

**SURVIVING A TERMINAL DIAGNOSIS: THE ULTIMATE  
LIFELONG LEARNING EXPERIENCE**

Alice E. McAndrew

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Albert Wiswell, Chair  
Marvin G. Cline  
Marcie Boucouvalas  
Thomas Reio  
Paul Glass

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Falls Church, Virginia

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# SURVIVING A TERMINAL DIAGNOSIS: THE ULTIMATE LIFELONG LEARNING EXPERIENCE

Alice E. McAndrew

Chair, Albert Wiswell, Adult Learning and Human Resource Development

## (ABSTRACT)

Every year in the United States, cancer accounts for one in four deaths. As the pool of those who have received diagnoses increases, more individuals can be encountered who have survived a terminal diagnosis or exceeded expected time limits for survival. Perhaps even more extraordinary, many of these consider it the “best thing” that ever happened to them. These are the modern eras’ “mythical” heroes; they return bearing maps for our own eventual journeys.

This study used a grounded theory research approach to illuminate the phenomenon of terminal diagnosis survivorship as evidenced in the psycho/social/spiritual learning process. The unit of analysis is the psychosocial and spiritual learning process as discovered and developed from three cases of individuals who described being positively transformed after receiving a terminal diagnosis. Three research questions were examined: (a) What are the components (e.g., coping strategies, problem solving techniques, emotion management) of the learning process employed by three cancer patients who have experienced a terminal diagnosis? (b) In what ways did the phenomenal meaning of their lives change as they coped with the trauma of a terminal diagnosis followed by remission persisting a significant time past doctors’ predictions? (c) What changes did they make in their lives, viewed from a holistic perspective, including thought processes, healthcare, emotion, spirituality and changes in their social lives? A comparative analysis of tape recorded interviews yielded the data resulting in a six-phase model of terminal diagnosis survivorship delineating a psycho/social/spiritual transformational learning process.

Death acceptance emerged as a central organizing construct facilitating transformational changes in those given a terminal diagnosis resulting in a constellation of attitudinal and behavioral change. This model challenges and extends theory in adult learning and post traumatic survival by challenging the heavily rational and cognitive based theories of these fields, emphasizing the importance of emotions, altered states, extrarational experiences and

spirituality. This model also explicates the role of denial that can alternatively hamper, facilitate or place on hold movement toward death acceptance, the ultimate transformative agent.

Additionally, this model elucidates the importance of holding environments on both sustaining and eliciting transformational and developmental change.

## **DEDICATION**

This dissertation is dedicated to the three cancer survivors who provided me their wonderful stories that comprise the basis of this research study. They are our modern day heroes whose bravery and courage in the face of adversity serve as an inspiration to us all.

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## CHAPTER 1

### INTRODUCTION

According to the American Cancer Society, this year 1.4 million Americans will be given a diagnosis of cancer, accounting for one of every four deaths in the U. S. Cancer ranks right after heart disease as a leading cause of death which will result in 1,500 deaths each day this year, a total of 560,000 in all. But after all, these are just statistics, or at least that is what I thought before I was diagnosed with breast cancer in January of 2001.

Today because of early detection of cancers and improved treatment, the outlook for survivors is improving. But a diagnosis of cancer still brings with it awareness of one's mortality. Those who receive a diagnosis of a stage I cancer, with 90 to 95% survival rates, can perhaps persuade themselves that they can swim back to the shore of life. However stage III and IV's, or "advanced cancer" as it is characterized, brings with it a sharper awareness of mortality or, following the metaphor, the shore of life begins to appear as a speck on the horizon and one soon needs to learn something about floating right where you are.

And yet as scary as this can sound to the uninitiated, once you become one of "them" and enter this strange land of survivorship, you soon learn that it is inhabited by some strange denizens. There are those far worse off than you who have been given a terminal diagnosis, faced all the possible consequences of their mortality and survived past all expectations. Most amazing is that these people not only survived, but thrived, achieving recognition of the beauty and possibilities of life most will never know in a long healthy life.

Existential philosophers and psychologists (Frankl, 1967; Tillich, 1959; Yalom 1980, 1989) advanced the idea that facing mortality can facilitate a transformative change in individuals, forcing a reevaluation of priorities and resulting in a more authentic life. Kubler-Ross (1969, 1975) reported that terminally ill clients frequently stated that they had learned more and lived more since receiving their terminal diagnosis. She believed that our death denying society contributed to people's expressions of living empty and purposeless lives.

Yalom (1980) delineated three issues of relevance for the terminally ill: fear of death, the need for hope and the importance of finding meaning in life. Kinnier, Tribbensee, Rose, and Vaughan (2001) found that people who had faced death found increased meaning from the experience, believed they had learned important lessons about life and were eager to share their new found wisdom. They also expressed less interest in materialism, increased interest in

spirituality and a need to care for and serve others. Parallels have been drawn between the treatment of HIV/AIDS patients and cancer patients (Holt et al., 1999). Both diseases are no longer perceived as death sentences but more often regarded as chronic illnesses with considerable stigma and long-range psychological effects. Questions about the meaning of life and spirituality are regular presenting issues for those confronted with these illnesses.

It is three of these stories that inform this research illuminating the phenomenon of terminal diagnosis survivorship. These are individuals who had drifted way out to sea but found their way back to the distant shore of life, bringing with them a special wisdom for all of us.

