a relatively predictable disease (in comparison to other diseases such as chronic obstructive pulmonary disease, diabetes, or dementia), approximately 80% of all hospice diagnoses are cancer related (Miller & Mike, 1995). Yet, other terminal diseases such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD) often result in extreme suffering; however, within this culture, a cancer diagnosis is nearly synonymous with suffering (Gregory, 1994). For these reasons, I selected the diagnosis of cancer as the major inclusion criteria and later included the diagnosis of end stage congestive heart failure (CHF) as a contrast diagnosis.

It may also be assumed that the meaning of adult experiences of diseases would naturally differ from children's experience. Although I had some experience working with pediatric hospice patients, most of my clinical experience was with adult hospice care. Furthermore, older adults account for over 80% of all deaths in Oregon (Oregon Department of Human Resources, 1998). It can be argued that this population is more at risk for suffering with terminal diseases than younger individuals.

While ethnic minority participants were not specifically excluded from the study, I did not actively try to assure a sampling mix that matched the natural demographic patterns of this geographical area. Although including heterogeneity is a significant factor in sampling procedures for other types of research, this research method supports the need for greater homogeneity than would be expected in a quantitative study. Again, this rationale lay in the method's assumptions. As stated, interpretative phenomenology seeks to explicate meaning through the analysis of shared background meanings and cultural contexts. While all ethnic groups may experience suffering as a result of living with cancer, it was anticipated that participants from ethnic groups may possibly exhibit extensive cultural diversity leading to disparate interpretations of the experience of interest. Moreover, the limited ethnic diversity in this geographical area would very likely result in a very small number of eligible participants. Furthermore, including only one or two ethnic participants, their inclusion may have actually diluted the ethnic participants' meanings embedded and could have flattened the richness of the experience of suffering found within those diverse ethnic groups. Thus, to assure the goals of this study and to also respect the depth of experience found in other cultures, I elected to limit the inclusion criteria to disease and age.

The inclusion criteria were designed to strike a balance between homogeneity to assure depth and the natural heterogeneity within natural groups to assure breadth (Patton, 1990). To summarize, the study's small, purposive sample consisted of (1) six oncology patients with any form of stage IV cancer and two CHF patients with end stage disease, (2) a prognosis of six months to one year and (3) patients who were at least 50 years of age. The age range was from 55 to 78.

Recruitment of Participants

I accessed two different healthcare organizations in Portland, Oregon to recruit participants. I contacted a total of 13 oncologists from both systems to explain the purpose and scope of the study and request assistance with recruitment. All oncologists and their representatives declined my offer to provide a copy of the study summary (Appendix A) that described the goals, methods, risks, and benefits of the study, a copy of the introductory letter, and a copy of the consent form (Appendix B). The oncologists requested that I contact the oncology clinical nurse specialists (CNS) to identify and screen potential participants. I used other recruitment strategies which included working with the directors of clinical programs, such as outpatient oncology, geriatrics, and palliative care task forces. My research sponsor and I also contacted social workers and nurses affiliated with other departments at these clinics.

The clinical nurse specialists from both organizations approached a total of 30 patients. Although only eight participants completed the study, the large number of possible participants allowed for natural and expected refusal and attrition that could result from exacerbations of illness and from death. Based on the CNS's advice and the oncologists' preference, I did not send the introductory letters with the study summary prior to making telephone contact with the participants. Using the inclusion criteria, the clinical nurse specialists elected to call the potential participants to explain the study and to ask for their participation. After these nurses received permission from the patients, they gave me their lists of possible participants. I then contacted the patients directly and asked if they would like to have the introductory letter and study summary sent prior to making the appointments to be interviewed. All participants declined the offer to receive the advance information.

Protection of Human Subjects

All study participants signed informed consent forms prior to beginning the interview series (Appendix B). The degree of risk to each participant was quite low;

however, one participant did report feeling sad after discussing her experience of living with cancer. Yet this particular woman also stated that her feelings of sadness were mitigated by talking with me about her feelings. I did not encounter other instances in which participants experienced distress after the interview. I did not identify any participants who were at risk for an exacerbation of depression or other emotional or psychological adverse reaction. Should this have occurred, I would have tried to therapeutically resolve the situation during the interview. If it had been necessary, I would have immediately referred the participant to the physician, a social worker, or other support person identified by that participant's physician.

Data Collection

One challenging issue that arose during the planning phase of this study was that few people will spontaneously admit to feelings of suffering. This hesitancy to apply the word "suffering" to oneself may reflect cultural norms and mores that emphasize personal independence and self-sufficiency (L. Ganzini, personal communication, January 15, 1999). Because of this potential problem, I elected not to use the word "suffering" in my preliminary interview guide. When participants told stories that I perceived as experiences of suffering, I asked them if they felt that they were suffering during that experience. When the participants were asked about suffering immediately after they told their stories, they were quite clear that the word, "suffering," did apply to their experience.

I initially developed the interview guide (Appendix C) to help prepare and focus the interviews; however, these guides did not prove to be very effective during the actual interviews. Throughout the interviews, the participants simply told their story without difficulty. In fact, they were distracted if I asked too many questions or tried to probe for specific detail. As a result, the interview guide became intrusive to the flow of the interview. In order to determine when and how the participants were suffering, I found it much more effective to simply ask if the participant suffered as a result of their story.

Thus, as is consistent with this method, the lines of inquiry naturally evolved and developed as the analysis proceeded along the forward arc of the circle with each interview and then flowed backward to explore and reflect on the data (Benner, 1994; Packer & Addison, 1989). The participants were interviewed a minimum of two times to a maximum of five interviews in one case. I interviewed each participant alone except for two instances in which family members wanted to be present during interview.

Using the general structure offered by Seidman (1991), the purpose of the first interview was to explore the participants' significant life events which shaped the meaning and context of their current experience. The purpose of the second interview was to uncover the participants' experience of living with cancer and to obtain narrative accounts of their experiences with physical, emotional, or spiritual suffering. In the third interview, the participants were asked to reflect on the meaning of their life changes, challenges, and events associated with being terminally ill in light of their life history and events. The goal behind this interview structure was to provide a framework to examine the meaning of these experiences by allowing the participants to reflect on the meaning after reconstructing the past and describing the concrete details of their present conditions (Mischler, 1986; Seidman, 1991).

Most interviews lasted between 30-90 minutes; however, some were abbreviated to adjust for participants' fatigue, attention, pain, or other factors that necessitated shorter interviews. These abbreviated interviews were repeated until the narratives reflected adequate depth. One participant frequently asked me to stop the tape recorder before he would continue our discussion. When this occurred, I made detailed field notes directly following the interview. The data from these abbreviated interviews were included in the analysis, in addition to the context of the interviews, body language, and manner.

All interviews were audio-tape recorded, transcribed using Microsoft Word, and the transcribed texts were inserted into and analyzed by Non-numerical Unstructured Data Indexing, Searching, and Theorizing (NUD*IST 4) software to facilitate the handling of the large data set. The transcribed texts were verified and corrected, and the field notes inserted into the corresponding text.

The verified and annotated transcripts were distributed to the advisory committee as soon as the interviews had been transcribed and verified. One committee member was not able to participate in all meetings, nor was she able to dedicate the hours needed to read all of the transcripts. However, two of the three committee members did read every transcripts and were instrumental to the discussions of the emerging thematic patterns and other issues related to analysis of the data.

Interpretive Analysis

As anticipated, the process of interpretation was characterized by fluid movement forward and backward along the hermeneutic circle. The process of interpretation can be summarized as a repeating process of entering the forward arc of the hermeneutic circle with the text, reading for initial themes and ideas and then returning along the backward arc for discussion with the committee to explore and challenge the emerging themes. I frequently contacted the external consultants by telephone to collect their insights and responses to my interpretations of the emerging thematic patterns.

The process then continued by re-entering the circle in the forward movement to methodically examine the text for deeper understanding and awareness. When the major thematic patterns and secondary themes began to solidify and take shape, I began writing to explicate the depth of the patterns and potential linkages between them. When no further themes arose, I perceived that the text had been adequately analyzed and interpreted.

The interpretive process cannot be reduced simply to a composite number of steps, but it is possible to describe some of the processes that helped organize and synthesize the emerging interpretation. The following description reflects the writings of Benner, Wrubel, Dreyfus, Heidegger, Kahn, Steeves, Packer, Addison, and van Manen and will not be individually cited.

<u>Influence of Forestructure</u>: While my hospice experience was a strong source of inspiration, it was also a source of strong biases, assumptions and beliefs regarding the experience and possible antecedents to the suffering of dying. One particularly strong bias was my belief in the interactions among integrity, feelings of violation, and shame as antecedents to suffering. I also held strong assumptions regarding the meanings and implications of physician assisted suicide. These naturally occurring biases and prejudices that were both sources of depth and potential threats to trustworthiness.

In order to anticipate and identify blind spots when they arose and influenced the analysis, the advisory committee helped to identify instances in which my biases were forcing the analysis (Dreyfus, 1992; Miles & Huberman, 1994). The external consultants provided significant insight into the unconscious biases while also helping to verify the relationship between the emerging themes and excerpts from the narrative accounts.

Preliminary Coding: After the transcripts were verified, corrected, and field notes added, the first stage of interpretation began with reading and re-reading the text. In this stage, the members of the advisory committee and I began to identify global concerns and themes that arose through examining the words of the texts. The purpose of this process was to begin to identify the themes and to explore other lines of inquiry. I also began working with the electronic database to code each interview and then sorted the themes across all participants. By sorting and coding the data electronically, the patterns become clear and the large data set became more manageable. As I continued interviewing, I consistently made notes, comments, and preliminary codes in the text and into the electronic database. These notes were then "tagged" as representative of identified themes. These notes, comments, and preliminary codes served as the basis for the study's audit trail.

Discussion, Review, and Analysis: The next stage of the analysis involved in-depth discussion of themes with both the advisory committee and the external consultants. The members of the committee were asked to meet periodically to discuss and analyze the text and the emerging interpretation. The major goals of these meetings were to address, challenge, and explore the global themes that were identified from each member's first and subsequent readings of the text and to organize the themes into a thematic outline.

Within this setting, the committee and I sought new insights regarding the lines of inquiry, the emerging outline, and the understanding of the phenomenon. This approach emphasized a collaborative atmosphere to assure (1) constructive dialogue regarding the meaning of the narrative accounts, (2) collegial debate to challenge other interpretations, (3) that themes were grounded in the text, and (3) that fresh interpretations would arise through discourse. In addition, I frequently met with or spoke on the telephone with the external consultants to discuss the emerging insights and asked for their opinions on competing interpretations.

The next stage of analysis was to work on interpretive essays of the thematic patterns. The intent was to deepen my understanding of the preliminary themes through writing and reflection on the thematic patterns and to incorporate and develop the comments that arose from team discussions with the advisory committee or the external consultants. As I worked with the data, it was useful to analyze the interpretations through writing and to illustrate the interpretations with excerpted narrative accounts. Through the process of writing, revising, and editing of the beginning interpretations, the experience of suffering began to unfold.

The interpretive essays were then reviewed by the committee for faithfulness to the transcribed text and to debate the significance of the thematic interpretation. Continual and careful return to the text was critical to assure that my opinions, biases, and ideas did not inadvertently color the interpretations or lead to missed significant themes.

Thematic Outlines and Organization: The thematic outline, including illustrative, excerpted narratives was presented to the committee for review and critique. Again, the emphasis was on collegial discussion of the patterns and constructive debate of competing interpretations. At this stage, the committee began to evaluate the interpretation for coherence, external validity, consensus, and practical applications. At this point, I was able to began to write the final version of the interpretation as a composite rendering of the phenomenon.

Evaluation of the Findings: Establishing validity and reliability standards to evaluate findings is an essential component of any research study. Because qualitative studies do not use numeric data, the qualitative investigator cannot statistically confirm the validity and reliability of their findings. As such, qualitative researchers must evaluate their data by other methods. In addition, the philosophical tenets underlying Heideggerian interpretative phenomenology posit that it is impossible to determine absolute truth or essence. To this end, the goal of phenomenology is not to uncover the truth or essence, but rather the goal is to deepen understanding. Thus, if truth or absolute essence cannot be determined, then applying quantitative standards of validity and reliability cannot be done. As a result, alternative procedures must be used to evaluate the veracity of the findings. The most commonly applied standard is to evaluate qualitative findings for trustworthiness rather than validity. Packer and Addison (1989) recommend four methods to evaluate trustworthiness for interpretive studies. These four methods are coherence, consensus, external validity (member checks), and practical application of the findings.

To assure that a study is coherent, the findings must be both plausible and must demonstrate internal and logical consistency. With this approach, the investigator, and all other persons involved with the interpretation, must evaluate the emerging and final interpretations for consistency with the narrative text and with the specific aims, study design, research methods. This approach recommends repeatedly scrutinizing the interpretative writing to assure that the meaning of the interpretation reflects the actual words of the narrative accounts and should be embedded in the process of reviewing the transcripts and gauging the text against the written interpretations.

The second approach to evaluating trustworthiness of a study is what Packer and Addison call external evidence or member checks. This approach involves taking the interpreted findings back to selected participants for review and critique. During the initial planning phase of the study, I had decided not to use this evaluative technique due to the participants' severity of illness. I had anticipated that the participants would die or become too ill before the narratives were fully analyzed and written. While I was able to contact one participant after the study was completed and I did ask her to review the final interpretation, she declined because she had recently had another round of chemotherapy and was too ill.

The third evaluative approach is consensus between the investigator, the advisory committee, and any external consultants. The purpose of this evaluative technique is for all individuals working with the data to reach agreement regarding the final interpretation. Again, this process is embedded in the process of discussion of the text and debate over the emerging ideas. The danger rooted in this method is the possibility that working groups can sometimes come to consensus regarding erroneous interpretations. This danger can be overcome by returning consistently using the original narrative accounts as the final interpretative authority.

The fourth approach is to evaluate the future implications of the findings. With this evaluative approach, the interpretation is assessed for its potential to improve and strengthen the understanding of phenomenon to move toward beneficial praxis or practical applications. While this approach can be challenging to achieve, Packer and Addison suggest that interpretative research be evaluated by pragmatic questions. As such, the investigators must ask themselves: Will the findings deepen the understanding of this particular phenomenon and do they have the potential to deepen the awareness of related phenomenon? Do the findings offer beneficial ways to address similar situations. similar people with similar diseases? Using this technique to establish trustworthiness, the investigator must continually pose practical, pragmatic questions and ask themselves how the findings may serve "to reorient, focus, or serve as a catalyst for improved practice" in the future.

Dissemination of the Findings: The final written interpretation was presented to the advisory committee for discussion, dialogue, and debate. The evaluative techniques of coherence, consensus, and practical application were used to establish trustworthiness of the data. Any elements that were unclear or needed clarification were identified as part of the evaluative process, and the committee sought to assure that the final interpretation resonated with the original text. The veracity of the text maintained the consistency of the interpretation and as such, remained the final authority. Any revisions and corrections were made at this point and the interpretation was inserted into the major body of the research study.

Advisory Committee and External Consultants: The transcribed texts were analyzed by the advisory committee, comprised of my sponsor, Christine Tanner, RN, Ph.D., an expert in interpretive phenomenology; co-sponsor, Beverly Hoeffer, RN, DNSc, FAAN, with specialized knowledge and funded research in gerontology and mental health including research on loneliness in older women; and Sheila Kodadek, RN, Ph.D. who brought extensive experience in qualitative research methods. The following external consultants provided expertise in specific content areas: Ann Didier Voll, M.Div, MA, a recognized expert and educator in ethics, theology, and philosophy; the Rev. Alla

Bozarth, Ph.D., was selected for her expertise in clinical psychology, hospice care, theology, and hermeneutics; Shodo Harada Roshi, Senior Abbot of the Sogenji Zen Buddhist Monastery in Okayama, Japan was included for his understanding of the nature of suffering from a spiritual perspective; and Ed Lorah, MSW, provided many years of experience in hospice social work and counseling.

Chapter 4

Study Results and Discussion

Suffering has been defined as a real or imagined threat to an individual's sense of integrity or personhood (Cassell, 1991) and implies that suffering is experienced at the deepest human core rather than solely as a result of physical assaults to the body. If we view integrity as a composite of the body, mind, intellect, emotions, and spirit, suffering becomes a holistic, ontological phenomenon and may impact every aspect of that person's life. Given this perspective, it is reasonable to suppose that suffering permeates a person's life and influences that person's sense of self, time, safety, and future. It is this position that makes suffering both difficult to describe and even more difficult to alleviate. While this definition provides a powerful framework to begin to understand suffering, it does not fully explicate what the person experiences when the sense of integrity is violated.

The purpose of this study was to explicate some of the patterns embedded within the experience of suffering and to interpret those patterns within the context of the participants' life experiences and background meanings. Three thematic patterns emerged through the process of data analysis. The most compelling and predominant theme was that of Not Being Heard. The first section of this chapter will describe and analyze the data supporting this theme and will also explore Not Being Heard as a potential threat to integrity. The second section of this chapter will describe and analyze the two secondary themes, Planning for Life Without Me and Searching for Understanding and again, will relate the thematic patterns to the definition of suffering.

Primary Thematic Pattern

The Experience of Not Being Heard

The most prominent form of suffering reported by all study participants arose when they perceived that their providers and caregivers did not hear or understand the depth and force of their experience. Throughout the transcripts, the participants repeatedly described how they tried to explain the severity of physical pain or their experience with other physical or emotional problems, but according to the participants, their providers or caregivers frequently did not listen to them. The pattern of Not Being Heard emerged strongly and was so compelling that I have designated it as the primary thematic pattern of the study.

To clarify the rationale for my selection of this particular phrase to describe the participants experience, it must be emphasized that there are no clear distinctions between the phrases, "to listen," "to hear," and "to be understood." There is no specific English word that describes adequately the quality of listening the participants wanted. I have selected the word, "to hear," to represent the process of taking in or absorbing, not only the explicit meaning of the individuals' words, but also taking in the meanings embedded in the manner, feelings, and body language of the verbal delivery. Moreover, various permutations of the verb, "to hear," arose naturally in the participants' narratives and as such, "to hear" reflected their habitual, ready-to-hand language.

