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Transcendence as a Human Response to Life Threatening Illness: Description and Understanding Through Narratives

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TRANSCENDENCE AS A
HUMAN RESPONSE TO
LIFE THREATENING ILLNESS:
DESCRIPTION AND UNDERSTANDING
THROUGH NARRATIVES
BY
JANE WILLIAMS

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY
IN
NURSING

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1995

ABSTRACT

This study explored the phenomenon of transcendence as it occurs in the context of life-threatening illness. Transcendence is a term that is frequently used to describe a patient's response to suffering, but it is an elusive, poorly understood phenomenon.

Narrative interviewing and analysis was the method. Participants diagnosed with terminal cancer provided personal accounts of their experience during in-depth interviews. Three participants were interviewed after being selected by professional nurses working in an oncology clinic as having transcended their illness. The linguistic approach to systematic study of the accounts (Gee, 1985, 1986, 1991; Riessman, 1993) and the voice-centered relational method of thinking about the data (Brown and Gilligan, 1992) were applied. Written interpretations of each account (including graphic representations of the entire accounts and schematic transcriptions of selected narrative segments) and a comparison across accounts were completed.

One of the participants exhibited the wisdom, connectedness, and sense of peace consistent with the tentative definition of transcendence I proposed. Comparison of the accounts revealed that they were similar in the degree of cognitive awareness and the ability to manage the physical manifestations of illness

and treatment. Differences were seen in attitude, communication patterns, perceived support and acknowledgement of prognosis. Displaying the profound dilemma posed by hoping for life while facing death, the accounts emphasized living and paid unequal attention to preparing for death.

The study contributes to the description and understanding of transcendence by providing an example of one case that is compatible with definitions and descriptions in recent literature and examples of similar but essentially different responses. Patient narratives provided a way to achieve deep understanding of the complex human experience of life-threatening illness. Implications for research, practice and education are identified.

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Dedication

This work is dedicated
to my mother, Nina Bodine,
and to the memory of my
father, Ralph Bodine

CHAPTER 1

INTRODUCTION

This study investigates the human experience, transcendence, that has been associated with human suffering. The purpose of the study was to enhance the knowledge base of nursing by contributing to the description and understanding of the phenomenon of transcendence as it occurs in the context of life-threatening illness.

To study transcendence as a human experience associated with life-threatening illness, a retrospective, descriptive inquiry was used. Transcendence is a term that is frequently used to describe a patient's response to illness - particularly life threatening illness (Cassell, 1992; Chopra, 1988; Haase, Britt, Coward, Leidy, Penn, 1992). Nurses can give examples of when transcendence occurs; it seems obvious when it happens. But, it is also an elusive phenomenon. Its definition is undeveloped; its frequency is questionable; it is difficult to detect before it occurs. At this point its nature makes retrospective study the most realistic. Attempting to encounter the phenomenon in the natural setting as it is experienced would be time consuming and generally unreasonable. Using in-depth interviews to capture accounts of the

experience from people who are likely to have experienced it was a viable research approach.

Based on the beliefs that human science needs to attempt to be fully appreciative of the uniqueness and commonalities of human beings and that human beings understand and express themselves through their stories, this qualitative inquiry of the nature of transcendence as a human response to life-threatening illness took an interpretive perspective and studied narratives. In-depth narrative interviews were conducted to explore the personal experiences of persons diagnosed with terminal disease who had been identified, by the nurses caring for them, as having transcended their illness. These narrative interviews produced stories that were analyzed and interpreted to add to the systematic description and understanding of this important human experience.

Research Questions

The research questions directing this inquiry were:

1. How do people who have been identified as having transcended their life-threatening illness describe their experience (in the form of narratives)?
2. What are the characteristics of each account in terms of form, content and meaning?
3. To what extent does a participant's personal account of this experience reflect a story of transcendence?

4. How is the experience of transcendence depicted in each account and to what extent is this similar across participants?
5. To what extent and in what ways does the context influence the stories (or story telling) of transcendence?
6. What emerges from the participant's accounts as factors that precipitate or facilitate transcendence and as positive and/or negative consequences of the experience?

Background and Significance

Human suffering is frequently associated with illness. Suffering may be a primary effect of an illness or an effect of treatment. Despite the expenditure of significant resources, illness continues to cause human suffering. And, health care professionals have failed to fully recognize and attend to suffering (Cassell, 1992; Kleinman, 1988; Watson, 1992). In part this state of affairs can be attributed to the physicalistic view of illness promoted and sustained by the natural science model of scientific inquiry. Medical science describes the biological courses of diseases and advances sophisticated technological treatments. Critiques of the modern health care system propose that the system discourages patients from voicing concerns (Fox, 1993; Mishler, 1986a) that descriptions of the social effects

and personal experiences of illness are lacking (Kleinman, 1988; Robinson, 1990) and that overall the treatment of human illness has become dehumanized.

Recognition that emphasis on the rational over the spiritual - on the objective over the subjective - ignores an important aspect of the human response to illness has fueled efforts to redefine and refocus health care. Nursing, with its longstanding commitment to and primary interest in caring for persons, is appropriately assuming increasing responsibility for improving knowledge of the effects of illness on the human being, of the individual human being's experience of illness, and of human suffering.

This study attempted to expand knowledge of the human experience of illness by exploring the nature of transcendence as a human response to suffering. Transcendence is an inherent human capacity that has been described as a human response to suffering (Chopra, 1988; Koestler, 1949). It is a response in which the person learns from and overcomes adversity. The current literature in nursing science identifies transcendence as an outcome itself and as having a positive influence on the outcome of personal crisis and on one's general state of health (Coward, 1990; Reed, 1991a; Watson, 1985).

Although there is a general recognition of transcendence as a potentially powerful human resource,

there is debate about the nature of the phenomenon. Watson (1985) proposes that transcendence is characterized by the discovery of inner power and control. Coward (1990) and Reed (1991a) both use the term "self-transcendence"; Coward views it as a human capacity, while Reed characterizes it as a pattern of development. Maslow (1966) concludes, in his analysis and comparison of his concept of "deep self" and Frankl's concept of "self-transcendence", that there is need for clarification. The intent of this study was to contribute to the description and understanding of the phenomenon of transcendence as it occurs in the context of a life-threatening illness. Such understanding is foundational to further study of the phenomenon - to the study of its nature over time and in different situations and in relation to its consequences for the experience of illness.

In this study it was assumed that terminal illness resulting from cancer is a situation that challenges human beings and that potentially provokes transcendence. Cancer refers to many diseases, all with a common basic pathophysiology, which have varying prognoses for patients. While medical science has made progress in treatment, some cancers still result in death. It is the reality of this terminality and the prospects of being able to better understand and assist those who are

dealing with it that is of interest here. As the human body is altered by the presence of cancerous tissue, the human person is simultaneously undergoing change. It is obvious that these changes are difficult. Cancer has been associated with a deterioration of mental health, emotional distress and psychosocial maladjustment. There are, however, some people who respond positively to the physical deterioration associated with approaching death. They in a sense gather their spirit. It is the response of enhancing one's essential humanness that is characterized by the term transcendence. Better understanding of the nature of transcendence as it occurs in persons with terminal illness may provide knowledge that might then be used to assist others in similar circumstances.

This study was based on preliminary work that involved in-depth interviews of nurses who care for terminally ill oncology patients (Williams, 1992a). The nurses described example cases of patients who had transcended their illness and those who had not. Analysis of the cases revealed that patients who in the nurses' opinions had transcended their illness were persons who exhibited not only self-awareness, but also an ability to continue to express and extend love for others, a sense of humor and ability to laugh at oneself, a sense of inner power and an ability to care for

themselves and to gather their own spirit. Analysis of the cases also revealed that patients who, in the nurse's opinion, had not transcended their life-threatening illness lacked an ability to express their feelings and self-awareness, were preoccupied with self, did not express concern for others, and were isolated, fearful, dependent and relatively unable to care for themselves. The preliminary work corroborated the existence of the phenomenon and the ability of nurses to identify patients who could be possibly distinguished as experiencing transcendence.

The association of transcendence with personal crisis and one's state of well-being provides the basis for studying transcendence within nursing science where the focus of inquiry is the health of human beings. In this regard, transcendence is a potentially powerful human resource, the understanding of which may help to "treat" illness from within as well as without. Transcendence may be an important adjunct to traditional medical therapies and to dehumanizing health care technologies. Attention to transcendence may improve satisfaction with and effectiveness of health care; it may decrease health care costs; it may promote needed change in the health care system.

CHAPTER 2

REVIEW OF THE LITERATURE

The Phenomenon of Transcendence

Transcendence is a recurring theme in the history of humankind. Transcendence appears in the folk tales of diverse cultures (Chinen, 1986), mythical literature (Apuleius, 1566; Neuman, 1956) and early religious thought (Morris, 1981). Its evolving presence in the history of humankind is testimony of its reality.

The insights, depictions, and examples of transcendence that appear in these writings, however, have not been developed for science. It is only recently that transcendence has been referred to as a scientific phenomenon. In psychology it appears as a marginal phenomenon, principally in the subfield of transpersonal psychology. Psychologists use the terms transcendence (Lifton, 1979) self-transcendence (Frankl, 1959) and transcendent self (Vaughan, 1988) to represent similar meanings. The scientific literature in nursing has identified transcendence as a topic of concern to the discipline (Sarter, 1988). Most nurse scientists have adopted Frankl's notion of self-transcendence as the basis for their conceptualization of the phenomenon (Haase, et al., 1992).

The review of the literature relevant to this study of transcendence as a response to suffering focuses on

the scientific literature of psychology and nursing and includes some pertinent literature from other disciplines. Since the incorporation of this elusive phenomenon into human science is relatively recent, it is important to work towards full description of the phenomenon and to avoid premature, incomplete definition. Drawing from both scientific and non-scientific writings helps to maintain a broad view.

The following review of the literature will begin by summarizing current understanding of transcendence as it has been studied in psychology and illuminated by writings from other disciplines. This part of the review will address: Transcendence as A Process and A Resulting State, Descriptions of Transcendence, Factors Precipitating and Facilitating Transcendence and Transcendence and Life Crises. Finally, the literature from the discipline of nursing will be described and analyzed in subsequent sections.

Transcendence as A Process and A Resulting State

Common definitions of transcendence characterize it as a process and a state of being, albeit one that is beyond the ordinary and difficult to describe. According to the Compact Edition of the Oxford Dictionary (1971) transcendence is defined as:

1. The action or fact of transcending, surmounting; ascent, elevation; excelling, surpassing; also the condition or quality

of being transcendent; surpassing eminence or excellence.

2. Elevation or extension beyond ordinary limits; exaggeration, hyperbole

(p.3378)

Definition of the related word "transcendent" includes, as third and fourth meanings, Kant's notion of the transcendent being obscure and/or unrealizable in human experience (Oxford Dictionary, 1971, p. 3378).

The idea that transcendence is a process and state is expressed metaphorically and descriptively in writings about transcendence. The images of "path", "journey", and "throne" are used in elder tales (Chinen, 1986) and religious writings (Morris, 1981). Alluding to its dynamic nature, early religious writings describe transcendence as "deepening of consciousness" (Morris, 1981, p.29). Suggesting its static essence, transpersonal psychologists describe it as a "trans-egoic" state (Wilber, 1990, p. 132). Derek Chopra (1989), a physician and author of Quantum Healing, reflects the ideas of both process and state in his description of transcendence as a "leap of consciousness" and a "fourth state of consciousness."

Psychologists generally conceive of transcendence as a "natural" state of consciousness. Frankl (1966) identifies self-transcendence as the "essence of human existence" (p. 104). Maslow (1969) thought it to be

potentially available to everyone. The writer Arthur Koestler (1949) describes self-transcending impulses as "organically rooted in the individual" or an "inherent tendency" (p. 171).

Although transcendence is usually held to be an inherent human capacity, human beings who experience transcendence are repeatedly characterized as possessing a special appreciation of reality - the reality of being - that comes with inner awareness, insight and wisdom (Chopra, 1989; Morris, 1981; Suter, 1986). The experience is typically one in which a "sense of truth" is achieved - "the person has become privileged to reality in a way not possible during ordinary consciousness" (Suter, 1986, p. 185). Transpersonal psychologists believe that the perception of transcendence as out of the ordinary has more to do with evolutionary forces than reality and that this perception needs to change for the good of society (Vaughan, 1988). Walsh (1988) expresses this view:

The great experiment in consciousness, human evolution, now stands at a precipice of its own making. That same consciousness which struggled for millions of years to ensure human survival is now on the verge of depleting its planet's resources, rendering its environment uninhabitable, and fashioning the instruments of its own self-annihilation. Can we foster sufficient self-understanding to reduce our destructiveness, and mature rapidly enough to carry us through this evolutionary crisis? . . . Humanistic, transpersonal, Jungian, Eastern, and some existential psychologists agree that the challenge of individual maturation and

evolutionary advance must be a major human motive.

(p.1, 4)

There is much debate about the nature of the process of transcending - of achieving the transcendent state (Washburn, 1990; Wilber, 1990). Psychologists describe the process that underlies transcendence as being developmental. As Karasu (1979) states:

the individual on his way to maturity, seeking fulfillment as a whole person, has to go the inward way and to discover a new dimension. . in which he experiences a transcendence of ego boundaries into a universal consciousness (p. 559).

Ken Wilber (1981) also sees the process as maturational: "For those who have matured to a responsible, stable ego, the next stage of growth is the beginning of the transpersonal, the level of psychic intuition, of transcendent openness and clarity, the awakening of a sense of awareness that is somehow more simple than mind and body" (p. 5). Chinen (1986) dramatically presents transcendence as a developmental, maturational phenomenon in his analysis of folk tales that feature older adults; as he states, "elder tales present transcendence as one of the main challenges for later life, and depict many different forms in which the process may occur" (p. 171). These tales arise from all religions, cultures and historical periods (Chinen, 1986, p.172). Questions about the developmental nature of transcendence remain. Although psychologists describe a

developmental process, most do not see transcendence as predictable. The process of transcendence "can be either smooth and secure or turbulent and precarious"; it can be a "gradual opening" or "sudden breakthrough" (Washburn, 1990, p.91). The philosopher Santayana (1940) captures this view in the following passage:

Insight and holiness may appear anywhere in anchorite or beggar, in prince or poet even in a child, when once the illusion of will is pierced, and the bias of time, place, and person is overcome (p. x).

Current literature in psychology and other fields appreciates transcendence as a dynamic process and state of being.

Descriptions of Transcendence

Although there are assuredly some who believe that transcendence belies description and many who would acknowledge the difficulties of such a task (Morris, 1981; Noble, 1987; Suter, 1986), there are commonalities in the various characterizations presented in the literature that do in fact provide understanding. These commonalities can be seen in the depictions of transcendence as it has been experienced by and manifested in human beings, and described in theoretical writings and anecdotal accounts. Key examples of these will be presented in order to fully describe the phenomenon. Descriptions gleaned from empirical studies are rare and exist primarily in nursing. These nursing

studies will be addressed later in the section discussing transcendence in nursing science.

The description will begin with Morris' (1981) summary of the writings of the 16th Century religious philosopher Mulla Sadra. This summary provides one of the most specific and extensive descriptive statements. In his translation of Sadra's work, Morris (1981) describes transcendence as:

- a condition of intrinsic finality, completion, fulfillment, and inner peace;
 - a unique sense of unity, wholeness and communion;
 - a distinctive suspension. . .of our usual perceptions of time and space;
 - where nature is involved a vision of all being as essentially alive;
 - a sense of profound inner freedom and liberation (or negatively stated, the absence of anxiety, guilt, regret)
 - a perception of universal love or compassion extending to all beings
 - a paradoxical sense of standing beyond and encompassing flow of particular events (including the actions of one's own body).
- (p.8-9)

Aspects of this description appear in other writings about transcendence, providing a beginning level of agreement.

Fulfillment and inner peace are frequently identified with the transcendent state. Transpersonal psychologist Ken Wilber (1990) states, "The trans-egoic state is, more or less, a unified whole which is often accompanied by feelings of bliss, fullness, and superabundance" (p. 132). Bellah (1969), writing from a

religious point of view, states, "the inner experience of fulfillment, not of needs, has always been the chief 'inner' dimension of the transcendent reality" (p. 88).

Similarly, "unity" is described by psychologists as an essential feature of transcendence. It is usually referred to as "being at one with the universe" (Suter, 1986; Steiner, 1987; Wilber, 1990). Maslow, describing the "experience of deep self", which he and others equate with a transcendent state, states that "all separateness and distance from the world disappear" (cited in Chopra, 1989, p. 164).

Writers often speak of the presence of "inner freedom and liberation" in transcendence, while at the same time noting the "absence of anxiety, guilt and regret". Those who have studied the elderly have identified "liberation from the past" (Eckert, 1984) as correlates of self-transcendence. Psychologist Claude Steiner (1987) associates transcendence with a lack of "fear of death or the future" (p. 104). Folk tales that symbolize transcendence as a life task typically "accept death as a part of a natural cycle and present protagonists who in their transcendence approach death with calm acceptance" (Chinen, 1986). It is acceptance and a positive outlook as opposed to fearfulness that is associated with the transcendent state.

Compassion and love permeate the experience of transcendence. In his analysis of Sadra's religious philosophy, Morris (1981) writes, "The signs of enlightenment are most clearly manifested in the 'knowers' inner ethical orientation, or power of love, not in his visions or magical powers." Frankl (1959) describes this dimension of transcendence in his powerful account of his own survival of concentration camps:

The salvation of man is through love and in love. I understood how a man who has nothing left in this world still may know bliss, be it only for a brief moment, in the contemplation of his beloved. In a position of utter desolation, when man cannot express himself in positive action, when his only achievement may consist in enduring his sufferings in the right way - an honorable way - in such a position a man can, through loving contemplation of the image he carries of his beloved achieve fulfillment. For the first time in my life I was able to understand the meaning of the words, "the angels are lost in perpetual contemplation of infinite joy"

(p.36-37)

Some include expressions of love as well as feelings of love as part of this phenomenon. The expression of love through giving seems to be sometimes, but not always, present. As Frankl (1959) states, "But I have to confess here that only too rarely had I the inner strength to make contact with my companions in suffering and that I must have missed many opportunities for doing so (p. 84)."

Perceptions of time and space appear to be altered during transcendence. Studying transcendence during

meditation, Suter (1986) documents changes in time perception -- "an instant seems to last forever", "heightened acuteness of perception", intensification of images, and possible hallucinations.

Specific physical symptoms, in addition to the above descriptors found in Sadra's work, have been associated also with transcendence. These have included descriptions of physiological changes such as "autonomic changes consistent with relaxation, lowered metabolism, decreased heart rate, decreased rate and depth of respiration and decreased attention to stimuli" (Suter, 1986, p.187). [It is interesting to note that, although meditation produces physiological relaxation, its purpose is to heighten awareness (Chopra, 1989)].