## **Background of the Problem**

### ***Importance of Paradigms***

The field of psychosocial and spiritual cancer research could use a paradigm shift not unlike the Copernican revolution portrayed by Thomas Kuhn in his seminal work *The Structure of Scientific Revolutions* (1962). The Copernican revolution proclaimed the sun to be the center of the solar system eventually supplanting the Ptolemaic world view of the earth as center of the universe. This revolution had profound social implications because the Ptolemaic view, supported by the Medieval Church, was effectively undermined for the first time by a scientific theory. Psychosocial research reflects the dominant biomedical paradigm that still has little room for conceptualization or understanding of patients' psychological, emotional, transpersonal and spiritual needs.

### ***The Biomedical Paradigm***

Challis and Stam (1990) analyzed medical reports regarding spontaneous remission from 1900-1987 and observed that extensive reporting appeared on various physiological factors, but observations regarding personality and lifestyles were conspicuously absent. Since there is much current research supporting the mind/body connection and importance of personality and lifestyle on health, this absence in medical case literature certainly illustrates the power and dominance of the materialistic biomedical paradigm. However, the popular literature has reflected the views of some doctors who have recognized the inadequacy of their own paradigm, who have truly listened to the stories of their patients and have heard their need to look for the deeper meaning and purpose in their experience (Geffen, 2000; Spiegel, 1993; Weil, 1995).

### ***Emergence of Psychosocial and Spiritual Research***

Psychosocial research on cancer has proliferated in recent years but is still considered in its infancy (Henderson, 1997). There is a growing recognition of the importance of looking at the psychological, emotional, social, spiritual and meaning-based aspects of the individual's experience. Researchers are beginning to recognize the importance of querying subjects on all of these aspects of their existence. However, while there is a great deal of theoretical speculation about a unifying process or healing system that may be operating in these cases, there is clearly a need for grounded research to look at process and begin to build theory.

The postpositivistic approach prevalent in the field of psychosocial cancer research accommodates the medical positivist methodology by adding small qualitative components to what is largely trait theory research. These qualitative components have allowed for a voice of survivors to emerge. Many studies now focus on spirituality because so many cancer patients expressed how important these concepts of spirituality were to their experience.

### ***Need for Holistic and Constructivist Approaches and Theory Development***

Still larger frameworks of personality transformation and the role of meaning making are rarely accounted for in psychosocial research (Temoshok, 1987). Temoshok's process model presents an exception to the dominance of linear trait studies. She demonstrated a paradigm shift of her own when she realized that her earlier work characterizing the Type C personality presented a static portrayal of characteristics usually seen in cancer patients. This process model was developed to describe the evolving characteristics evidenced by Temoshok's subjects over time.

While Temoshok's (1987) process model attempts to account for process in postpositivist research, this is only an accommodation within the paradigm to acknowledge differences with trait theory approaches. What seems to be missing are constructivist approaches which seek to understand process in the lived experience of cancer patients. The area of research that comes closest to this is the research literature on spontaneous remission which tends to be largely dissertation research. This suggests that funding for more in- depth qualitative studies may not be forthcoming because it does not fit the dominant paradigm of research previously discussed.

A review of the literature revealed limited research specifically geared to studying psychosocial and spiritual aspects of those who have experienced a terminal diagnosis,

particularly looking for a process that may be common to all cases. Looking at the more dramatic examples of cancer survivorship as provided by those surviving terminal diagnosis may provide a good start to the overall development of theory regarding survivorship. The grounded theory methodology used in this study provided a systemic approach for the collection and analysis of data in order to generate explanatory theory that should offer a starting orientation for scholarly debate.

### **Statement of the Problem**

Research on psychosocial and spiritual aspects of cancer appears to cluster on either side of a fault line. There is a need to find common ground: those who perform linear based or trait theory research need to understand that their work would be enhanced by relating to a larger whole and those who perform studies on the lived experience of cancer survivors can benefit from looking at trait research to understand how it might inform their own research. New paradigms of research indicate the importance for researchers to look both within and without their respective fields in order to establish broader connections to other work and approaches.

This grounded research study provides a beginning theory of process that has applications for extended cancer survival and terminal diagnosis survival. The theory presented here is more nuanced and comprehensive because it challenges the heavily rational and cognitive based theories of both adult learning and post trauma survival. The importance of emotions, altered states, extrarational experiences and spirituality were evidenced by each of the survivors of this study, demonstrating the importance of these elements in major transformational processes of individuals.

Previous studies on transformation of cancer survivors have reported and emphasized the different paths taken to recovery by each person. All studies have delineated the importance of facing mortality and described various attitudinal, affective and behavioral changes that are characteristic of this recovery. However, very little effort has been made to describe or ascertain an underlying process to the various behaviors delineated in these studies. Too often attributions offered by the individual are taken for face value as an explanation of behavior and researchers appear to have missed the dichotomy between what the individual explains as causal and what an analysis of his/her process reflects.

## **Purpose of the Study**

This study has used grounded theory research approach to construct a model that explicates the process of learning used by individuals who have been given a terminal diagnosis but have lived years past their diagnosis. The unit of analysis is the psychosocial and spiritual learning process as discovered and developed from three cases of individuals who have been positively transformed after being given a terminal diagnosis. A case study approach was used to examine the lived experience, meaning and consequent changes made in the individuals' lives. This inquiry has focused on learning about the individuals' lives prior to diagnosis, their coping with the terminal diagnosis and reconstructing their lives. Interview questions were holistic, covering how process manifests in thought processes, healthcare, emotions, social life, spirituality and meaning of life.