The participants frequently told stories expressing their frustration when providers or caregivers exhibited poor listening skills and did not grasp the depth of their words. Throughout the narratives, the data revealed that the participants wanted to be heard not only on literal or concrete levels, but they also wanted to be heard on the more symbolic or metaphorical levels, and sometimes even on a deeper level. In some instances, the participants wanted their deepest essence or existential meanings to be heard and to be understood. As I worked with the transcripts, the importance of listening to the layers of literal, symbolic, and existential meanings emerged consistently. Over and over again, the stories revealed how the participants wanted and may have even needed to have these layers of meaning heard and understood by their providers and caregivers.

The more symbolic or metaphorical meanings arose most frequently as they spoke of their feelings of suffering. In these instances, the metaphorical meanings served to illustrate the participants' more complex concerns. The actual words the participants used certainly held clear literal meanings, yet within the symbolic context, the words were used metaphorically to indicate deeper layers of meaning.

This may be delineated by examining the multiple meanings that may be derived from the simple phrase, "I want to go home." In the most literal context, this phrase indicates that the speaker wants to return to the literal or physical home which may be associated with a specific geographical location; however, this phrase may be also used to describe the desire for protection and safety conveyed by the more symbolic interpretation of the word, "home." Thus, the symbolic meanings may be representative of the feelings or experiences embedded within the broader, metaphorical definitions of words and by the context in which that word is used.

Existential meanings are more difficult to define. The myriad philosophical schools of existentialism are noted for wide variation in definition and application. Due to this diversity of definition, I have elected to describe existential meanings as those meanings related to the sense of being alive, or to the ontological experience. As such, I am defining existential meanings as the meanings that arise out of the experience of being within the speaker's specific and contextually driven circumstances. While this may appear similar to the definition of symbolic meaning, if we look again to the example of "I want to go home," it may be possible to recognize how the symbolic and existential meanings are differentiated. Given this example, the existential interpretation may be the desire to feel at home within one's own beingness (or *Dasein*) or within the speaker's sense of authenticity. Thus, within this context, existential meanings are associated with the speaker's ontological concerns and connected to the experience of being alive. In contrast, the symbolic or metaphorical meaning may refer to the sense of at-home-ness in the environment.

Throughout the narrative accounts, the participants told stories of Not Being Heard on literal, symbolic, and existential levels. Moreover, this theme was peppered throughout the varieties of situations that gave rise to suffering. Some participants told stories of times when their physicians and nurses ignored the words they used to describe physical pain; other participants told stories of lost time or instances in which curative treatments were postponed because doctors would not return telephone calls; still other participants told of being insulted or ignored by their providers or caregivers.

The Suffering of Unattended Pain

One of the more dramatic examples emerged from the narrative accounts of a participant that I have identified as Jack. He had been diagnosed with lymphoma early in 1998 and had been treated many times with varying trials of chemotherapy. At the time of his last hospitalization, he began to experience both increasing difficulty with his memory, as well as experiencing extreme physical pain. He described the pain as follows:

> "[The pain] was right here on my lateral thigh. During WWII, I was a welder and a burner and we used to take a hot torch and put gas in it and you'd heat up the piece of metal you were going to cut and got it hotter and hotter and hotter. Pretty soon, you'd hit the oxygen and just cut a big hole through it. And that's just exactly what it felt was happening to my thigh. And [it felt as if] they'd put that down and then take a ball bat and just beat the tar out of it."

He told me that he had repeatedly tried to "get the neuro guys" to understand him; however, although he used similar language as found in the above captioned excerpt, he told of how his doctors did not understand him. He tried to explain the severity of the pain to his physicians, yet while he repeatedly requested an increase in pain medication to cover the pain, he did not receive enough morphine to relieve it. Jack told me that he struggled for more than 48 hours with excruciating pain that remained untreated. He continually told his physicians that the pain was so severe that "there's going to be a 'no show' here if something isn't done." Even with his thinly veiled threat of suicide, the physicians did not change his medication. According to Jack, the doctors increased the dosage of pain medications only when they received the results from his lumbar puncture that revealed extensive malignancies circulating in his spinal fluid. Jack told me that it was as if the physicians required a specific, documented reason to prove the severity of pain before they increased the pain medication. In Jack's view, the physicians did not adjust the medications based on his spoken words, but only increased the medication when they had a physiological reason to explain the severity of his pain. In this instance, the pain was clearly the stimulus for the suffering, but when Jack tried to communicate and was not heard, he suffered. It was the experience of Not Being Heard that amplified his pain so that he suffered both physically and emotionally.

Almost as a result of Not Being Heard, he began to doubt his own experience. He spoke of how he began to question whether he even "deserved" pain medication. The following are two excerpts from his transcript in which he expresses his frustration over his unsuccessful attempts to communicate with his medical team.

> "Maybe I didn't get through to them what I needed? Because I'll tell you, I would go out and beg and plead and say, 'Look guys. I just can't……I can't handle this. Something got to give. And then they finally started listening, but then maybe I didn't make it clear. I don't know, but getting the issues before them. Like 'Look, do you guys understand what I'm telling you? This is excruciating. And something's going to blow apart here.' And I see that there's an area in human understanding that unless you get the person's attention and say, 'Do you hear me? Do you understand what I'm saying? Do you know what's going on? Are you listening? Do you follow me? Do you have any questions?' "
>
> "I went round and round and round with my own self asking what am I not getting? Why are they not seeing what I'm trying to tell them? Am I over playing it? Am I asking for sympathy? Do I want something that I'm not entitled to? You start asking yourself 'Am I sincere? Am I honest? Am I real in this?' Darn tootin' right I am!"

In this example, it may be possible to see how Not Being Heard was experienced on the literal level and was also experienced on the existential level. The literal and most obvious level was that of Jack's physical experience of intense pain. However, as his descriptions of the pain were Not Heard, his words of anguish reflected an existential dimension. As illustrated by the excerpts, the pain was so severe and the experience of Not Being Heard so intense that he spoke of how he began to doubt his honesty and integrity and even began to doubt his own lived experience. In this way, Jack began to question his deeper sense of being within his experience of pain. His literal experience of physical pain negatively influenced his ontological experience (or *Dasein*) as evidenced by his suicidal ideation. If we return to the idea that suffering can only be interpreted through the ontology of the experience, it may be possible to understand how Jack's experience of suffering may have carried existential or ontological implications.

Although the physicians did not act or respond when Jack described his pain as excruciating, he continually tried to comprehend their position and tried to find reasons to explain their lack of understanding. Instead of blaming them for not listening, he tried to find some reason to explain why he was Not Being Heard.

> "They aren't trying to disregard me. I'm sure of that. At least, I don't feel that the physicians I have are .... Because when I say, 'Do you understand me? Do you know what I'm driving at?' They say, 'I think so, Jack.' But.....that hurts. You know you're not trying to pull the wool over their eyes. You're not trying to get something for nothing. You're trying to be as honest, as forthright and reflect the situation as I see it......You know you're sincere. And you're honest and you want to be understood..... But this is beyond me."

Yet, he could not tolerate the idea that he was being tacitly disregarded. He tried continually to find other reasons to explain why the physicians did not act on his pleas for pain medication. Jack clearly articulated his anguish when he could not find a reason to explain the physicians' behavior.

> "I don't think anybody, if they really could understand where an honest individual is coming from, would want to be purposely misunderstood......If the person rejecting him realizes that he's rejecting him, and I don't think they always do. I just can't hardly believe that. To me that's rotten. That he would do that because the anguish is so absolute, so dreadful. You know the guy isn't going to take it. There's no way he can continue to put up with rejection. And it's maybe just my [fault] ....I don't think that anybody wants to be sincerely turned down. Someone would do almost anything for somebody that's truly hurting and that's truly getting across what they are trying to preach."

This episode becomes even more dramatic when one considers that Jack had been a family practice physician for over 50 years. He spoke naturally the same ready-to-hand language as his medical team and tried to interact in ways he felt they would understand.

However, he stated that his physicians still did not hear his words. I asked him about his experience in light of his own medical school training and particularly in terms of the older medical standard that if pain medicine is prescribed before the diagnosis is made, the medication will mask symptoms and complicate the pending diagnosis. In response to this question, he began to cry and said:

> "That may have gone on for the first twenty years, but I now believe the patient ……Who in medicine hasn't had a person try to take them for all the narcotics they can get? And we're all aware of that all the time. But finally, we've got our head out from under the pillow and saw the fact that when patients are really hurting, they're really hurting. And I believe that. And maybe I'm gullible and don't know what's straight up from straight down, but ….my basic honesty has now slid from the doctor to the patient."

It is not surprising that Not Being Heard may have intensified Jack's suffering. The importance of compassionate and active listening is well documented in the literature (Byock, 1994; 1997; Frank, 1995; Gregory, 1994; Lerner, 1998; Rogers & Stevens, 1967). It is also well substantiated that listening and acting on the patients' reports of pain are fundamental to good medical and nursing care (AHCPR, 1994; Bascom & Tolle, 1995; Emanuel, 1996; Ferrell, Rhiner, Cohen, & Grant, 1991; Gregory, 1994; McCaffrey & Beebe, 1989). Yet Jack perceived that his medical team was not practicing these principles.

His story revealed that he did not receive the current standard for pain assessment and intervention that urges physicians to medicate on the basis of the patients' descriptions of the pain, not on the clinicians' beliefs regarding the patients' experience (AHCPR, 1994; Bascom, Tolle, & Cassel, 1996; Emanuel, 1996; Ferrell, et al, 1991; McCaffrey & Beebe, 1989). In Jack's narrative account, he believed the quality and depth of physician listening was ineffective and as a result, Not Being Heard may have fueled the anguish that arose from his unrelieved physical pain.

The reason behind Jack's experience of Not Being Heard may be due to the increasing pressures on health care providers to care for more and more patients in shorter and shorter periods of time. It may be due to lack of training or may be due to the physicians' lack of experience with strong opiates. It may be that the current scarcity of healthcare resources may explain this theme. While the literature supports the need for active and careful listening (Byock, 1994; Ersek & Ferrel, 1994; Frank, 1995; Kleinman, 1988; Moustakas, 1961), in conjunction with prompt and aggressive titration of pain medications (AHCPR, 1994; Byock, 1994; Emanuel, 1996; Ferrell, Rhiner, Cohen, & Grant, 1991), Jack reported that he continued to not be heard and his pain medications remained unchanged. Given Jack's carefully chosen and descriptive words, the reader may be able to understand the depth and severity of his pain; however, he felt that his spoken words fell on deaf ears.

Jack's account was one of the more dramatic examples of Not Being Heard. One may hope that this was an isolated case in the narrative; however, all study participants told similar stories. Nearly all participants told stories of times when their words were not heard and their literal, symbolic, and even existential needs remained unmet.

Symbolic Meanings of Suffering

Bill had been diagnosed with lung cancer early in 1999. At the time of the interviews in May of 1999, his doctors had just discovered widespread lung metastasis throughout his body including to his liver, colon, and abdomen. Simultaneously, his wife was diagnosed with Alzheimer's disease within hours of hearing of Bill's poor prognosis.

As expected, he was quite emotional and concerned about his own impending and possibly painful death, but was more concerned about making plans for his wife's care after he died. His children did not live in the area and he was struggling to communicate with them about what his wife would need in the future. As a result of these worries, he said he quickly became depressed and started to have difficulty sleeping. He told the nurses at the care facility that when he had had difficulty sleeping at other times during his life, he took Benedryl with good results. He then told of how the nursing staff disagreed with his explanation and his proposed treatment of the insomnia. He said they attributed his sleeping difficulties to his coffee intake. As a result of this interpretation, the nurses discontinued his coffee with his meals and refused to allow him coffee at any other time.

Coffee may be viewed as a simple beverage that should be relatively unimportant to the quality of an individual's life, yet in Bill's case, coffee carried symbolic meanings. He told me that savoring his coffee after meals was one of the more enjoyable parts of his day. By denying him coffee, he felt he was denied one of the few things he could still enjoy as his body was rapidly deteriorating. Moreover, he told me that he began drinking coffee shortly after he entered the Army during World War II in 1942 and as a result, coffee became associated with adult activities and responsibilities. In Bill's view, the nurses' denial of his request for coffee with meals became symbolic of the losses he had experienced as his body was being destroyed by cancer. He frequently stated that he felt the nurses were treating him as an "unruly or naughty child" when he asked for coffee with his meals. These words may be interpreted that when he was "treated as a child," he may have felt his autonomy threatened. As a result of the nurses' decision to discontinue his coffee, Bill told me that he felt angry and frustrated.

Bill was understandably upset over the nurses' unilateral decision and firmly told them that he was dying and he would continue to receive coffee with his meals. He told me that he believed the nurses had interpreted his firm words as evidence of psychological disturbance. This position was confirmed when the nurses asked Bill's physician for a psychiatric referral. The accusation of psychological problems, again understandably, upset Bill further. Our second interview occurred a few hours after his visit with the psychiatrist. He was able to talk with me for only a few minutes before he became visibly upset and developed hiccups. When this occurred, he asked that I turn the tape recorder off. When the recording stopped, he told me candidly that he continued to have difficulty with the staff and when he became upset, he would develop severe hiccups. Throughout my interviews with him, his level of upset and hiccups made long interviews impossible. As a result, his transcribed narrative accounts are limited. However, I made extensive field notes immediately after each interview ended. Shortly after our last interview, Bill was transferred to another facility where he died.

I was able to discuss his case with the director of the original facility and was able to learn the outcome of Bill's care. According to the director, Bill started to have severe pain as he moved closer to death. Like Jack, she told me that he would tell his nurses that his pain was 10/10 on a 1-10 scale and describe the pain as "excruciating, awful, terrible, unbearable." While these words were noted in the chart, the nurses also reported that they "didn't think he was in pain" or that "he didn't look like he was in pain." His doctor had written PRN orders rather than applying the current standard of around-the-clock dosing of pain medications (AHCPR, 1994; Emanuel, 1996) and the nurses did not give adequate amounts of the PRN medications when Bill requested it. The director of the facility stated she was very upset about the situation because she had been unaware of the severity of the problem until the family elected to move him to another facility for comfort care.

Again, like Jack, the physical pain may have been the stimulus to suffering, but Not Being Heard made the situation untenable. According to both Jack and Bill, they stated that they had told the doctors and nurses of their anguish and suffering, but they felt their voices were ineffective. While the medical and nursing literature frequently combines "pain and suffering" as a single entity, through these two narrative accounts, one can readily see that the suffering aspect of the experience may have been more closely related to poor listening and to the physicians' and nurses' limited understanding than to the quantifiable degree of pain. The pain may have been the initial focus of suffering, but being ignored, rejected, and receiving inadequate pain management were the critical elements that amplified the intensity of suffering.

Both Jack and Bill experienced layers of suffering when their words and meanings were not heard. The most obvious, literal layer was their poor pain management, yet the symbolic and existential suffering may have been equally as severe as their physical pain. Again, the participants clearly experienced suffering on the literal or physical level, but more importantly, Not Being Heard amplified their suffering on symbolic and existential levels.

Silenced by Fear of Recrimination

Another participant told of similar experiences. Edith was a 67 year old woman with lymphoma and metastatic disease to her shoulder and the muscles in the surrounding area. As she told me about her personal life history during our first interview, she told stories filled with instances in which her feelings and needs were disregarded or denied by her family. She repeatedly told stories of times when her family and her community did not listen to her words. As a result, she stated that she did not expect the nurses and other caregivers to listen to her voice. Thus, it did not surprise her when her voice was an ineffective means of getting her needs met. However, during her first few nights in the care facility, she came to quickly understand that not only would her voice not be heard, but she also found that she should not believe her caregivers' words.

> "They keep telling me that I can ring for anything that I want. Or needed or wanted or whatever. The night before last, I decided it was time for ice water. Just ice water. And it was late. It was the night shift on, I think. Things had quieted down. It must have been after 10:00 because the lights were off. And I decided I'd like some ice water and I rang and the gal came in and I told her what I wanted and she said, 'Is that all you wanted? Is that all you called me down here for?' Now, I assumed that she had just gone off from one 12 hour shift and was doing another one. And she was tired. So I let it ride. I saw [she was tired] instantly and I apologized. I said, 'I'm sorry. I won't call anymore.' "

She spoke of how this experience caused her to be hesitant to call again for help when she needed it. She said she had learned quickly that asking for help could be futile, but more importantly, she told me that she was afraid that asking for help might lead to potential recrimination from the staff. While she did not interpret the above episode as an example of recrimination, she did tell me that this instance had "proven" that she should not call when certain nurses and aides were on duty. She said she had consciously decided that she would avoid problems rather than risk recriminations.

She did not wish to ask for special help or to risk anything that might "get her in trouble." For example, she was allowed to have a shower just once a week. She felt that this was for the staff's convenience because the shower had to be closed to male residents during the time she would take her shower. Edith told me that she felt it was probably too much trouble for the staff to make this special arrangement. When I asked her if taking a shower once a week was adequate, she spoke the following:

> "……but I only get to [shower] once a week…….I only get to go in once a week. I don't like that too well. Because I like a shower. With a shower, you don't get clean just once a week……. Well, I would like my shower every day, or every other day at the very least. But, the facilities aren't such that I can do that."

When I suggested that we explore other bathing options with the staff, Edith immediately declined the offer. Again, she reiterated her concern regarding recrimination from the staff or even other residents. Although I told her that I would try to discuss the situation diplomatically, she was still hesitant to give me permission. When I asked for further clarification on this, she responded:

> "Oh, because different people react differently to people nudging them. And some of that may reflect on their treatment of me….."

We continued to discuss the possibility of working with the staff and the facility's administration to come to a creative solution to the showering dilemma, and throughout the discussion, she maintained her position that asking for what she wanted might lead to recrimination. In fact, she only agreed to my offer to intervene after she had my assurance of a "gentle" approach.

> "[Speak to them] gently. Very gently. Because I don't want that to reflect back on me. That's the only thing that I'm afraid of….. Because I'm an old person …… But maybe the [staff and residents] are saying, 'What's she doing around here?' "

During her stay at the facility, she told me that she had come to clearly "know" that the words of the staff should not be trusted. This was driven home during a painful, diagnostic procedure. Edith had been told by her physician's nurse that the procedure could be painful and that the nurse had sent specific orders for the diagnostic technician to call the nurse prior to beginning the procedure. The nurse assured Edith that she would come to be with her and make sure she was medicated for anxiety or pain. Edith told me that the staff had not followed the nurse's orders. Because she felt using her voice was futile, she did not ask for help at the time of the procedure. She remained silent.