The perception of distinct light commented on by some writers represents the actual moment of revelation that sometimes is part of the experience. Frankl (1959) describes this image of light:

Another time we were at work in a trench. The dawn was grey around us; grey was the sky above; grey the snow in the pale light of dawn; grey the rags in which my fellow prisoners were clad, and grey their faces. I was again conversing silently with my wife or perhaps I was struggling to find reason for my sufferings, my slow dying. In a last violent protest against the helplessness of imminent death, I sensed my spirit piercing through the gloom. I felt it transcend that hopeless, meaningless world, and from somewhere I heard a victorious "Yes" in answer to my question of the existence of ultimate purpose. At that moment a light was lit in a distant farmhouse, which stood on the horizon as if painted there,

in the midst of the miserable grey of a dawning morning in Bavaria. . .and the light shineth in the darkness (p.39-40).

The nature of transcendence suggested by Morris (1981), used as a basis for description here, and addressed by others appears to different degrees in many discussions. These themes and variations are visible in the following comment:

Those who suffer from bondage and confinement see it as promising liberation and expansion. Those who suffer from darkness look to it for light. To those who groan under the weight of death and transitoriness it intimates eternity. To those who are restless it betokens peace.
(Smith, 1969, p.6).

With its colorations and variations, transcendence is a source of inner, human power (Nino,1990; Steiner, 1987,). Inner strength and wholeness are fruits of the process. Paradoxically, inner power is also a possible initiator of the process. The individual human being must choose transcendence over despair, self-centeredness, and separateness.

Factors Precipitating and Facilitating Transcendence

Although there are ideas about what precipitates and facilitates transcendence, most would agree that there are no absolute precipitating factors and that it is not a predictable experience. Citing current research Noble (1987) states:

demographic variables such as age, gender, race, socioeconomic status, educational level, occupation, religious beliefs, attendance at religious services, practice of physical

exercise or meditation and the use of consciousness altering drugs have little or no relationship to the incidence of transcendence (p.603).

It is, however, useful to present thoughts about factors that have been associated with initiating transcendence. Morris (1981) states that just "becoming aware of the possibility of transcendence may initiate the process (p. 12). "Clearing a place" is a recurrent theme in folk tales about transcendence that, according to Chinen (1986), represents the idea of creating mental space for thinking (p. 175). Santayana (1940) expresses a similar notion when he states, "the spirit requires no new matter or energy besides that of its organ, but only order and harmony in the matter or energy at hand" (p.x). These factors are consistent with the idea that a person thinks about and chooses transcendence.

Whether or not transcendence can be "learned" is debatable. Chopra (1989) would say it is not thinking. Although it may not be a pure cognitive process there is evidence that one can learn to transcend! Meditation is a process that can be learned.

According to Noble, "researchers (e.g. Goleman, 1971, Greeley, 1974; Maslow, 1972; Sullis, 1982; Shapiro, 1980; Walsh, 1983) would argue that many individuals who experience transcendence do so not as a result of life crisis, but as the specified outcome of psychological preparation" (p. 605).

Interpersonal relationships have been associated with transcendence. Nino (1990) poignantly describes the nourishing role of interpersonal relationships in his analysis of Augustine's Confessions as an illustration of self-transcendence. Lievegoed (1979) states that "the spiritual potential of the human being does not develop as a matter of course, but is dependent on the interrelationships resulting from his own confrontations with human beings (p. 110)."

Social forces may also influence the transcendence of human beings. There is mounting concern that the nature of society may facilitate or restrict individuals' ability to experience transcendence. Koestler's (1949) view is that although self-transcending "impulses are organically rooted in the individual" . . . "the social environment may facilitate or thwart their unfolding" (p. 171).

In summary, although factors are best viewed as influencing rather than causing transcendence, it is important to recognize the repeated mention of the following important influences: creating a mental climate that allows for self-reflecting, becoming aware of the possibility of self-transcendence and engaging in interpersonal relationships that are characterized by love and compassion.

Transcendence and Life Crises

There is agreement that life crises are frequently associated with transcendence. Taylor (1983) states "when people face a life-threatening crisis they feel a desperate need to restore self-esteem by attempting to gain mastery of the situation and by finding some meaning in it" (p. 1162). According to Noble (1987):

Some researchers suggest that prior to transcendence people frequently are wrestling with a major life transition such as midlife crisis, period of intense stress or despair, a sense of inauthenticity or disillusionment, the emergence of previously repressed insecurities or strong feelings, difficulty coping with grief, aging, illness and death (p. 605).

In fact, "The most frequently reported catalyst of transcendence is survival of clinical death" (Noble, 1987, p.603). The importance of life crisis as a consistent facilitator is supported by history:

"Anthropologists generally agree that in situations of life crises and emotional stress primitive man experienced rescue through myths that showed him a way of escape where empirically none had existed" (Smith, 1969, p. 9).

The identification of transcendence as a human phenomenon that is associated with life crisis, and specifically with the crises of illness and death, is important for nursing. The realization of the association raises the relevance of the phenomenon for nursing science.

The definitions and descriptions of transcendence and the factors influencing its occurrence just described have been drawn from the psychological literature and other writings. What is apparent is that transcendence is frequently identified as a phenomenon, but is not clearly delineated nor fully understood. The literature contains a wealth of possible ideas about transcendence as a human experience, ideas that do encourage those who attempt to describe it to remain open to variations and complexities.

Transcendence in Nursing Science

The discipline of nursing views transcendence as a human phenomenon that is significant in the lives of people who are dealing with illness. Recognition of its significance comes from the practice as well as the science of nursing. Expert nurses sharing knowledge from their extensive clinical practice have described transcendence as a response to life threatening illness and have suggested strategies that encourage it (Belcher, Dettmore, & Holzemer, 1989; Busick, 1989; Brailleur, 1992). While the attention the general professional literature has paid to transcendence helps to establish its import for nursing, the primary interest here is its development as a topic in nursing science.

Over the past decade nursing scientists have shown increasing interest in the phenomenon of transcendence.

Self-transcendence is acknowledged as a theoretical theme and major concept in nursing. According to Sarter (1988), self-transcendence is a common theme in four major contemporary nursing theories: Rogers' Science of Unitary Human Beings, Newman's Theory of Expanding Consciousness, Watson's Theory of Human Caring and Parse's Theory of Man-Living-Health. Haase, et al., (1992) identify and develop self-transcendence as a concept of concern to nurses. Empirical research has included phenomenological study of self-transcendence in women with Breast Cancer (Coward, 1990) and in gay men with AIDS (Coward & Lewis, 1993), and, using primarily a quantitative approach in elderly groups, the investigation of the relationship of self-transcendence and depression (Reed, 1989), feelings of hopelessness and self-neglect (Reed, 1987), and mental health (Reed, 1991a).

Self-transcendence is the name most often given to the phenomenon of transcendence as it is evolving as a topic in nursing science. In 1993, self-transcendence became a subject heading in the Cumulative Index to Nursing and Allied Health Literature. However, there is not total agreement on terminology. The term transcendence is sometimes used (Watson, 1985; Weenolsen, 1991). Steeves and Kahn (1987) name a very similar phenomenon in hospice patients as "experiences of

meaning" (p. 116). Battenfield (1984) and Hinds (1992) label behaviors much like those that signify transcendence as a factor, "Finding Meaning" characterizing the recovery phase of response to suffering. With the apparent similarities in the phenomena these terms describe, there is a need to keep the discussion of terminology open.

Nursing Science Definitions

The most current nursing definition cited focuses on self-transcendence as a process. The theoretical definition agreed to by the major nurse scientists working on self-transcendence, Doris Coward and Pamela Reed, and presented in an article that analyzes self-transcendence and related concepts (spiritual perspective, hope and acceptance) is:

"self-transcendence is defined as the experience of extending one's self inwardly in introspective activities, outwardly through concerns about the welfare of others, and temporally such that the perceptions of one's past and anticipated future enhance the present."

(Haase, et al., 1992)

According to Haase, et. al., (1992) this theoretical definition is based on the work of psychologists (Ellison, 1983; Frankl, 1969; May, 1981; Yalom, 1982) and nurses (Lane, 1987; Reed, 1989, 1991) (p. 144). The definition begins with the idea that self-transcendence is an experience but explicates selected dynamic

processes theorized as facilitating the state. Including such processes in the definition is questionable because they are restrictive and because the same authors also concluded that "self-transcendence was identified as an outcome attainable through processes of spiritual perspective, acceptance and hope" (Haase, et al., 1992, p. 146). This definition suggests that self-transcendence is a process, but it doesn't fully describe it. The definition is imprecise and fundamentally inadequate.

There are pitfalls associated with using inadequate definitions in scientific inquiry. The empirical study of transcendence in nursing has been marred by problems of definition. Reed (1991a), in her triangulated study of the relationship between self-transcendence and mental health in persons 80 - 100 years of age, stated first that her qualitative interview was designed to "elicit the participants' own descriptions of self-transcendence perspectives and behaviors that promoted their sense of well being" but then asked three broad, open-ended questions based on her definition of self transcendence. The questions addressed the participants' 1) "focus on things beyond themselves or other than themselves", 2) "perspectives about their past, present and future", 3) "perspectives on physical changes or bodily changes' they were currently facing." The qualitative data

unsurprisingly revealed four patterns of self-transcendence, Introjectivity, Generativity, Temporal Integration and Body Transcendence. The research serves to confirm the researcher's conceptualization not to elicit participants' views.

In a similar vein Coward (1990) deviated from her stated theoretical definition of self-transcendence. In her phenomenological study of the lived experience of self-transcendence in breast cancer patients, she asked her subjects to describe the lived experience of self-transcendence and then defined self transcendence for the participants prior to interview as "a sense of well being, purpose in life and interconnectedness with others". Well-being, purpose and interconnectedness appeared as themes in the analysis of subjects' descriptions. Coward biased her subjects' descriptions by providing them with her definition and telling them in so many words that she expected them to have a sense of well being, purpose in life and feelings of interconnectedness with others.

These examples from Reed's and Coward's work not only show how definitions may subtly bias inquiry, but also demonstrate the inconsistencies in current definitions. Both Reed and Coward used definitions in their qualitative questions that differed somewhat from their stated theoretical definition of self-

transcendence. It may be that inconsistency is more likely to occur with fundamentally inadequate definitions.

Moving from the theoretical definition, Reed (1991a) operationally defines self-transcendence as a property and measures it in quantitative terms by the self-transcendence Scale. The Self-Transcendence Scale, the development of which is fully documented by Reed (1989; 1991a), is administered by interview with the final score reflecting an overall level of self-transcendence:

"The Self-transcendence Scale (STS). . . consists of 15 items which identify intrapersonal, interpersonal, and temporal experiences characteristic of later life that reflect expanded boundaries of the self. . . The STS was developed from a 36-item scale, the Developmental Resources of Later Adulthood (DRLA) Scale (Reed 1986). Exploratory Factor Analysis, supported by cluster analysis, yielded four interpretable factors that explained 64% of the variance. The Self-transcendence factor alone accounted for 45.2% of the variance in the DRLA with an Eigenvalue of 12.1."

(Reed, 1991a)

There has been significant criticism of the use of quantitative methods to study human experiences (Duffy, 1992; Steeres & Kahn, 1986). The creation of a 15 item scale to measure a complex and at this point poorly understood human phenomenon like self-transcendence fortifies that judgment.

The collaboratively refined and frequently cited nursing definition of self-transcendence narrowly

interprets the notions of transcendence as process. There is a need for more systematic study of the phenomenon as it is experienced by people whose care is the concern of nurses and to refine the definition of the phenomenon in light of that study.

Nursing Science Descriptions

Nursing science descriptions of self-transcendence have evolved from theoretical ideas and a very limited amount of empirical work. Principal contributors to the nursing account are Doris Coward (1990), who provides the only descriptive research with her phenomenological study of five women with breast cancer, Pamela Reed (1989, 1991a), who furnishes limited empirical evidence with her quantitative investigations, and a collaborative group (Haase, et al.) who present a description that integrates the empirical work of Coward and Reed and theoretical ideas from nursing and psychology.

Agreeing with virtually all who write about transcendence, nurse scientists describe it as a basic, inherent human capacity (Coward, 1990; Haase, et al., 1992; Reed, 1991b). Haase, et al., (1992) identify it as an "essential antecedent" of self-transcendence the "inherent tendency of humans to move beyond their own interest" (p. 144). That all human beings are capable of self-transcendence is a basic assumption.

Since Haase's (1992) description represents a collaborative synthesis of nursing descriptions, the entire description is excerpted to demonstrate the content of and documentation for each "outcome".

The outcomes of self-transcendence are a sense of well being (Ellison, 1983; Reed, 1989; 1991), enhanced feelings of self-worth (Coward, 1990; Kovacs, 1986), a greater sense of connectedness with others, nature, and God (Coward, 1990; Reed, 1987; Rogers, 1980; Vaughan, 1979; Watson, 1985), personal growth (Frankl; Parse, 1981; Maslow, 1971; May, 1981; Vaughan, 1989; Watson, 1989); finding purpose and meaning in life (Coward, 1990; Dixon & Dixon, 1984; Ellison, 1983; Frankl, 1969) and sense of being healed (Coward, 1990; Vaughan, 1989).

(Haase, et al., 1992, p. 145)

The comprehensiveness of these "outcomes" needs to be examined. But, this analysis is complicated by the fact that the meanings and boundaries of the outcomes are not clear. For example, it is not clear what "sense of well-being" means. Haase (1992) doesn't define it. In previous work, Coward (1990) represented it as an "emotional awareness of a sense of well being that includes a physical sense of lightness" (p. 166), and Reed (1989, 1991a) essentially defined well being as mental health. The meaning of each "outcome" needs to be clarified.

Also, the boundaries of the concept of self-transcendence are unclear. The "outcomes" cited reflect self-transcendence as it is experienced in a variety of populations - including persons with potentially terminal

illness (Coward, 1990), and the elderly as they presumably face end of life issues (Reed, 1989, 1991a). The "sense of well being" experienced by women with potentially terminal breast cancer may well be different from that experienced by the elderly or general population. And it is unlikely to be equivalent to the common meaning of sense of well being, that is, a "state of being happy, healthy or prosperous". Each "outcome" needs to be defined and reconsidered in relation to its applicability in different situations.

Returning though to the question of comprehensiveness, the extent to which this current collaborative description represents prevalent ideas about the phenomenon has been addressed. Do the listed "outcomes" represent all possible experiential characteristics of self-transcendence?

First, the "outcomes" presented do seem to reflect the broad view of transcendence. For example, "a greater sense of connectedness with others, nature and God" is the idea of unity -- of connectedness rather than separateness -- that is generally thought to characterize this experience. The idea of unity appears as a strong element of the broad view described earlier. Another "outcome", the "sense of being healed", is expressed elsewhere as a sense of wholeness (Morris, 1981). The other "outcomes", "sense of well being", "enhanced

feelings of self worth", "personal growth", and "finding purpose and meaning" appear in Coward's description and are documented by the nursing and psychological literature as cited by Haase (1992).

Secondly, although the "outcomes" presented do seem to reflect the broad view, there are some omissions. The stated "outcomes" do not include elements of self-transcendence found in the empirical work of the authors themselves and in other writings. Two major omissions include 1) a lessening of fear, anxiety, guilt and regret (positively stated as a sense of inner freedom and liberation) which was reported as characteristic of self-transcendence by Coward (1990) and Reed (1991a) and contained in the descriptions of others (Chinen, 1986; Eckert, 1984; Morris, 1981; Steiner, 1987) and 2) physiological alterations (including lessening of pain as well as other physical changes) that have been mentioned in the descriptions from the nursing (Coward, 1990; Reed, 1991a) and medical/physiology (Chopra, 1989; Suter, 1986) literature.

Other aspects that appear in other descriptions of transcendence and are not made explicit in the nursing conceptualization are peace, inner fulfillment, love and compassion, an altered sense of time, sense of feeling uplifted (Coward, 1990), sense of self-understanding

(Coward, 1990), sense of acceptance of personal circumstances (Coward, 1990).

One conceptualization of transcendence needs to be recognized as having an unequivocally different trajectory. Weenolsen (1991) proposes that transcendence may be "healthy, complete or incomplete, maladaptive or even pathological" (p. 62), while others clearly view it as a potentially profound healing process. She describes "mechanisms" of general transcendence as being "watching movies or television, reading, involving oneself in art, travel, religion, sports or the use of alcohol or drugs" (Weenolsen, 1991, p. 62), when others identify personal growth experiences as the most likely facilitators of transcendence. Weenolsen's conceptualization needs to be appreciated for what it is - flawed with contradictions and inconsistencies and disconnected from the foundational ideas about the phenomenon.

Before closing the presentation of the description of self-transcendence in nursing, attention must be paid to similar, possibly alternative, conceptualizations. Battenfield (1984), as part of her work on suffering, developed a schema entitled "Qualitative Responses Observable in Situations of Suffering" which she field tested and confirmed with nine subjects. The "observable" attitudes Battenfield identifies as characterizing the highest level of response to

suffering, that is the Phase III Recovery phase, are "expanding self-awareness, growth; developing unity of existence with nature; developing and strengthening interpersonal relationships; reappraising and strengthening values; developing creative activities, finding joy despite suffering". All of these observable attitudes could be shown to be equivalent or similar to components of self-transcendence.

Another closely related conceptualization is the "experience of meaning" as reported by Steeves and Kahn (1987). Arrived at by clinical observation and analysis of hospice patients' stories, the "experience of meaning" is similar to the current nursing description of self-transcendence. It is characterized by connectedness, healing and acceptance. The patients "described discrete experiences during which they were affected by something greater than themselves". . . and relieved of their suffering; they "appear to have risen above their own condition" (Steeves & Kahn, 1987, p. 115-116).

However, the concept of "experience of meaning" is different from self-transcendence. It is a discrete, time-limited phenomenon. No time boundary has been used to describe self-transcendence. And, as Steeves and Kahn (1987) state, "The hospice experiences were not understandings or explanations of their illnesses but experiences of the whole person" (p. 115). The

"experience of meaning" is qualified as an aesthetic not cognitive experience: many believe self-transcendence can be learned.

In a sense these alternative conceptualizations complicate the description of the phenomenon of self-transcendence. At the same time, they also add credibility to the reality of the phenomenon.

The nursing description of self-transcendence is at an initial phase of development. The description in the literature is reflective of empirical and theoretical work done on the phenomenon, but it lacks clarity and comprehensiveness. There are unexplained omissions. There needs to be a stronger base of systematic description. Key words and phases need to be defined. And lastly, transcendence needs to be differentiated from or reconciled with alternative conceptualizations.

Identification of Related Factors in Nursing Science

Many factors influence the human phenomenon of self-transcendence. Nursing science descriptions and explanations of these factors have begun to be tentatively advanced.

Agreeing with generally held beliefs (Noble, 1987; Smith, 1969; Taylor, 1983), nursing scholars have viewed self-transcendence as being associated with life crises (Coward, 1990; Haase, 1992; Reed, 1989, 1991b). The women with breast cancer in Coward's (1990) study

identified "instances in which they had searched for new purposes in their lives after life events that caused them emotional and physical pain, loss and the threat of loss" (p. 167). Reed (1991a) theorizes that, "life events that heighten a sense of mortality" . . . such as "terminal or chronic illness, bereavement, disability, aging, childbirth, or other life crises" can trigger self-transcendence (p. 5). Reed draws empirical support for her proposition from her quantitative investigation (N=300) of spirituality in which she found that "terminally ill hospitalized adults indicate a greater spiritual perspective than non-terminally ill hospitalized adults and healthy, non-hospitalized adults" (Reed, 1987, p. 335).