## **Research Questions**

The research questions that guided this study are as follows:

1. What are the components (e.g., coping strategies, problem solving techniques, emotion management) of the learning process employed by three cancer patients who have experienced a terminal diagnosis?
2. In what ways did the phenomenal meaning of their lives change as they coped with the trauma of a terminal diagnosis followed by remission persisting a significant time past doctors' predictions?
3. What changes did they make in their lives, viewed from a holistic perspective, including thought processes, healthcare, emotion, spirituality and changes in their social lives?

## **Significance of the Research**

The centrality of the importance of death acceptance emerged as the main organizing construct in facilitating transformational changes in those who have been given a terminal diagnosis. Related studies on extended survival and spontaneous remission have delineated a constellation of positive attitudinal, affective and behavioral changes that include many commonalities, including facing mortality, exploring meaning and purpose to life, assuming responsibilities for life, transcending ego and development of personal meaning through transpersonal levels of consciousness, altered states and spirituality. Although virtually every

study has indicated the critical importance of coming to terms with one's mortality, what has not been delineated is that this process is the central organizing construct and focus around which the constellation of behavior change is organized.

This study presents a model of terminal diagnosis survival that challenges and extends theory in adult learning and post traumatic survival. These fields of research are dominated by heavily rational and cognitive models of transformation that do not sufficiently delineate the role of emotions in facilitating behavioral change; nor do they describe the role that extrarational processes, altered states and spirituality have in furthering meaning-making in the transformational learning process. Additionally, this model highlights the importance of holding environments, in both sustaining and eliciting developmental change.

This research also highlights the importance of explicating the role of denial or positive avoidance as an adaptive mechanism that facilitates the individual's processes of assimilation and accommodation to the loss of his or her assumptive world. There is still much controversy in the psychological literature about whether or not denial is a conscious or unconscious process. This study adds to the literature that demonstrates how it can be used to facilitate achievement of essential goals when the individual becomes overwhelmed with the implications of his/her diagnosis. Additional research is required not only to understand the process but to reach greater clarity of terminology.

## CHAPTER 2

### LITERATURE REVIEW

#### Introduction

Chapter Two provides a theoretical/conceptual framework for a grounded theory study of the learning experience of cancer patients who have successfully confronted a terminal diagnosis and have been positively transformed as a result of the experience. This chapter is organized into four sections: (a) the first section will briefly review how scientific paradigms and related epistemologies influence psychosocial/spiritual cancer research; (b) followed by the specific theoretical/conceptual orientation for this study; (c) definition of the gap in the literature both challenging and extending theory; and finally, (d) a review of the major research areas in the field of psychosocial and spiritual cancer research.

#### Psychosocial/Spiritual Cancer Research

In this research study an emphasis has been placed on the importance of explicating one's theoretical perspective. Chapter three presents a more detailed discussion of the influence that scientific paradigms and their related epistemologies have in shaping our perceptions of the world. This discussion will be briefly reviewed here because it is important to the review of the literature for two reasons: to understand the theoretical learning framework of this study as delineated by two transformative learning theorists, Jack Mezirow and Robert Boyd; and to describe how this research study challenges the epistemological foundations of psychosocial and spiritual cancer research.

#### *Psychosocial/Spiritual Research: Overview of Scientific Paradigms and Epistemologies*

Thomas Kuhn (1962) introduced the concept of the scientific paradigm which he defined as “a constellation of achievements – concepts, values, techniques, etc. -- shared by a scientific community and used by that community to define legitimate problems and solutions.” (p. 37) At any specific point in history the scientific community shares a prevailing paradigm that informs and shapes the direction of work in the field. Perhaps John Casti (1990) stated it best when he said, “for most scientists major paradigms are like a pair of spectacles that they put on in order to solve puzzles.” (p. 41.) Following his metaphor he further indicated that when a paradigm shift occurs, the glasses are smashed and a new pair is put on; once again, transforming the shape of

everything and providing a new vision of “truth.” The new glasses provide scientists with new puzzles to be solved while advancing what Kuhn referred to as “normal science.” As Einstein so succinctly stated, “The theory tells you what you can observe.” (p. 42)

Descriptions of the starkly contrasting Quantum and Newtonian paradigms (Capra, 1975; Casti, 1990; Zohar, 1990) reflect the prevailing scientific research of our times. The Newtonian paradigm describes the linearly based, causal and deterministic themes that derived from Newton’s work, an epistemology of nature as objective reality and quantitative and positivistic approaches constituting dominant scientific thought.

The spectacular successes of the Newtonian paradigm of research as seen in the hard sciences such as medicine, physics and chemistry define the average person’s concept of science. However, all of this changed in the first three decades of the twentieth century when the findings from relativity theory and atomic physics completely shattered the central ideas of the Newtonian world view. This new paradigm represented a holistic world view that is reflected not only in physics, biology and chemistry, but other fields including the social sciences.

### ***Psychosocial/Spiritual Research: Positivism and Constructivism***

The epistemology that best reflects the still dominant Newtonian paradigm is positivism which is based on a linear, deterministic and reductionistic interpretation of reality. The corresponding ontology is naïve realism which assumes reality to be apprehendable; therefore, research can determine ‘true’ nature of the way things are (Denzin & Lincoln, 1994, p. 109). Methodology consists of verifying hypotheses and questions by empirical testing and often reporting results in the form of cause-effect laws.