> "This was the second time I went through this and the first time, it wasn't too bad because I was reasonably calm. I had just had some medication, pain medication or something so I wasn't hurting bad. So I was pretty calm. But this time. No medication. Nothing ahead of time. They kept saying, 'You're doing fine. You're doing fine.' And I was practically in tears, in hysterics and they just ....I had to force myself to control myself and at some point, they were supposed to call the nurse. And [the nurse had said] she would come down and help me through it. And she said that I could stop at any time I wanted to. But I didn't really want to because then I'd have to go through it all again. So I didn't exactly grit my teeth because I would have broken them."

> "No. They didn't call her. I didn't ask them, but she had given them orders to call her. Period. They were used to handling macho men, I guess, and I didn't care if it was macho or not. It hurt. It hurt. And I didn't feel good."

Repeatedly, Edith spoke of her concern over bothering the staff with her needs and how she remained hesitant to talk with them about her preferences. She told me that she "somehow felt safer" being silent. However, she also spoke of how lonely she felt living at the facility. Loneliness had been a recurrent problem throughout her life and it was surfacing again as she was treated for cancer. She spoke of how she tried to avoid feeling lonely by compartmentalizing her feelings.

> "Well, I don't hide it. I used to push it away and try not to think about it. I don't like to think about it. Because I've got no need to. But it's in a compartment. It's not hiding behind anything. It's right there. I know right where it is and I know what it is. And I don't much care about it anymore."

She went on to describe how the combination of having and being treated for cancer in conjunction with being at the facility was difficult. When asked directly to describe her greatest struggle with cancer, she replied:

> "Surviving this being here. Not being able to do what I want to do. Getting on with my life. Whatever's left of it."

In Jack's, Bill's, and Edith's accounts, the experience of suffering and of Not Being Heard were characterized by layers of meanings. Jack spoke of his frustration, anguish, and of feeling rejected by his physicians. Bill told of feeling angry at being treated as "a child" by the nurses' decision to discontinue his requests for coffee in addition to the poor management of his pain. Edith told of her feelings of loneliness and fear of recriminations that arose from the staff's inability to hear and honor her sense of vulnerability. Thus, these accounts support the position that the suffering of Not Being Heard may carry layers of negative implications.

As I continued to search for additional participants, I began to question if patients with other diseases had similar stories of Not Being Heard. I included two patients with severe congestive heart failure as a contrast diagnosis to see if there were disease related differences. While some of the dimensions of suffering were different among the participants with congestive heart failure (CHF), I did not find disease specific differences concerning the issue of Not Being Heard. The participants with the contrast diagnosis also spoke to the many layers of suffering that arose as a function of the experience of Not Being Heard.

The Hopelessness of Not Being Heard

Elaine was diagnosed with congestive heart failure approximately 20+ years prior to our interview. She had had a pacemaker placed four weeks before our time together and she reported that she did not feel she was recovering well from the surgery. Even after the placement, she continued to have angina and radiating arm pain, in addition to severe pain at the pacemaker site. Concurrent with her difficulties recovering from the pacemaker placement, she also had trouble tolerating her new heart medications due to concomitant problems with her gastrointestinal system. At the time of the interview, she was openly discouraged and depressed. Her husband, Steven, who was also interviewed regarding his own heart condition, spoke of her hopelessness.

> "She's so tired she can't fight back. She's reaching the point where she's not going to fight back ...... there's a place where you feel that it's like diving into the snow. It's just like...I've had it. I'll fall asleep or something. It makes you want to fall asleep in the snow. Then nothing more."
>
> "She needs mental support even more than the physical support. Because she's lost total confidence in the process. There is [little] respect and confidence left in her toward the doctor. It's not 100%. It's not 80%. It's probably only 30%."

Steven went on to discuss his concern about Elaine's hopelessness and the times she expressed suicidal ideation.

> "She's reaching the point where she's practically suicidal. That's it. There's no hope. I see no hope. The situation is so bad that I see no hope...... And I'm standing by and saying, 'Please don't.......please don't....' Not directly, but this is what I'm trying to do. But on the other hand, I'm suffering from depression as a result. So it's the domino effect........ It is not only disturbing for the patient, but it's disturbing to the whole family. The direct environment of the patient suffers as a result."

Elaine spoke plainly of her concerns should her health become worse in the future. She stated that she did not worry about the process of dying, nor did she express words that could be interpreted as indicative of fear of death; however, she was very fearful of becoming a burden on Steven or if she became cognitively impaired as the result of a stroke or myocardial infarction. If she became a burden or became cognitively impaired, she felt her suffering would become unbearable.

> "Of course, in the case of ..... oh .... let's say, of a heart attack or stroke, the consequences can be very bad if you're left half paralyzed. But if you die, to me, that is really nothing. You die. It's nothing. So when I feel really bad, I think, just endure, but often I say, I may go? So don't worry about it. The only thing I worry about is if I lose my brain. Or if I really become a burden to him. If I can't walk or am paralyzed, or ....this would be the thing that would bother me more than anything else."

In response to her words, Steven was able to clarify how her fears of the future amplified her sense of hopelessness and drew the connection between suffering and loneliness.

> "When a patient finally reaches a point who says, 'Oh, you know, I'd rather die then.' And right there. That explains the whole situation. For when the patient reaches the point where it .... You just heard it [from Elaine's comments]: 'I don't want to be a cripple. I don't want to be .....[a burden].' We are now talking about suicide. I'm sorry, but death is beautiful. I don't want this Goddamn life! You know, I've had it. So you see the loneliness of the patient within the medical frame? How lonely is the person?"

In a private interview with Elaine, she spoke of her feelings of hopelessness and despair and how these feelings made her frequently lose her will to live.

> "It's like .....it's sort of an impotency, really. You have plans, you have dreams, but even those have died. Just by being continually rejected by illness or pain. It's like a barrier. But it's frustrating. It makes you feel twice as old....There are no big vistas anymore. No plans, no dreams, no reason to be alive, really. And then one [spouse] drags the other [spouse] down. I mean, either depression or sadness

> or anger, even. I think it's worse than the discomfort itself. Worse than the pain. Worse than ….. my tummy. That is the worst part."

I asked Elaine to tell me more about what might be the source of her hopelessness. She immediately spoke of her frustration and anger with her cardiologist.

> "Well, I'm angry about the medical situation and that doctor. Who is probably totally unaware how discouraged I am. He's the strangest person. And I have the feeling that he is really very bright and he knows his stuff, but he should have been in a lab. In research or writing books. But not with patients."

In this excerpt, she implied that her cardiologist did not hear or understand the depth of her discouragement. She spoke of being angry that he did not have the ability to understand how congestive heart failure had changed her life and how it had altered her perspective.

In Elaine's words, the worst suffering was not the pain and physical manifestations of congestive heart failure, but rather, her words indicated that the existential loneliness and hopelessness were harder for her to bear. She went on to tell me an experience she had had with another cardiologist who denied not only her experience, but denied her diagnosis.

Several years before, she had contacted a new cardiologist for a second opinion. As she told her story, she spoke of her high hopes when she made the appointment. She said she hoped that she would finally get an accurate diagnosis and expressed her hope that the cardiologist might offer effective treatment. As she continued her story, she told of how upset she was when this new cardiologist told her that not only did she not have CHF, but he denied her experience with her own body.

> "I thought that [doctor] was a man I could trust. He examined me and he said, 'There's nothing wrong that a good gall bladder operation won't cure.' That guy brushed me off. I was so embarrassed. I said I must be a real hypochondriac. Telling him my problems and he says there's nothing wrong with my heart! It was so embarrassing! All those years! I mean, it had been a good 8-9 years by then. So why did I feel so bad? And being from [a research facility], I thought, now they're going to have a treatment that's really going to be effective. But you know [after being denied], you don't have the physical energy to fight whatever was wrong."

In this instance, Elaine spoke of how she felt embarrassment and possibly shame as a result of the doctor's words. While her response may be somewhat irregular given the reported conversation between them, her response may be representative of the depth of vulnerability she experienced and how her years of suffering may have rendered her powerless to question the physician's opinion. Thus, one of the more troubling dimensions of this theme may be how Not Being Heard may lead people to relinquish their personal power or to live with profound hopelessness.

With both Elaine and Steven, it is also important to note that they were from different cultures, with different languages, and had experienced different historical events. These cultural and social differences may have influenced their responses. Elaine was born and raised in Europe; Steven was also of European descent, but had been raised in Africa. In addition, they had both experienced the invasion of their native countries during World War II. Their differences in national heritage and life experiences may have influenced aspects of their stories, especially their feelings about physicians and healthcare professionals. Cultural factors may account for some of Elaine's sense of shame that arose when the doctor denied her disease; however, these cultural differences also provide natural heterogeneity to the study results. In particular, their diversity may offer insight into the possible interactions between Not Being Heard, vulnerability, hopelessness, and shame.

In addition, while Elaine's words indicated that she was Not Being Heard or understood by her physicians, it is possible that some of her difficulty may have arisen from her cultural expectations of physicians. It is possible that she may have addressed her doctors with a more deferential manner, or given that English was her second language, her ready-to-hand language may have been more timid. However, her stories did indicate that her physicians did not engage her in discussions to explore her physical and her emotional needs. Elaine and Steven also stated that her cardiologists and other physicians did not provide the emotional and educational support they needed. This lack is potentially of greater significance given her increasing hopelessness and suicidal ideation.

To further clarify Elaine's sense of embarrassment, it may be useful to reflect on Beebe's (1992) position, as detailed in Chapter 2. According to Beebe, shame is the most common indicator of violations to integrity and as such, may be a symptom of suffering. To illustrate, in the above captioned excerpt, Elaine relayed not only the words of the physician, but she told of her feelings of embarrassment and shame. As she told me about her feelings, I observed that her verbal intonation and manner were spoken with a degree of embarrassment and shame that may have been similar to her embarrassment at the time of the incident. In particular, she did not wish to elaborate on her feelings and moved quickly from this story to another. As I tried to delve into her feelings of shame, she became reluctant to expand on any of her feelings that arose from the embarrassing episode. This reluctance is reminiscent of Erikson's (1963) statement regarding the experience of being ashamed:

> "Shame supposes that one is completely exposed and conscious of being looked at: in one word, self-conscious .... He who is ashamed would like to force the world not to look at him, not to notice his exposure" (p. 252-253)

From these excerpts, it may be interpreted that Elaine's experience of suffering occurred on a deep, existential level. We can see from the above excerpts that Elaine spoke to the multiple layers of suffering that can arise from the longevity and severity of disease coupled with the absence of connection to physicians and caregivers. According to Steven, her experiences of embarrassment and Not Being Heard may have influenced her concomitant loss of interest in life and may have heightened her hopelessness. In addition, Elaine expressed interest in learning more about physician assisted suicide (PAS) which may be another indicator of hopelessness. She had read widely on this topic and was actively seeking information about the mechanics of PAS. When I asked if she felt that she would like to discuss PAS with her physician, she stated:

> "I haven't reached that point. But I would like to know if it should come to that eventually. You never know. It may not be because of my problem, you don't know what will happen ...... You know, it's like money in the bank. You don't touch it, but you know it's there if you need it."

Throughout the interviews, Elaine spoke of how her hopelessness and depression were significant aspects of her experience of suffering. In the hope of exploring how depression and hopelessness may have influenced her interpretation of Not Being Heard, I tried to probe deeper into these dimensions of her experience. Because she said that she had never been heard by her cardiologists or other doctors, Elaine initially looked quizzical and asked questions to clarify my meaning. I asked if she ever felt hopeless when her doctors did not listen to her words about her pain, discouragement, and depression. At this point, she brightened and stated that she better understood my question.

> "Well, if you're getting to the understanding of that person. More than just talking. I mean, like taking [PAS] as a desperate move. But if you cannot share your concern, you might as well talk to the wall."

In response to our discussion of PAS, she mentioned that while she would very much like to find someone with the ability to listen and understand, she had given up her search for such a person. Both Elaine and Steven stated that they believed psychiatrists and psychologists should be trained to hear and understand the patients' words and meanings; however, they had never personally experienced this depth of understanding. In a similar fashion in which Edith spoke of becoming silent in response to Not Being Heard, Elaine also became silent as a result of increasing vulnerability. Elaine's words indicated that she had believed that some clinicians, and particularly psychiatrists and psychologists, were more focused on changing her to fit the model rather than allowing her own beliefs to be heard and affirmed. When asked if she felt psychiatrists would listen and understand her feelings, she replied:

> "It seems that people go to a psychiatrist are being pushed back into the mold of the society. Like we're going to make you well – not to accept or understand or see what you feel, but to make you feel what is the proper thing to feel."

The hopelessness and isolation of Not Being Heard may be one of the more important findings from this study. Given Elaine's multiple references to physician assisted suicide, it may be wise to reflect again on the connection between PAS and suffering. While the findings from this study cannot fully explain the extent of this connection, the findings do emphasize the need for further analysis of the potential connections between the desire for suicide and the experience of suffering.

Making One's Voice Heard

Although all participants told stories of Not Being Heard, one participant was able to make herself heard. This participant's narrative accounts became a contrast case for this theme. Alice was an extraordinary woman who had lived through many tragedies and challenges. She was the mother of 12 children, widowed from her first husband and divorced from her second. In addition, she was a polio survivor and a survivor of malignant melanoma and ovarian cancer. During her on-going treatment for ovarian cancer, she developed congestive heart failure and was actively considering by-pass surgery at the time of our last interview. What was most striking about Alice's narrative accounts was that she, too, told stories of Not Being Heard by physicians and others, yet she found ways to make her voice and her needs heard. Throughout the interviews, she sustained a confident and open manner and told of times in which she confronted her providers and caregivers when they were not respectful or appropriate. Not surprisingly, she denied feelings of suffering although her history and current illnesses could be construed as strong antecedents to suffering.

The power of her voice was clearly illustrated when she told of her experience with a young physician who treated her for an infection.

> "I went to the doctor and he gave me a medication, an antibiotic of some kind. And within a few hours, I was itchy, all over……So I called him up and said, 'Is there a side effect to this drug that causes some kind of itching? It's not just mucous membranes, [the itching] seems to be very generalized.' And he said, 'No. But where are you itching?' When I said I was itching all over, but the [itching] inside of my vagina was terrible, he said, 'You need it scratched. You need a new boyfriend. You need to have sex.' I hit the ceiling and I said, 'Wait a minute. I

> think we are coming from different directions here and I don't like this at all' and I slammed the phone down. I looked at the [antibiotic's] brochure and read that one of the side effects was itching. So I called him back and said, 'If you will read the brochure that comes with this drug, it will tell you.....And I said, 'I don't need any crap about my lack of sex life.' He then said, 'I'll call something in.' I almost reported him, but I didn't' know who to report it to. But I felt that was extremely inappropriate."

In this excerpt, Alice responded immediately and effectively when she was insulted and embarrassed by an immature physician. She did not attempt to excuse the doctor's behavior by trying to understand it, nor did she try to find reasons why he might have made these comments, but rather, she confronted him directly. She told him that he had not done his homework and that his comments were unprofessional and rude. Thus, Alice found a way to bridge her experience of Not Being Heard with her own assertiveness and confidence. While it may be somewhat easier to act with assertiveness and confidence when responding to something so obviously inappropriate as this particular physician's words , Alice exhibited a consistently strong sense of self in other instances in which she was not heard by physicians or others.

Possibly because of her deep sense of self, she was able to overcome her feelings of Not Being Heard when faced with her provider's incompetence or insensitivity. The following account illustrates how Alice responded with confidence and assertiveness when her needs were Not Heard or were misunderstood.

> "I [told the doctor], 'I'm leaving in a week. I'm [moving] to Oregon a week from tomorrow. This was Friday. I need to know before then what is wrong. How quickly can the blood test be done and he said, 'Oh, it shouldn't take more than 2 hours.' So I called back in the afternoon and he hadn't heard anything. I called every single day. I had everything all set to leave on Saturday. On Friday, I got a frantic call from the nurse, 'Can you come in and see the doctor today?' And I said, 'I'm sorry, I'm leaving tomorrow. I am very busy. There's no way I can come in today and the doctor knew this. When did you get the results of the test?

> Why is it so important that I come in today to see the doctor?' 'He says he needs to see you.' I said, 'May I speak to him on the phone. Let him tell me what he thinks is wrong and what the test is showing.' The nurse said, 'He's too busy. He wants you to come in and see him.' And I said, 'I'm sorry. He has had all week. I don't know when he got the results, but I'm sure he had plenty of time to examine them. I assumed because he hadn't called that they didn't show anything. And then I said, 'Please. Put him on the phone and let him tell me what he suspects or what the test is showing.' The nurse said, 'He said he's busy and you should come in.' And I said, 'I'm sorry. Tell him I will go to a doctor when I get [to Oregon].' And when I got up here, [the ovarian cancer was diagnosed.] He should have taken the time to attend to his patients."

Alice's account provides a marked contrast to other participants who were not able to stand up to the physician's demeanor or words. Had she not forced the issue of the blood tests by calling the office every day, the doctor may not have seen or noticed the results until well after she had left the state. In this instance, she not only used her voice effectively, but understood the implications of the blood tests and acted on her own behalf. Based on her sense of concern for her health and the physician's "frantic" request to see her, she told of how she had a strong intuition that something was seriously wrong with her body. She contacted a new physician immediately after arriving in Oregon. Again, she told of being assertive and direct about her needs. She described how she told the new doctor the name of the tests done and detailed her symptoms in depth. Throughout her narratives, her sense of self and her confidence were powerful tools to make herself heard and to get her needs met.

While contrast cases are interesting in themselves, their importance is grounded in their potential to bring the meaning of themes into sharper focus. The study data reflect that the experience of suffering can be strongly and negatively exacerbated by providers and caregivers who are inattentive, overworked, or simply too busy or unable to listen to the words of their patients; however, the data from Alice's transcripts revealed that the suffering of Not Being Heard may be mitigated if the person acts with a strong sense of authority and assertiveness.