While the association of self-transcendence with life crises is well accepted, there are diverse explanations of the dynamics of the association. Some nurses propose that life events stimulate cognitive restructuring (Haase, et al., 1992), whereas others suggest it is an aesthetic experience (Steeves and Kahn, 1987). Others describe the nature of the association as "cognitive" (Taylor, 1983), as "not thinking" (Chopra, 1989) and as "becoming aware of the possibility" (Morris, 1981; Chinen, 1986; Santayana 1940). How life crises stimulate self-transcendence is not well understood.

Although the empirical work is limited, factors have been identified as influencing self-transcendence. Both Coward (1990) and Reed (1991a) indicate that "inward" (introspective activities) and "outward" (reaching out to others) foster self-transcendence. The women in Coward's (1990) study emphasized the meaning experienced through helping and receiving help from others. Introspective activities, such as hobbies, travel, housework, reading, taking formal courses: spiritual or self-reflection were identified to be somewhat more important than generative activity (helping others) in Reed's (1991a) depiction of self-transcendence patterns (p. 10). Steeves and Kahn (1987), based on informal interviews and concept analysis, propose that "free time", "solitude" and freedom from pain are necessary for -and that "quiet, the presence of a variety of potentially interesting objects, freedom from constant responsibility and decision-making, and clean and comfortable surroundings are helpful for - an "experience of meaning". These limited observations suggest various meanings or contexts of "inward work". The idea that both "inward" and "outward" personal work encourages self-transcendence is reflected in psychological theories that suggest that maturation (Karasu, 1979; Wilber, 1981), psychological preparation (Maslow, 1966) and conscious awareness and choice (Morris, 1981; Santayana, 1940) foster transcendence.

The nature of the "inward" and "outward" work needs further study.

Theoretically, Haase, et al., (1992) identify self-transcendence as an "outcome attainable through the processes of spiritual perspective, acceptance and hope" (p. 146). The authors acknowledge that these processes are difficult to distinguish from self-transcendence. Indeed spiritual perspective (defined as "highly individualized awareness of one's own spirituality") acceptance (defined as "resolution of fear and resistance" and hope (defined as one's "sense of having a positive future") are characteristics of the state of transcendence as it has been described in the available empirical studies (Coward, 1990; Reed, 1991a).

"Antecedents" emerge as part of the "outcome". It may be important to conceptualize some factors that foster self-transcendence as inseparable from it. In nursing science Pamela Reed has made the major formal attempt at theorizing about transcendence that is explicated in the article, "Toward a Nursing Theory of Self-Transcendence: Deductive Reformulation Using Developmental Theories" published in Advances in Nursing Science (Reed, 1991b) and summarized, in slightly revised form, in Reed's (1991a) article entitled "Self-Transcendence and Mental Health in Oldest - Old Adults". Although Reed has a history of thoughtful research concerning resources of

adults facing developmental crises (Reed, 1986a; 1986b; 1986c; 1987; 1989; 1991a; 1991b; 1992), her proposed theory does not provide a basis for studying the phenomenon. In Reed's theory there is serious inconsistency in definition of the major theoretical terms, troublesome circular theoretical reasoning and mismatched ontological, epistemological and methodological perspectives (Williams, 1992b).

Summary

While there is general acknowledgement that self-transcendence has import for nursing, review of the nursing science literature regarding transcendence reveals major problems of definition, conceptualization and theorizing. There is a lack of agreement about how transcendence should be defined and what terminology should be used. Conceptualizations are incomplete and inconsistent. Proposed theories are specious and not useful. The existing work demonstrates the worthiness and complexity of the topic and the difficulties that arise from premature conceptualization and theorizing. Scientific inquiry regarding transcendence as a human response to life-threatening illness needs to be directed toward description in order to develop meaningful, useful knowledge of the experience.

The work to date also demonstrates the need for approaches to human science inquiry that appreciate the

uniqueness and commonalities of human beings and that are developed so that the philosophical underpinnings of the research are consistent with the methodology. The approach to inquiry taken in this study is grounded in the interpretive view. This perspective, referred to as "perspectival realism (Bruner, 1990) and "subtle realism" (Hammersley, 1992) rejects both the essentialistic idea that there is an absolute truth and the relativistic acceptance of all perspectives as equal. Multiple perspectives on reality exist but have different value. Knowledge is related to perspective, tentative, and uncertain.

These beliefs about reality and knowledge support meaningful study of human experience. Human beings need to be studied in context. For this study the human being is conceptualized as a unique biological species that has the distinguishing characteristic of consciousness, expresses the self through thought and action, and lives in a cultural world. This conceptualization recognizes the presence of biological, psychological and social elements of human experience. It appreciates the "self" as a construction that appears from the inside out from culture to mind as well as from mind to culture (Bruner, 1990, p. 108). The conceptualization is compatible with the idea that human beings express themselves through their stories. It is through interpretive study that

merges the participant's with the interpretation of the researcher that meaningful knowledge of human experience is gained. This study is designed to gain knowledge of human response to life threatening illness through interpretive description of human experience.

Initially, I set aside the literature definitions and descriptions of transcendence in order to focus on the experience of participants. Secondly, the participants' accounts of their experience were compared to the literature. Drawing from the literature, the following tentative definition and key descriptive elements for transcendence were formulated and used as guidelines in addressing the research questions:

Transcendence is a dynamic state of human consciousness that is characterized by wisdom, connectedness and a sense of peace. Wisdom is the knowledge and insight that are demonstrated in being aware of what is going on and in making sound judgments. Realistic hope (expectations for the future) is maintained. Connectedness is being in meaningful relationship and association. It is expressed as feelings of love and harmony. Bonds may be with other people, animals, nature and God. A sense of togetherness (not separateness) prevails. Peacefulness includes being free of

disturbing thoughts or emotions and precludes anxiety, guilt or regret. Being at peace may include expressions of feeling secure, unafraid, fulfilled, satisfied with one's life, and of a sense of completion. The movement in transcendence is progressive. There is a sense of finding purpose and meaning and growing as a person.

My intent was to inform the description and understanding of transcendence by eliciting participants' views.

CHAPTER 3

METHODOLOGY

Approach to Inquiry

An interpretive perspective combined with narrative interviewing and analysis was used in this study to examine the phenomenon of transcendence as experienced by patients diagnosed with terminal cancer. The specific research questions were:

1. How do people who have been identified as having transcended their life-threatening illness describe their experience (in the form of narratives)?
2. What are the characteristics of each account in terms of form, content and meaning?
3. To what extent does a participant's personal account of this experience reflect a story of transcendence?
4. How is the experience of transcendence depicted in each account and to what extent is this similar across participants?
5. To what extent and in what ways does the context influence the stories (or story telling) of transcendence?
6. What emerges from the participants' accounts as factors that precipitate or facilitate transcendence and as positive and/or negative consequences of the experience?

This chapter includes an explication of the approach to inquiry, a description of how participants were selected and how the narrative interviewing and analysis were done, a delineation of ethical considerations, and an explanation of how the method and results were evaluated.

As noted earlier, the interpretive perspective underlying this study views knowledge as tentative, uncertain and related to one's perspective (Bruner, 1990; Geertz, 1973, 1983; Hammersley, 1992; Morgan, 1983; Rabinow, & Sullivan, 1987). It conceives of human science as the study of human beings in context. Undergirded by this perspective, the study of narratives has been developed as a method for the human sciences in psychology by Brown and Gilligan (1992), Bruner (1990), Mishler (1986a 1986b), and Sarbin (1986), in sociology by Riessman (1993), in medicine by Kleinman (1988), and in nursing by Sandelowski (1991). The study of narrative in the human sciences needs to be understood as related to, but distinct from, its use in other disciplines such as linguistics, literature and history. Developing knowledge of human experience through the study of narratives is based on the idea that individual human beings make sense of their experience by constructing narratives (Bruner, 1990; Mishler, 1986a; Riessman, 1993; Rosenwald & Ochberg, 1992; Sarbin, 1986). Narrative

accounts or personal stories hold the key to understanding human experience. In fact Polkinghorne (1988) and Sarbin (1986) have gone so far as to argue that it is the understanding of narratives that is the purpose of human science.

The idea that individuals understand and represent their experience by creating personal narratives is supported by the existence of cultural narratives. Cultures have "commonly accepted narratives" (Gergen, & Gergen, 1986, p. 31). Individual narratives contribute to evolving cultural narratives and are affected by them (Kleinman, 1988; Riessman, 1993). Both individual and cultural narratives contribute to knowledge of human experience.

The narrative approach involves analysis of individuals' stories as obtained through in-depth interviews. The narrative interview has roots in the unstructured interview methods used in the social sciences. Early work in some disciplines, including anthropology and sociology, was directed at gaining informants' stories. However, the stories collected were viewed as descriptions that could be objectively reported. Narrative interviewing and analysis do not take this realistic perspective, but rather assume an interpretive view. Gaining insight from the critiques of positivism, the interpretive view conceives of personal

accounts as more than just descriptions. Life stories are no longer considered mirrors of life events and experiences (Riessman, 1993; Rosenwald, & Ochberg, 1992). As Rosenwald & Ochberg (1992) state, "Personal accounts are now read with an eye not just to the scenes they describe but to the process, product, and consequences of the reportage itself" (p. 2) . . . It is no longer plausible to regard the events informants describe as intelligible without further inquiry into the background assumptions of the speakers and their audiences" (p. 3).

As Reissman (1993) summarizes, the object of study in narrative is the story itself (p. 1). . . with the purpose of the research being "to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives" (p. 2) . . . "Narrative analysis allows for systematic study of personal experience and meaning: how events have been constructed by active subjects" (p. 70).

Although narrative interviewing and analysis have only begun to be used as a research methodology in nursing science (see Sandelowski, 1991), others have observed the importance of narrative to nursing. Narrative has been described as contributing to the development of understanding of the "lived" experience of the nursing situation (Boykin, 1991) and of the patient's view (Bartol, 1989), to nursing education (Bevis &

Watson, 1989, p. 11), and to nursing practice (Benner, 1991; Sandelowski, 1991; Tanner, Benner, Chesla, Gordon, 1993).

Proficient nurses have intuitively utilized narrative interviewing in their nursing practice. Individually nurses accumulate knowledge about certain types of patients and develop expert experiential knowledge bases about patients' responses to illness. Developing narrative interviewing as a deliberate method of scientific inquiry in nursing science is a natural progressive step for the discipline. It is taking an effective clinical approach that has worked for individual nurses and been documented anecdotally, and developing it as a deliberate method of inquiry that can contribute to the development of shared, common, scrutinized knowledge for the discipline.

Selection of Participants

The study sample consisted of three English-speaking adult (18 years or older) persons with a diagnosis of terminal cancer who were identified by at least two of the professional nurses responsible for their care as having "transcended" their life-threatening illness and as being able to talk about their experiences. There are no rules about how many participants to include in a study using narrative interviewing and analysis:

"Samples in narrative studies are small, and cases are

often drawn from unrepresentative pools" (Riessman, 1993, p. 70). Although I originally planned to interview "approximately six" persons, the time required to obtain and interpret each participant's story and the limited availability of participants made three a reasonable sample size. At the initial meeting with the oncology clinic nurses held in September 1994, nine patients were identified as potential participants. Two of the original group participated in the study and one refused. Because I knew the people recommended were very ill and because I intended to finish interviewing one participant before beginning the next, I arranged with the nurses to check with them before contacting each participant. This allowed me to insure that it was still appropriate for me to contact the persons on the original list. By the time I finished interviewing the second participant, all of the other persons had died. The nurses then suggested an additional patient who is the third participant.

An effort was made to include both men and women, since there is evidence that gender influences narratives produced (Gergen, 1992; Riessman, 1993), and members of various racial/ethnic groups. Because the literature on transcendence suggests that the phenomenon occurs throughout the life span, an effort was made to include adults of different ages. As there were a number of potential participants identified, I contacted persons

whose gender, racial/ethnic backgrounds, and age were different from participants already interviewed. There is diversity in the sample. The sample includes a 72 year old white female, a 62 year old black male, and a 46 year old white female.

I intended for the sample to be comprised of persons who had experienced transcendence. Others have had success with identifying persons who were likely to have had a particular experience. Mihaly Csikszentmihalyi (1988) of the University of Chicago identified persons who were likely to experience a describable state of consciousness while doing activities they enjoy for their own reasons. His initial work included interviews of artists, surgeons, musicians, chess masters and athletes and produced the original description of what he terms the "flow" or "optimal" experience.

The meaning of the term transcendence was clarified with the professional nurses through informal dialogue at the initial meeting. In a previous study by this author, (Williams, 1992a), nursing colleagues were easily able to identify patients who they perceived as having transcended their illness. An introduction similar to the one used in that study was used here to identify patients. Specifically, I began by saying, "I'm going to ask you to identify a certain type of patient, but I'm not sure the term I am using, transcendence, is going to

be meaningful to you. . . so, we can talk about it a little to make sure we're thinking about the same thing". Although the literature and my previous study suggested that nurses would be able to identify patients who are experiencing transcendence (see pages 6 and 22 of this study), this basic assumption proved to be incorrect. The analysis of participants' accounts revealed that of the three participants only the third was experiencing transcendence. After interviewing the third participant, I met again with the nurses to see if they saw the third participant as being different from the first and second; the nurses stated that they did not. They related that they saw all three as transcending their illness. When asked to identify what made them say the patients had transcended they said that they were "upbeat", "able to go with the flow of life", "able to see good in everything that happens", "doing well", and "surmounting their illness".

People with a diagnosis of terminal cancer, considered a diagnosis for which treatment for cure is unavailable, were included in the study. Confirmation of the status of the participant as terminally ill was obtained from the medical record. Participants in the study could be and were receiving palliative medical treatment.

After obtaining permission from the patient's physician, I contacted prospective participants by telephone at which time they were told that they had been recommended as someone who may be willing to talk about their experience with illness. A first interview was scheduled if the prospective participant expressed interest in participating in the study. Informed consent was obtained at the first interview.

There was no attempt to choose persons with exceptional ability as study participants, although there may be individual variations in the ability to produce narratives. Narrative ability is viewed as universal (Riessman, 1993; Sarbin, 1986). Research has demonstrated that children begin to tell stories at an early age (Polkinghorne, 1988). Even though there is some indication that narrative ability is linked to reading skill (Mancuso, 1984) and that a person who produces obscure stories may be misunderstood or incomprehensible (Keen, 1984), attempting to design the sample to include or exclude on the basis of narrative ability is not advisable. Variations in level of narrative ability are expected. The assumption that people generally construct narratives to make sense of their experiences is the assumption that was the basis for the choice of the study sample.

As previously stated, persons who the professional nurse described as being able to talk about their experiences and who are English speaking were potential participants. Because there are a variety of reasons why persons might not be "able to talk", such as extreme fatigue or distress and neurological impairments (including brain metastasis), the criterion for inclusion was left broad and essentially up to the professional judgment of the nurses recommending persons for participation.

Since I needed a group of nurses who could recommend participants for the study, I decided to use the oncology outpatient clinic of a hospital in New England as the link to potential study participants. I applied to the hospital review board for expedited review and received approval to proceed with my study on August 1, 1994.

Narrative Interviewing

Narrative interviewing is a relatively new type of qualitative interview used in research. It was developed in order to elicit individual stories. Narrative interviews seek to display fully the perspectives of the participants. They are a means of gathering meaningful information about human thoughts, feelings and actions. The interview is considered to be an "occasion for storytelling" (Mishler, 1986a). In the unstructured interview, the interviewer poses open-ended questions

that encourage the participant to respond in his/her own words or "voice".

The role of the researcher in this study is to facilitate the telling of the story. The interviewer spontaneously responds to participants' comments in order to "support extended response" (Paget, 1983) and thereby understand the meaning of what is being said. An important quality of narrative interviewing is "attentive" or "expectant" listening (Mishler, 1986a; Wyatt, 1986). As Mishler (1986a) states the "general stance of an interviewer as an attentive listener and how the interviewer responds to a response are more important than the form and content of a question in whether or not a story will be elicited" (p. 235). Given that "shared interests" have been shown to be helpful in creating narratives (Rosenwald & Ochberg, 1992, p. 34), my experience caring for oncology patients would be considered an asset.

The participant was encouraged to take an active role in the interview process, since the purpose of the narrative interview is to achieve mutual understanding of the participant's story. It is the participant who determines the direction the interview takes and the story that is told. The participant is "empowered" to relate his or her experience rather than questioned about it (Paget, 1983).

The interviews completed for this study began with a question that reminded the participant of the purpose of the study and encouraged the telling of his or her story. For example, "As you know, I am interested in trying to describe and understand the experience of living with a life-threatening illness. Could you start by telling me what your experience has been . . . beginning with the onset of illness, how you came to know your diagnosis and what has happened since". Additional questions were used to encourage storytelling of the experience of terminal illness. These included, "Thinking about when you learned your diagnosis, can you tell me what thoughts and feelings you had and what you did?", "What was your life like before your illness?" "How is your life different because of it?" "Can you talk about what helped you deal with your illness?"

Given that the purpose of the interview was to produce an account, I was flexible about time. Initially, two or three hour-long interviews with each participant were planned. What was most important was for the participants to feel that they had time to complete their accounts without undue stress or tiredness. I thought that participants, because of their illness, might have limited energy requiring shorter interviews. The energy level of participants was not a factor in this study. In all cases the first interview

was approximately two hours long. Two hours seemed a natural time span for the interviews. I did two interviews with the first two participants and one with the third.

The date, time, and length of interviews were planned for the convenience of both participant and interviewer. If at the beginning of a planned interview a participant had an immediate concern that prevented him/her from participating in the planned interview, I would have assisted him/her as appropriate and delay the interview. All interviews for the participants were conducted as originally scheduled.

Since it was important to avoid interruptions, the interviews were held in a private conference room of the participating agency or in another quiet space. After explaining that the place for the interview had to be quiet, I left the choice of location up to the participant. The first participant chose to be interviewed at the outpatient clinic while she was receiving chemotherapy and the nurses graciously arranged for us to use a quiet treatment room. The other two participants were interviewed in their homes. I conducted, audiotaped, and transcribed the interviews. I also made pertinent written notes during the interviews. The tapes, transcriptions, and written notes were identified by code number and secured.

In order to prepare the participant for the interview, I provided a description of the purpose and aims of the study. Participants were told that the purpose of the study was to understand more clearly individual experiences with terminal illness with the aim of providing better care to those so afflicted. Since the participants were expected to produce an account of their experience, prospective participants were encouraged to reflect upon their thoughts, feelings and actions since the onset of the illness. These general guidelines helped participants produce narratives in which they were the major actor, and for which there was a time frame, and an experiential focus.

The interview produced an account that was a one-sided dialogue between the researcher and participant in which the bulk of the account was the participant's reply. The participant's narratives or stories were embedded in the account. I served as an interested audience. My questions and comments expressed interest in and involvement with the topic. Very little probing was needed.

There was a consistent, spontaneous outpouring of stories from study participants. All commented that they hadn't talked about their illness in quite this way before. Having a life-threatening illness is undoubtedly a profound experience and the abundance of stories told

during these interviews is consistent with the notion that narratives serve to give meaning to problematic experiences (Gee, 1985, p. 25).