The corresponding epistemology for the Quantum paradigm is best reflected in constructivism, where multiple realities are a possibility, as knower and subject establish an interactive linkage to literally create findings and construct an understanding of reality. As multiple socially constructed realities occur, the aim of inquiry is to understand by reconstructing the constructions of both the inquirer and participants and working toward consensus. The growing prevalence today in academia to acknowledge and understand under what paradigm particular research studies issue is directly attributable to Kuhn’s (1962) seminal work.

Lincoln and Denzin (1994) indicate that positivism as a paradigm for research methodology has weathered significant criticism and transmitted itself as postpositivism. Postpositivism is based on the ontology of critical realism in which reality can only be

imperfectly and probabilistically apprehended. While this represents an effort at damage control, as opposed to a reformation of basic principles, it is still the same basic linear construction of reality, although now with accommodation to inclusion of qualitative research. Emic<sup>1</sup> viewpoints are acknowledged and recognized given that behavior of human, unlike physical, objects cannot be understood without the particular construal of meaning and motivations conceived by those under inquiry.

Paradigms also present another important consideration for the researcher in that research under the dominant paradigm is rewarded by society. Denzin and Lincoln (1994) state that positivism has for several centuries held hegemony over the scientific world, but the new mantle for hegemony has fallen to the postpositivists. Postpositivists and positivists are the beneficiaries as well as controllers of “publication outlets, funding sources, promotion and tenure mechanisms, dissertation committees and other sources of power and influence” (p. 116). So it is that innovative research may languish on the margins of acceptability and remain largely unknown because it does not get funded or published because it is viewed as inferior science by those committed to the dominant paradigm. The following section will describe how this is happening in psychosocial cancer research.

### ***Psychosocial/Spiritual Cancer Research: Psychosocial and Spiritual Cancer Research with Reference to Paradigms and Epistemologies***

In the field of psychosocial research the preponderance of work is postpositivistic reflecting mostly quantitative studies that have a qualitative component usually consisting of structured interviews. Broderick (1987) indicates that psychosocial cancer research is characterized by a proliferation of trait theory research which describes traits that lead to the onset of cancer, coping or survival with no model of linkage, or process about how one set of traits could possibly evolve to the other. Broderick brings this issue into sharp focus when she asks, “How could the personality characteristics of those who survive cancer be different than those of people who get cancer?” She suggests that personalities are not static; an individual’s cancer prone personality traits can be transformed by the trauma of his/her experience, morphing to the traits evidenced by a survivor.

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<sup>1</sup> Emic is a term used by ethnographers to refer to an insider’s (native) view of his or her world; as opposed to etic or outsider’s view (researcher) of a specific cultural group.

The larger frameworks of personality transformation and the role of meaning-making are rarely accounted for in cancer psychosocial research. Broderick (1987) emphasizes that the one exception to the linear and static presentations of trait theory research can be seen in the process model presented by Temoshok (1987). This model was developed to account for evolving and transforming characteristics observed in Temoshok's subjects over time. She postulates that individuals achieve periods of homeostasis as they accommodate to the world (i.e., suppressing their needs and feelings in order to appease others). Eventually the individual becomes overwhelmed by this repression of self and experiences a crisis bringing about several alternative outcomes: (a) movement to a more stable coping style; (b) the domination of hopelessness; or (c) maintenance of the initial Type C behavior at the price of excessive strain and stress to the system.

Temoshok (1987) appears to have experienced a paradigm shift of her own when she realized that her earlier work conceptualizing the Type C personality presented a static portrayal of these characteristics. Broderick (1987) describes Temoshok's findings: "She outlines, in essence, a style of coping that serves to equilibrate the patient's current meaning system. Unlike the trait models outlined in other work on prognosis and survival, her argument leaves room for the systemic changes necessary to accommodate shifts from less to more adequate coping 'styles' or meaning systems."

The process model presented by Temoshok (1987) represents an attempt to account for process in postpositivist research. However, this only represents an accommodation within the paradigm to acknowledge deficiencies with trait theory approaches. There is still a dearth of constructivist approaches that search for process in the lived experience of cancer patients. In depth qualitative studies of the lived experience of cancer survivors tend to come from dissertations, particularly on spontaneous remission (reviewed later in this chapter), which suggest that funding may not be forthcoming for this type of research that does not fit the dominant paradigm.

The literature on spontaneous remission stands apart from most psychosocial research because much of it is qualitative and involves research oriented to more holistic approaches to the lived experience of cancer survivors. Even within this subset of psychosocial cancer research, very few studies actually attempt to look holistically or multidimensionally at the individual's cancer experience and account for a dynamic process or construction of meaning that describes a

relation of parts to the whole. Many studies describe a holistic approach that includes looking at multiple aspects of the person's life but generally focus on one aspect of the experience such as attributions (Berland, 1994) or existential and spiritual experience (Blu-Wagner, 1998). Certainly all of these studies and their various approaches, contribute important findings but what is still rare are efforts to identify a model or process involving extended cancer survival or terminal diagnosis survival. This study will present such a model. The following section will describe two studies that have informed this investigation: one seeking to describe a process of spontaneous remission (Huebscher, 1992) and another presenting a model of transformational change in male cancer patients (Tower, 2000).