In contrast to Alice's response to her physician's insensitivity, Elaine did not respond to her doctors with confidence or assertiveness. During our second interview, Elaine told of having a mammogram at a local breast clinic. At the time of the interview, she was noticeably upset and told of feeling that the physician and staff were forcing her into having a breast biopsy.

> "I went there and saw a young doctor. Spoke to him – I'll be generous with the time. It wasn't 20 minutes, but let's say 20 minutes. It was more between 10 and 15. He made a diagnosis, which was easy, I suppose. And he said, 'You need a biopsy. So when can we do it for you?' 'Well,' I said, 'I want to think about it. It comes as such a surprise.' I said, 'I want to talk to my husband and….' And then he said, 'We can set up a date for you.' And I said, 'Well, I don't know.'….. Later, I [told my husband], 'Either I'm on a used car dealership lot or I have such cancerous tumors that it's an emergency to have these people insist like that!'

She went on to tell how the physician's nurse, receptionist, and even the billing representative continued to push her to schedule the breast biopsy. She stated that she felt so insulted and demeaned by the experience that she refused to return to the clinic for any reason. I contacted her recently as a follow-up to our last interview and she stated that she has decided to "forget about the biopsy" because the experience at the breast clinic had made her feel so uncomfortable. In this instance, Elaine's sense of shock and denial over the possibility of a breast tumor was not heard or understood by her physician, nor by his staff. Given the potential virulence of some breast tumors, her decision to "forget the biopsy" may have serious consequences for her in the future.

Based on the literature, shock and denial are well documented as common patient responses to news of cancer or other potentially serious diseases (Frank, 1995; Kubler-Ross, 1969; Valente, Saunders, & Cohen, 1994). Given the likely frequency with which a breast clinic may encounter patients who express varying degrees of denial and shock at the possibility of a malignant breast lump, it might be assumed that the physician and his staff should have reasonably understood Elaine's hesitancy to schedule the biopsy. Yet, because of Elaine's history of Not Being Heard and because of her sense of shame that arose in response to the cardiologist's words in the previous excerpt, it is possible that she may not pursue any further assessment or treatment of the suspicious breast lump.

Forever Changed by Disease

The process of learning to live with disease may include finding ways to make peace with being changed forever, both physically and emotionally. The participants often spoke of how they felt their lives were permanently changed by having cancer or heart disease. They stressed that after living with their disease they would never perceive the world or the future in the same way as before their diagnosis and they wanted their family members and friends to acknowledge and honor these changes. Throughout the narratives, the participants spoke of how they suffered when the people in their closest circles did not hear how they were permanently changed by their diseases.

> "People who have not had a life threatening illness, I would say the vast majority, could not simply understand that your life is forever changed. That when they say, things will get better and then just be the way they were. That is not going to happen."

This phenomenon is well substantiated in the literature (Becker, 1973; Byock, 1997; Frank, 1995; Frankl, 1963; Kahn & Steeves, 1995; Younger, 1995). Almost any serious and incurable disease has the potential to change a patient's perspective on the meaning of life and the sense of hope and the future. Accepting the changes associated with their serious illnesses coupled with understanding the future eventuality of death became an opportunity for some participants to see life anew. While they spoke of how they perceived that their lives had improved by focusing on living in the moment, they also told me that they had found it difficult to share their experiences with certain people. In fact, when they felt their experiences of living within an impermanent body were not heard or denied, they stated that that could become an experience of suffering.

> "[When someone says] 'You had the cancer. You had the surgery. Now the cancer is gone. You're finished. You're fixed. That's it. All done. And you never think the same way again. You can't look into the future with the same feeling. You don't perceive your body for sure. Depending on how many scars and where they are and that not allowing you to be where you are at that moment. Where you need to be. In your own process. To have that denied, it's almost for me, feels like what it must be to be on the brink of dying. That you are going to be stripped of your person."

> "Now when you talk about suffering, mostly it feels like to me what happens when someone denies what I am going through. Doesn't allow me or I think I am not allowed to say how I feel."

The existential meanings embedded in Not Being Heard were most notably found when the participants felt that their sense of self or integrity were denied. This existential layer was illustrated through Ruth's words regarding her feelings when people did not take the time to listen to her experience of living with cancer. She valued how her inner feelings and her deepened sense of integrity had changed by living with cancer and she felt that if her new self was not honored, she suffered

> "They don't honor who I am. They don't see me as myself, as an individual. They see me as either a patient, a pest, or whatever label the caregivers decide to apply to me."

> "What I am feeling for some of the women in my group whose husband absolutely deny that things are wrong. That things are not the way they were and are not going to be the way there where. Who cannot hear what their spouses need from them. Won't listen because that is giving up. That is giving in. That is being a whiner. Often a negative unhealthful thing one can hear. How that drains energy. How that drains the will to help you body fight in whatever way you can. If you are going through chemo or whatever you do. If I tell somebody that I have had cancer, they look at me and say, 'Gee. You look so healthy.' The last time that happened, I said, 'Yes, and I'll probably die looking healthy, too.'"

This sentiment was reiterated by other participants who suffered when their altered awareness and the deeper, more intimate aspects of their lives were denied or ignored. The natural corollary to this position may be that if the person's awareness is heard and honored, suffering may be relieved. This corollary was supported by several participants who stated that they believed maintaining themselves and their authenticity were essential tools to overcome suffering.

> "Not to stop working on trying to find out who and what I am just because I may die. Well, that's going to happen anyway. To try and learn it's okay to be my own strong advocate and to say what I need, what I need and what I want.
>
> "To be strong enough to get through it and still be yourself. To keep yourself through this kind of thing and come out being yourself."

Overcoming Suffering Through Integrity

As I worked with these excerpts, I began to perceive that the participants who had strong visions of themselves or had what appeared to be inviolable integrity were also the participants who were not as threatened when their words and meanings were not heard. Not surprisingly, Alice was one of these participants. When asked about her philosophy of life and how that may have mitigated her suffering, she spoke of her joy in being alive and how her philosophy of life led her to that joy. I became curious about what might have initiated this philosophical position and I asked if she had experienced cancer as a major event or even as "wake-up call" that may have "startled" her into this way of thinking. In response to this question, she spoke of how she had come to understand the nature of impermanence at a very early age and how this understanding enabled her to see the world in a different way.

> "I don't think I ever had a wake-up call in the sense you are speaking of because I have always been aware of the impermanence of life and of the beauty of it and appreciated it.....I feel like I have walked through a lot of things that might have taken someone else down, but I can handle them.....I don't know. I am not afraid of losing my life, but I do realize that we are only here for a certain period and we should live to our fullest."
>
> "I always had the feeling, if I die, I'll die. I will appreciate what I've got now and do the best I can. If I lose my life, I'll lose it."
>
> "I figured whatever God sends you, you accept. You do what you can. You live with it and you live above it and it's just another thing. It's there and you deal with it the best you can."

Alice perceived that it was through understanding the existential dimensions of her life that gave her the strength to respond assertively when her words were not heard by her physicians, nurses, or others. Other participants substantiated this position and stressed the importance of living each day and how they tried to pass that understanding on to their children. According to these participants, the most important part of being alive was to enjoy each moment and to recognize how their close relationships were precious because their very nature was transient.

> "I remember being told when you were having children, they were just borrowed. You take care of them, but they are borrowed and you are going to have to give them back some day."
>
> "This whole concept of treasuring the children, treasuring life was very valid and I thought to myself, you know, I have lived with this concept [of impermanence]

> without realizing it. The value of people, the value of life itself and the fact that you can lose it."

By understanding that life must be lived moment by moment, Alice and others found ways to focus on enjoying their lives rather than focusing only on the difficulties and discomforts of their disease.

> "[Without cancer] I would not have done [this interview or participated in support groups]. I do not think this would have ever happened if I would not have gone through the process of having cancer. And really understanding in my heart, what is the most important."
>
> "[The diagnosis of cancer was] almost the first time that I connected with who I was or could be. And it's a long process and sometimes I lose the sense of who I am. Especially going through cancer. I have done a lot of inner work in the breast cancer support group."

The medical, nursing, social work, and theological literature maintains that living with cancer may lead some individuals to find new meaning in being alive (Ersek & Ferrel, 1994; Frank, 1995; Lerner, 1998; Moustakas, 1961; Younger, 1995). This body of literature proposes that when people are confronted with serious diseases, such as cancer, they may come to appreciate their lives in deeper, and possibly more philosophical ways. Patients may realize that they must learn to be fully alive in the present moment because their future may be truncated early by illness.

This position is reminiscent of Christian contemplative and Eastern philosophical interpretations of the nature of impermanence (Becker, 1973; Easwaren, 1978; Epstein, 1995; James, Fox, 1991; Huston, 1958; 1982; Johnston, 1970; Merton, 1969; Suzuki, 1983). According to these interpretations, joy, happiness, and integrity result from understanding that anything of value has a finite character. Thus, impermanence becomes a powerful tool to understand joy. While this may appear to be a slightly foreign or theological position, the data from this study support the stance that understanding the nature of impermanence as a result of living with serious diseases may lead individuals to uncover deeper, more existential meanings within their lives. The process of searching for meaning is a powerful way for patients to try to relieve some forms of suffering and the narrative accounts from this study underscore this position. In this way, the participants may have found relief through being heard and honored for the deepened, philosophical changes.

Overcoming Isolation: Being With Their Love Ones

The data clearly show that Not Being Heard may be both an antecedent to suffering and may even increase existing antecedents. However, Not Being Heard may have additional implications. If we return again to Edith's and Elaine's excerpts, it may be possible to see that when these two participants were Not Heard, they spoke of their growing sense of isolation and loneliness. Although loneliness may have been a likely and expected outcome for these participants, Alice did not experience loneliness or isolation.

After her surgery for ovarian cancer, Alice was bedbound for several weeks after she returned home. She told of how she had always tried to be "in the thick of things" and how she felt isolated when she was confined to bed. Because her children were concerned about her need to be with them, they found ways to keep her fully involved in the family activities.

> "Not being with my family really bothered me. I wouldn't know what was cooking. 'Is that pea soup?' 'No, mother. It's not pea soup.' 'Oh, I thought I smelled pea soup.' I was so hungry for pea soup that finally one of my granddaughters came over and made me some. She had never made it before and it was wonderful. The children took turns taking care of me."

> "My daughter wheeled the bed out at an angle so I could see the kitchen. Right to the doorway. She couldn't pull it through and she said, 'I don't want you to get tired, but you lay there and watch me.' So I watched her as she was kneading the bread and working it on the counter and everything. Then making it into loaves. She was so proud when they came to pick [the bread] up. One of those kind of support things. These girls were willing to anything."

To understand how these excerpts are related to Not Being Heard and not merely an attempt to maintain control, it is necessary to reflect on how Alice's physical, emotional, and nurturing presence was an essential part of the context of her family. By being with her family in the daily tasks and chores of life, she was able to maintain her sense of herself and her role in her children's lives. Thus, being with her family gave her time to hear her children's fears and concerns and for them to listen to her. For Alice, being heard was not limited to just her spoken words, but being heard also involved finding ways to be with her children and to cherish and honor her deepest and most significant relationships. She summarized this position in the following statement.

> "My children are my inspiration. They help me a lot. They take me places where I am afraid to drive because [this city] is a mad house to drive in, but we do a lot of things together and I enjoy them."

As I continued working with the theme of Not Being Heard, I began to see that it held much more complexity and was woven into deeper and deeper layers of the participants' lives. Ruth echoed this complexity when she spoke of how being with her mother was essential part of being heard and how she was changed forever by her own experience of cancer and by being with her dying mother.

Ruth spoke poignantly of how being with her mother as she died enhanced her ability to overcome her isolation and alienation. She felt that being with her mother during the last few weeks of her life lead her to understand her own life and her cancer in a special way. In particular, she stated that being with and being open to the experience became an extraordinary turning point in her life.

> "My mother and I decided it would be best for her to leave the hospital and come here. I learned so very much and I learned it in a part of me that always...that part that I'm kind of tempted to say 'I can't do this because I'm going to throw up' or 'I can't do this because it makes me nervous.' But my mom made it easy for me. She never demanded. She never....she was very graceful in this whole process......And it felt so all right even though I was sad and I was so tired. I was open to whatever was going to happen and I don't think I ever trusted anything like that before that."
>
> "There was something so very special that my mom allowed what she did in her care and then allowed me to be there. That was a tremendous turning point for me."

Not only did being with their loved ones give the participants an opportunity to be heard and to listen to the people who were most important to them, but being with loved ones may have also enhanced the participants' sense of self and integrity. In this way, by being with and being heard by their closest family members, Alice and Ruth found new strength and deepened their authentic connections to the people they loved most.

Not Being Heard as a Threat to Integrity

The theme of Not Being Heard was strongly evident in all interviews. In order to deepen our understanding of how Not Being Heard relates to the experience of suffering, we must return again to the stated definition of suffering as a threat to integrity. Integrity has been defined as the sense of wholeness, soundness, honesty, authenticity, and may be experienced at the deepest human core. Given the excerpts in which the participants spoke of their physical pain, isolation, hopelessness, and depression, and particularly their words describing the existential dimensions of their lives, it may be quite plain how a person's sense of integrity, or self, soul, or spirit can be violated if the caregivers or providers do not hear or understand the layers of meanings embedded in the sufferers' experience. As such, Not Being Heard becomes pivotal to understanding the experience of suffering as a violation to integrity.

In Jack's case, he tried to get his physicians to understand the degree of physical pain he was experiencing; however, when they did not understand and respond to his pleas for help, he began to question his own honesty and his experience. He began to doubt his integrity and even came to question whether he deserved pain medication. This example illustrates how the suffering of Not Being Heard may have manifested as a threat to Jack's deepest sense of existence and integrity.

Bill also experienced threats to his integrity on literal and symbolic levels. He, too, did not receive enough pain medications to relieve the pain of metastatic cancer. While the pain was assessed by the nurses, the pain protocols did not meet the current medical guidelines. Moreover, the physicians and nurses did not address or evaluate the efficacy of their interventions. In addition, he experienced an even deeper threat to integrity on a more symbolic level when his nurses discontinued his coffee. In both these instances, Jack and Bill experienced the threat to integrity through its violation.

Yet, contrast cases may provide another view of integrity. If we recall Grudin's (1982) work on integrity, we may interpret Alice's response to Not Being Heard as an example of integrity defined as the "persistence of spirit" and "self-sufficiency." It is significant that while Alice may have had ample cause for suffering, she did not describe herself as suffering. If we define integrity using Grudin's framework, integrity becomes the sense of self or the deepest human essence. Within this interpretation, Alice's sense of integrity, as evidenced by her narrative accounts, seemed so impenetrable that she was able to overcome threats to integrity that could have led other individuals to experience profound suffering. Conversely, for Elaine, she did not trust herself or her experience enough to act from the strength of her integrity and respond with confidence when physicians did not listen to her words of hopelessness and despair or when she felt pushed to do something before she was ready, as in the example of her treatment at the breast clinic. Not surprisingly, Elaine did describe herself as suffering with congestive heart failure.

Hearing Words, Hearing Integrity

If we assume that words are one of the few ways we have to communicate the parameters of our feelings, our symptoms, ourselves, or our integrity, then words become the predominant way to communicate the directions and dimensions of the perceived threats. Simply stated, if the person's words are not heard and not understood, the suffering cannot be addressed. These excerpts indicate that it may not have been possible to ameliorate suffering when the participants were not heard, and in fact, the participants' suffering may have even increased when their attempts to communicate were impeded. This position is reminiscent of Younger's (1995) description of suffering as a process of alienation. In her theoretical paper, she states that suffering involves

> "the loss of community and the sense of connectedness. In fact, it is in suffering that the realization of one's aloneness becomes most acute. First, suffering alienates the sufferer from himself or herself. Then, it alienates the suffer from others." (p.53).

As I examined the transcripts, I began to see that Not Being Heard almost kindled a cycle of alienation that stemmed from the underlying antecedents, such as physical pain, and was then driven by the distress of Not Being Heard. Therefore, if we do not attend to the sufferer's words and meanings, it may not be possible to overcome the isolation and alienation of suffering. In fact, it may be that the alienation of Not Being Heard is the most a potent form of suffering. Ruth provided a concise summary of this position:

> "Now when you talk about suffering, mostly it feels like to me what happens when someone denies what I am going through. Doesn't allow me or I think I am not allowed to say how I feel. When a doctor would stand there and say something and when I would ask a question or verbalize anything. A lid would go down, almost an inner eyelid, and you would see they disconnected."
>
> "Anything, anytime I'm not heard is, to me, a time of suffering. It can be as simple as going in and knowing that I am going to have an IV put in and tell the nurse that this area might not work so easily ....Then they punch through 2 or 3 times and they can't get it. That to me, is suffering. That not being heard. If I could kind of cook down or whatever the term might be....come to the smallest denominator. That not being heard is the worst thing that can happen to me."

Thus, to address the issue of Not Being Heard, providers and caregivers must find ways to deepen their listening and understanding to match the layers of meaning in the sufferer's words. Listening cannot be limited to just the literal meanings of the spoken words, but the listener must hear and honor the deeper dimensions woven into the words, the body language, the emotions of the delivery, in addition to the layers of meaning embedded in those words.

Again, it is important to reflect on the definition of integrity. Within this context, integrity is the sense of being fully intact, whole, complete and may encompass a sense of "focused delight," confidence, and self. Integrity then becomes the deepest core of human experience. Given the narrative accounts of Not Being Heard, the participants tried to use words to describe their pain, feelings of insult, rejection, and embarrassment as a way to speak to the violations to their deepest cores. Yet, they felt their words were largely ignored and disregarded. Based on this theme, we must return to the basic fundamental precepts of compassion if we are to find ways to alleviate the suffering of terminally ill patients. Given the results of this study, the first precept of compassion must be grounded in the principles of listening and absorbing the meanings, feelings, and intentions of the speaker.

Secondary Thematic Patterns

Two additional, strong secondary themes were uncovered from the data. Not every participant spoke to these secondary thematic pattern and as a result, these patterns could not be classified as primary themes. Although not every participant spoke of these secondary themes, when the participants who did speak to them, they expressed deep emotions as revealed through their intonation, body language, and verbal delivery. Thus, the frequency and the emotional content contained within these themes are indicative of their potential to illustrate other aspects of suffering.