Narrative Analysis

The audio-taped research interviews were analyzed using narrative analysis. This type of analytical approach has been discussed in the literature (Brown, Tappan, Gilligan, Miller, Argyris, 1989; Mishler, 1986a; Riessman, 1993; Sandelowski, 1991; Wise, Plowfield, Kahn, Steeves, 1992). Narrative analysis recognizes the unstructured interview as purposefully producing complex, real life narratives that "reflect situational, personal and cultural factors, including issues of language, perspective, and the relationship between the readers and the narrator's language and perspective" (Brown, et al., 1989, p. 149). Narrative analysis "comprehends patterns in actions and events that could not have been predicted in advance, and it does so by looking back over what has happened" (Polkinghorne, 1988, p. 116).

Narrative analysis was conducted to answer the research questions in relation to each case. Originally, the research questions queried about how the accounts might reflect transcendence. But when it became obvious, upon analysis of the first interview, that the account was not a story of transcendence, I placed more emphasis on characterizing the nature of the accounts in terms of

form, content and meaning and determining whether each account was an example of transcendence. In keeping with the original research questions, the accounts were analyzed separately and then compared.

The process of interpretive analysis of the individual accounts involved four phases with each phase having a distinct purpose. During each phase the audiotapes, verbatim (rough) transcriptions, and researcher notes were reviewed many times. The use of purposeful phases as a general approach to analysis was based upon Brown and Gilligan's notion of "readings".

In Brown and Gilligan's (1992) "voice-centered relational method" the interview data are reviewed (listened to and read) at least four times with each "reading" having a purpose in order to achieve the "voice-sensitive method" that truly hears and captures the person's story. Others have written about the need to develop awareness of the narrative as the participant's unique interpretation of his or her reality. As Spence (1986) states, the researcher develops "sensitivity to the newness of the text; awareness of what makes it different and distinctive can only operate when we are not searching for standard meanings or validating favorite hypotheses." The repeated review of interview data allowed me to immerse myself in the participants' accounts. The fact that I

did the interviews and transcriptions myself enhanced my familiarity with the data. The four phases of analysis for the study were designed to purposefully 1) arrive at the structural and thematic analysis of the account, 2) characterize the "voice" of the participant, 3) describe the context of the account, and 4) examine the account as a possible example of transcendence.

Most emphasis was placed on the first phase, in which a structural and thematic analysis of the account was produced. The first phase allowed for the nature of the account to be depicted and the first and second research questions relating to the form and content of the narratives produced to be answered. Characterizing the "voice" of the participant in the second phase afforded an opportunity to reflect on and refine the initial interpretation. The third phase of the analysis allowed for consideration of context - cultural, situational and other factors - influencing the account. This consideration of context addressed the fifth research question about how context influenced the stories (or storytelling).

In the fourth phase of the analysis of individual accounts, the accounts were compared to theoretical definitions and descriptions of transcendence. Only one of the accounts was found to be an example of transcendence. Therefore research questions four and six

were partly applicable. The experience of transcendence was depicted (question four) and factors and consequences relating to it (question 6) were analyzed in one case. However it was possible to analyze similarities and differences across participants.

What follows is a detailed description of each phase of the analysis. As I have already mentioned, the purpose of the first phase was to arrive at the structural and thematic analysis of each account. The focus was to understand the framework of the entire account. The account may represent a story itself or, more likely, have stories embedded in it. This phase of the analysis involved careful listening to and transcribing of interview tapes, identifying narratives embedded in the account and determining the structure and themes of the account.

Participants' personal accounts of their illnesses were systematically studied using the linguistic approach to narrative analysis developed by Gee (1985, 1986, 1991) and Riessman (1993). Initially, thinking it might be necessary to adapt the type of analysis used to the individual account, I planned to use a variety of approaches. But, as I did the analyses, I found the linguistic approach consistently effective. Determining the structural properties of the accounts (analyzing

their poetic structures) did indeed allow for thematic analysis.

Other approaches to analysis, in contrast, seemed too detached from the participant's language. For example, identifying the "plot" or organizing theme of a story without systematically analyzing the poetic structures easily resulted in imposition of meaning; the plot identified being very much what the interpreter (researcher) sees. Although analysis of poetic structures is undoubtedly interpretive, it keeps analysis close to the participant's language. Themes that emerge are related to structure - how the story is told.

Using different types of analysis also would have made it difficult to compare and contrast accounts. Since the research questions of the study require such comparison, it was methodologically sound to use one analytical approach.

I transcribed each audiotaped interview. Transcribing interview tapes is an interpretive process. Transcription of the narrative is a bridge between the interview and the analysis; it is a process that requires analytical decision-making. The first transcript of the taped interview is a verbatim or "rough" transcription that includes the entire interview conversation, including words and other features (pauses, emotional

displays - like crying or laughing). Appendices C-J provide examples of rough transcriptions.

After the rough transcription was produced, it was reviewed for the types of talk it contained. There were various forms of discourse, such as question and answer exchanges, arguments, and descriptions as well as narratives. Since the narratives or stories are of primary interest, they must be identified. And, as Riessman (1993) says, "locating the stories told in research interviews. . . is often a complex interpretive process" (p. 18).

The narratives embedded in the accounts of the participants were located by listening to the audiotapes and reading the transcripts. Gee's (1986) observations about the linguistic nature of narrative discourse provided useful guides for listening. According to Gee (1986) long pauses, a change in the pitch of the voice, and an increase in false starts, hesitations and incomplete expressions often mark a major change in the form of discourse (e.g. the beginning of a narrative) (p. 393-396).

The content of the discourse was also used to identify narrative segments. Like a story, a narrative has a beginning, middle and end and usually has a readily identifiable topic, actors and location. In a narrative, events are put into a sequence and interpreted. It is

important for my study that "story" be loosely defined. A story does not have to meet rigid criteria, but rather represents "an account of something which develops and changes. . . and has action which occurs over time (Paget, 1983, p. 75). Riessman's (1993) technique of bracketing sections of the rough transcription that appear to be stories was used.

The initial analysis of the entire interview was summarized in a graphic representation. A useful way to depict a lengthy interview, it is composed of a horizontal story line representing talk about living with illness and juxtaposed triangles representing talk that departs from the main story line, that is, talk about things other than illness (C.K. Riessman, personal communication, December 8, 1994). As developed here, the graphic representation identified what was said (content) and how it was said (form). To differentiate narrative from non-narrative forms of telling, titles of narrative segments were capitalized while those of non-narrative parts (such as descriptions, comments, question and answer exchanges, etc.) were typed with lower case letters. (Examples of graphic representations appear on pages 75, 89, 104).

Following the initial analysis of the entire account, the stories located were analyzed using the linguistic approach developed by Gee (1985, 1986, 1991)

and Riessman (1993). In this approach, which emphasizes poetic structures, the language used by the teller is carefully represented to reflect form and content. The teller's words, with extraneous words deleted, are retranscribed as lines. Each line represents an idea or two closely related ideas. The lines are numbered and presented in the order they were said. The lines are then grouped as stanzas (series of lines on a single topic that seem to go together). A stanza represents a larger idea or a topic. Stanzas may be further grouped as parts (larger idea units). The stanzas and parts may be titled to reflect the topic they present. The narrative itself is titled for identification purposes. The linguistic analysis is displayed as a schematic transcription of the story. (An example of a schematic transcription appears on p. 76-78.)

Analysis of narrative segments of the entire interview provided insight into the person's account. Each story contributed to knowledge of the whole. Some narrative segments, representing key elements, were selected for presentation in the written interpretation. This first part of the analytical process produced a structural and thematic analysis of each participant's account that is presented in a written interpretation of each account. The written interpretation includes a graphic representation of the account and selected

schematic transcriptions of narrative segments and is presented for each participant's account in chapter four.

Characterization of the "self" or "voice" of the participant was the purpose of the second phase of the analysis. It is here that contact was made with the thoughts and feelings of the participant. An explicit effort was made to understand the participant as a separate, unique person. In order to know the uniqueness of the person telling the story, I differentiated that person from myself, reflected upon and identified my own thoughts and feelings and finally characterized the participant.

It became important to acknowledge that the self-narrative is what the participant remembers and chooses to share. It is the participant's view of the experience. Considering that the narrative is a recollection and presentation of oneself, there is a potential for self deception (Crites, 1986; Wyatt, 1986; Scheibe, 1986). According to Crites (1986) "it is useful to reserve the word 'experience' for what is incorporated into one's story, and thus owned, owned up to, appropriated" (p. 161). Accuracy and candidness are goals. As Steele (1986) suggests, one can decide if the narrative makes sense (p.258). But the narrative must be appreciated as an individual person's version of

events. Inconsistencies, omissions and illogical thoughts detract from the coherence of a story.

Although Gee's (1991) analysis of coherence in a schizophrenic's narrative sparks debate, incoherent stories, such as those some have shown to be told by those experiencing mental illness (Keen, 1986, p. 176), need to be recognized as such. Coherent stories are those in which the thoughts, feelings, motives and actions are the narrator's own and through which the person telling the story demonstrates a "steadiness of purpose" (Rosenwald & Ochberg, 1992, p. 14). The analysis addresses the questions of self-deception, candidness and accuracy by identifying inconsistencies and/or omissions in the story. The second analytical phase characterized the person as that person has presented him (or her)self and estimated the coherence of the presentation.

In the third phase of the analysis the contextual nature of the account was appreciated: the person in context-in relation to others, in relation to their socio-cultural environment, and in relation to their illness. What relationships are important to the participant? What is the quality of the relationships? How have the relationships been changed, if they have, by the participant's experience with life-threatening illness? Socio-cultural factors, particularly cultural

norms and values, were analyzed for their significance. Cultures provide narrative conventions, but the extent to which these influence individual narratives varies (Rosenwald & Ochberg, 1992, p. 16). What cultural norms and values, including gender stereotypes and sick role constructs (cultural narrative frames) are expressed and how have they influenced the personal response to illness? The interview situation was recognized as social context. What did the narrative data reveal about roles assumed by the participant and researcher? Describing the progression of the illness as a pathophysiological process affecting the physical body of the participant was an important aspect of analysis of context. It was projected that participants would typically be experiencing remarkable impairments in physical condition including difficult and debilitating symptoms. As has been shown elsewhere (Robinson, 1990), these downward physical courses associated with profound illness are not always accompanied by declining or regressive personal response patterns. The physical course presented in the narrative was compared to the general pattern of the participant's story. The interpretation identified and analyzed the significance of the inter-personal, socio-cultural and physical factors influencing the participant's story.

The final aspect of the analysis evaluated the accounts to determine if they were examples of transcendence. Acknowledging my belief that transcendence exists as a potentially powerful resource and that technologically and disease-oriented health care ignores the importance of this inherent human resource demanded that the analysis look for evidence to counter these beliefs and identify ways they may have effected the discourse itself.

The interviews were analyzed in relation to the literature. Were the elements of the tentative definition and description drawn from the literature present in the descriptions of life-threatening illness provided by persons who have been identified as transcending their illness? Depictions in the literature were juxtaposed with the interview accounts. The research questions relating to if and how each narrative contributes to the description and understanding of transcendence as a response to life threatening illness were addressed.

In summary, the above systematic interpretive analysis allowed for the characterization of each account as an example of the experience of living with life threatening illness. In the next chapter each account is presented in a written interpretation that delineates the framework of the account, (giving general consideration

to its structure and themes), characterizes the voice of the participant, describes the context of the account, and evaluates it to determine if it is an example of transcendence. The written interpretation includes a graphic representation of the entire account and schematic transcriptions of selected narrative segments. Attention is given to describing the interpretive process.

Ethical Considerations

A potential risk for the participants was the possibility of experiencing discomfort. Recalling the feelings, thoughts and actions associated with dealing with a life-threatening illness can be uncomfortable. This risk was identified in the Consent Form for Research (see Appendix B). It was anticipated that, in the study sample of persons who were selected because they had dealt well with their crisis, the risks were not likely to be frequent or serious. As expected the study participants did not report any discomfort. It was understood that if there was a need the researcher would inform participants of available support services that would allow continuation of discussion of sensitive issues.

The process of creating a narrative may have a therapeutic effect (Rosenwald & Ochberg, 1992; Sarbin, 1986). While there was not a therapeutic objective for

this study, participants seemed to have gained a deeper understanding of themselves as a result of the research interview. Participants expressed a sense of satisfaction with the interview. They said they hadn't thought about their entire experience in the same way before and implied a sense of greater understanding that was helpful to them.

Measures were used to protect the confidentiality of the study data and are detailed in the consent form. The Consent Form for Research, signed by the participant, and a Face Sheet identifying the participant's name and case numbers (see Appendix A) were kept separate from study data. All interview data, including audiotapes, verbatim transcriptions, and written notes were secured in a locked cabinet.

Critique of Method and Evaluation of Results

Narrative interviewing and analysis is a developing methodology and is not totally refined at this point. Moreover, the interpretive view assumes that methods of inquiry are to be evaluated as they are applied. The methodological approach of this study included continuing and purposeful evaluation of the method. In particular, the researcher reviewed the interview transcripts to determine if the interviewer's questions and comments encouraged the telling of a story. Was the participant able to complete thoughts uninterrupted? Was the

participant able to articulate a "proper story" which "must account for how and when as well as why something happened and detail some resolution of the predicament" (Robinson & Hawpe, 1986, p. 120). Was the time frame allowed appropriate? The interviewing process did produce meaningful accounts.

Evaluation of the narrative analysis rests on the "trustworthiness" rather than "truth" of the researcher's interpretation (Mishler, 1986a; Polkinghorne, 1988; Riessman, 1993; Rosenwald & Ochberg, 1992; Sarbin, 1986). Trustworthiness depends on 1) "Persuasiveness", "plausibility" or "believability": Is the interpretation reasonable and convincing? 2) "Correspondence" of the researcher's interpretations: Do the participants agree with the researcher's descriptions and interpretations of their stories? 3) "Usefulness" of the work - Does the study stimulate or contribute to other scholarly endeavors?

A major factor in establishing trustworthiness is the degree to which the research process is documented (Riessman, 1993; Rosenwald & Ochberg, 1992). For this study the original tapes, transcripts and re-transcriptions will be available to a small number of professional colleagues of the researcher. The raw data, with real names of persons and places replaced by

fictitious ones, and interpretive process are displayed in the written research report.

Correspondence of the researcher's interpretations with those of participants was addressed by establishing mutual understanding between participant and researcher during the interview. This correspondence can be assessed by review of verbatim transcripts.

Finally, consensus of scholars as to the credibility of the interpretation increases its trustworthiness (Polkinghorne, 1988, p. 116) and the doctoral committee will serve to establish degree of consensus for this study.

CHAPTER 4

RESULTS

The results of this narrative study of the experience of living with life-threatening illness are interpretations of the personal accounts of study participants. Narrative analysis of the accounts, told during research interviews, was used to arrive at the interpretations. The purpose of the analysis was to answer the following research questions:

1. How do people who have been identified as having transcended their life-threatening illness describe their experience (in the form of narratives)?
2. What are the characteristics of each account in terms of form, content and meaning?
3. To what extent does a participant's personal account of this experience reflect a story of transcendence?
4. How is the experience of transcendence depicted in each account and to what extent is this similar across participants?
5. To what extent and in what ways does the context influence the stories (or story telling) of transcendence?
6. What emerges from the participants' accounts as factors that precipitate or facilitate transcendence and as positive and/or negative consequences of the experience?

The study sample was comprised of three study participants. Each participant's account was analyzed and is presented separately. As is common practice in presentation of results in narrative studies, I have given people and places fictitious names. In the transcripts, the participant's utterances are indicated by P and the interviewer's by I. Lines are numbered for easy reference. Each presentation includes a Graphic Representation that places the titles of narratives (and some important non-narrative segments) on a story line and Schematic Transcriptions that display selected narratives. Interpretive analysis of individual accounts is followed by a discussion of the similarities and differences across participants.

FIRST PARTICIPANT

The first participant, whom I will call Kate, is a 72 year old white woman who has had breast cancer since November of 1990.

Upon the initial telephone contact, Kate requested to be interviewed at the outpatient oncology clinic while she was receiving her chemotherapy. Since patients typically receive their chemotherapy in a large room with many patients present, I arranged with the clinic nurses and the participant to have her receive her therapy, on the days of the interviews, in a quiet, private room.

During the two interviews, both of which lasted approximately two hours, the participant was animated and spontaneous. She was remarkably energetic. While accompanying her from the community treatment room to the private room where we talked, I remember being struck by the quickness of her walk. I was guiding her IV Pole and had to accelerate to keep up with her!

Structural and Thematic Analysis

My analysis of Kate's experience with a life-threatening illness begins with the presentation of a graphic representation of her two interviews. (See Graphic Representation 1.0 on next page).

In her account, Kate develops her ideas about living with her illness. She represents herself as a strong woman who is living with her illness by participating in treatment, cultivating a positive attitude, adjusting not changing her lifestyle, and by maintaining herself as an integrated member of her family and community.

Kate begins with a story about how her condition was diagnosed and initially treated (DIAGNOSIS AND TREATMENT located on the first line of Graphic Representation 1.0). She follows this with many narratives about physical signs and symptoms, mainly side effects of treatment, she has experienced (NEUTROPENIC EPISODE, ALLERGIC REACTION, ALOPECIA, LYMPHEDEMA). Participating in treatment and

Graphic Representation 1.0

1st Interview

DIAGNOSIS AND TREATMENT	RADIATION TREATMENT	VOLUNTEER WORK	THE FAMILY	CHEMOTHERAPY	NEUTROPENIC EPISODE
ALLERGIC REACTION	Infusaport	Chemotherapy Delay	ALOPECIA	Chemotherapy (cont.)	Adapting at Home
Family Christmas	THE BLIZZARD	Accepting Side-Effects	ATTITUDE TOWARD IT	TALKING ABOUT IT	Becoming Complacent
LYMPHEDEMA	CHEERFUL RESENTMENT	TRIP OUT WEST			

2nd Interview

TALKING ABOUT IT	Full Life	MARY LOU	TUMOR RECURRENCE	Description Of HCP	TUMOR RECURRENCE (CONT.)	MAKING PLANS
EATING WHAT YOU WANT	Febrile Neutropenia	DECISION MAKER	HOME MAKER	BEING INTEGRATED	HUSBAND'S CARETAKER	
EMPLOYEE	SISTER	Satisfied & Content	DWELLING ON IT	Adaptation Not Changed	NOSTALGIC REFLECTIONS	

dealing with physical signs and symptoms is a major part of her account of her illness experience.

The analysis of segments of an entire interview provides insight into the structure and meaning of the whole. The story of ALOPECIA (see the second line of Graphic Representation 1.0) presents the major themes of Kate's account, including her active participation in treatment.

The linguistic analysis of poetic structures described by Gee (1991) and Riessman (1993) is used here to reveal the major ideas expressed. The analysis of poetic structures of ALOPECIA is displayed in Schematic Transcription 1.1.

Schematic Transcription 1.1

STANZA 1: (Hair Loss)

00 the hair loss is
03 I've lost it twice
04 It's come back both times
05 This time, because of the constant treatment
06 its like a little fuzz there.

PART I (Asking the question)

STANZA 2 (Big time loss)

09 I asked them,
14 because one time I didn't lose it
15 enough to wear a wig
16 unless I were going someplace special,
17 "What is this going to be?"
19 They said, "Big time loss"
20 And it did.