### **Purpose of This Study**

This study seeks to identify a process evidenced by cancer patients who have survived a terminal diagnosis or are diagnosed with a type of cancer in which survival beyond a few years is less than 20%. The area of analysis within psychosocial research that most approaches the dynamics of this study is the investigation of spontaneous remission. Spontaneous remitters have often faced a terminal diagnosis but refused some portion, or all of traditional treatment, frequently seeking help from alternative therapies, sometimes of an unorthodox nature. The participants in this study all pursued treatment within the standard medical system and only used adjunct alternative treatments of a non-medical variety.

The review of the literature will show that there is limited research oriented to assessing psychosocial and spiritual aspects of those who have experienced a terminal diagnosis, particularly looking for a process that may be common to all cases. Examining the more dramatic examples of cancer survivorship as seen in cases of terminal diagnosis provides a good start for the development of theory regarding survivorship. This research will both challenge and extend psychosocial and spiritual cancer theory by synthesizing disparate bodies of research and questioning the epistemological foundations upon which they are based.

### **Theoretical/Conceptual Basis for the Study: Introduction**

This section describes the theoretical and conceptual basis that undergirds this study. This researcher has thoroughly explicated the constructivist approach and has chosen two learning theorists that support a complementary holistic orientation for the transformative learning delineated in this study.

### ***Theoretical/Conceptual Basis for the Study: Mezirow's Transformative Learning Theory***

Transformative learning emerged as a theory with the work of Jack Mezirow (1981, 1991, 1997). He clearly elucidates the foundation of his theory as rooted in constructivism, cognitivism and critical theory. This is described in the preface to his book, *Transformative Dimensions of Adult Learning*, (1991):

My approach to transformation theory, as elaborated in this book, has as its current context the insurgence of constructivism, critical theory and deconstructivism in social theory and in all of the social sciences, law, literature and art. Transformation theory also grows out of the cognitive revolution in psychology and psychotherapy instigated by scores of studies that have found that it is not so much what happens to people but how they interpret and explain what happens to them that determines their actions, their hopes, their contentment and emotional well-being and their performance (page xiii).

In adult learning Mezirow (1991) is unique in explicating his constructivist roots. In the literature of adult learning, little reference is made to constructivism, perhaps because much of the work of constructivist learning theorists has been performed with children. Additionally, adult learning separated itself from the mainstream educational field decades ago, thereby eschewing the theoretical formulations of that field. However, both constructivism and adult learning theory place primary importance on the experiences of the learner in constructing reality. As opposed to behaviorism and cognitivism, constructivism is not objectivist in nature; that is, reality is not viewed as being “out there” and the mind viewed as being merely the instrument to process this external reality (Cooper, 1993; Jonassen, 1991). Constructivism presents a new view on both the nature of knowledge and how it is perceived as internal to the learner. Cooper (1993) describes the main differences between constructivism and the other two major learning theories of the 20th century this way:

The constructivist . . . sees reality as determined by the experiences of the knower. The move from behaviorism through cognitivism to constructivism represents shifts in the emphasis away from an external view to an internal view. To the behaviorist, the internal processing is of no interest; to the constructivist, the internal processing is only of importance to the extent to which it explains how external reality is understood. In contrast, the constructivist views the mind as a builder of symbols – the tools used to represent the knower's reality. External phenomena are meaningless except as the mind

perceives them.... Constructivists view reality as personally constructed and state that personal experiences determine reality, not the other way around (Cooper, 1993, p. 16).

Building on this constructivist base, Mezirow (1996) describes transformative learning as a theory whereby “learning is understood as the process of using a prior interpretation to construe a new or revised interpretation of the meaning of one’s experience in order to guide future action” (p. 162). Centrality of experience, rational discourse and critical reflection are three central themes in Mezirow’s theory (Taylor, 1998) which draws heavily on Freud’s psychoanalytic theory (Boyd & Myers, 1988) and the work of Jurgen Habermas’ theory of communicative action which provides the social theoretical context for his transformation theory of learning (Mezirow, 1991).

Based on Habermas’ epistemology, transformative learning (Mezirow & Associates, 1990) describes how meaning structures change and evolve in two domains of learning, termed instrumental and communicative learning. Instrumental learning involves task-oriented problem solving, specifically, how we perform or do something. Basically, this process involves controlling and manipulating the environment and people. Reflection in this form of learning involves reviewing and reflecting on content or procedural assumptions to validate the strategies and tactics used.

Mezirow et al. (1990) considered communicative learning as the more important of the two domains of learning because it is related to understanding the meaning behind what is communicated by others regarding “values, ideals, feelings, moral decisions and such concepts as freedom, justice, love, labor, autonomy, commitment and democracy” (Mezirow et al., 1990, p. 8). The main focus of communicative learning is achieving coherence rather than, as in instrumental learning, improving performance by exercising control over cause-effect relationships. “Communicative learning is less a matter of testing hypotheses than of searching, often intuitively, for themes and metaphors by which to fit the unfamiliar into a meaning perspective, so that interpretation in context becomes possible (Mezirow et al., 1990, p. 9). Transformative learning takes place in both domains when the learner attempts to construe meaning from experience by engaging in critical reflection on all presuppositions and cultural assumptions.

### *The Theoretical/Conceptual Basis for the Study: Mezirow's Perspective Transformation*

Perspective transformation is the process whereby adults change their meaning structures. Meaning structures are culturally defined frames of reference which include both meaning schemes and meaning perspectives. Meaning schemes are “made up of specific knowledge, beliefs, value judgments and feelings that constitute interpretations of experience” (Mezirow, 1991, pp. 5-6). They can be considered habitual, implicit rules for interpreting experience. Transformation of meaning schemes occurs rather routinely as individuals reflect on their lives, challenge previous assumptions used to solve problems and change those assumptions to interpret experience differently.