The first of the secondary themes emerged as a pattern of Making Plans for Life Without Me. As expected, many layers of meaning were uncovered within this pattern and will be explicated in the following pages. The second secondary theme that emerged was Searching for Understanding. While the most literal level of meaning found within this secondary theme was certainly the desire to acquire accurate information about the participants' diseases, the data reveal multiple layers of complexity embedded in this theme.

Making Plans for Life Without Me

The most emotionally laden of the secondary themes was strongly related to the participants' concern for their families' and friends' future health and welfare. This pattern was significant both in terms of its frequency and its temporal location in the interviews. During the interview process, the participants often spoke immediately of how they were making specific, detailed plans to assure that their loved ones would be well cared for in the event of their future death. Based on my reflections of this finding, I began to see evidence that the participants' responsibilities and affection for their families and friends were at the root of this theme. In nearly all the narrative accounts, the participants' concerns for their children, families, and friends were of deeper significance than the participants' experiences of physical pain or other physical manifestations of the disease. While the physical experiences of cancer and congestive heart failure are often cited as the principal antecedents to suffering, planning for their loved one's future may have been of more pressing and immediate concern.

These concerns were found in a variety of instances including planning for the physical care of young children and fragile or ill family members, planning for the educational and emotional well-being of their families, and making concrete plans for practical issues such as funerals or for the participants' additional care needs when they became worse or approached death in the future. The participants did not generally describe making these plans as a direct cause of suffering, but instead, their need to make these plans suggested the need to continue to love and protect their children or family members even in the face of death and after they died. Yet in some cases, the participants did speak of intense suffering when they tried to make future plans while their families were grieving over the news of their serious illness. The participants often cried throughout these portions of the interviews and sometimes had to stop the interview because of their own grief. The emotional depth found in these narrative accounts may suggest the depth of the commitment to their loved ones and to caring, protecting, and planning for their families' future needs. Indeed, the depth of emotion the participants provides weight to the importance of Planning for Life Without Me.

Making Plans for Their Love Ones' Future

One of the more poignant examples of this theme became apparent when Alice spoke of her wrenching fear over the immediate future for her 9 small children and 3 grown children. On hearing of her diagnosis of malignant melanoma and her later diagnosis of ovarian cancer, her first and foremost thought was to find a way to hold her family together and to provide for their well-being. She emphasized these concerns several times throughout all her interviews and repeatedly spoke to this worry as a "heartbreak." As such, Alice felt that Planning for Life Without Me was of more serious concern than her own health or prognosis.

> "My first worry was would I lose the children and if I died what would happen to these children? Would they be scattered? Who would take 8 or 9 children?"

Her feelings of love and responsibility to her family drove her to focus her energy on her family before addressing her own health or treatment decisions. Futhermore, her worries about keeping her family together were intensified by her experience of watching her neighbor's family fall apart and dissolve as the neighbor struggled and died from the same disease. Alice was determined to actively find ways to keep the family safe and intact.

> "At first, after watching [my neighbor die of malignant melanoma] I thought this was it. This is the end of my life. And I did call welfare to see if the children were left alone, could they all go into the same home. Is there any place that would take the 8 or 9 children that would be left? It was just absolutely frightful, dreadful."

> "I knew that I wanted my children to stay together to support each other, so I waited until the littlest ones were asleep. The bigger ones were gone. I had called [welfare] and I did ask if they would call during the day, during school hours because I was not working except for occasionally as a substitute teacher. They assured me there would be somebody who would be glad to take a group like that and keep them together."

She called the local welfare office immediately after receiving her diagnosis to discuss the future of her children. She told of how she became able to focus on other issues only after she was assured that her family would be together. After this assurance, she was then able to consider her second layer of concern which centered on the educational needs of her children.

> "And then, of course, I worried about whether they would be educated. I wanted them to [be educated] because my goal was to put them all through college. And I felt that this would not be so important for some other mother. ..... All the goals that I wanted, I felt may not be reached for my children. I was very concerned about that."

Alice's need to be assured of her children's future health, education, and safety arose over and over again in her transcripts and in the transcripts of the other mothers.

> "I've had quite...what would you call it? Worried because of what the future will be for my children without me there to guide them. You know, you kind of hang onto those reins."

This may be interpreted as the need to plan and protect one's children and would be a normal and expected finding for conscientious mothers. However, these concerns were found not only in the narratives of participants who had small children. This theme was also important to participants with other close relationships. Bill was deeply concerned about the welfare of his wife and how his family would cope with her dementia after he was gone.

> "The worst part [of having cancer] is dealing with my wife. No question about it. And the kids, in part. But the kids get over it. Like right now they're arguing about what kind of home [my wife's] going to go into. We know she's gonna have to go into a home because they've all got work and they can't keep the place going and help out. Like taking care of her. So now they've all got to do this. And they're realizing that we are stuck. And it's time that everybody got to the point that we're going to have to put her in a home. And I said, that's the last thing I want to do."

Bill reiterated this concern many times throughout his interviews. For him, making plans for his wife was his highest priority and his greatest worry.

> "My wife is my primary worry and it always will be. And now, [my daughter] is trying to find a place for her .... To hook her up to a nursing home. At least to go to during the day. Some way of doing it. So she's covered with care..... So in essence, she's going to end up in a nursing home, too. And that's as simple as I can see it. That's the way it's going to be, whether I like it or she likes it or what [sobbing] ......I know I'm going to die. It's that simple. No question in my mind .....What's hard for me is handling my wife. Trying to get past [the uncertainty of his demented wife's future]."

It is clear that these participants were markedly concerned about their family responsibilities and how their families would cope with the unexpected difficulties in the future. As I worked with this theme, I came to acutely appreciate how people do not experience suffering as single, isolated entities, but people live within a constellation of families, friends, relatives, and other acquaintances that will all be potentially influenced by that person's experience of disease. Given this position, the entire family constellation must be the critical focus when exploring the experience of suffering.

While the traditional healthcare practices have focused on the physical care and treatment of specific diseases, in this study, the participants' focus was more immediately directed to their close and meaningful relationships. Some medical and nursing settings, such as pediatrics, do provide family care as part of the physical and nursing care, yet the data from this study indicate that even more emphasis could be placed on understanding and caring for the patient and family as a fully functioning and relational entity.

The participants expressed other concerns related to their families and friends. In another example, Alice expressed worries regarding how her children would tell her grandchildren and the neighborhood children about her disease and how these small children would react to the news. She wanted to be certain that her family was fully aware of the seriousness of the situation, but more importantly, she wanted reassurance that her children would comfort her grandchildren when they were told that she may die.

> "Well, I forced a lot of things. I forced if this happens, what will you do. The cause and effect kind of thing. If I'm not here, how will you handle the children that I have been taking care of. The stories of my death. Telling the children that this is going to be possible and they will see me go downhill. Will they be able to handle this? How will you explain this to the children. We did a lot of talking about that."

As an illustration of how she "forced" these issues, Alice asked her children directly if, when and how the grandchildren and the neighborhood children should be told of the seriousness of her disease. She also wanted to know the setting in which the children were told the news.

> "The response was 'Yes, [the grandchildren and neighborhood children] should be told and maybe you should be there when we tell them.' All the children who were close in the area were told by me and their mother. The ones that were at a distance, their own parents told them. But I felt everyone should be aware and several of the grandchildren came and helped take care of me."

Ruth was also worried about making plans for her family. Although she did not have young children or grandchildren that would need special care regarding the news of her cancer, she was quite concerned for her daughter's future health. Ruth had an unusual manifestation of cancer in that she had several primary, rather than metastatic sites which included colon, lung, and breast. Because one of her primary sites was her breast, she expressed concern about her daughter's potential for developing breast cancer in the future. She stated that she did not worry as much about her colon or lung cancer as potential risk factors for her daughter; however, she was worried that her daughter could be at greater risk for breast cancer due to the possible genetic link. In this excerpt, she speaks of how her fear for her daughter's health exacerbated her own struggle to live with her disease.

> "I've got breast cancer. Now I'm really concerned for my daughter at this point. So [knowing of my daughter's increased risk] was definitely more difficult mentally and physically to come back from and that was much more in my face at that point."

The theme of Planning for Life Without Me is certainly not new in healthcare literature and is prevalent in the nursing, oncology, and ethcs literature (Bascom & Tolle, 1995; Byock, 1996; Frank, 1995; Moustakas, 1961; Post, 1995; Steeves & Kahn, 1987; Younger, 1995). As such, this pattern was an expected and natural outcome of the study, however, Planning for Life Without Me can also be linked to the primary theme of Not Being Heard. The participants wanted their emotional and family concerns to be heard almost as much as they wanted their families and friends to hear what was happening to them physically. In this way, they needed those people who were most important to them to fully understand and know what was closest to their hearts. If their families could not hear their concerns, the participants' suffered.

For example, due to his wife's cognitive impairment, Bill was not able to explain how his impending death was going to change her life, yet he wanted her to understand his worries and he repeatedly tried to explain the situation to her. Because she could not understand cognitively, his children became quite upset as a result. Bill told me that he felt this situation was one of the more difficult conflicts his family had ever experienced. When I asked him about the extent of the problems that had resulted from this conflict, he emphasized that his wife's inability to understand and accept his disease was at the root of the conflict.

> "Because she won't accept it. That's the problem. That's a real big problem. And I don't know how to solve it [crying]. And crying won't cure it ….. I know I'm going to die [crying]. It's that simple. But what's going to happen to her is….. unknown. I have no idea what's going to happen to her. I know she'll be taken care of by the kids, but they've got their own problems. They should not be forced to suffer with it either."

Planning and Celebrating Life

Again, the need to be heard and understood was found to have layers of meaning. Yet the layers of meaning embedded in Planning for Life Without Me was not always sorrowful. Many participants told of how they intentionally set aside times to discuss their plans for the future with their families, and in some instances, that "gathering of the clan" became a time to celebrate the meaning and closeness of those relationships. These special times served not only as a forum to give their families or friends information about the disease process, but it also provided a way to pull the group together toward a common goal.

> "It was like they put a bubble of love around me. You're heard about the boy in the bubble? They would love to have Momma in a bubble, I think, to protect me from all the exterior influences. [Her children] wanted to really extend themselves toward me."

In this way, discussing the practical and emotional aspects of cancer may have served to strengthen the bonds between the participants and their loved ones. As such, it might be interpreted that a powerful dimension of Planning for Life Without Me was the desire to acknowledge and honor the depth of emotional connections while informing loved ones about the disease and about their concerns for the future. In the following excerpt, Ruth addresses the layers of meaning found in making plans for party at which she planned to tell her family and friends about her cancer.

> "What am I going to do? How am I going to handle what potentially might be a terminal illness and I said, 'I think what I need to do is contact everybody that I love and the people I have the most connection with. So we had a party and in the interim I wrote letters to my husband, to my three children, to whoever it was that I wanted to let them know not to be afraid. That I love them and this may be difficult, but not to be afraid and not be afraid to show how you feel and reach out for whoever you needed. And it was like, I never have done this before. It took cancer for me to kind of do this and the night before surgery, I listened to Mozart and...I think that you are or I was in such a sense of 'Wow. This is so incredible'."

Alice also emphasized how honoring and acknowledging her disease and her love for her family strengthened their bonds.

> "I think the family is much, much closer because of the fact that the children thought they were going to lose me and they kind of grew together to protect me and themselves. So they kind of face the world together no matter what happens. It made them stronger."

In the above accounts, much of the feelings associated with Planning for Life Without Me carried pragmatic as well as emotional attributes. Many of the stories were about practical decision making; however, some of the stories reflected symbolic or existential dimensions. In particular, Bill's transcripts revealed that his concerns for his wife's care carried practical as well as existential meaning. Not only was Planning for Life Without Me of emotional and practical concern, he may have felt as if his value as a person was being threatened if he was unable to readily find solutions.

> "I was with her when she fell in the bedroom and she just dropped down to the floor. And I couldn't help her. I couldn't pick her up. I couldn't do nothin'. In fact, she laid down on the floor for a half an hour until I got somebody. She was bleeding all over the place and she split her head open. So, I don't want to go through that again. It kind of took it off my hands about her being alone. Because if I can't help her, what good am I? You tell me?"

Another aspect of Planning for Life Without Me involved finding ways to anticipate and relieve the future burden of care from their families. Margaret had had many years of direct experience caring for her husband who had been severely disabled by a neurological disease. Her experience as a caregiver had been so hard that she wanted to shelter her children from experiencing this burden. In the following excerpt, she spoke of her desire to reduce the potential burden on her family and specifically told her children to place her in a nursing home when she could not longer care for herself.

> "I've already told my children, I said, 'Should I have a stroke or should I get to the point of where I can't take care of myself, don't hesitate to put me in a nursing home. Because that's a good place for me.' I'm going to be taken care of and I know you are not going to like coming to see me, so don't try and come and see me, like all the time. Come and see me once in while because in the nursing home, I noticed that patients seem to know when people are having a good day and a bad day and patients seem to perk that person up when they are having a bad day. I mean people say, 'Oh, you are never going to a nursing home,' and my boys say, 'You are never going to a nursing home.' And I said, 'No. Don't hesitate because I will be okay there, at least everything will be on one level and the doors will be bigger. Don't worry about that because I will be around people and when you are around a lot of people, it will be taking your mind off your pain and what you are not doing'."

Many writers have identified being a burden as a source of suffering that results from the loss of dignity and autonomy that can arise from debilitating illnesses. This issue has been frequently implicated in the physician assisted suicide debate (Battin, 1994; Bopp & Coleson, 1995; Quill, 1991). Much of the PAS literature has interpreted the fear of being a burden as a control issue or related this idea to fears of losing independence or autonomy. While there may be some indicators that fears of being a burden may be related to the need for control and autonomy, one of the more significant findings from this study is that the fear of becoming a burden may be more accurately associated with the desire to protect loved ones and the desire to lessen their loved one's future load. As the above excerpt illustrates, one of the deeper issues behind the fears of being a burden may not be simply control, but rather was an outgrowth of love and affection.

Besides the emotional and specific care related worries, the participants had other practical issues they wanted to discuss with their families. For example, Bill explained how he tried to start the process of Planning for Life Without Me on the very day of his diagnosis. In the following excerpt, he referred to his financial concerns about the future and went on to describe his actions to address these more practical concerns.

> [About discussing the news of his cancer] "I tried to tell everybody that it's there. 'You've got to pay attention to what they're telling us. And that's the way it's going to be.' But I told them I had a year. I said, 'We've got to make the most of it.' And I've been working on all the bills, and all the household stuff ever since. Now I've turned everything over to [one of my daughters]. I've got everything in her name. I've been working on it ever since. Our bank accounts. And she's got the whole thing now. And I made out the will. Not the will, but the bill of trust or trust. And filed all that. There's nothing that I can make out anymore. I have it all done. Even sitting down with her to teach her, what I've been doing with the bills."

The participants' concerns went beyond making plans for the financial, emotional, and physical well-being of their families. They spoke of other practical issues that were part of Planning for Life Without Me. Some reported having made funeral or cremation plans in order to relieve that future burden on their families. For these participants, they included discussions of funerals and cremation in their family meetings to assure that their families were aware and "okay" with their decisions.

> "I've been trying to figure out how to make it. I'm a person who does not believe in spending a lot of money on a funeral. I think I have it pretty well figured out. I think you should plan on [on your future death] and you should plan on making sure your soul is ready to go, you know. You should, if you want to. I want to be next to my husband, so I have to let everybody know that. I have to let everybody know that I have already paid for my funeral plot down there."
>
> "I think you should think ahead of that. I think you should let your children know what you want and the kids want me to get the kind of head stone that I would like to have. I just want to get rid of the one we got from the government and a brass plaque on a stone. Something that will last a long time."

Many participants indicated that they knew making funeral arrangements could be difficult for their family members and elected to make these arrangements prior to becoming more ill or more fragile. Alice, in particular, wished to try to alleviate some of the strain on her family during a time that she knew would be potentially difficult.

> "I had a stroke three years before [her cancer diagnosis] and had to retire, but at that time I had made arrangements for my own death and burial because I didn't want the children to make the decisions for me after I was gone. Also, I was afraid they wouldn't go along with cremation and I wanted to make sure that was taken care of. Because I'm not afraid of dying, so I had done all of this and that was one of the first thoughts that went through my mind. Thank God [the funeral arrangements have been and] I've already prepared and the children won't have to worry about it."

To summarize the significance of the theme, Planning for Life Without Me, it was not just that the participants wanted to fulfill their responsibilities to friends and families, but more importantly, I believe the deeper meaning of the theme may lie in the strength of the relationships that surrounded the participants. People rarely live within a solitary vacuum, but rather, most people are part of a larger constellation of family, friends, co-workers, neighbors, and other individuals who will all be influenced by their disease. If we are to deepen our understanding of suffering, we must come to acknowledge and listen to the multiple layers of concerns that patients may have for themselves, their families, and for others who are connected to them in meaningful ways. As with the previous theme of Not Being Heard, listening deeply to these concerns may be a significant source of relief for the suffering associated with serious disease. Again, if we are to actively work to relieve suffering, we must broaden our scope to listen and understand the layers of meaning found in the experience. In addition, while making Plans for Life Without Me may be a relatively concrete theme, it must be remembered that this, too, carries deep emotional as well as symbolic or existential layers.

The Search for Understanding

Another strong, secondary theme that emerged from the transcripts was that of the participants' desire to understand their disease. While education and teaching are well recognized components of good medical and nursing care, the participants' words indicated that they wanted an even deeper understanding of their diseases than was offered through standard medical and nursing interventions. Not only did the participants want to become knowledgeable about their diseases and the concomitant treatments, they needed information for a variety of reasons.

Nearly all participants did some form of "research" on their diseases. Some used the Internet; others consulted various agencies and specialty clinics; nearly all requested information from their doctors and nurses. They wanted to know details concerning the pathophysiology, the treatment options, the side effects of major medications used in the treatment, the statistical success rates with radiation and chemotherapy treatments, and other concrete facts and figures. The more information they had about their condition, the more comfort they seemed to feel. They expressed frequently that learning about the disease was one way of "taking care of themselves." In some instances, doing research on cancer became a family endeavor.

> [My daughters] looked [ovarian cancer] up. She went to the computer and pulled everything she could find. She had pages and pages.....she gave me quite a bit of information and she marked pages she thought were more pertinent and, of course, I read that."