PART II (Taking action)

STANZA 3 (Buying the wig)

24 So, I left [the clinic]
25 I went to
26 the Ming Wigs in Pleasantville

27 Where I had got my wigs
 32 While I'm trying on the wig on
 33 its [her hair] falling all over the place
 35 I got one
 and my daughter and I went to lunch afterward.

STANZA 4 (Brushing hair out)
 37 I think in a day
 38 I said, "I'm going home and brush this
 39 and get it over with

PART III (Prior hair problems)

STANZA 5 (Straight hair)
 44 my hair is straight
 45 and to do it up
 47 and comb it
 48 And, you didn't take it down
 49 much before you were going out
 50 because my hair was straight.

PART IV (Choosing a wig)

STANZA 6 (The grey one)
 53 I had grey hair
 54 it was right here (pointing to temple)
 55 and it was shot through
 59 So I went out and bought a wig last year
 60 that has grey hairs shot through it

STANZA 7 (Needs a dye job)
 62 I'll put the wig on
 63 and they're probably thinking
 64 it's time she has a dye job

STANZA 8 (Had a dye job)
 65 I go home and put this (auburn wig) on
 66 "Oh, she had her hair colored"

STANZA 9 (Looks good)
 67 'Cause a lot of people
 68 I tell, "this is a wig"
 69 "Oh ya that looks good"

STANZA 10 (Is it a wig?)
 71 I had red hair when I was younger
 73 My hairdresser had said,
 74 "you probably will never have grey hair",
 75 it will change color
 76 it will go on a brownish
 78 I think that's why a lot of people
 79 didn't realize that it was a wig.

STANZA 11 (The perfect one)

80 When I walked in
 81 my daughter spotted it
 82 way up near the ceiling
 83 and she said, "Oh Ma, that's you"
 84 the girl took it down,
 88 it looks like your color

STANZA 12 CODA

89 it's all in accepting, not just accepting
 things
 90 but getting them done right there.

In her story about her experience with alopecia (hair loss), a common side-effect of chemotherapy, Kate presents a micro-version of her entire account. She begins the story by naming her subject (line 00) and describes her present condition (lines 03 - 06) in STANZA 1. The candid manner in which she describes herself (as having "fuzz") is typical of her references to physical signs and symptoms.

In PART I, Asking the Question (STANZA 2) she describes how she gets her questions about hair loss answered. Her ability to ask her questions and receive information about what this new round of chemotherapy will do is a good example of how she actively and effectively participates in treatment.

In PART II, Taking action, (STANZAS 3, 4) she gives an example of her action-oriented approach to dealing with signs and symptoms. Immediately after learning that her hair loss is inevitable, she manages a successful buying trip to the wig shop. Then she brushes her hair vigorously to get it to fall out faster. Throughout her

illness she actively makes adjustments necessitated by changes in her condition.

Next, in PART III, Prior Hair Problems (STANZA 5) she gives us an example of how she maintains a "good outlook" by seeing the positive in her situation. Telling about how her real hair wasn't that great, she implies that there are definite advantages to the adaption (wearing a wig) that she has had to make.

In PART IV, particularly STANZAS 7 - 10 in which she considers how people react to her wigs, she reflects her intention to maintain her lifestyle, particularly to remain an integrated member of her family and community. People's reactions are important to her. With characteristic wit and humor she plays with ideas about how people will react (STANZAS 7 - 9) and seems pleased that most think the wig looks good. The careful choices of wig color, the topic in STANZAS 6 and 11, demonstrate the care she takes with her physical appearance. In PART IV she presents ideas that let us know she intends to continue being with people.

The CODA is a narrative device that brings the reader back to the present. In her powerful CODA (STANZA 12) Kate ties the story to the whole. She clearly identifies the point of the narrative: accepting and actively adjusting to illness. As she says, "It's all in

accepting, not just accepting things, but getting them done right there."

Kate talks in detail about her mental and emotional experience. She considers her attitude important to her survival - an implicit goal. In her story ATTITUDE TOWARDS IT, (see the third line of Graphic Representation 1.0) she presents the idea that she consciously chose to have a "good outlook", which to her means "accepting it and adjusting to it". An important event in the development of her attitude was that the nurses in the oncology clinic, during educational sessions about chemotherapy, told her "don't listen to horror stories. . because this should be your OWN reaction, your OWN attitude toward it".

Central to maintaining her good outlook are her efforts (presented as actions in many of her stories) to adjust to her illness. For example, she tells of adjusting to losing her hair, by getting wigs, to not being able to use her lymphedematous arm, by leaving the garage door open (so she doesn't have to close it), and to having ulcerations from recurrent tumor growth on her chest and back. In her stories of dealing with these physical signs and symptoms of her illness and its treatment, she does not emphasize the pain and suffering they cause but focuses on the ability they inspire to adapt.

Stories that further describe her attitude include those that tell about dealing with her emotions. In the following segment from her story DWELLING ON IT (line 7, Graphic Representation 1.0) she credits her busy schedule and not having too much time to think as helpful things:

Schematic Transcription 1.2

STANZA 1

01 And ah, it's really been
02 as I say
03 I think the main thing is
04 I don't have time to dwell on it

STANZA 2

05 And this is where
06 if you sit alone and dwell on it

STANZA 3

07 It's a . . you know
08 I can always read

STANZA 4

09 And that was the funny thing
10 In the hospital,
11 I got so I couldn't read that much
12 This was killing me, too."

Although she doesn't want to have time to dwell, she reveals that she's unable to keep herself busy (reading). Something is keeping her from her favorite pastime. She never explicitly says that she's preoccupied with her cancer, but infers it when she says "This was killing me, too". Her cancer is killing her body's ability to function and her mind's ability to focus. By trying to not dwell on it, she prevents herself from gaining awareness and peace.

Similarly, she describes helpful conversations as including talk about "honestly and basically" what

happens, talk that "doesn't dwell on it", talk about things other than illness. As she says in TALKING ABOUT IT (located on line 3 of Graphic Representation 1.0)

Schematic Transcription 1.3

STANZA 1

01 And ah
02 I don't think anybody wants to hear
03 too much about your illnesses either,
04 I don't talk about it.

STANZA 2

05 In fact
06 one of the men
07 that is in the singing group with us
08 Oh God, he's um, 82 or 83,

STANZA 3

09 And he's having
10 he's having radiation
11 his is prostate
12 which I guess that's very good
for that

STANZA 4

13 This man was coming six months
14 before anybody knew
15 and I think it was just
16 that there was a time
17 for us to go someplace

STANZA 5

18 and he said
19 "No I have to go to radiation"
20 But he doesn't talk about it
21 And, I don't talk about it."

She and her friends do things together and avoid discussing illness in any depth.

The mental and emotional position Kate presents is remarkable given the reality of her illness experience. Her attitude is reflected in the following isolated comment. During the second interview, after telling of

her diagnosis and treatment, her acutely life-threatening neutropenia, her alopecia and the recurrence of her tumor, she says, "I have been very fortunate. . never had any severe vomiting. . or so-called side effects." Her good outlook is maintained against heavy odds. Although some might suggest her attitude verges on denial, Kate knows and states she has cancer and deals with it realistically and practically. By focusing on her good fortune, she maintains the attitude she aspires to.

And, although her goal is to have a positive outlook, she herself reveals that her acceptance is qualified - not full. When asked if she accepts her illness she replies, "I RESENT IT".

Kate repeatedly states that her illness experience has not resulted in change. She sees the adjustments she makes as helping her maintain a positive outlook; she doesn't view them as changes. As she states, "I remember one of the things you said was how did it change your life, well really I tolerated everything so well right through the operation and seeing doctors and everything that my life didn't change much at all."

Not allowing change, maintaining the lifestyle she has known, especially remaining an integrated part of her family and community, is another goal. In her stories about herself, she presents herself as devoted to her family and active in her community (VOLUNTEER, THE

FAMILY, HOMEMAKER, SISTER). These narratives about her personal identity as an integrated human being reveal an important aspect of her life. By including being integrated with family and friends in her stories about her illness, she develops this same aspect as an important part of her illness experience.

Analysis of the structure of this first interview reveals a description of living with illness, with the emphasis on living. Kate's stories of personal identity, even though tangential to the main story line, provide the basis for understanding her account. As she presents it, her experience with life-threatening illness is one of participation and determination. The themes of participating in treatment, maintaining a positive attitude, and maintaining her lifestyle are themes of action and ability. If she has had concerns and problems, they are not the focus, how to deal with them is. She is the center of the story. Other people, such as family, friends and health care professionals have been depicted as supportive, but they have not been the main actors of her narratives. Hers is a heroic story of how she has lived with her illness.

Voice

Following the analysis of the structure is the characterization of the voice of the participant. Kate's voice is strong, determined, spontaneous and laced with

humor. Her speech was expressive and had good tone throughout the interviews. She is a realist and action oriented. The actions she takes in her stories are based on decision making. She relates how she talks to herself to make decisions. She isn't ambivalent, but knows what to do. Telling stories of how she has competently performed in a variety of roles during her lifetime, she creates the solid impression that she has the wherewithal to deal with her illness. She possesses a great sense of humor, easy laugh, and ability to tell humorous anecdotes.

Her voice is not contemplative or reflective. There is more action than feeling in her account. Keeping busy, maintaining a positive attitude, talking about her illness in terms of "basically what happens" and "not dwelling on it" (not thinking too much about her illness) is her approach. She has difficulty talking about feelings. In her discourse, when she begins to think about a difficult subject she talks around it, (doesn't develop a story) and then changes the topic.

Context

Regarding context, the participant is a white, Irish-Catholic, 20th Century female. There are many ways her history undoubtedly influences her account, but she does not make them explicit. Because she speaks her own mind and doesn't appear to be mouthing thoughts and

opinions she doesn't believe, she presents herself as having a strong sense of self.

Somewhat surprisingly, the religious aspect of her life does not seem significant. Although mentioned in relation to her children's upbringing, she does not talk about it in relation to her own identity or her illness.

The participant was very comfortable in the research setting. She spoke in an uninhibited, spontaneous manner and seemed to enjoy talking. She freely voiced preferences about time and location arrangements.

Examination of Transcendence

Finally, does the participant's account reflect a story of transcendence? I suggest that it does not.

Although the account contains some elements that are characteristic of self-transcendence, in general the conceptualization is not present. This is a story of stability - not change and growth. It is a story that emphasizes action and adjustment rather than reflection and pursuit of purpose. There is, in the story, a sense of "being as well as I can", rather than a "well being of the spirit". There is a sense of connectedness, but, it is a maintenance of life's connections - not a greater sense of connectedness with others, nature and God. Kate exhibits a positive attitude and is not fearful, but she doesn't present a sense of inner freedom and liberation.

Kate's story is one of living with and of dealing well with life-threatening illness. It is the story of a courageous woman who has used her abilities to confront the challenge of illness. Her response to her illness has been to participate in treatment, cultivate a positive attitude (to adjust and accept) and to maintain her connections with family and friends. Her response has not been to transcend.

SECOND PARTICIPANT

Robert is a 62 year old African American man who has had lung cancer since November 1993. He was initially treated with chemotherapy and radiation. In August 1994 he suffered a recurrence. He received additional chemotherapy and radiation in November and December of 1994 (during the time of his research interviews).

Upon his request the interviews were conducted in the living room of his home. The setting was comfortable, quiet and without interruptions, except for an occasional telephone call and, towards the end of the second interview, two female visitors. Robert had a calm, friendly demeanor and talked easily throughout the interviews. Two interviews, each lasting approximately two hours, were completed.

Structural and Thematic Analysis

The analysis of Robert's account begins with a graphic representation of his entire interview (see Graphic Representation 2.0 on next page).

During his telling, this participant struggles with sharing his illness with his family, demonstrates a stoic, passive acceptance of his illness and expresses his pride in who he is.

In his introductory story, DIAGNOSIS AND TREATMENT, Robert relates important events and interprets their meaning. He presents themes that will be repeated throughout his account. My structural analysis of this introductory story is displayed in Schematic Transcription 2.1.

In this story Robert presents the major problems his illness has posed for him. He identifies telling his family about his illness (STANZA 11) and worrying about his eleven year old daughter (STANZA 13) as his major concerns. Although he's reluctant to share his illness openly with his family, he acknowledges that holding his feelings in is difficult (STANZA 12). However, overall he reveals a lack of concern for himself. Having the cancer isn't the problem, telling about it is.

Graphic Representation 2.0

1st Interview

DIAGNOSIS
AND
TREATMENT

THE
FAMILY

UNHELPFUL
FRIEND

PROBLEM
TELLING

CONCERNED
FRIENDS

THE
FAMILY

Recurrence

Unable
to work

Diesel
Fumes

Weight
Loss

Daughter

RADIATION
TREATMENT

RELATIONSHIP
WITH DAUGHTER

RELATIONSHIP
WITH SON

STEP KIDS

WHAT SHE KNOWS

FATHER
ROLE

Feeling
tired

I'm a
loner

My
Will

Union
Officer

2nd Interview

CANCER
IS BACK

NEGATIVE
THINKING

YOU NEVER KNOW

DON'T UPSET
ANYONE

Living
Will

DON'T TELL

DAUGHTER

GOOD
BUS DRIVER

GOOD
CITIZEN

Schematic Transcription 2.1

STAMZA 1

01 I think I got sick
02 around August 1993

PART I (Diagnosis)

STANZA 2

03 I thought it was just a cold
04 I just kept taking medication,
05 over the counter medication things,
06 and the cough would never go away

STANZA 3

07 Finally,
08 I went to my family doctor
09 He took X-Rays
10 and said I had pneumonia

STANZA 4

11 He gave me some medicine for the pneumonia,
12 after the medication he wanted me back.

STANZA 5

13 I went back.
14 Took another X-Ray.
15 He found something
16 he didn't like.

STANZA 6

17 He sent me to Dr. Smith
18 I guess he's a cancer expert.
19 He more or less verified
20 What Dr. Jones had suspected.
21 That I had cancer in my lungs.

STANZA 7

22 From there he sent me,
23 he did a biopsy on me,
24 at the Midland Hospital

STANZA 8

25 After he looked at the X-Rays,
26 he said it definitely was Cancer.

STANZA 9

27 So after that
28 he sent me
29 to Dr. Wilson

PART II (Problem of Telling)

STANZA 10

30 It was hard for me to adjust.
31 Not to adjust that I had cancer
32 that wasn't the problem.

STANZA 11

33 In October of '93
34 I had my next older sister die of cancer.
35 And I found out about mine in November.
36 My problem was telling the family.
37 I didn't want to upset them
over the holidays.
38 My sister just passing away and things
like that.

STANZA 12

39 So I just held everything in.
40 That was straining on me.

STANZA 13

41 Then, I have my eleven year old daughter,
42 and me and her are very close.
43 Thinkin' about her,
44 and how she would respond to it.

PART III (Treatment)

STANZA 14

45 Dr. Wilson told me,
46 the good part of my cancer,
47 I had the fine cell cancer,
48 that responded to chemo very well.

STANZA 15

49 He set me up for me to have eight treatments,
50 three days every three weeks.
51 I'd go into Midland Hospital for three days,
52 from Monday morning to Wednesday afternoon,
53 and take the chemo.

STANZA 16

54 And I'd come back out
55 I'd take the week off.
56 Cause, chemo has a tendency to make me
feel tired

PART IV (The Telling)

STANZA 17

57 I had two treatments
 58 before I told my family about it.
 59 And that was so the holidays were
 over then.

STANZA 18

60 My daughter,
 61 I just told her
 62 that I had to go to the hospital
 63 for treatment

STANZA 19

64 Smart as she is
 65 she didn't question me
 66 Which I was glad in a way
 67 you know.

Sharing his illness with his family is difficult. He describes his distress in subsequent stories titled PROBLEM TELLING and WHAT SHE KNOWS (see lines one and three of Graphic Representation 2.0) and in non-narrative comments and descriptions. He relates some of his difficulties with sharing in the story PROBLEM TELLING and these are revealed in my structural analysis of the story that follows (Schematic Transcription 2.2).

Schematic Transcription 2.2

STANZA 1

01 But I
 02 called my oldest sister
 03 after the third treatment
 04 which was about just going into February

PART I (Reason for telling)

STANZA 2

05 See,
 06 I hadn't lost no hair or nothin'
 07 But I figured
 08 if was just a matter of time
 09 cause they all told me

10 I was goin' to lose my hair
11 that they were goin' to see
12 and they were goin' to question me

PART II (Partial telling)

STANZA 3

13 So
14 Like I say
15 my main thing
16 would be Kitty
17 my youngest daughter
18 how she was goin' to take it
19 accept it, you know

STANZA 4

20 Like I said
21 I just told her
22 Daddy was sick
23 and had to go for treatment.

STANZA 5

24 She didn't question me
25 which made for the best
26 because I might have had a problem.

PART III (Couldn't tell: A hurtin' thing)

STANZA 6

27 I couldn't talk about it
28 for a long time
29 It was a hurtin' thing

STANZA 7

30 In fact
31 that lady I told you
32 she was a psychiatrist
33 that came to see me
34 the first or second time
35 I was in there for treatment

STANZA 8

36 She came in
37 and I tried to talk to her about it
38 but I couldn't
39 I just couldn't get it out
40 and I just cried
41 thinkin' about it you know

PART IV (Problem unresolved)

STANZA 9

42 I think
43 once I had told the family and things
44 I didn't have no more problem talkin'
45 I talk about it now

STANZA 10

46 But ah,
47 about four weeks ago
48 they found out
49 it came back on me

STANZA 11

50 And ah,
51 that didn't bother me

STANZA 12

52 But ah
53 my friend that I tell you
54 I told before
55 I told her
56 I haven't told the family about it.

He acknowledges in STANZAS 6-8 that he initially had trouble talking about his illness. As he says, "For a long time, it was a hurtin' thing". Dealing with painful emotions is not easy. It's upsetting to oneself. It's hard to know what to say to loved ones. He was glad his daughter didn't ask him questions, because he "might have had a problem" (STANZA 5).

In STANZA 2 he presents his reason for telling. His reason isn't his own need to share his pain, but "they were goin' to see" his hair loss.

In PART IV he reveals his lack of resolution. He has identified that telling about his illness is a problem and infers with his statement "I can talk about it now" (STANZA 9) that he has resolved it. But then

discloses that when he learned of his recurrence he didn't tell his family, he told his friend (STANZA 12).

In the story WHAT SHE KNOWS he presents another aspect of the problem of telling; he is concerned about what his daughter learns from others. He is upset when he hears that his daughter went outside crying after overhearing her mother (his ex-wife) and grandmother talking about him. His view is others shouldn't talk about his condition to (or around) his daughter.

He also wonders about why his family doesn't ask him about his becoming hoarse when the cancer recurred. Talking about his recurrence he says, "For some reason nobody suspected, you know. I guess maybe they said, 'the first time he didn't get hoarse, so it must not have anything to do with the cancer'. Nobody questioned me on it".

Thinking about when he might tell his family, he seems to be waiting for the right time. As he says "I guess if I felt like if Dr. Wilson said that mine was life-threatening, then maybe I would have told my family. But, you know, I said, 'why bother!'"