Meaning perspectives are collections of meaning schemes or general frames of reference made up of “higher order schemata, theories, propositions, beliefs, prototypes, goal orientations and evaluations.” (Mezirow et al., 1990, p. 2) Meaning perspectives are usually acquired through uncritical socialization and acculturation during early exchanges with parents, teachers and mentors. These meaning perspectives provide useful paradigms for our understanding of the world but also constrain our perceptions by bounding our view of reality in cultural and psychological assumptions. Each new experience we encounter becomes viewed through the lenses of our meaning perspectives.

Meaning perspectives, like meaning schemes, can become transformed. Unlike meaning schemes which become transformed as a routine part of life, meaning perspectives become transformed through rarer and more dramatic events of disorienting dilemmas, such as death of a loved one, divorce, loss of a job, or other such events and result in a world-view shift. This is the kind of learning that is the focus of this study on cancer patients who have had to confront a terminal diagnosis. Perspective transformation is a process of becoming critically reflective in examining the presuppositions of one's existence and how they constrain perception, understanding and feelings about the world. Transformation is further promoted and developed through rational discourse which goes beyond every day discussions, to question comprehensibility and truth of various world-views, thus moving toward a more inclusive worldview (Mezirow, 1997):

More inclusive, discriminating, permeable and integrative perspectives are superior perspectives that adults choose if they can because they are motivated to better understand the meaning of their experience. Meaning perspectives that permit us to deal

with a broader range of experience, to be more discriminating, to be more open to other perspectives and to better integrate our experiences are superior perspectives (p. 6).

Mezirow's view of transformative learning is not as an adjunct to educational practice and techniques, but rather the essence of adult education. The movement through critical reflection and rational discourse provides a model of adult learning and development that illustrates how personal paradigms evolve through adulthood and how individuals become more autonomous thinkers by continually developing new values, meanings and purposes rather than accepting uncritically the views of others (Mezirow, 1997).

While Mezirow (1981, 1990, 1991, 1996, 1997) has certainly been the defining writer on transformative learning, other writers have offered significant models as well. Robert Boyd's (Boyd & Myers, 1988, 1989, 1991) model of transformative education offers some significant criticism and balance to the highly cognitive perspective of Mezirow's theory.

### ***The Theoretical/Conceptual Basis for the Study: Robert Boyd's Transformative Education***

Most of the dominant thinking and theorizing of the collective work on transformation theory which includes such authors as Jack Mezirow, Paulo Freire, Phyllis Cunningham and Laurent Daloz have emphasized the highly cognitive and rational processes involved in critical reflection (Dirkx, 2000). However, another perspective promulgated by Robert Boyd has emerged based on Carl Jung's work on analytical (depth) psychology. Boyd's work (Boyd, 1989, 1991; Boyd & Myers, 1988) presents a complementary and dramatically different view of transformation incorporating a greater focus on emotional and spiritual dimensions that many have found missing in prevailing conceptions of this theory (Merriam & Cafarella, 1999). In addition, Boucouvalas (1997) elaborates that Boyd and Myers place great importance on 'expansion of consciousness' as critical to transformation, while Mezirow has chosen not to use this term believing that it detracts from clear understanding.

Boyd's (1991, 1989) research exploring analytic psychology in the context of small group work describes a model of transformative education which delineates the process of individuation as a lifelong journey of increasing self-awareness through reflection and understanding of the inner landscape of consciousness – the psychic structures of ego, persona, collective unconscious and shadow. Boyd differs from Mezirow in that he sees transformation as a process that must be resolved within the individual's psyche as opposed to Mezirow who views transformation as a cognitive and rational struggle of the individual within culture. Mezirow's

central vehicle for understanding perspective transformation is the ego, while Boyd's approach is more holistic involving not only extrarational processes but creativity, emotions and intuition (Grabov, 1997).

Central to Boyd's concept of transformation is the process of discernment which is comprised of receptivity, recognition and grieving (Boyd & Meyer, 1988). The individual's interior experience is viewed as containing both the rational thinking and the extrarational, as seen through images, emotions and symbols and discernment is the dialectical movement between both forms of understanding. The individual must have receptivity in order to receive 'alternative expressions of meaning' and then be able to recognize the authenticity of the message (Boyd & Myers, 1988, p. 277). Most relevant to this study is Boyd and Myers's view of grieving as an emotional crisis forming the central phase of the process of discernment. This certainly is supported by the work of Elizabeth Kubler- Ross (1969) whose stages of death acceptance have been widely applied to understanding the grieving process of losses involving an array of human crises such as job change, divorce and health emergencies.

The transformation learning theories of both Mezirow and Boyd together provide a solid theoretical perspective in which to consider this holistic study of cancer survivors. Mezirow's perspective is important for viewing the survivors' experience with particular reference to meaning construction, rational critical reflection, consideration of values and societal influence. Boyd provides a good balance to this approach by emphasizing the role of emotions, extrarational processes and spirituality. Together Boyd and Mezirow provide the holistic perspective sought in this study.