However, some participants did not find it easy to get adequate information on their disease or on their treatment options. Elaine and Steven expressed frustration at the lack of information their doctors had provided about congestive heart failure. They stated frequently that they had tried to ask their doctors questions about their disease, but were rarely satisfied with the answers. In addition, they expressed particular difficulty in getting information about pacemakers and the pacemaker placement procedure. Yet even in the face of difficulty, they were almost driven to find the information they needed.

> "But as a lay person, how do you know which questions to ask? [You have to find out by] trial and error. And try to read. Go to the libraries. Get some videos. Tapes. [Information on] the pacemaker was almost impossible to get. I mean, it's

> so difficult. We were just lucky that there was a documentary or something that was recorded and the hospital lent us a tape. Then I got one in the mail. I always send for free copies. So I got one from Johns Hopkins, from Cornell, and from various places and many times they have very, very interesting studies going on."

It is well established that patients benefit from clear and concise explanations of their diseases. In addition, accurate and timely education may reduce disease related anxiety while also increasing the patient's commitment to treatment (Bascom, Tolle, & Cassel, 1996; Cassell, 1991a; Enck, 1994; Ersek & Ferrel, 1994; Frank, 1995; Gregory, 1994; Lerner, 1998). Nearly all serious illnesses require some type of treatment decision and the participants in this study echoed the need for solid information before they could make those decisions. Yet, they also sought explanations of their condition in order to cope with the disease and to explain the disease and treatments to their families. In addition, information served as a way to maintain a positive and hopeful outlook as well as to understand their disease. Furthermore, the data reveal that the participants sought understanding as a way to help themselves and their families and friends cope with their seriousness of their potentially life threatening condition. As Alice stated, "You have to be able to understand things to be able to handle them." In this way, acquiring accurate and meaningful information about their condition may have reduced somewhat the severity of their suffering.

Research as Coping

While the Search for Understanding may be one way the participants took care of themselves or found some comfort with their treatment decisions, Ruth stated that she felt that the process of "doing research" may have served simultaneously to protect her from the emotional upheaval that can arise from living with cancer and from her more personal, internal fears related to having cancer.

> "But if I think only about the medical advances and all the technology, it will never…….[the emotions] won't get to me. I won't have to think about it or feel it ……. I think it is so easy for many of us to get disconnected from our feelings by, what I use to call going through that 'research' mode. I am going to sit and do all this research and I am going to call here and there and I'm going to check this and that and it gives me some time and space to have a big breath. I'm aware that when I do that, there is stuff going on underneath that I am not ready to allow into my consciousness."

Ruth frequently found living in her body was more than she cared to handle emotionally. At these times, she expressed that "doing research" provided a brief, but slightly unconscious, respite during times in which she felt emotionally overwhelmed. She stated that she sensed that her attempts to understand the disease may have provided a more objective and distant mental stance and enabled her to maintain some separation from her fears. While Ruth interpreted her research activities with a slightly negative cast, her purpose in "doing research" may have resulted in carving out positive coping strategies.

As was first noted in noted in Kubler-Ross (1969) work and was substantiated by studies from a variety of disciplines (Block & Billings, 1995; Byock, 1996; Cherny, Coyle, & Foley, 1994; Fields & Cassel, 1997; Kahn & Steeves, 1995; McCormick & Conley, 1995), the emotional cost of living with cancer can require special coping mechanisms to lessen the daily load. Given this perspective, the process of "doing research" may be useful from not just the more literal perspective, but the Search for Understanding may have symbolic and existential benefits as well. In this way, Ruth's drive for information may have given her the positive edge of acquiring needed information while receiving some much needed respite from the emotional load of living with cancer.

Ruth's excerpts may be representative of the layers of meaning found within the Search for Understanding. In the following excerpt, she again interpreted her thoughts with symbolic and existential inclinations.

> "I keep asking what do I have to learn. Remember I asked you that? What do I have to learn? What do I have to do? Why is this going on? And I think what I came to after the meditation, after the support group, which I still go to, is that it is all a crutch. And there's isn't an intellectual answer that I am going to get. I can ask all the questions I want, I am not going to get my answers from that."

In this example, the Search for Understanding may have given Ruth layers of benefit. It may have provided her with much needed respite while she gathered information to confirm her existing decisions and anticipate her needs in the future. As such, the multiple layers of meanings underlying her research activities may have enhanced her ability to cope with the demands of the disease. While the reasons behind Searching for Understanding may be rich and varied, the more pertinent dimension of this theme may be in how it can serve to ameliorate several dimensions of suffering at once. Based on this data, it is not possible to draw specific conclusions regarding the participants' motivation for seeking information; however, it may be enough to recognize that people with serious illnesses can derive many layers of benefits by broadening their knowledge.

Searching for Understanding as an Act of Love

The types of questions the participants asked may offer additional clues into the experience of suffering. Given my hospice practice and much of the hospice, bereavement, and theological literature, I had anticipated that some of the participants might have asked the classic, yet unanswerable "Why me?" question. Interestingly, I found that this question was not generally of concern. Whereas some participants stated that they had asked "Why me?" immediately after the diagnosis, as they lived with the disease, their desire to answer this question faded. For example, when I asked one participant if she ever asked the "Why me?" she replied:

> "I think you do [go through 'Why me?'] even with something small like a headache. But something big like this, sure I went through the 'Why me?' then I thought 'Why not?' I would rather it be me than one of my children."

> "I guess I'm lucky, because [my friends and family] are all so optimistic and outgoing and things like that. I know some people draw on the 'Why me?' but I don't think I would. You have got to go beyond that. Most of my friends might say, in the first shock of finding out something, 'Why me?' but then they would say, 'Okay, it's me. Let's do something about it'."

The specific directions of their questioning were markedly varied, but in general, one strong focus was their desire to explain the origin of the disease, possibly in the hopes of finding ways for their family and friends to circumvent cancer or heart disease in the future. The participants focused more on finding logical and understandable explanations as to why their cancer occurred at that particular time and which treatment would be most effective. With the exception of a few participants, most of them were more concerned with finding an understandable and logical cause and treatment of the disease, rather than staying with the existential or philosophical question of "Why me?" For example, some participants stated that they did not feel shock or denial or anger, but rather were baffled as to the diseases' origin.

> "Everything says that if you have several children, you are not very likely to get ovarian [cancer]. So that was the first question. We needed an explanation. I didn't have all these children to prevent ovarian cancer, but everything I read told

> me I couldn't have it. I've nursed the babies, I've had several and all the girls had questions. They all had been reading up on it when I said it sounds like ovarian cancer even though I shouldn't. I'm not in the market for it."

Margaret "decided" that the disease was related to her years living on a farm and eating homegrown and prepared meats that were preserved with nitrates or acquired carcinogenic components through the smoking process. As she examined her dietary and nutritional history and compared her history to her family's, she was able to assure herself that her cancer may not have occurred from genetic or familial pattern, but she maintained that it was more a result of the food choices that had been a part of her life prior to starting her own family. She referenced frequently this idea throughout her narrative account and she stated that this understanding gave her some comfort.

> "[The cancer] was not such a shock as it was that I couldn't understand why I got it. It didn't seem to be in my family. The family background [wasn't there] and then I spent a lot of time trying to figure out what caused it. I tried to think of the things that I had done in the past that I might have done wrong, of course, one of them was the sausages that I love. I thought was it the nitrates or the sweeteners and stuff like that? It was more of a ….but it only involved me. It didn't involve any of my other family so I was the only one being affected by it and I think that made it easier."

Again, these responses point to the participant's abiding concern was for the welfare of their children and families. Thus, as the participants lived with the knowledge of cancer and congestive heart failure, the "Why me?" and questions of causation questions were more related to fundamental concerns for their loved ones.

Finally, the participants wanted explanations of their physical pain and suffering. Not surprisingly, this was particularly true for Jack. When his physicians did not listen to his pleas for pain medication, he reflected not only on why the physicians did not increase his pain medication, but he also wanted to know what could be the cause of the pain. It was not until he, too, received an explanation of the cause of the pain that he was able to stop doubting himself. In this way, understanding the cause of physical pain may have made the process of being with the pain more bearable.

> "I couldn't figure out what it was. What in the world is making me hurt like that? There's no lesion down here. Do I have a nerve impingement? Do they understand that this to me is like a nerve impinged? The nerve is being traumatized. Because the pain is so excruciating and there aren't any clinical manifestations behind that I could see. But at the time, I didn't know that I had metastasizes in my cerebral spinal fluid."
>
> "And then when they said, let's do a lumbar puncture. And to me that lead to 'Oh, Jack,' you've got a lot of malignant cells in your cerebral spinal fluid. No wonder you're hurting. And you're going to hurt. And then, 'Ahhhh! It's not in my head!' Until the next morning. When I was … when they did the LP and the count came back. They came right down and told me "You're got a real high white count, Jack." Oh. That makes sense. Yeah. That makes sense."

There were many possible motivations behind the participants desire to obtain information about their diseases and their theoretical causes. While some of the reasons were concrete or literal, such as wanting to find the underlying physiological causation, some of the rationales behind the strong need to search for information may have been to protect their loved ones. In conclusion, if Ruth's perceptions could be applied to others, it is possible that the process of Searching for Understanding could be a positive defense mechanism to soften the many blows of living with cancer and relieved some of their worries about their families. While the data from this study do not definitively point to specific motivations behind the desire for information, the data do reflect the need for further analysis of the reasons and rationales behind the strong desire many patients have to understand and analyze their disease.

Chapter 5

Summary, Conclusion, and Implications

Study Summary and Conclusions

The purpose of this study was to deepen the understanding of suffering that may arise during the end stages of illnesses by fulfilling the specific aims which were (1) to describe adult terminally ill patients' experience of pain and suffering and (2) to interpret the patients' experiences of pain and suffering within the context of their lived experiences and background meanings. While previous medical, nursing, and theological literature explored the nature of suffering, more needs to be known specifically about the suffering extant within diseases such as cancer and heart disease.

Because much of the nursing, medical, and theological literature maintains that suffering is grounded in the meanings the suffering individual holds about the experience, I chose interpretive phenomenology as the study method. While qualitative studies have inherent limitations, their strength is to offer a means to analyze phenomena in an in-depth way. In order to accomplish this end, the sample inclusion criteria must be established to ensure enough homogeneity to provide for both depth and breadth. To accomplish this goal, this study's sample was based on both age and disease diagnosis. The older adult population was selected because cancer tends to be an older person's disease and because the adult lived experience of suffering is likely to be quite different than children's experience. The age criteria was set at 50 years or older to provide some degree of developmental and experiential homogeneity. In addition, the original design established Stage IV cancer as the primary diagnostic inclusion criteria. This criteria was selected because in this society, cancer is often believed to be analogous to suffering. However, as the data collection process continued, I encountered increasing difficulty finding eligible participants and as a result, I broadened the inclusion criteria to include advanced congestive heart failure as both a contrast diagnosis and to help increase the total number of participants. The final sample consisted of six participants who had been diagnosed with Stage IV cancer and two participants with the contrast diagnosis of advanced congestive heart disease.

Each participant agreed to a series of unstructured, in-depth interviews. The interview series ranged from a minimum of 2 interviews to a maximum of 5 interviews. The variation in number of interviews was based on the participants' preferences and physical stamina. The first interview of the series focused on uncovering the participants' history and background meanings; the second interview concentrated on their diagnosis and life events since the diagnosis of cancer or congestive heart failure; and the third interview provided time for the participant and the interviewer to reflect on the previous interviews and delve deeper into specific issues that needed clarification. One participant was interviewed two times, six participants were interviewed three to four times, and one participant requested a total of five interviews. Each interview lasted approximately 30-60 minutes; however, one participant was only able to talk for 15-20 minutes before becoming tired. The purpose of this interview strategy was to obtain the participants' stories describing their experiences with cancer or heart disease and to give special attention to the stories that illustrated how, when, and why they may have experienced suffering. After the participants' interviews were transcribed and verified, their narrative accounts (including field notes describing the participants' intonation, behaviors, and inflections) became the data set for the study.

As I analyzed the participants' actual words, three thematic patterns emerged. The most predominant theme was that of Not Being Heard. Because every participant spoke of this theme, I classified Not Being Heard as the study's primary theme. Throughout the interviews, the participants described instances in which they experienced their feelings, circumstances, or requests for pain medication were not heard by their providers, nurses, and caregivers. Over and over again, the stories reflected the anguish and emotional pain the participants felt when their words were ignored or misunderstood. They told of instances in which their physicians did not respond to their pleas for pain medication or attend to the severity of their pain and their nurses did not administer adequate PRN dosages to cover their physical pain. One participant told of how his nurses disregarded his request for sleeping medication and decided his insomnia was the result of his coffee intake.

The participants stated that they usually knew the moments in which their providers and nurses stopped listening to their words and they also knew that Not Being Heard was a potent source of their suffering. One participant knew the moment a clinician stopped listening and described it as "when a lid would go down, almost an inner eyelid." She even defined suffering as arising when her sense of self or her experiences were denied or disrespected. "Anytime I'm not heard is, to me, a time of suffering ….. Not being heard is the worst thing that can happen to me."

The stories the participants told often were difficult to read and absorb. Many times, my advisory committee and I spoke of how reading these stories was emotionally painful. One of the external consultants began to sob when I described how Jack's physicians did not listen, nor respond to his pleas for pain medication. All involved with this study found it challenging to believe that these accounts of poor pain and symptom management occurred at this time in medical and nursing history. Given the dramatic advances in pain assessment and management, it seemed unlikely that this degree of uncontrolled physical pain could still exist. Yet, pain and the suffering associated with Not Being Heard arose from the transcripts time and time again.

Moreover, Not Being Heard was not only found in the words of participants with physical pain. The participants spoke of suffering on many levels, including literal or concrete levels which encompassed physical pain and other physical symptoms, symbolic or interpretive levels which emerged from the meanings the participants ascribed to their illnesses and experiences, and also existential levels in which the participants came to question their identity, sense of purpose, their honesty, and even themselves. Given this interpretation of the data, suffering may be perceived as a phenomenon that can impact many layers of a person's life. Not only did the antecedents to suffering threaten the body, but they threatened the participant in deeper, more interior ways of being.

Two secondary themes arose from the transcripts. These themes were Planning for Life Without Me and Searching for Understanding, Unlike the theme of Not Being Heard, these themes were not found in every participant's transcripts. However, when these themes did arise, the participants expressed profound emotion and often cried or sobbed throughout the telling of their stories. One participant became so distraught while telling his story that he abruptly ended the interview because he could not speak through his tears.

These secondary themes also were layered with meaning. As with the theme of Not Being Heard, the participants told stories that revealed their practical or literal concerns along with their symbolic and existential issues. Throughout the narrative accounts that revealed Planning for Life Without Me, the participants told of making specific, concrete plans to ensure their children and family members would be cared for in the future. In particular, when the participants had small children or fragile family members, they spoke of their concerns for their loved ones and their specific plans in the first interview of the series and then returned to discuss those concerns over and over again.

Other concerns embedded within the theme of Planning for Life Without Me were related to making plans for their children's future education, making funeral arrangements to ease their family members grief at the time of their deaths, and making plans for their own future care in the hopes of relieving the burden of care from their loved ones. In contrast to some existing literature on the emotional pain of being a burden to others, the participants did not make plans to avoid being a burden of a psychological need to control, but, rather, their plans reflected the desire to relieve the burden from their loved ones. In particular, their efforts to relieve the future burden arose from the love and tenderness they felt for their families and friends. As a result, Planning for Life Without Me carried rich and complex meanings that were based on assuring that their loved ones would be protected and cared for after the study participants' death. Through these plans, the participants wanted to express their love and to fulfill their responsibilities as they became weaker and possibly, even after their deaths.

Searching for Understanding also was infused with layers of meanings. The participants all tried to get information about their diseases from their physicians and nurses. Some participants used the Internet; other participants went to libraries or requested audio and video tapes from medical centers, specialty clinics, and agencies to help them understand their disease. Their need to acquire factual, concrete information about their medical condition was strongly evidenced in the transcripts.

However, their need to search for understanding had other dimensions. Some participants were driven to get more and more information about the cause and course of their diseases in the hopes of preventing their children or other family members from developing cancer in the future. One woman found that "doing research" became a coping strategy. By focusing her attention on researching her disease, she was able to get some psychological distance from her overwhelming feelings and fears. The hours she spent "doing research" gave her some much needed emotional respite. Other participants told of arranging special meetings with their loved ones to teach them about their disease and the proposed treatment plans; these meetings also became an opportunity to pull their families together toward a common goal.

While patient education has historically been an important aspect of medical and nursing care, these data reflect layers of complexity contained in the participants' need to search for deeper and deeper levels of understanding.

Some Reflections

As I reflected on the findings from this study and as I worked toward the final report, I remembered a specific conversation I had, in 1997, with one of my external consultants, Shodo Harada Roshi, the Abbot of the Sogenji Zen Monastery in Okayama, Japan. Harada Roshi has been firmly committed to this study and his counsel has been very useful as I struggled with interpreting the narrative accounts. He was especially helpful in exploring the spiritual and existential meanings embedded in the participants' transcripts. In this particular conversation, he and I spoke of my initial reason for conducting the study, as well as discussing the background and significance of current palliative care and physician assisted suicide (PAS) literature. Our conversation in 1997 was focused primarily on the broader issue of PAS in addition to my dissertation research. I told him that as I reviewed the existing literature, I had come to the opinion that PAS was very likely a symptom of unresolved suffering, and not only an ethical, moral, and legal dilemma. In fact, in the original draft of the introduction of my research proposal, I had posed the following, rather dramatic question: "What is it about the healthcare environment that is making people suicidal at the end of their lives?" My advisory committee quickly and quite wisely identified that sentence as an exceedingly value laden statement and encouraged me to remove it. Yet I continued to hold this belief and it was this belief that I discussed with the Roshi.

After I had finished telling him of my concerns for terminally ill patients and PAS, he paused for several minutes. He slowly began to speak and said, in his opinion, the desire for physician assisted suicide was the "shriek of the soul." As is consistent with Zen practice, he did not clarify his meaning. When I asked for clarification, he smiled a little Zen smile and shook his head. He told me to "sit with it a while."