Robert begins our second interview with a series of stories in which he presents his resolution to his problem telling. (CANCER IS BACK, NEGATIVE THINKING, YOU NEVER KNOW, DON'T UPSET ANYONE, DON'T TELL) The solution he offers is, don't tell. Don't tell because people

immediately think negative. That is, they think you're going to die. Don't tell because it might upset someone before they have to be upset. Don't tell because it might not happen. (People don't always die from what and when they are supposed to). As he sums it, "I ain't tellin', and it worked out perfect."

This is a fitting resolution for him. He remains the person burdened. He has, in his view, spared everyone else the pain of knowing. And, he feels good about that. He becomes a stoic figure.

By emphasizing his concern for others, Robert turns the focus of his account away from himself. His attitude toward his illness and its treatment is one of stoic, passive acceptance. He displays a lack of concern for how his illness is affecting him. He says he wasn't "bothered" by the diagnosis or by the news of recurrence. He spends little time talking about symptoms. Although he reports losing weight, decreasing appetite, feeling tired and becoming hoarse, he does not say that he is distressed by these physical changes. (The occurrence of symptoms has been carefully monitored during frequent medical check-ups and treated effectively). When he does talk about symptoms he typically discounts their overall effect by saying, "but I feel good". He participates in treatment in a resigned, cooperative manner. He displays his attitude toward the physical effects of his disease

and treatment in his story, RADIATION THERAPY. The structural analysis of this story is displayed in Schematic Transcription 2.3.

Schematic Transcription 2.3

STANZA 1

01 that radiation of the head treatment
02 that was part of my protocol.
03 It didn't call for the chest,
04 I guess.
05 Call for the head

PART I (Burnt me pretty bad)

STANZA 2

06 They burnt me pretty bad.
07 They did that over on Union Street
08 Number 16
09 They burnt me pretty bad.

CODA:

10 But my hair has started comin' back
11 where I was since I had that.

PART II (It didn't bother me)

STANZA 3

12 Not that it,
13 it don't bother me
14 or mean nothin'.
15 I'm just makin' a statement.
16 Sayin' that.

PART III (Burned black)

STANZA 4

17 My ears was all black.
18 They do a minute and a half.
19 My ears was sore.
20 I couldn't hardly wear my glasses
for awhile.

STANZA 5

21 My face and my head burned completely black.
22 It turned my hair.
23 People looked at me,
24 they thought I had dyed my hair.
25 I had no hair.

STANZA 6

26 My head turned black.
 27 My moustache turned black.
 28 Under my arms turned black,
 29 completely black.

CODA

30 The color came back in my head and things
 31 But the last two or three treatments
 32 made it like that.

PART IV (I do what I gotta' do)

STANZA 7

33 Like I said
 34 I do what I gotta do
 35 Whatever Dr. Wilson tell me to do
 36 I do

STANZA 8

37 I'm not concerned
 38 about the family anymore
 39 I'm just concerned
 40 about the little old lady there (his daughter).

After vividly describing being burned and blackened by the therapy, he says, "it don't bother me or mean nothin". (STANZA 3) He minimizes his own suffering. In STANZA 7 he expresses his approach to treatment, "I do what I gotta do". And he again reminds us in the final stanza that his concern is his daughter (not himself).

During his account of his illness experience, Robert tells stories about who he has been and is. (FATHER ROLE, UNION OFFICER, GOOD BUS DRIVER, GOOD CITIZEN). He presents himself as someone who takes pride in being a good father, friend and citizen.

Voice

As he experiences his illness, he struggles to maintain his dignity, to be the person he wants to be.

He is hurting and he doesn't want to show it. He is hurting and he doesn't know how to share it. He identifies problems he's having, but seems ambivalent about how to resolve them. He stoically accepts his illness and cooperates with treatment. But, there is an ever-present undercurrent of distress and lack of resolution in his voice.

Context

The world Robert lives in is important to his story. His social group, his family, is a complex reality. Although he spends a significant amount of time talking about his family, it's structure is still unclear. He describes his sisters as his immediate family. He tells me that he is unmarried. His children, step-kids, ex-wives, and ex-mothers in-law appear as minor actors in his stories. But I do not have a clear image of these people.

How this family functions is also a complex matter. His family is important to him. Beautiful large portrait photographs of different family members cover two walls in his living room. But their major role in his story is that they cause him distress. He worries about upsetting them. They do not emerge as providing support. His youngest daughter, his "heart", as he says, provides a loving relationship. But she does not know of or understand his illness.

Robert's major support in relation to his illness comes from health care professionals and a few friends. His doctors and nurses have shown an interest in him, made him feel like a person. He has made it possible for his youngest daughter to know his doctor and suggests that, if he couldn't answer her questions, his doctor would.

Understanding Robert as a twentieth-century black man gives depth to his story. His ability to deal with painful emotions and to share his illness with his family in an effective way may be rooted in historical realities; realities in which blacks endured profound pain and disruption of family.

This interview must also be understood as an interaction between a black man (participant) and a white woman (researcher). During the interview the conversation flowed easily. Robert seemed open and willing to talk. His tone was respectful and friendly but somewhat guarded. His expression of feelings and thoughts might have been different if the researcher had been a man. Thinking about his description of radiation treatment (see Schematic Transcript 2.3), his description of being blackened seems to be one of growing anger that is never realized. He assumes a stoic posture: "It don't bother me. . ." He might have done otherwise with

a different interviewer. The research context may have restrained Robert's telling.

Another aspect of the research context that possibly influenced this account was the entrance of two women toward the end of the second interview. The first visitor entered as the participant was finishing the story DON'T TELL. As is shown in the last two lines of Graphic Representation 2.0, all subsequent talk was about himself (stories of identity) not of his illness experience. Robert's telling needs to be appreciated as influenced by the research situation and the social context of the participant.

Examination of Transcendence

My analysis of Robert's account concludes with the question of whether his account is an example of transcendence and it is not.

Robert has "done well" living with his physical illness. He has cooperated in treatment that has minimized physical symptoms of his lung cancer and its treatment. Physical changes have not caused him his major distress. His interactions with health care professionals have been positive for him.

But this is a story of a man struggling: "it's a hurtin' thing". He is unable to fully appreciate his own feelings "it don't bother me". He is unable to share his experience with loved ones, "I just cried thinkin' about

it". It is not a story of reflection that leads to self-awareness, and experience of life's meaning.

Connectedness to others is not enhanced; it is strained. Robert is distressed. Although he tries, he is unable to satisfactorily understand and relieve his distress, to achieve a sense of peace.

THIRD PARTICIPANT

The third study participant, whom I will refer to as Rosemarie, is a 46 year old woman with breast cancer. Her cancer was diagnosed and initially treated in October of 1990. The cancer recurred in October of 1993 and since then she has been receiving chemotherapy for recurrence.

I met with Rosemarie in her home the day after contacting her by telephone. She reported being somewhat nervous about participating, but wanted to if there was a chance that sharing her experience might help others. She requested that the interview occur the very next day, so she wouldn't have to think about it too long.

When I drove up the driveway of her small, suburban home, she quickly came to the door. As I got out of the car she greeted me with "I love people who are on time" (it was 10:20 a.m. and we had agreed to meet at 10:30 a.m.). I looked at her cheerful face, erect posture and well groomed appearance and wondered "am I going to get a

story about dealing with life-threatening illness from this person?"

She had arranged for us to sit at the kitchen table in her neat, comfortable home. While I got the tape machine ready, she made us coffee. She also arranged for the answering machine to take messages during the interview to avoid interruptions.

One research interview two hours long was conducted. At the end of this interview, this participant felt that she had completed her story. We agreed that I would call her in about one week to review questions I had and to give her an opportunity to revise her account. During the follow-up telephone call, she reaffirmed that she wanted her account to stand as it was told. I, too, felt a sense of completeness. Rosemarie captures the sense of completeness when she says at the end of the interview, "I think you know my soul now. I really do, that's really it."

During the interview Rosemarie reveals herself as having fully integrated her illness into her life experience. As the graphic representation of her account shows, all her stories and descriptions are about her illness experience. She doesn't detour from it. (See Graphic Representation 3.0).

experience. As the graphic representation of her account shows, all her stories and descriptions are about her illness experience. She doesn't detour from it. (See Graphic Representation 3.0).

Graphic Representation 3.0

DIAGNOSIS, TREATMENT AND RECURRENCE	VACATION THERAPY	KINDS OF SUPPORT	TELLING OUR SON I	SON'S FRIENDS	CHANGE IN PLANS
GETTING PREPARED	FINDING MEANING	TELLING AN ACQUAINTANCE	HEALING SERVICE	GROWING AND LEARNING	LIVING EACH DAY
MEDITATING	PRAYERS	CENTER	HEALTH CARE PROFESSIONALS	TELLING OUR SON II	WHAT WE KNOW
NOT TELLING	Description of Fatigue & Nausea Weight Change	HAIR LOSS			ADDENDUM: ADVOCATES EARLY PREVENTION

From the outset she emphasizes the reality of her prognosis. In her introductory story, after relating the events preceding and following the news of the cancer's recurrence, she says:

(P) "after this last,
this chemo that I'm on now,
I really didn't want to know
farther down the road,
what's going to happen
Ya. So, but

(I) It's just how you

(P) It's just how I am

(I) you are.

(P) Because I feel faith
and the right medical treatment
can buy me time
The time that I need.

(I) Mm, mm.

She is buying time and she acknowledges it. By acknowledging it at the end of her introductory story, after reviewing the sequence of medical events, she makes clear the meaning these events have for her. The clarity of her knowing is profound.

Certainly, acknowledging the reality that she is "buying time" has influenced the nature of her experience. The presence of her illness is never denied. She openly grieves for herself and for the loss she knows her loved ones feel. During the interview, she occasionally cried softly. She described how she, her husband and their son have cried together. Knowing that

her illness has changed her prospects undergirds her account.

But her stories are not of despair. Hopefulness and a determination to live each day well coexist with her sadness about her prognosis. Her stories emphasize how she has developed her own strength and her connections with others.

In the stories FAITH, HEALING SERVICE, and PRAYERS, she tells of the strength she derives from her religious faith. It is through attending mass, she says, that she gets her "DOSE of power to go on and face this thing." She feels the power of prayer and is empowered when others pray for her. News that others are praying for her helps her turn around down days.

Recognizing prayer as a non-medical approach to dealing with an illness, she confronts possible conflict openly. In her story "HEALING SERVICE" she describes the amicable confrontation she had with her doctor over the issue of prayer. Out of "duty" to her priest she asks her doctor to participate in her bearing witness to the value of prayer. When he refuses, "because he wouldn't want anyone to think it's just prayer", she respects his position. She is very aware of what works for her. As she says,

"So, I'm not a lunatic to think
my God if you pray
this disease is going away.

It will not.
And I don't want anyone
to think that.

You need your good medical treatment,
and prayers help mentally, I think
My case anyway.

In her account she also tells about using meditation. In her story MEDITATING, she describes how she was first motivated to learn meditation as a young adult attempting to deal with exceptionally difficult decisions. (She had to make decisions about the care of her mother and grandmother). And then she tells how she uses meditation to solve problems that arise due to her illness. It helps her "clear her mind". Both she and her husband meditate regularly.

There is evidence throughout our interview that Rosemarie solves problems effectively. In her story CHANGE IN PLANS, she tells about how as a result of her illness she and her husband changed their plans to purchase a new, "dream" home and decided to "stay put" in the home (and neighborhood) they were comfortable in. She also demonstrates thoughtful decision-making as she tells about, 1) carefully choosing the time to tell her son about her illness (TELLING HER SON), 2) preparing her own grave site (GETTING PREPARED), 3) limiting her involvement in support groups (HOPE CENTER), 4) deciding with her family not to tell her ill Father-in law about her illness (NOT TELLING), and 5) marshalling help to

look good (HAIR LOSS). Sustained thoughtful problem-solving characterizes this participant's approach to the dilemmas precipitated by her illness. Developing and demonstrating personal strength is a major theme of this participant's account.

Rosemarie shows her good sense and sound judgment, as well as her sensitivity to others and her connection with nature, in her story VACATION THERAPY (the story is located on the first line of Graphic Representation 3.0).

Schematic Transcription 3.1

PART I: (Needing a vacation)

STANZA 1

01 Finally we. . .
02 my devastating chemo ended July 28th
03 and it was in October
04 we decided

STANZA 2

05 well we needed
06 a little vacation
07 so we took like
08 a two week vacation

PART II: (Making careful plans)

STANZA 3

09 But it wasn't anywhere
10 we did not go out of state
11 we just stayed here

STANZA 4

12 and maybe just travelled
13 to Connecticut one day
14 and Massachusetts one day

STANZA 5

15 cause I said to Bill
16 if I get sick
17 I really want to be home

STANZA 6

18 I don't want to be
19 somewhere else
20 or in an expensive hotel
21 getting sick
22 I didn't want that

PART III: (Friendly offer refused)

STANZA 7

23 In fact
24 We have friends
25 who offered us a beach home
26 right on the water
27 in Marilee

STANZA 8

28 It's like a duplex
29 So, they're on one side
30 and we'd be on this side

STANZA 9

31 And I said to Bill
32 I can't do that to them
33 if I'm not feeling well
34 or I'm huggin' the bowl
35 in the bathroom

STANZA 10

36 I don't want them to hear
37 or to feel bad for me
38 you know
39 So we didn't take it

PART IV (Time at the beach)

STANZA 11

40 But we went down
41 to the beach a lot
42 and we walked the beach
43 and it was wonderful
44 I loved that.

STANZA 12

45 I'm a Pices
46 so I have to be
47 on the ocean
48 near the water

Her stories also tell of her purposeful
strengthening of connections with family and friends.

The connections she describes are characterized by mutuality. She openly but deliberately expresses her thoughts and feelings. She is very conscious of others' needs. In the stories about telling her son about her illness (TELLING OUR SON I) and then about its recurrence (TELLING OUR SON II) she shows how she balances her desire for her son to know the truth of the situation with her knowledge that he must be able to mentally focus on his school work to achieve his goals.

Similarly, the stories of support encountered during her illness are stories of receiving and giving. She tells of the support she receives from her husband and son in the story KINDS OF SUPPORT. Her husband accompanies her to doctor's visits. Both her husband and son provide physical care for her at home and assume her home duties when necessary. Her account contains many mentions of support. Her story SON'S FRIENDS is a good example of the spontaneous occasions of support that occur because of her openness. In this story displayed in Schematic Transcription 3.2, she tells of an encounter with her son's friends in which, instead of feeling ashamed of her appearance, she feels supported.

Schematic Transcription 3.2

PART I (Summer scene)

STANZA 1 (visits)
 00 His friends were so good to me
 02 they'd come over in the summer
 03 because they'd all be home from colleges

STANZA 2 (resting)
 04 The summer was so darn hot
 05 that I'd be laying on the couch,
 06 and it was too hot to wear
 07 like my wig, or a turban or anything
 08 (I would keep a turban here)

PART II (Surprise encounter)

STANZA 3 (surprised)
 09 So I was on the couch,
 10 and the darn kids RAN up the driveway,
 11 ran into the front door

STANZA 4 (exposed)
 12 and I couldn't get up in time
 13 to get my turban on for them.
 14 So they saw me bald.

STANZA 5 (hiding)
 15 And they came over
 16 I went like this here,
 17 to try to hide my head
 18 with my hand.

STANZA 6 (accepting)
 19 And in the meantime, I'm laughing
 20 and they came in
 21 and they gave me a hug
 22 and a kiss.

STANZA 7 (knowing)
 23 And they said, Mrs. Croman
 24 don't worry about it.
 25 We KNOW that you don't have any hair
 26 We know from Billy
 27 Don't worry about it.

PART III: (Bonds "to keep you in our prayers")

STANZA 8 (remembering)
 28 So they were very good to me.
 29 and then they went back to college
 30 I got from two of them
 31 lovely notes

STANZA 9 (praying)
 32 you know, saying
 33 I'm going to keep you in our prayers.
 34 I'm going to keep you in our prayers

STANZA 10 (keeping)

35 The notes were just lovely
 36 I've kept them all, all my cards
 37 I must have 150 of them

CODA

38 So anyway
 39 that's the support
 40 I've been very lucky and very blessed
 41 with the support I get from everyone
 42 is really good.

She indicates in STANZAS 4 and 5 that she would have preferred to cover her baldness. But, STANZAS 6 and 7 show how her attitude towards her illness encourages support. She laughs at her embarrassment. Being open with her son has helped. Since he told his friends about his mother's condition, they aren't really surprised. They are ready to accept her and give her support and show this by giving her a hug and a kiss. Subsequently the young men remember and pray for her. She feels cared about, accepted, and supported.

Giving to others is an important part of Rosemarie's response to her illness. In her story FINDING MEANING she reflects upon the idea that there is a reason she has been afflicted and creates her meaning by providing support for others. Her physicians "refer" people to her who are in need of support.

Strengthening connections, for this participant, means not only relationships with people but also connections with God and nature. Her spirituality is deeply rooted in her Catholic upbringing and strong in

her life at present. As I have already mentioned, she believes that the power of her faith helps her deal with her illness. Her connection with nature is found in the comfort she feels being close to water. She likes to walk on the beach with her husband for "peace of mind". She chose a grave site that was close to water. (She wanted the ocean, but is contented with the pond she was able to get). Her connections are important aspects of her account of her illness.

Enduring the physical changes that have occurred as a result of her treatment is another important aspect of Rosemarie's account. Although she reports having undergone mastectomy and hysterectomy, it is the side effects of chemotherapy that she talks most about. Her chemotherapy resulted in fatigue, nausea, and hair loss. From April to August of 1994, she reports being either in the hospital receiving chemotherapy or at home with nausea.

But, she concludes, in her story HAIR LOSS, that her hair loss, which included the loss of her eyebrows and eyelashes, was the worst part of her illness. She hated looking in the mirror because she didn't look like herself. She was glad she didn't feel well enough to go out, because she didn't want people to see her looking as bad as she looked. She didn't want to go into a store for fear she'd scare someone. In her story of this

trauma, she also reveals how her personal strengths and support system help her prevail. With the help of her sister she accesses the resources of the "Look Good - Feeling Good Program" at the hospital to learn ways to improve her appearance. She cries and laughs with her family. As unpleasant as her physical problems have been, she never suggests that she regrets participating in therapy.

The themes of Rosemarie's account of her experience with breast cancer emerge from my structural and thematic analysis. Her stories are about acknowledging the reality of her illness and becoming the person she wants to be. She participates in medical treatment to live as long as possible. She strengthens herself and her relationships in order to be a responsible, considerate, loving person throughout this fundamentally difficult life experience.

Voice

This woman's voice has a humble power. She has some insecurities and fears, but she is openly aware of them. Ultimately her voice is deliberate and self-assured. She thinks through things carefully, and plans toward goals. She is reflective and flexible. With her eye firmly on doing the right thing, she is willing to change if warranted. Valuing mutuality, she willingly gives and

receives kindness and support. Her power comes from her purposefullness, her morality and her faith.

Context

A well defined family is the primary context of this participant. She clearly describes her family in her account and, along with herself, they are major actors in her narratives. She is experiencing her illness with her significant others. Repeatedly she used the plural "we" when talking about events; for example, "when we were first diagnosed", "we had that needle biopsy done", "we had some real rough chemotherapy we had to go through". In her account, she creates the sense that she isn't going through this alone. Family members communicate frequently and effectively. Together they have solved problems before and are providing this participant with assistance and support.