### **Defining the Gap – Challenging and Extending Theory: Research from Which This Study is Derivative**

One study that stands out and has particular relevance for this research is Huebscher's (1992) investigation of nine individuals who had spontaneous remissions from cancer. The object of Huebscher's study was to find an answer to the question, "What is the process of spontaneous remission?" The phenomenon for the subjects of this study on terminal diagnosis survivorship and Huebscher's spontaneous remitters is essentially the same, all had to confront a terminal diagnosis. The difference between the two sets of subjects is that most of Huebscher's subjects refused some portion of standard medical treatment and/or received medical verification that a tumor had regressed or disappeared. The participants in this study all pursued standard

medical treatment and while they never refused their doctor's recommendations, they did challenge recommendations causing doctors to alter some aspects of treatment.

Huebscher used grounded theory (Glaser & Strauss, 1967), a methodology for gathering and analyzing information that results in theory development that is grounded in the data. Participants were questioned using unstructured, tape-recorded interviews of one to three hours in duration and had brief follow-up interviews for clarification. Huebscher (1992) found that her participants shared some commonalities, even though they represented a wide range of backgrounds and belief systems and even pursued different strategies for recovery. The theory of spontaneous remission that emerged from Huebscher's study delineated four theory constructs: the first category entitled "Reading the Handwriting on the Wall" described the shock and disbelief of the diagnostic phase, a personal image or description of what the cancer meant to the participants and the impact on them of hearing from the health care system the repeated message, 'There's nothing we can do or all we can do is...'

The following three categories or constructs Huebscher (1992) described did not follow in sequential order but could occur in any order or even simultaneously. "Bucking the System" included subcategories of (a) going against medical advice, which was necessitated in most cases due to the severity of the diagnosis; and (b) ordeals. Reflecting this category, many of Huebscher's participants refused some or all of their recommended treatment. Since many of the patients received their original diagnoses in the 1970s and 1980s, part of this resistance to treatment may have been due to the poorer treatment alternatives available at the time. The other part of this category, ordeals, includes the participants' emotional struggles to cope with their own personal issues as well as burdens put on them by others related to the perceived cause of their disease.

"Healing the Body/Mind/Spirit" included the participants' choices about alternative health care, finding their paths in life and spirituality. This category referred to the various beliefs and practices that participants used to transcend the implications of the diagnosis. Huebscher described the freedom participants felt in pursuing spiritual and mind/body practices in a way that allowed them to get back into life. The remission itself was viewed as a secondary issue, a byproduct, of their beliefs and practices that promoted taking charge of their lives and healing the body, mind and spirit.

The final category “Deciding on Life” which included three subcategories (a) existential questioning or a meaningful encounter with the underlying principles of existence including life and death; (b) letting go of the implications of the cancer diagnosis, including repressed issues and feelings; and ultimately (c) abiding in a faith that transcends hope. This category reflects the participants existential questioning that occurred after diagnosis as they realized their life would never be the same again. This category also included the term “weird things” to refer to some paranormal or transpersonal experiences that were reported by many of the participants at this time of life and death questioning. Participants reported a sense of letting go of unproductive beliefs, emotions and issues that had been seen to hold them back previously. Their spirituality became an abiding faith in which they emerged, by their own descriptions, as more powerful, confident and knowing.

The participants in Huebscher’s (1992) study move from the tumultuous emotions of their diagnostic period to searching for alternative treatment, frequently fighting the recommendations of the traditional healthcare system, to working on understanding what was not working in their previous lives, questioning their existence and seeking answers through spirituality. Ultimately, they take control of their lives, letting go of unproductive emotions and issues and finding an abiding faith through spirituality. Huebscher’s core category, transcending, explains how the participants, who have followed this process, ultimately transcend the implication of their diagnosis.

One still wonders what was the salient changing point for their transformation? Huebscher’s (1992) study appears to attribute a somewhat equal significance to the four main constructs of her theory, especially in the critical areas of existential questioning and healing of the body, mind and spirit. No focal points of change appear to have emerged around which constellations of behavior occur.

Huebscher (as cited in Berland, 1994) has indicated that all nine of her participants experienced an existential/spiritual shift prior to their remissions. This existential/spiritual shift has been indicated by many other researchers of spontaneous remission (Berland, 1994; Hawley, 1989; Ikemi, Nakagawa, Nakagawa, & Mineyasu, 1975; Roud, 1985; Schilder, 1992). The studies on spontaneous remission (described later in this chapter) all report a range of possible behaviors characterized by assertiveness or the “determined fighter” stance as characterized by Greer (1985) and/or a range of psycho/social/spiritual changes including: increasing meaning

and connection to a transcendental dimension; greater satisfaction and appreciation for life and often a need to give back something to others.

Even though this similar constellation of behaviors has been observed in many studies, no attempt has been made to describe the nature of the process that produces these changes. The literature on spontaneous remission indicates support for an existential/spiritual shift, but also reflects some debate as to when the shift occurs and whether it is initiated by conscious efforts or occurs outside of conscious control driven by emotional despair. This study on terminal diagnosis presents a model that encompasses and explains the shift, how it arises; or contrarily, why it does not and why it can occur both before and after remission. This issue of the shift will be discussed in greater detail in the section on spontaneous remission.

Some other questions that bear additional study include: Does the immediate impact of the diagnosis bring about a realization of needed change or will this occur later for some individuals? How do people deal with the impact of paralyzing emotions in order to move on with what they need to do? How do individuals move to their identified state of 'abiding faith'? Is this part denial or a genuine consequence of having faced death and emerged with a sense of confidence that even the worse can be faced with equanimity?