As I continued working with the data, Harada Roshi and I have had several other opportunities to discuss the data and analysis. In our last meeting together, in September of 1999, I asked him again to clarify the meaning of his phrase, "the shriek of the soul." This time, he nodded and smiled, and said he would now answer my question. However, before he would explain his meaning, he said that understanding suffering is similar to answering a Zen koan. A koan is a seemingly ridiculous or unanswerable question that a Zen Master sets before the student to solve. One of the more famous koans is "What was your face before you were born?" A koan has no specific answer, but the process of solving it necessitates "cutting and chopping" through old habits of thought that have clouded the student's ability to perceive the deeper meanings of being alive. If properly understood, a koan may become a path to enlightenment. In this case, he told me that while my research was certainly not intended to be a koan, and the findings did not indicate enlightenment, this research method of understanding suffering had unfolded almost as if it had been designed as a koan. He reiterated that the purpose of the koan is to cut through previously unconscious thoughts and patterns in the hopes of shocking or shaking the student awake.

After that preamble, he stated that in Zen Buddhism, suffering is believed to be an experience that has the potential to shatter our deepest core of being. In this view, suffering is not an experience of the body, but it is an experience of our most fundamental essence and soul. When we try to speak of our suffering, we often are afraid to speak from the depth of that essence because we fear that our essence is too fragile and can be easily broken. According to the Roshi, the essence or soul equates to integrity as defined in this study. It is the essence and soul of the person that suffers.

When we suffer, we speak in quiet, contained, and fearful voices in the hope of protecting and shielding our presumably fragile core of integrity. Yet, if those quiet, fearful, contained voices remain unheard, rejected, or ignored, that timid, cautious voice may become more and more vociferous. When the pain and suffering of the soul becomes increasingly intense and the pain remains unheard, that voice will become the strident "shriek of the soul."

He then went on to relate how interpreting the narrative accounts as a koan was necessary to understand how Not Being Heard could resemble the "the shriek of the soul." According to the Harada Roshi's view, to understand suffering, the investigator must come to understand suffering almost personally. This does not mean that the investigator must experience the same antecedents as the sufferer, but the investigator must reach inside and examine how those aspects of suffering resonate with the investigator's own experience. When the investigator begins to "shriek" with the pain of understanding, the koan is resolved and suffering is understood. In conclusion, he told me that he believes that it is this pain of learning to understand suffering that may explain why clinicians seem reluctant to listen with the needed depth. He stated that if clinicians are to understand suffering, they must "reach inside for their own understanding."

Thus, if we view these findings through Harada Roshi's eyes, it may be that the significance of this study is how the transcripts captured examples of the "shriek of the soul." While it is clear that the data cannot support my contention that unresolved, unattended suffering is at the root of PAS, the data do reveal that the inability and reluctance to listen to the soul of those struggling with serious illnesses may be at the heart of profound suffering.

Implications for Future Research

The findings from this study describe several themes that may exacerbate the experience of suffering for patients with cancer and congestive heart failure. While the study findings cannot be generalized to broader populations due to the limitations found with this qualitative method, this study does provide a solid foundation to build my future program of research into the nature of suffering at the end of life. As such, the next steps in this program of research will involve designing a series of research studies to delve progressively deeper into the experience of suffering and into the themes that emerged from this study.

Given that the most prominent theme of this study was Not Being Heard, I would like to focus on this issue in the next phase of my program of research. In order to more fully investigate this theme, I would like to design a study to combine quantitative and qualitative methods to explore the domains of Not Being Heard and how those domains may be related to medical and nursing practice.

Other areas of future research include investigating temporal components of suffering. For example, the findings hinted at how suffering may change as the disease progresses; however, the relationship between time of diagnosis, longevity with the disease, and the point at which suffering becomes a salient issue remained unclear. In addition, because this study limited the ethnic diversity to achieve adequate sample homogeneity, further research into cultural aspects of the experience of suffering is strongly indicated. Other issues that would benefit from greater analysis are the experience of becoming a burden to loved ones, abandonment (by providers/caregivers and by society), depression, and other physical symptoms.

Because completing interviews and surveys require participants with intact speaking and writing abilities, I plan to continue to focus primarily on cancer patients. However, the experience of suffering is clearly not limited to just cancer. Many other diseases and conditions may result in intense suffering. In particular, I have recently become much more concerned about the suffering experienced by families and patients with Alzheimer's Disease. Another future aspect of my program of research will include examining the experience of suffering for non-verbal Alzheimer's Disease patients and their families.

Implications for Clinical Practice

This study uncovered powerful narrative data that suggest that some patients with cancer and congestive heart failure are suffering because their words and feelings are not heard by their providers and caregivers. These interpretive findings provide several clues to help clinicians begin to alleviate some aspects of suffering through modifying their clinical practice.

The first and perhaps the most important clinical outcome of this study was that inadequate clinical listening skills were often implicated in the participants' experience of suffering. Thus, the study reveals that one possible way to relieve suffering may be to improve the clinicians' ability to listen and understand the meanings of their patients' words. The natural reader response to this findings may be that listening deeply for understanding will require additional time with patients and this response may be quite challenging given the present healthcare emphasis on working faster and seeing more patients in less time. While the call for increased time with patients may be reasonable given these findings, the narrative accounts may more accurately reflect that it is in the quality of listening that was more important rather than the quantifiable length of clinical visit. As such, it must be acknowledged that it is the quality of listening for the meanings embedded in the words that was of greater importance to the participants than the actual time spent discussing their experiences.

Thus, the more hopeful interpretation may be that clinicians must learn to listen deeply with their full, undivided attention. While it may be that clinicians will initially need more time to develop and enhance their listening skills, clinicians should be assured that it is the depth of listening that is more important than number of minutes allocated for patient and clinician discussion. If clinicians learn to consistently listen with their "full mind," this deepened style of listening may not adversely effect their efficiency, but rather listening well may actually reduce the number of complications patients and families experience. In this way, listening deeply may actually lend itself to greater efficiency. This position was strongly supported by Harada Roshi. He reminded me of the Zen maxim that listening for depth and meaning does not necessarily require additional time, but listening in this way will absorb all the clinicians' time.

There are other important clinical implications embedded in the theme, Not Being Heard. The narrative accounts revealed that when the participants felt they were Not Being Heard, they simultaneously reported feeling that they did not feel honored or even acknowledged for their struggles. More importantly, the participants frequently told of how they felt as if they were just another cancer (or CHF) patient and as such, they were not important as individuals. Honoring patients as individuals may also be related to clinician practices. Again, it is in the quality and depth of listening that may hold the clue to this concern. According to the participants, the seemingly simple act of listening openly to and acting on the participants' words was an essential component in assuring the participants of their inherent value as people. Thus, the study illustrates the need for clinicians to not only allow enough time for patients to describe their experience and to listen deeply for meaning, but clinicians must also listen to affirm their patients' sense of self and individuality.

One question that arises from these findings is whether this depth of hearing and understanding can be taught. While it is clear that this depth of listening is difficult and may be quite rare, listening for meaning and understanding is not impossible to teach. Based on my review of literature, analysis of the participants' transcripts, and my experience in hospice and palliative care, it is my contention, and the contention of many others, that this quality of listening can and should be taught. Writers including Arthur Frank (1995), Arthur Kleinman (1988), Elisabeth Kubler-Ross (1969), Carl Rogers and Barry Stevens (1967), in addition to Shodo Harada Roshi (1993) have addressed the importance and process by which this type of listening may be learned and practiced. However, the largest body of literature that addresses the process of deep listening comes from the religious, spiritual, and theological literature.

Based on a review of this literature, there appears to be a strong connection between the listener's ability to focus attention and the listener's ability to hear the meanings embedded in the speaker's words (Easwaren, 1978; Fox, 1979; Frank, 1995; James, 1982; Johnston, 1970; Merton, 1969). In particular, Easwaren (1978) and Johnston (1970) emphasize that it is by learning to still the mind and to practice "one pointed attention" that the listener can come to focus directly on the words and meanings of another person. Merton (1969) also speaks of how contemplative practices offer a means by which the listener can learn to give attention completely to the speaker. This has also been His Holiness, the Dalai Lama's message throughout his many books, lectures, and in his private teachings (Thubten Chodron, personal communication, May 5, 1999). According to these writers, only when the mind has learned to be still and the noisy internal dialogue has been quieted is it possible to compassionately listen for meaning.

The need to still the listener's internal dialogue is also proposed by several secular authors. Arthur Frank (1995), Viktor Frankl (1963; 1970), Arthur Kleinman (1988), Michael Lerner (1998), and Rachel Remen (1996) all emphasize that it is through listening deeply to the narratives and chaotic stories of suffering that listening and healing can occur. These authors, and many others, state that it is responsibility of the listener to find ways to be fully present and aware while the speaker tells the story. They have proposed that without learning to be open and aware of the words, meanings, and presence of another, listening will not be deep enough to hear the meanings. Unless the inner dialogue is stilled, the time of listening is not a process of absorbing and understanding the meaning of the speakers' words, but rather merely a time of waiting for an opportunity to speak.

While it is beyond the scope of this manuscript to adequately discuss the various strategies to help clinicians improve their ability to attend to the voices of suffering, the findings suggest that enhancing professionals' listening abilities may help alleviate the suffering of Not Being Heard. Given the findings from this study, relieving suffering requires much deeper listening than the simple task of noticing the superficial meanings of the spoken word, but rather listening to overcome suffering necessitates absorbing and taking in the layers and layers of meanings that are extant in the words and delivery.

One of the more significant study findings was that the participants wanted and needed to be heard and honored as persons and they wanted to be understood on the literal, symbolic, and existential levels. To accomplish the goal of listening and honoring the speaker and to return to Harada Roshi's beliefs, healthcare clinicians must also offer themselves as authentic and open individuals while listening deeply to the words describing the experience. If both providers and patients share their understandings and experiences, we may be able to begin the process of intervening in ways to relieve the suffering at the end of life. In this last captioned excerpt, Alice may have synthesized not only what she, personally, wanted in her clinicians, but more importantly, may have summarized the type of person that can potentially relieve the suffering at the end of life.

> "It's an inner peace that prevents the suffering….I don't know. Maybe it's a feeling of calmness or something. I see people who are up and flitting around and they don't seem to accomplish anything and I think why don't you just sit down and take a minute and kind of let the peace wash over you or something."

It should now be abundantly clear that listening well may be a valuable way to alleviate the suffering of terminally ill patients; however, an argument against this conclusion is that the present economic ills afflicting healthcare are rapidly applying time limitations on clinicians in the name of cost effectiveness. It is all too true that for many, many years, medicine, nursing, and the other ancillary disciplines have not heeded the economic limitations of practice and we are now faced with overcoming a serious economic healthcare crises. However, if we are also to relieve the depth of human suffering that was illustrated in the study's narrative accounts, we cannot continue to practice solely from the position of economic scarcity. A balance is required between time for compassionate listening and economic health.

If we borrow from the wisdom of Wendell Berry's words found in his essay, "Poetry and Marriage" (1982), we may recognize how economic scarcity may have lead us to a certain formlessness of practice, or in other words, focusing on economic health may have resulted in an uncertainty regarding how to practice within the conflicting demands facing healthcare today. Prior to the 1980's, researchers and clinicians were encouraged to liberally use available resources to find innovative ways to cure and treat innumerable diseases. The years of flourishing enthusiasm led to remarkable advances in surgery, biotechnology, pharmacology, and experimental procedures, yet these advances frequently were not cost effective. Now economic pressures have forced many clinicians to become profoundly cost and time conscious. Yet, the findings from this study suggest that the participants' more important concern was for their clinicians to take the time to listen and understand their words and meanings. As such, it may be perceived that to fulfill both the demands of economic health and to practice compassionate listening may be beyond the time limitations of current practice. Thus, we are now facing what Wendell Berry may describe as practicing outside of previously established form.

In "Poetry and Marriage," Berry draws a comparison between the form of a poem and the form of a marriage. In both cases, he speaks of the necessity to be true to the form if we are to remain true to the deeper meanings embedded in that form. He further states that if we ignore or arbitrarily change the established forms, it is possible to fall into a state of formlessness. Furthermore, he states that formlessness most often arises from listening to a single Muse rather than opening to the possibility of a second. Following Berry's assertion, we will undoubtedly fall into formlessness if we attend solely to the Muse of Inspiration or solely to the Muse of Realization.

To apply this notion to the practice, it seems that historically, we listened primarily to the Muse of Inspiration. This Muse encourages us to reach beyond the limits of our knowledge and to focus on the dreams of how things might be. This Muse has enabled us to overcome the obstacles that impeded our goals and go on to find cures and treatments for countless ailments. To illustrate this idea, the Muse of Inspiration may be discerned within the words of Dr. Eric Cassel that were included on the masthead of a September 1999 letter from the Hastings Center. Cassell is quoted as saying, "When I was in medical school, I wondered if there would be anything left to cure by the time I graduated." For years, the Muse of Inspiration was at the heart of research and as such, encouraged researchers to search for cures and treatments for innumerable conditions. Yet the enthusiasm for medical, nursing, surgical, and pharmacological gains seemed to be at the exclusion of economic consideration. If we return Berry's position, attending solely to the Muse of Inspiration may have resulted in the disappointment, angst, and economic ills presently facing healthcare. We clearly know that the Muse of Inspiration must be tempered by understanding the limitations posed by the Muse of Realization.

In contrast, the Muse of Realization contends that things are much more difficult than we thought and that the economic realities of medicine and nursing can no longer be ignored. Yet, the danger in listening too closely to the Muse of Realization is that we may achieve economic health at the expense of our inspiration. Berry advises that to abandon one muse in favor of another leads inevitably to the loss of form.

The formlessness of our present healthcare practices may be evidenced by the standard practice of multi-tasking, abbreviated visits, and doing more with less. In addition, it may be that the underlying antecedents to the participants' suffering resulted from the formlessness of attending to only the Muse of Realization. The participants may have wanted their stories also heard by the Muse of Inspiration.

So, the next logical question is what can be done? If we consider Berry's position, attending to the Muse of Inspiration must not be at the risk of forsaking the wisdom of the Muse of Realization. To overcome the suffering of Not Being Heard, revealed in the study's narrative accounts, it will be necessary to find ways to attend to and appreciate both Muses at once. Possibly, it is through blending these two muses that the compassion of medical and nursing practice can be revisited. In closing, if we can learn to hear the essence and soul of the words of suffering while listening to the wisdom of the Muse of Inspiration and the Muse of Realization, it may be possible to address the pain of suffering with concentration and compassion. If Rachel Remen (1996) and Michael Lerner (1998) are correct, it is in listening to the stories that the healing can occur.

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Appendices

Appendix A

Study Summary

The Experience of Suffering of Advanced Cancer Patients

Oregon Health Sciences University School of Nursing
and Portland VA Medical Center
Lee Paton, RN, MSN, Principal Investigator: (503) 494-2367
Christine Tanner, RN, Ph.D., FAAN, Sponsor: (503) 494-3742

What is the Purpose of This Study?

We know that cancer can often lead to pain and suffering. In fact, in the United States, a cancer diagnosis is often equated with pain and suffering. While pain may be a significant problem for patients with cancer, there are other kinds of suffering that are just as important. However, very few studies have analyzed the kinds of suffering that cancer patients experience.

It is the purpose of this study to go directly to people who may be experiencing pain and suffering. We want to find out what these people think, feel, experience, and believe about their lives before and after they became sick.

This information from this study will be very helpful

- to doctors as they try to help people who are suffering,
- to nurses who care for people and families at home and in the hospital, and
- to public officials who are trying to determine healthcare policy.

Who can participate?

Anyone with stage IV cancer who is at least 60 years of age.

What will I do if I decide to participate?

You will be asked to participate in a series of three interviews at a convenient time in your home. The first interview will explore your life before you received your diagnosis. We may talk about what made you happy as you were growing up or we may talk about the importance of your family to you or we may talk about your profession and other accomplishments.

In the second interview, we will talk about what has happened to you since you found out you had cancer. We want to know what has changed since you became ill and how did those changes make you feel. We want to know if there are parts of having cancer that are particularly hard and what parts are not too bad.

The third interview will be a time to reflect on your life and your disease and discuss what meanings the experience of being ill have had for you. This interview may be the most important because it will give you an opportunity to really tell us about the meaning of cancer and about your life right now.

Are there any risks to me?

The worst thing that might happen is you might get tired. Each interview will take about 30 minutes and may continue for an hour or longer if you like. It is important to know that you can stop the interview whenever you like. Your comfort is very important to us.

It's possible that some people may feel sad when they talk about their life and especially when they talk about their disease. This may be a sad time of your life. But sometimes it's helpful to have a chance to talk about your feelings with someone who will listen.

Will you tell my doctor or anybody else what I've said?

All the interviews will be tape recorded and then transcribed at a later date. The information will only be seen by the research team. Your doctor will not be notified at all. We won't talk to your family about what you've said. The results of the study may be published in professional journals, but you will not be identified.

We will call you in about two weeks to ask if you are interested in participating. Please call Lee Paton at 494-2367 if you have any questions.

Appendix B

Consent Forms

Portland Veteran's Administration Medical Center and
Oregon Health Sciences University
Cancer Patients Consent Form

Research Study Title

The Experience of Suffering with Advanced Cancer or Congestive Heart Failure

Principal Investigators

Lee Paton, RN, MS, Oregon Health Sciences, University School of Nursing, (503) 494-2367 and Christine A. Tanner, RN, Ph.D., FAAN, Oregon Health Sciences, School of Nursing, (503) 494-3742.

Purpose

You have been invited to participate in this research study because you have stage IV cancer and are at least 50 years of age. The purpose of this study is to explore the experiences of pain, suffering, and living with a serious disease as seen through the eyes of patients.

Procedures

We are asking people to participate in a series of at least three interviews that will take about 30 minutes to 90 minutes each. The interviews will take place in your home. You may speak to us longer or shorter based upon your preference. Each interview will be tape recorded and then transcribed at a later date.

Risks and Discomforts

Fatigue may be a potential difficulty for you. Some people become very tired when talking and you may find that 60-90 minutes may be too long. Some people enjoy talking and want to talk longer. We will adjust the length of the interview based on your needs and preferences.

Some people also feel a little sad when discussing their disease and what has happened in their life. It is possible that you may feel sad, however, it is important to remember that some authors have suggested that talking about your feelings of sadness may help.