An important aspect of her world is her religious affiliation. She has developed her faith throughout her life. The Catholic Faith bonds the participant with her family and other people. The family regularly joins in expressions of faith. Obviously knowing that it would be meaningful to her, her son's friends offer to keep her in their prayers. When she tells of conversing with an acquaintance about her illness, the acquaintance is someone she knew from church. Her social interactions seem very much connected with her religious affiliation.

Examination of Transcendence

This participant is exhibiting transcendence (see Table 1). There is obvious correspondence of her ideas and the meaning of transcendence documented in the literature. Table 1 presents selected interview segments that exemplify key elements of the tentative definition and description of transcendence drawn from the literature and presented earlier. (Titles of the stories in which the segments appear are cited and can be located in Graphic Representation 3.0).

Table 1: Comparison of the tentative definition and description of transcendence drawn from the literature and topics expressed by the participant

TENTATIVE DEFINITION AND DESCRIPTION	TOPICS EXPRESSED BY ROSEMARIE
WISDOM	
realistic expectations of the future	"I said to Bill This is the time now because of recurrence. . .
awareness of what is going on	So we went to the. . um. . funeral home. . .
good sense and sound judgment	I knew where I wanted to be buried which is in the Holly Cemetery. I wanted to be there."
knowledge and insight.	[from GETTING PREPARED] "When the time comes When I have to give it [chemo] up then I'll be mentally prepared and we'll all be strong enough to know where we go from here"

"Anything that buys time,
that's fine,
But I don't want to know
right now
Well, after this chemo,
this is it."
[from WHAT WE KNOW]

CONNECTEDNESS

meaningful
relationships

"my husband's the type
that I can talk to
can talk my feelings
over with him

expressions of love
and harmony
bonds with people,
animals, nature,
and God

And he gives me
his feelings
And it's been like that
since ah,

sense of togetherness

Well it's always been like that
for our marriage
We've been married
almost twenty-five years"
[from KINDS OF SUPPORT]

"And then the hardest thing
was during the recurrence
which. . December '93
he [her son] was home,

And that's when,
we had to tell him. . .

That kid broke down
and just crying and hugging me,

He didn't want that to happen
and that was that"
[from TELLING OUR SON I]

SENSE OF PEACE

freedom from disturbing
thoughts or emotions

"We walked the beach. . .
it was nice. . .
you have to do that

expressions of feelings
secure, unafraid,
fulfilled, satisfied
with one's life and a
sense of completion

It's for peace of mind, too
for me and my husband

You get a clearing
when you go down there

Then you can come back
and deal with
what you have to deal with"
[comment after the story
VACATION THERAPY]

"I go to this healing service. .
And I think that's how
I get my DOSE of power
to go on and face this thing,
as ya OK, but Im strong,
I can deal with it.
[from HEALING SERVICE]

"as I wake up in the morning
and everybody in my family
and my people too,
my friends too,

We wake up saying
this is a good day"
[from LIVING EACH DAY]

GROWTH PROCESS

"you have to think
of so many things
I never knew I was capable
of thinking of all this stuff..

It's made our whole family grow
up
And it's made our whole family
look at things differently

Like, little things don't matter,
things don't bother you as much
as they did before,
You sort of look at the big
picture,
[comments related to
GROWING AND LEARNING]

Rosemarie views her illness as a challenge that has made her grow and mature. Seeking purpose in being so afflicted, she finds meaning in helping others who have cancer. She also finds meaning in the growth she and her

family have experienced. Throughout her illness, she has maintained her ties with family and friends. She is able to give and receive love and compassion. She feels supported. By nature reflective, she exhibits a sense of self-awareness that she has developed over time. She knows and expresses her feelings and thoughts. Continuing to be considerate of and sensitive to others, she gains a sense of self-worth from being the person she wants to be. Although she is sad about her situation, she is not unduly anxious or filled with regret. She knows and accepts the terminal nature of her illness and lives each day as fully as possible. She has demonstrated wisdom in her acceptance and in her ability to help her family adapt to their loss. She experiences a sense of peace in her connection with nature (walking on the beach) and through her spiritual activities.

Rosemarie's description of her response to her life-threatening illness is very much like the description of transcendence presented in the literature. However, there are a few differences. Her account of her illness does not report a sense of physical lightness or a sense of being healed or a sense of well being. But even without these elements, this account is an example of transcendence.

Comparison of Accounts

Analysis of the individual accounts of experiencing life-threatening illness created by participants in this study demonstrates that, of the three accounts, only one exhibits transcendence. So, despite my intent, the study is not a comparison of three examples of transcendence. However, the three can be thought of in other terms. All three participants are accepting their illness, but to different degrees. In order to distinguish the shades of acceptance represented and to better understand the stories told, similarities and differences are considered.

It is useful to begin the analysis by considering the overall structure of the accounts as depicted in the graphic representations. As the graphic representations indicate, the first story in all the accounts is about initial diagnosis and treatment. Of course, all the participants are responding to my direction to begin with how they learned about their diagnosis and they do this well.

The initial stories are similar in that they are all very vivid, detailed descriptions of the events that occurred. They were also all told in a matter-of-fact tone. These people know (are cognitively aware) that they have cancer. Without hesitation they use the word

cancer and relate their physical signs and symptoms and the details of their diagnosis and treatment.

Being knowledgeable about their illness is a significant common characteristic of the accounts. It is standard nursing and medical practice to foster acceptance by educating patients about their diagnosis and treatment. The ability to demonstrate knowledge of one's illness is evidence of a degree of acceptance. Conversely, if a person is unable to say the word cancer or talk about their treatment they would be denying. The introductory stories told by all of the participants in the study indicate a degree of acceptance.

The most profound difference in the generally very similar introductory stories is found in statements appearing near the end of each story. It is common in narratives for the teller to indicate the meaning actions and events have for them toward the end of a story, which does happen in these stories. In stories about diagnosis and treatment the participants hint at differences in meaning. Implying that the events aren't going to change her, the first participant says, "But I was fine." The second participant indicates his distress by saying, "It was hard for me to adjust. Not to adjust that I had cancer, that wasn't the problem. . . My problem was telling the family." After relating the sequence of events of her diagnosis and treatment the third

participant indicates that she knows she's going to die and is "buying time". These statements of meaning contained in the introductory stories signify the different shades of acceptance that do in fact become more clear as the accounts are completed.

Returning to the graphic representations, review of the topics of stories told reveals that all the participants include stories about similar topics. In addition to participating in diagnosis and treatment they tell stories about physical signs and symptoms, attitude, support, plans for the future and identity. The emphasis participants place on these topics helps to characterize their experience and suggests some universal or common features to it. The following table indicates the number of stories each participant told on a topic.

Table 2 The number of stories told by study participants in each different topical areas

TOPICAL AREAS						
	Participating in Dx & Tx	Physical Signs & Symptoms	Attitude	Support	Future Plans	Identity Development
I	3	7	3	3	0	12
II	3	2*	4	4	2*	10, 3*
III	1	1, 1*	9	9	1	0

* significant descriptions not narratives

As Table 1.0 shows, the first two participants spent a significant amount of time telling what I have called "Identity Development" stories. These are stories that detour from the main story line - their experience with life-threatening illness. The stories are identified in the graphic representations by triangles. In these stories participants are telling about who they are (or were) or what they do (or did). They are talking about themselves without illness.

As the table indicates, the third participant did not divert from the main story line about illness to present herself in such stories. She told about herself (her girlhood, her vocation), but in relation to her present experience. By integrating her identity into her stories she shows deep acceptance. To a greater extent than either of the other participants, she embraced the reality of her prognosis, grieved with others and prepared for her death - while living each day as fully as possible.

All the participants presented stories about their physical illness, but they were not stories of deterioration and distress. The first participant told many stories of physical signs and symptoms, but she focused on her ability to adapt to them. The participants experienced physical changes that, with vigilant nursing and medical care, they were able to

handle. Although their participation in work and other activities decreased, they continued to participate in activities that were important to them. Personal appearance was important. They expended significant effort to counteract the physical evidence of disease - to act and look "normal".

The participants expressed the belief that a "positive attitude" was important. But what they mean by it varies. As the first participant said, "They will tell you, your outlook on it does mean a lot. And I think what they mean is toward accepting it and adjusting to it." In stories that reveal her attitude, the first participant talks about having her own response (not listening to others' horror stories), taking it as it comes, focusing on good things, and keeping busy (not having time to dwell on it). For her, no sadness is allowed. Her busy life precludes time for despair or reflection.

Although the second participant says he has a positive attitude, he is unconvincing. Positive attitude for him is "not thinkin negative" - not thinking about cancer. As he says, "that word cancer is a dirty word." The attitude leads him to "not telling." By stoically trying to shoulder the burden of illness, he isolates himself, lives with unresolved distress, and limits the degree of acceptance he is able to achieve.

To the third participant, positive attitude means hopefulness, a hopefulness maintained in the presence of the reality that her illness will result in a premature death. She acts on her hopefulness by living each day well, appreciating little things, and by being the person she wants to be.

Sharing the experience with others is another topic each participant discusses. The experiences are very different. The first participant lives and receives help from her family and friends who don't talk about her illness. She is aware of what she needs and gets it. The second participant has a lot of difficulty trying to communicate with his family about his illness and resolves the difficulty by not communicating. The third participant purposefully builds her support by being open about her illness, by receiving gestures of support graciously, and by giving support to others.

In addition to the topics of the diagnosis and treatment of illness, identity development, attitude, and support, two of the participants talked about the future. It needs to be said that overall the accounts were focused on the present. The first participant didn't talk about the future at all. She did not mention making any preparations for her death. The second participant described making out his will and preparing advanced directives upon the encouragement of his physician. The

fact that he did this fits with his desire to be a responsible father. His will provides especially for the eleven year old daughter he is concerned about. But he shows his continuing ambivalence and inability to face the real implications of his actions when he tells about answering his son's query as to why he was preparing advanced directions. He tells his son that everyone should have them, not that his disease makes him vulnerable. The third participant embraces the reality of her death by preparing her grave-site and writing her obituary.

Comparison of these accounts, provided by people with terminal illness who were willing and able to talk about their experience (and who were also identified as transcending their illness), reveals significant similarities and differences in their experience. Although all of the accounts represent some degree of acceptance, there is wide variation. Robert's acceptance is fixed at the level of knowing. He is able to deal with the physical aspects of his illness and maintain his daily activities, but he is unable to acknowledge his illness emotionally, socially, or spiritually. The first participant, Kate, knows and adapts to her illness in a manner that she and her family are comfortable with. It is in Rosemarie's (third participant) story that a deep acceptance, a process of transcendence, is exhibited.

That such variation is present in accounts of persons "responding well" to their illness needs to be appreciated.

Another topic that, I think surprisingly, did not get mentioned was money. With the current concerns regarding health care costs, it is interesting that none of the participants talked about the financial aspects of the experience. Drawing participants from a single clinic probably standardized the level of health care and influenced the apparent lack of concern with cost.

Comparison of these accounts also makes clear that living with life-threatening illness poses a profound dilemma and one that I suggest is generally incompletely acknowledged. Fundamentally, the experience involves living and dying simultaneously. According to participants, the emphasis is on living. They and, they report, health care professionals place great value on the quality of life achieved. Hope is fostered. Certainly the goal of living the best one can is appropriate. However, the absence of attention to dying is interesting. Only the third participant talks about preparations for death. Yet, all are considered terminal. The fact that there are so few mentions of preparing for death is important.

CHAPTER 5

SUMMARY AND CONCLUSIONS

Summary

This study explored the human experience of life-threatening illness. The general focus was on gaining understanding of the experiences of people dying from terminal cancer through interviews designed to help the people tell about their experiences from their points of view. More specifically the purpose of the study was to contribute to the description and understanding of the phenomenon of transcendence as it occurs in the context of life-threatening illness. Transcendence is a term that is frequently used to describe a patient's response to suffering and particularly to life-threatening illness (Cassell, 1992; Chopra, 1988; Haase, Britt, Coward, Leidy, Penn, 1992; Koestler, 1949). But, it is an elusive, poorly understood phenomenon and one that has only recently been used in science.

The methodological approach was narrative interviewing and analysis. Developing knowledge of human experience through the study of narratives is based on the idea that people make sense of their experiences by constructing narratives about them (Bruner, 1990; Mishler, 1986; Riessman, 1993; Rosenwald & Ochberg, 1992; Sarbin, 1986). Individual's accounts obtained through in-depth interviews were analyzed. The study sample

consisted of three, adult, English-speaking persons with a diagnosis of terminal cancer who had been identified by professional nurses responsible for their care as having "transcended" their illness, and as being able to talk about their experience. The audiotaped and fully transcribed interviews were analyzed using narrative analysis. The socio-linguistic approach developed by Gee (1985, 1986, 1991) and Riessman (1993) guided the systematic study of the accounts. Brown and Gilligan's (1992) "voice centered relational method" provided general ideas for thinking about the data.

One of the participants exhibited transcendence. The others, while maintaining their lives through treatment, did not produce accounts that were consistent with "transcendence." Although only one of the participants exhibited transcendence, there were similarities among the three participants. The accounts were similar in the degree of cognitive awareness and the ability to manage the physical manifestations of illness and treatment. Differences were exhibited in attitude, communication patterns, perceived support and acknowledgement of prognosis. The participant exhibiting transcendence expressed hopefulness while embracing the reality of a premature death, communicated frequently and openly about being ill, and maintained strong connections with people, God, and nature. Displaying the profound

dilemma posed by hoping for life while facing death, the accounts emphasized living and paid unequal attention to preparing for death.

This study contributes to the understanding of transcendence by providing an example of one case that is compatible with definitions and descriptions in recent literature and examples of similar but essentially different responses. The study of narratives provided a way to achieve deep understanding of the complex human experience of life-threatening illness. Implications for research, practice and education are identified.

Substantive Conclusions

The results suggest that transcendence is an elusive phenomenon that is difficult to differentiate from other meliorative responses to terminal illness. Although the participants were identified by experienced clinical nurses as having transcended their life-threatening illness, only one of the accounts was, when compared to the literature description, an example of the phenomenon.

This study contributes to the description and understanding of transcendence by providing an example of it. At least the one account substantiates the existence of the phenomenon.

A certain degree of acceptance was inferred from the participants' level of cognitive awareness and their ability to manage their physical illness. All the

participants knew they had cancer. They were knowledgeable about the physical aspects of their disease and its diagnosis and treatment. They participated in self-care in order to control physical change. Maintaining their personal appearance and daily activities was important. They all knew that a "positive attitude" was important, but individuals had varying interpretations of the term.

In addition to informing the conceptualization of transcendence, the accounts display the profound dilemma posed by the experience of life-threatening illness; the hope for life coexisting with the reality of death. The way the dilemma is played out in the three accounts varies, but in all the emphasis is on living. The participants live as if they were going to live. Quality of life is a goal shared by participants, their families and health care professionals. The poignant stories one of the participants tells about the comfort she derives from getting prepared for death raises the question about attention to dying. In general, how dying is dealt with is not clear. For the most part there was little talk about preparing for death. It appears to be ignored by participants and professionals.

Methodological Conclusions

The methodological approach of the study provided a meaningful way to systematically study the personal

experience of terminal illness. Participants achieved and conveyed meaning by telling stories. Although it is well recognized that illness is much more than a physical process, we lack ways of understanding it as more than that. The study of narratives has proven to be a useful way to begin a deeper understanding. The implication for nursing science is that the method offers a way to build knowledge of human beings' experience with illness.

The story telling (the term "narratizing" has been used) that occurred in the study confirms some basic ideas about the importance and nature of narrative in human experience. The seemingly innate narrative tendency, the need to make sense of experiences by constructing narratives about them, was demonstrated in the interviews. Once a participant had begun a story she/he usually finished it. If a participant was in the process of telling a story and I asked a question or made a comment, she/he typically answered the question and then returned to the story. Sometimes if they knew what they wanted to say and I was taking too long asking my question, they would politely cut me off.

Sensitive topics are difficult to talk about and there were examples of this in the accounts. At times a participant would introduce a topic but then not develop it into a story - or change the topic abruptly.

Narrative is also known to be an identity development device. Two participants spent significant time developing their sense of identity in stories about themselves without illness. They reminisced about their life before the cancer. The person who transcended did not detour from the main topic of her illness. She told about herself in relation to her present illness experience. This finding seems significant. It may be an indication of the depth of her acceptance, but further study is needed.

Implications for Nursing Practice

This study confirms that narratives are important in nursing practice. Producing them helps patients make sense of their experience, voice their concerns, and express their problems. Listening to them helps the nurse to understand (and therefore to assist) the patient better. Listening to patients over time builds a knowledge base of patients' experiences that can be used in practice.

Narratives take time. How nurses are to expand their knowledge of patients in this way, when their time with patients is decreasing, will require ingenuity and commitment.

The narrative interview is very different from the type of nurse-patient exchange that takes place in the typical clinical nursing situation. The typical

encounter might legitimately involve specified assessments (e.g. a report of "pain" requires asking specific questions about location, duration, precipitating factors, etc.). However, narrative can be added to assessment by allowing extended responses (listening for the patient's story). Narrative can also be added to nurse-patient encounters by taking time out to sit with the patient and by using time during extended treatments or care (bathing, dressing changes) to encourage "talk."

A basic assumption of the study, related to nursing practice, was that experienced clinical nurses would be able to distinguish terminal patients who had "transcended" from those who had not. The assumption proved to be incorrect.

Reflecting on the nature of nursing practice experienced by the participants reveals that much about it was very good. Participants' comments about their doctors and nurses were unequivocally positive. All of the participants stated that the nurses treated them as people (not numbers). To quote the second participant, "All those nurses, they really build you up. They really act like they are interested in you, they make you feel welcome, they make you feel comfortable, they talk to you and explain things to you." It was important that the nurses remembered their names (even when sometimes they

didn't remember the nurses'"). One told about how good he felt when he got a Christmas card from the oncology nursing staff.

Participants all felt they had access to staff; that they could call at any time and have their calls returned quickly. As Rosemarie recalled,

"if you have a problem
you can call up.
They'll call you back
within five to ten minutes

So you're not hanging around all day
and worrying about
What you had to ask them about.
What the answer is going to be
[from HEALTH CARE PROFESSIONALS]

They appreciated being told what to expect and taught about what to do. That the participants exhibited good knowledge of their illness and ability to deal with signs and symptoms is undoubtedly related to the good teaching.

Reasons for the nurses' inability to identify patients' response as transcendence need to be identified and studied in the future. Possible reasons include different interpretations of the term and limited knowledge of patients' experience. It may also be that the persons recommended were generally so much "better" than other patients being treated that "transcending" was a comparative thing.

Review of the nursing literature identifies transcendence as a positive response to personal crisis that nurses should work to help patients achieve. In

nursing practice, transcendence needs to be appreciated as a complex human response. It is not a patient outcome that can be achieved with a direct cause and effect approach. It is not a "goal" that if not reached amounts to "failure." It is a state of being that is a possibility for all, but that may be easier for some to realize than others. However, since creating narratives does help people make sense of their experience, nurses may help patients move toward transcendence by encouraging them to tell stories about their experiences with life-threatening illness. The participants' stories familiarize us with the experience of terminal illness, an experience that, even with its common aspects, is different for each person. Fundamentally, nursing involves being with each person who is dying his or her own death. The possibility of transcendence must be reconciled with the patient's reality - the patient who, at the time of death, is "being" as well as he or she can be.

Implications for Nursing Education

The personal accounts and the interpretations of them would be instructive to nursing students. Descriptions of the personal experience of illness are not a part of standard nursing texts. For example, all of the accounts contain stories about alopecia. Losing one's hair is a traumatic side-effect of chemotherapy.

These stories could be read and discussed in order to broaden student's understanding of the experience of alopecia and ways it can be managed.

Although nursing education already focuses on therapeutic interviewing, sensitizing students to the role of narrative in their own lives and in their patients' would be a way to enhance their preparation for practice.

It would also be possible to develop ways for students to participate in narrative studies in nursing in order to enhance their understanding of nursing science.

Implications for Nursing Science

The narrative approach has produced in-depth understanding of a human experience of concern to nursing. There needs to be continued development of the method in nursing science.

The study also indicates a need for continued exploration of the experience of life-threatening illness in order to:

1. enhance the description and understanding of transcendence as a response to terminal illness.
2. expand the collection of stories to ill persons willing to talk (eliminating the criteria of "transcendence") to achieve

broader range of human experience.

3. explore the dilemma posed in terminal illness of hoping for life while preparing for death.
4. expand understanding of the experience in populations receiving different quality and types of health care (including the uninsured).
5. clarify the meaning and function of detours (development of identity stories) in the accounts of illness.

Recommendations for further study of transcendence include the need to:

1. study human experiences (other than life-threatening illness) where transcendence may occur (e.g. life crises, chronic illness).
2. explore the universality of transcendence by studying different cultures.
3. clarify cross-cultural expressions of the phenomenon, particularly in relation to how elements of the tentative definition (wisdom, connectedness and sense of peace) are expressed.

Nursing science is a human science. In my view the study of narratives provides a way to be true to the

complexities of human beings while developing scientific knowledge. The study is only a beginning, but it already demonstrates the power of the method. The method honors the participant. It produces valuable understanding for both the participant and the science. It has produced understanding of life-threatening illness - a subject of vital concern to nursing.

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APPENDIX A

Interview Guide
Face Sheet

Identification of Participant

Name:

Address:

Phone Number:

Contact Record _____

Interview Date _____ Time _____

Case Number _____

APPENDIX B

Consent Form for Research

The University of Rhode Island
White Hall
Kingston, Rhode Island 02881

CONSENT FORM FOR RESEARCH

I have been asked to take part in the research project described below. The researcher will explain the project to me in detail. I should feel free to ask questions. If I have more questions later Jane Williams, R.N., the person responsible for this study (Phone (401) 934-2027; Address, 46 Hunting House Lane, North Scituate, R.I. 02857) will discuss them with me.

Description of the Project:

I have been asked to take part in the study which looks at how people deal with life threatening illness. The reason for doing the study is to describe and understand the experience of living with a life threatening illness so that, in the future, others can be helped more to deal with illness and their treatment more effectively.

What will be Done:

The researcher will plan two or three interviews of approximately one hour in length. The interviews will be conducted in a private room at an agency or in another quiet space I agree to. During the interviews I will tell about my experiences since the beginning of my illness. I will think about and share my feelings and thoughts and describe my actions. The interview conversation will be tape recorded. My medical records at the agency may be reviewed by the researcher.

Risks or Discomfort:

I may feel upset talking about some of the topics that may come up during the interview. I may choose to stop the interview any time I want to.

Benefits of the Study:

There may be some benefits to me from participating in this study. These benefits may include some or all of the following: a sense of comfort from being able to talk about my feelings and thoughts; a sense of importance as a human person; a sense of contributing to better nursing care for others in the future.

Confidentiality:

My part in this study is confidential. My name will not be used on any notes, reports or publications resulting from this study. My signed consent form and identifying face sheet (with my name, address, and phone number) will be kept separate from the rest of the study data. The interview data will be identified by code number. Study records, including audiotapes and written notes, will be shared only with the researcher's faculty committee and a small number of professional colleagues. At the end of the research all audiotapes and written notes will be kept in a locked cabinet and kept indefinitely.

In Case There is any Injury to the Participant:

If the study causes me any injury, I can write or call the University of Rhode Island's Director of Research, 70 Lower College Road, University of Rhode Island, Kingston, R.I. 02881, telephone: (401) 792-2635.

Decision to Quit at Any Time:

The decision whether or not to take part in this study is up to me. I do not have to participate. If I decide to take part in the study, I may quit at any time. Whatever I decide will in no way affect the care I'm receiving. If I want to quit, I just tell Jane Williams (Phone: (401) 934-2027; Address: 46 Hunting House Lane, North Scituate, Rhode Island 02857) of my decision.

Rights and Complaints:

If I am not satisfied with the way this study is performed, I may share my concerns with Jane Williams (Phone: (401) 934-2027; Address: 46 Hunting House Lane, North Scituate, Rhode Island 02857) or Dr. Donna Schwartz-Barcott (Phone: (401) 792-2766; Address: University of Rhode Island, White Hall, Kingston, Rhode Island, 02881). If I want to, I may do this without identifying myself.

I HAVE READ THE CONSENT FORM AND MY QUESTIONS HAVE BEEN ANSWERED. MY SIGNATURE ON THIS FORM MEANS THAT I UNDERSTAND THE INFORMATION AND I AGREE TO PARTICIPATE IN THE STUDY.

Signature of Participant

Signature of Researcher

Printed Name

Jane S. Williams
Printed Name

Date

Date

Appendix C
Rough Transcription 1.1

- (P) This is usually within four or five days after the treatment. Like tomorrow, I'll probably feel fine. But then, as, I guess as it works through the system is when it starts to pick up these things. But um, um . . .
anyway. . . I. . . I . . . of course the hair loss is a . . . I've lost it. It's come back . . . I've lost it twice. It's come back both times. . . This time, because of the constant treatment, it's just like a little fuzz there. But it was funny because. . . I don't know which one it was . . . and I asked them . . . I had got my hair back, and I said . . . they mentioned hair loss. . . and I said, "Oh, because ONE time I didn't loose it enough to really wear a wig unless I were going someplace special, I kept quite a bit of it. So, I said, "What is this going to be?" They said "Big time loss" (laughs). And it did. Never before. But, I had heard people say it. You know, you go like this. So, I left and I went to . . . um . . . the Ming Wigs in Pleasantville, the wig shop where I had got my wigs. So, I said, "I've got to try this one. I want a new one" . . . and um. . . "because they tell me it is going big time." And I'm trying the wig on and it's falling all over the place (laughs). But anyway, I got one and my daughter and I went out to lunch afterward. And um, I think in a day. . . I said, "I'm going home and really brush this and get it over with."
- (I) Oh
- (P) And ah, you know it's going to go. Don't try to. . . But anyway, it um. . . and um. . . the wig is . . . somedays I wouldn't . . . my hair is straight: and to do it up, and then to take it down, and comb it. And, you didn't take it down much before you were going out, because my hair was straight. So these are kind of . . . um . . . you know I have one. . . never had, well I had grey hair but it was right here (pointing to her temple area) and it was shot through, and everybody said, "You don't have any gray hair". I said, "Well, if you look close enough" But ah, so I went out and bought a wig last year that has grey hairs (laughs) shot through it. So, I'll wear this, then, I'll put the wig on and they're probably thinking, Oh, it's time she has a dye job (laughs).

(I) Laughs

(P) Then, I go home and I put this on. Oh, she had hair color (laughs). A lot of people don't . . . even friends that I tell - have told them - this is a wig. . . "Oh ya, that looks good" I say, "I'm wearing a wig" you know, and a, but

(I) It does look very nice.

(P) Thanks. It's. . . I had red hair when I was younger. But instead of going. . . My hairdresser had said "You probably never will have grey hair. . . she said, "it will change color. . . it will go on a brownish. ." you know, so, which was. . . it had gone on this color. . . you know, and I think that's why a lot people didn't realize that it was a wig, because it was. . . When I walked in, my daughter spotted it way up somewhere near the ceiling and she said, "Oh, Ma, that's you". And so, when the girl took it down she said, "Oh, this is eery" (laughs) 'cause, I had, you know, I had the hair. She said, "It does. . . it looks like your color". But um, it's all in accept. . . not just accepting things, but getting them done right there.

Appendix D
Rough Transcription 1.2

- (P) And, this is one thing. I'm always glad that I did hang onto it. And ah, because they can all come, you know (laughs). And, I've taken them in over the years. When my older son came back from Colorado, he stayed with me. Although he had two other houses here. . but, one he's rented for years to the same people. But the other one, um, um. . had an upstairs and down, he could have moved in there. There was room there. But he stayed, and ah, then when my daughter came home, then he said "well now I'll go out". And ah, ah, but oh, and when my daughter first came home from Worcester with her two children I took them in until they could find an apartment for themselves. And ah, its really been, as I say, I think the main thing is I don't have time to dwell on it.
- (I) Mm, mm
- (P) And this is where if you sit alone and dwell on it. It's a. . you know. . I can always read. And that was a funny thing. In the hospital, I go so I couldn't read that much. This was killing me, too.
- (I) Mm, mm.
- (P) I think it was a combination of the two things. I was probably always on my mind, "when am I going to get out of here" and it was around the holidays. It took in, a, a like I have a dinner to go to for the Legion and, that my husband belonged to. W have an annual. . its a very small group. . cause we're all dying off. . . and a. . only the women are going to be left pretty soon. But anyway, I missed that. And, I missed the Appreciation Dinner. And then, there was Thanksgiving. And um, it was um, a, so I might have been depressed then. But, over the years I've never been depressed so I, I don't think that I really knew what it was until, as you say, I sat there and I said, "What is the matter with you". Why can't you. But anyways, I don't know, I just take it as it comes
- (I) Mm.

(P) You know, I wouldn't be afraid to. . if I went into like a deep depression, like I have seen some patients, that um. . they, they just can't think of anything else. But um. . one was a young girl, I. . she actually used to tremble when she'd come in. And, she talked to the doctor. And she called feeling better.

(I) Mm, mm.

(P) But um, hers was one of those things where she had to force herself to go out, too. But, I wouldn't be afraid of, um, going and saying to the doctor I think I need outside help, you know.

(I) Mm, mm

(P) And ah, but I can't see it right now. (laughs) I don't have time. (laughs). So, over the tape. . I know you have asked me things that I think were very pertinent on, you know, enlarging on or explaining, you know, whatever, but um.

Appendix E
Rough Transcription 1.3

- (P) And ah, I don't think anybody wants to hear too much about your illnesses either, I don't talk about it. In fact one of the men that is in the singing group with us. . . Oh God, he's um 82 or 83, and he's having, now he's having radiation, I. . his is prostate, which I guess that's very good for that, and a, but um, this man was coming six months before anybody knew, and I think it was just that there was a time for us to go someplace and he said, "No, I have to go have radiation. But, he doesn't talk about it. And, I don't talk about it. One of the other women had um, in fact she was a nurse at Main before she retired, Um, she just had a mastectomy. And she's been out for maybe about six months or so, and um, but she was back last week. And we all just said, you know, "how are you feeling?" Fine, And she really looks great. And um, so um, but I guess she just stayed home for awhile and now she felt, well now I'm ready to get out and get going. And ah, as I say, she looks good.
- (I) It sounds like you have a lot of activities . Volunteer. . things that you enjoy and don't talk a lot about it to them. As a routine. Do you talk about it to someone? or sometimes do you find you need to
- (P) No, no, I don't know. If, with the family, if I find anything that is going to change, then I will tell them (eyes filled up and became reddened) and, with the Taxol is. . I think they know more about that because of the writeups that have been in the paper. Um, my oldest son who brought me over today. I said, "I'm on Taxol". I'm sure that didn't mean anything to him And I said, "that is the one they. . the big thing about getting the bark from the tree" And he said, "Oh yes, I heard about that". But I think you read it once. . you don't hang on to the nitty as much, but if you can explain what it is. As I go from drug to drug. It was explained. I mean, as much as I could explain it to them I would. Or, if it effects. . my face'll get flushed afterward and they'll say "Oh your face is all red." And I'll say, "Well its from the treatment and I'm probably getting ready to run a slight temperature.

(I) A-ah

(P) And a, so, but as far as, you know, from day. .
they'll come in "Hi, how are you?" . . "Good" .
and a, I always feel good when I'm sitting down
(laughs). I say, just don't
chase me anywhere, that's all (laughs).

Appendix F
Rough Transcription 2.1

(P) Really, I think I got sick around, ah, August of 1993. And ah, I thought it was just a cold. And ah, I just kept taking medication over the counter medication things and the cough would never go away. Finally, I went to my family doctor, and ah, he took X-rays and said that I had pneumonia. And ah, he gave me some medicine for the pneumonia, and after, ah, the medication. wanted me back. I went back. Took another X-ray. And ah, he found something that he didn't like. So ah, he sent me, ah, to ah, Dr. Smith. And ah, I guess he's a cancer expert. He more or less verified what Dr. Jones had suspected. . that I had cancer in my lungs and ah, from there they sent me. . . he did a biopsy on me at the Midland Hospital. After he looked at the X-rays, he said it definitely was cancer. So after that he sent me to Dr. Wilson. and ah. . . . it was hard for me to adjust. Not to adjust that I had cancer, that wasn't the problem. In October of '93 I had my next older sister die of cancer. And ah, I found out about mine in November. And ah, my problem was telling the family. But I didn't want to upset them over the holidays, you know my sister just passing away and things like that, so I just held everything in me. That was strain on me with that. Then, I have my eleven year old daughter and me and her are very close. An ah, thinkin' about her and how she would respond to it. Dr. Wilson told me, he said "the good part of my cancer, I had the fine cell cancer. that responded to chemo very well. So ah, he set up for me to have a. . eight treatments three days every three weeks. And I'd go into Midland Hospital for three days, from Monday morning to Wednesday afternoon and take the chemo. And, I'd come back out. I'd take the week off cause. . chemo has a tendency to make me feel tired and so ah, I had two treatments before I told my family about it. And that was so the holidays was over then. And ah, my daughter, I just told her that I had to go to the hospital for treatment. Smart as she is, she didn't questions me. Which I was glad in a way you know.

Appendix G
Rough Transcription 2.2

- (P) But I told, called my oldest sister and after the third treatment. Which was about just goin' in to February, see, I hadn't lost no hair or nothin. But, I figured it was just a matter of time, cause they all told me I was goin' to loose my hair. That they were goin see. And they were goin' to question me.
- (I) Yes
- (P) So, ah. . like I say my main thing would be Kitty, my youngest daughter. How she was goin' take it. And ah, accept it you know. Like I said, I just told her Daddy was sick and had to go for treatment. She didn't question me. Which made for the best, because I might have had a problem. You know, ah. . this thing, and ah. . But I ah. . and ah, you know, I couldn't talk about it for a long time. It was a hurtin' thing. In fact that lady I told you was, she was a psychiatrist that came to see me
- (I) Mm, mm
- (P) Ah, the first, the first or second time I was in there, ah, for treatment, you know she came in and I tried to talk to her about it, but I couldn't. You know. I just couldn't get it out. And I just cried, thinkin' about it. You know.
- (I) Mm, mm
- (P) Once I'd got at, I think once I had told the family and things, I didn't have no more problem talkin you know.
- (I) Mm, mm
- (P) And ah, I talk about it now, you know. But ah, bout ah four weeks, ya, about four weeks ago I guess, they found out that it came back on me. And ah, that didn't bother me. But ah, my friend that I tell you I told before. I told her. I haven't told the family about it, you know.

Appendix H
Rough Transcription 2.3

- (P) And ah, that radiation of the head treatment, that was part of my, a. . a. .
- (I) the protocol.
- (P) the protocol. But it didn't call for the chest I guess. Call for the head. And ah, they burnt me pretty bad. But ah, they did that over on Union Street No. 16. And they burnt me pretty bad. But my hair has started comin' back, where I was since I had that. Not that it, you know, it don't bother me or mean nothin'. I'm just makin' a statement. Sayin' that. And my ears was all black. And ah, they do a minute and a half.
- (I) Did it hurt then, as well, your skin?
- (P) No, but my ears was sore, for I couldn't hardly wear my glasses for awhile. Ah my face and my head turned completely black. And ah, it turned my hair. People looked at me, they thought that I had dyed my hair, I had no hair, my head turned black. My moustache turned, black and under my arms turned black, completely black. You know, in fact most of the hair under my arms is black, you know. The color came back in my head and things. But ah, the last two or three treatments of it, it made it like that. But otherwise.
- (I) Was that painful?
- (P) No,
- (I) Ah.
- (P) As I said behind, my ears was sore, an'wearin' my glasses, catchin' 'em; but for it really scabbin' up, no. Ah, you know, like I said I do what I gotta do. You know, whatever Dr. Wilson, or whatever, tell me to do, I do. And ah, I'm not concerned about the family anymore, I'm just concerned about the little old lady there.

Appendix I
Rough Transcription 3.1

- (P) So, we had a, a, finally we. . my devastating chemo ended July 29th and it was October we decided, well we needed a little vacation. So we took like a two week vacation. But it wasn't anywhere, we did not go out of state. We just stayed here. And maybe just travelled to Connecticut one day, Massachusetts one day. 'Cause I said to Bill, if I get sick, I really want to be home I don't want to be somewhere else or in an expensive hotel getting sick. I didn't want that. In fact we had friends who offered us a beach home right on the water in Marilee. It's like a duplex, so they're on one side and we'd be on this side. And I said to Bill, "I can't do that to them". If I'm not feeling well, or I'm huggin' the bowl in the bathroom. I don't want them to hear or to feel bad for me. So, we didn't take it. We went down to the beach alot. And walked the beach. And it was wonderful. I loved that. I'm a Pices. So I have to be on the ocean, near the water.

Appendix J
Rough Transcription 3.2

- (P) His friends were so good to me. And ah, they'd come over in the summer, because they'd all be home from colleges. And um, the summer was so darn hot. that, I'd be laying on the couch, and it was too hot to wear, like, my wig, or a turban or anything. And I would keep a turban here (*pointing to counter*).
- (I) Are you wearing a wig?
- (P) This is a wig (*pointing to hair*)
- (I) Oh.
- (P) I keep a turban,
- (I) It looks great.
- (P) Oh, thank you. This was me (*pointing to a picture on the kitchen table*). This is natural here. So this is the wig, and this is in the same style, that classic style.
- (I) Mm, mm.
- (P) But, I keep a turban here. And I was on the couch, and the darn kids ran up the driveway, ran into the front door, and I couldn't get up in time to get my turban on for them. So, they saw me bald. And they came over. I went like this here to try to hide my head (*puts hands over her head*) with my hand. And in the meantime I'm laughin, And they came in, and they gave me a hug, and a kiss. And they said, Mrs. Croman, don't worry about it. We know that you don't have any hair. We know from Billy, Don't worry about it. So, they were very good to me. And ah, and then when they went back to college, I got from two of the, lovely notes. Ah, you know, sayin' I'm going to keep you in our prayers, I'm going to keep you in our prayers. And um, ah, the notes were just lovely, I've kept them all, All my cards. I must have about a hundred and fifty of them. But um, so anyway, that's the support. I've been very lucky and very blessed with the support I get from everyone, is really good.

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