Your participation in this research study is voluntary, and you may withdraw from this study at any time without prejudice to yourself or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

Liability

For Portland VAMC Patients:

Every reasonable effort to prevent any injury that could result from this study will be undertaken. In the event of physical injuries resulting from the study, medical care and treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in come circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situations where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

Any patient participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairmen, Subcommittee on

Human Studies, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service, (503) 220-8262, extension 55122.

For OHSU Clinic Patients:
The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

Benefits

You may not personally benefit from this study, but the information that you give us may help other people when they reach this point in their lives. You will be helping the medical community understand more about what your needs are and how we can help people like you.

Confidentiality

Neither your name nor your identity will be used in any publication or for any other public purpose. The information you provide will be anonymous and will be reviewed just by the research team at Oregon Health Sciences School of Nursing. The results of your participation in this study may be used for publication or for scientific purposes, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Costs

There will be no costs to you for your participation in this study.

Participation

Lee Paton (503 494-2367) will be available to answer any questions you may have about this study. If you have questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. Your participation is voluntary; you may refuse to participate, or you may withdrawn from this study at any time without affecting your relationships with or treatment at the Portland VAMC or the Oregon Health Sciences University Hospitals or clinics. You will receive a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant ____________________________________ Date ____________

Principal Investigator ____________________________ Date ____________

Witness ____ Date ____________

Portland Veteran's Administration Medical Center and
Oregon Health Sciences University
Congestive Heart Failure Consent Form

Research Study Title

The Experience of Suffering with Advanced Cancer or Congestive Heart Failure

Principal Investigators

Lee Paton, RN, MS, Oregon Health Sciences, University School of Nursing, (503) 494-2367 and Christine A. Tanner, RN, Ph.D., FAAN, Oregon Health Sciences, School of Nursing, (503) 494-3742.

Purpose

You have been invited to participate in this research study because you have congestive heart failure and are at least 50 years of age. The purpose of this study is to explore the experiences of pain, suffering, and living with a serious disease as seen through the eyes of patients.

Procedures

We are asking people to participate in a series of at least three interviews that will take about 30 minutes to 90 minutes each. The interviews will take place in your home. You may speak to us longer or shorter based upon your preference. Each interview will be tape recorded and then transcribed at a later date.

Risks and Discomforts

Fatigue may be a potential difficulty for you. Some people become very tired when talking and you may find that 60-90 minutes may be too long. Some people enjoy talking and want to talk longer. We will adjust the length of the interview based on your needs and preferences.

Some people also feel a little sad when discussing their disease and what has happened in their life. It is possible that you may feel sad, however, it is important to remember that some authors have suggested that talking about your feelings of sadness may help.

Your participation in this research study is voluntary, and you may withdraw from this study at any time without prejudice to yourself or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

Liability

For Portland VAMC Patients:

Every reasonable effort to prevent any injury that could result from this study will be undertaken. In the event of physical injuries resulting from the study, medical care and treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in come circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situations where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

Any patient participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairmen, Subcommittee on

Human Studies, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service, (503) 220-8262, extension 55122.

For OHSU Clinic Patients:
The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

Benefits

You may not personally benefit from this study, but the information that you give us may help other people when they reach this point in their lives. You will be helping the medical community understand more about what your needs are and how we can help people like you.

Confidentiality

Neither your name nor your identity will be used in any publication or for any other public purpose. The information you provide will be anonymous and will be reviewed just by the research team at Oregon Health Sciences School of Nursing. The results of your participation in this study may be used for publication or for scientific purposes, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Costs

There will be no costs to you for your participation in this study.

Participation

Lee Paton (503 494-2367) will be available to answer any questions you may have about this study. If you have questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. Your participation is voluntary; you may refuse to participate, or you may withdrawn from this study at any time without affecting your relationships with or treatment at the Portland VAMC or the Oregon Health Sciences University Hospitals or clinics. You will receive a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant ______________________________ Date ____________

Principal Investigator ______________________________ Date ____________

Witness ______________________________ Date ____________

Appendix C

Interview Guide:

Interview Guide

Interview One: Focused History

The task is to put the participant's experience in context by asking him to tell as much as possible about himself in light of the topic up to the present time. They will be asked to reconstruct early experiences in their families, communities, neighborhoods, work, and military service. The participant will be asked about events in their past family, community, and work experience that place the meaning of their disease in the context of their lives.[51]

Sample Questions:

1. Tell me about your life before you were diagnosed. What kind of work did you do? Did you enjoy it? What kinds of things did you do for fun? Family members?
2. Tell me about how you learned about your disease. From the doctor? From family members?
3. Tell me about what has happened since you were diagnosed.
4. Tell me about the last few weeks.

Interview Two: Experience with Suffering and Disease Progression

The purpose of interview session(s) two is to concentrate on the participants' present experience with their disease and symptoms. No opinion based questions will be used, but rather questions geared to obtain details of the experience on which opinions may be built. We will ask them to talk about their relationship to their doctors, nurses, family members, friends, and to their symptoms. Ask them to reconstruct a typical day of living with their disease and what happens to them from the moment they wake up to the time they go to bed.

Sample Questions:

1. Tell me about your typical day. What happens when you get up in the morning? What happens in the afternoon, evening, after you go to bed?
2. Tell me about any specific physical problems you have.
3. What activities are you unable to do now? Which ones do you miss the most?
4. Tell me a little bit about any concerns or unresolved issues that are important to you.
5. Tell me about what kinds of things your family does for you.

Interview Three: Meaning of Experience of Suffering

The purpose of the third session(s) is to reflect on the differences between the first and second interviews. This strategy may enable the participant to identify episodes of suffering that resulted from living with cancer. This approach also seeks to describe any gaps and connections between the participants' work and present life with their illnesses. This enables the participants to look at how the factors in their lives have interacted to bring them to their present situation. It may also enable them to look at their present experience in detail and within the context in which it occurs.

Sample Questions:

1. Given your experience with cancer and your daily experience with managing and living with your symptoms, how do you make sense out of all this? What has changed the most for you since you've had this disease?
2. Do you think this experience has had any special meaning for you? Tell me about those meanings.
3. Are there any benefits that you have experienced from living with your illness?
4. What kinds of losses have you experienced?
5. What kinds of discomfort, pain, or challenges have resulted from your disease?

The combination of exploring the past to clarify the events that led participants to where they are now, and describing the concrete details of their present experience, establishes conditions for reflecting upon what they are now doing in their lives. The third interview can be productive only if the foundation for it has been established in the first two.

Appendix D

Institutional Review Board Approval
Portland Veteran's Administration Medical Center

Subcommittee on Human Studies
Review Date 9/2/98

Your proposal has been *Approved with modifications,* please make the necessary modifications and return to the below address no later than 8 days after your original review date. This is to ensure your proposal will be reviewed at the R&D Committee meeting on the third Monday of that same month. If modifications have not been received within the 8 days, your proposal will not be reviewed until the following month's R&D Committee meeting.

Title: "Experience of Suffering at the End of Life"
Principal Investigator: Lee F. Paton, MsN.
Assigned to: Max Metcalf, Chaplain

Please make the following changes:

1. Title – Change phrase "End of Life" to alternatives:
    - "of Cancer Patients"
    - "of Advanced Cancer Patients"
    - "of Those Seriously Ill"

      or just "Experience of Suffering"

1. Consent Form/Risks and Discomforts - ¶ 1 Add word "minutes" after 60-90.

3. Delete all references to Physician Assisted Suicide to the Study Summary and all consent forms.

Review and Approval from the R&D Committee is required before studies can be started. An approval memorandum will be sent to you.

Return address:

Research Office
Building 101, Room 502
Mailcode R&D
Attn: Jodi Pass

Department of Veterans Affairs

REPORT OF SUBCOMMITTEE ON HUMAN STUDIES

Project/Program Title “The Experience of Suffering of Advanced Cancer Patients”

Principal Investigator Lee Paton, RN, MSN

VAMC Portland, Oregon Review Date 9/2/98

COMMITTEE FINDINGS

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or surrogate who possesses standard reading and comprehension skills. ☑ YES ☐ NO

2. The informed consent is obtained by the principal investigator or a trained and supervised designate under suitable circumstances. ☑ YES ☐ NO

3. Every effort has been made to decrease risk to subject(s). ☑ YES ☐ NO

4. The potential research benefits justify the risk to subject(s). ☑ YES ☐ NO

5. If subject is incompetent and surrogate consent is obtained, have all of the following conditions been met: a) the research can’t be done on competent subjects; b) there is no risk to the subject or, if risk exists, the direct benefit to subject is substantially greater; c) if an incompetent subject resists, he/she will not have to participate; d) if there exists any questions about the subject’s competency, the basis for decision on competency has been fully described. ☑ YES ☐ NO

6. If the subject is paid, the payment is reasonable and commensurate with the subject’s contribution. ☐ YES ☐ NO ☑ N/A

7. Members of minority groups and women have been included in the study population whenever possible and scientifically desirable. ☑ YES ☐ NO

8. Comments: (Indicate if Expedited Review)

RECOMMENDATION: ☒ APPROVED ☐ DISAPPROVE/REVISE

SIGNATURE OF CHAIRMAN

DATE 9/18/98

VA FORM
OCT 1995 **10-1223**

Memorandum

Date: May 17, 1999

To: Dennis Mazur, MD
VA IRB
VA Medical Center

From: Lee Paton
Predoctoral Fellow

This is a short note to inform you that I have slightly modified my inclusion criteria for my study, *The Experience of Suffering of Advanced Cancer Patients*. I am broadening the age requirements to include patients 50 years of age and older instead of my prior criteria of 60 years and older.

There are no changes to my consent form, except for the second paragraph under Purpose. This will be modified to read as follows:

> You have been invited to participate in this research study because you have stage IV cancer and are *at least 50 years of age*.

No other changes in the consent form or protocol have been made. Please let me know if you have any questions or concerns. My telephone number is 635-2701.

Department of Veterans Affairs

REPORT OF SUBCOMMITTEE ON HUMAN STUDIES

Project/Program Title: **"The Experience of Suffering of Advanced Cancer Patients"**

Principal Investigator: **Lee Paton, RN, MSN**

VAMC **Portland, Oregon** Review Date **6/2/99**

COMMITTEE FINDINGS

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or surrogate who possesses standard reading and comprehension skills. ☑ YES ☐ NO

2. The informed consent is obtained by the principal investigator or a trained and supervised designate under suitable circumstances. ☑ YES ☐ NO

3. Every effort has been made to decrease risk to subject(s). ☑ YES ☐ NO

4. The potential research benefits justify the risk to subject(s). ☑ YES ☐ NO

5. If subject is incompetent and surrogate consent is obtained, have all of the following conditions been met: a) the research can't be done on competent subjects; b) there is no risk to the subject or, if risk exists, the direct benefit to subject is substantially greater; c) if an incompetent subject resists, he/she will not have to participate; d) if there exists any questions about the subject's competency, the basis for decision on competency has been fully described. ☑ YES ☐ NO

6. If the subject is paid, the payment is reasonable and commensurate with the subject's contribution. ☐ YES ☐ NO ☑ N/A

7. Members of minority groups and women have been included in the study population whenever possible and scientifically desirable. ☑ YES ☐ NO

8. Comments: (Indicate if Expedited Review)
Memorandum dated 5/17/99

RECOMMENDATION: ☒ APPROVED ☐ DISAPPROVE/REVISE

SIGNATURE OF CHAIRMAN DATE 6/15/99

VA FORM
OCT 1995 **10-1223**

Continuing Protocol Review
Subcommittee on Human Studies (SHS)/Portland, OR

Principal Investigator: **Lee Paton, R.N., M.S.N.**

Project Title: **The Experience of Suffering of Advanced Cancer Patients**

Proj No: **0001** Grant No: Approval Period: **September 1999 to September 2000**

Funding/Administration: **VA - Office of Academic Affairs/VA**

Electronic Research Flag: ☐ Yes ☒ No

1. Project Status: *(Check one)*
   - ☐ Project has Terminated.
   - ☒ Project is active and human subjects are being enrolled.
   - ☐ Project is active but no human subjects are currently enrolled or being followed and none will be enrolled in the future. Delete human subject approval for this Project.
2. A signed consent form is in my files for each subject entered into this study and, if SHS has determined that this is an invasive study, I have activated a flag in Vista for each subject enrolled.
3. Total number of subjects entered into study since last report: 8
   Please complete the attached form listing every patient enrolled.
4. One or more subjects have claimed injury from participating in this study at this medical center. ☐ Yes ☒ No
5. Unexpected adverse effects have occurred at this medical center. ☐ Yes ☒ No
6. Serious, but expected adverse effects have occurred. ☐ Yes ☒ No

If item 4, 5, or 6 is "Yes", for this medical center or at another site, attach a detailed explanation citing dates, subjects, and circumstances, and state if a report was filed with the Subcommittee on Human Studies (SHS) or an agency such as the NIH or FDA.

> *I am aware that all research projects involving human subjects must receive prior approval by the Subcommittee on Human Studies (SHS), that any change in the protocol requires prior approval by the Subcommittee, that a signed consent form must be obtained from each subject before entry into the study, that continued enrollment of human subjects requires annual review, that participation of human subjects in projects not receiving favorable review must be discontinued, and that a copy of all consent forms and such other related matters as correspondence must be retained by the Principal Investigator for three (3) years after the study has terminated. This form, together with any requested additional information, is submitted in compliance with these regulations.*

Lee Paton

Principal Investigator Signature

8/26/99

Date

[✓ Approved]/Disapproved:

Dennis Mazur, M.D., Ph.D.
Chair, Subcommittee on Human Studies

8/30/99

Date

Date: October 5, 1999

To: Dennis Mazur, MD
VA IRB
VA Medical Center

From: Lee Paton
Predoctoral Fellow

This is a short note to inform you that myself and my committee feel it would be very helpful to include one to two patients with congestive heart failure as contrast cases to the research project entitled, *The Experience of Suffering of Advanced Cancer Patients*. I am broadening the inclusion criteria to include patients with advanced congestive heart failure. As a result, I must alter the title of the study to read as follows:

The Experience of Suffering with Advanced Cancer or
Advanced Congestive Heart Failure

As a result of this change, I have changed the consent form accordingly. Please review the attached changes to the text of the form. I am not copying it directly onto the VA form, however, will do so prior to using the form with patients.

I appreciate your consideration of this change. We feel that it will provide a deeper understanding of the experience of suffering and will benefit the results of this study. Please let me know if you have any questions or concerns. My telephone number is 635-2701.

Portland Veteran's Administration Medical Center and
Oregon Health Sciences University
Congestive Heart Failure Consent Form

Research Study Title

The Experience of Suffering with Advanced Cancer or Congestive Heart Failure

Principal Investigators

Lee Paton, RN, MS, Oregon Health Sciences, University School of Nursing, (503) 494-2367 and Christine A. Tanner, RN, Ph.D., FAAN, Oregon Health Sciences, School of Nursing, (503) 494-3742.

Purpose

You have been invited to participate in this research study because you have advanced congestive heart failure and are at least 50 years of age. The purpose of this study is to explore the experiences of pain, suffering, and living with a serious disease as seen through the eyes of patients. We also want to find out more about how health care providers can help you be comfortable.

Procedures

We are asking people to participate in a series of at least three interviews that will take about 30 minutes to 90 minutes each. The interviews will take place in your home. You may speak to us longer or shorter based upon your preference. Each interview will be tape recorded and then transcribed at a later date.

Risks and Discomforts

Fatigue may be a potential difficulty for you. Some people become very tired when talking and you may find that 60-90 minutes may be too long. Some people enjoy talking and want to talk longer. We will adjust the length of the interview to based on your needs and preferences.

Some people also feel a little sad when discussing their disease and what has happened in their life. It is possible that you may feel sad, but it also important to remember that this can be a sad time of your life and talking about it can also help.

Your participation in this research study is voluntary, and you may withdraw from this study at any time without prejudice to yourself or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

Liability

For Portland VAMC Patients:

Every reasonable effort to prevent any injury that could result from this study will be undertaken. In the event of physical injuries resulting from the study, medical care and treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in come circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situations where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

Any patient participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairmen, Subcommittee on Human Studies, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service, (503) 220-8262, extension 6620.

For OHSU Clinic Patients:
The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

Benefits

You may not personally benefit from this study, but the information that you give us may help other people when they reach this point in their lives. You will be helping the medical community understand more about what your needs are and how we can help people like you.

Confidentiality

Neither your name nor your identity will be used in any publication or for any other public purpose. The information you provide will be anonymous and will be reviewed just by the research team at Oregon Health Sciences School of Nursing. The results of your participation in this study may be used for publication or for scientific purposes, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Costs

There will be no costs to you for your participation in this study.

Participation

Lee Paton [(503) 494-2367] will be available to answer any questions you may have about this study. If you have questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. Your participation is voluntary; you may refuse to participate, or you may withdrawn from this study at any time without affecting your relationships with or treatment at the Portland VAMC or the Oregon Health Sciences University Hospitals or clinics. You will receive a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant ________________________________ Date ___________

Principal Investigator ________________________ Date ___________

Witness __________________________________ Date ___________

Subcommittee on Human Studies (SHS)
Review Date 11/3/99

Your project amendment has been **Approved pending modifications**. Please make the following modifications and return to the address below:

Title: "The Experience of Suffering with Advanced Cancer or Advanced Congestive Heart Failure"
Principal Investigator: Lee Paton, PhD
Comments: broadening inclusion criteria per memorandum dated 10/5/99
Primary Reviewer: William Wickham, Chaplain
Reviewer Comments:

1. Consent Form/Purpose: Delete last sentence.
2. Consent Form/Risks & Discomforts: 1st ¶, last sentence remove the word "to"
3. Consent Form/Risks & Discomforts: 2nd ¶, revise last sentence to "It is possible that you may feel sad, however it is important to remember that some authors have suggested that talking about your feelings of sadness may help."
4. Consent Form: Page 2, top line – change Dr. Mazur's extension to 55122.

Review and Approval from the R&D Committee is required before studies can be started. An approval memorandum will be sent to you.

Return address:

Research Office
Building 101, Room 502
Mailcode R&D
Attn: Jodi Pass