Huebscher (1992) also indicated that many of her participants described extrarational processes (transpersonal or paranormal occurrences) she referred to as "weird things". These are often events that have a profound effect on the individual. What role do these experiences play? These are also some of the questions this study will seek to understand. The model presented will elucidate the role of denial, emotions, extrarational experiences and altered states have in the individual's process of recovery.

Huebscher (1992) found remission to be a secondary issue which did not emerge as a category or part of a category. The question must be asked, was there sufficient effort made to focus on this aspect of the process? It is suggested that by the time the individuals have done the work involved in Healing the body, mind and spirit and deciding on life, the importance of learning that they no longer have cancer has lost its significance. Perhaps this issue was focused on sufficiently in this study, however it bears additional investigation.

The work of this study could be extended in a number of useful ways. Huebscher suggested that her work could be augmented either by a replication study or by studies looking at remissions of subjects who had received standard medical treatment. This study of terminal

diagnosis used participants who received standard treatment. As with Huebscher's study, this research uses a grounded theory approach to discover a process by looking holistically at the lived experiences of the participants. One or two studies trying to identify learning or organizing processes of cancer recovery will not be sufficient to give definition to this phenomenon.

Huebscher's (1992) research is typical of studies on spontaneous remission, although hers is unique in seeking to discover a process to the phenomenon. What is characteristic of spontaneous remission literature is an effort to investigate this phenomenon because it represents a possible mind/body healing mechanism in nature. These studies generally seek to have "authentic" spontaneous remission cases often verified by medical authorities. The idea here is to discover certain attitudes, beliefs, emotions and behaviors that may be characteristic of those who have found a natural healing path. Huebscher, who is clearly aligned with the nursing profession, characteristically focused on patient care implications of her research in her conclusions and did not highlight and promote the dynamics of her identified process.

Another study only discovered at the completion of research for this study is Tower's (2000) study of transformation in 14 long-term male survivors of cancer. Tower's work used the literature of post-traumatic growth which is a fairly recent literature base addressing personal growth which often follows trauma. Since this study addressing terminal diagnosis survivorship used the psychosocial/spiritual research base for cancer, Tower's study was not discovered until a final literature review was performed. His study parallels in intention to the current study.

The methodology used for his study was hermeneutic-phenomenology in which Tower also augmented and illuminated his findings with his own personal experience of cancer. His interviewees were selected on the basis of self-reported transformation and growth following their recovery from cancer. Findings were presented as a 6-stage model of survivor transformation. Tower states that his 6-stage model does not "highlight anything particularly startling compared to other models of personal growth following trauma"(p. 66 ). This model describes the survivor's journey from a pre-cancer state, through the experience of cancer, followed by a long transitional period resulting in a final stage of integration and growth. Perhaps most significant in this study is Tower's emphasis on the moment of diagnosis as "providing a clear existential insight into the unconsciousness of this past life spent in pursuit of societal goals" (Tower, p. 239). Tower goes on to suggest that this diagnosis followed by an extended and frightening period of treatment provides a course correction to the survivor's life

that initiates essential changes involving new possibilities, relationships, spirituality and a desire to live life more fully.

This important finding bears additional study: What aspect of the diagnosis produces the clear existential insight into the person's life? Is this a life review similar to what dying people have reported? Is everyone automatically snapped out of Heidegger's "entangled everydayness" or the unconscious life to recognize the false societal goals they have pursued? What would be the role of denial at this point – can everyone have this existential insight without any trace of denial? Tower (2000) indicates that the moment of diagnosis is the turning point of the transformation moving from a largely unconscious existence to one that is self-directed. Additional information around these points could significantly extend the work of his study and will become focal points for this research on terminal diagnosis.

Tower's (2000) model of transformation in cancer survivors is presented as research in the field of post traumatic survival. As such, he presents a unique perspective from the spontaneous remission literature that informs much of the basis and impetus of the present study on terminal diagnosis. Tower elaborates his model of transformation drawing on symbolic interactionism, as dominance of a socially constructed 'me' that shatters the survivor's world. The individual realizes that his/her life "has been spent in the pursuit of false meaning and governed by an invisible societal hand." (p. 247) Tower concludes that this existential insight occurring at diagnosis is the foundation of all subsequent changes made in the process of transformation.

The model presented in this dissertation will incorporate Tower's (2000) insights, illuminate the nature of the existential/spiritual shift described previously in spontaneous remission literature and account for the role of denial. In addition, this model will extend theory by synthesizing disparate bodies of literature including psycho/social/spiritual cancer research, post traumatic survival, adult development and adult learning.

### **Psychosocial and Spiritual Cancer Research: Introduction**

Because this is a relatively new field of research, little more than thirty years duration, it does not appear to be characterized by vigorous debates that might be seen in more well established fields having multiple schools of thought. Mostly debate is characterized by which researcher's variable(s) are more predictive of certain aspects of the cancer experience such as onset, coping, or survival. Also, as mentioned previously and further discussed in this section,

the literature on spontaneous remission has some controversies that have remained unsolved, but which this study will help illuminate.

The following studies on psycho/social/spiritual research are organized as follows: spontaneous remission (this research has the greatest relevance to this study and are listed first); Type C behavior (Temoshok's Process Model is described because it represents a break in the traditional linear orientation to studies in this field); and other main categories that describe the field and provide an overall context of research for this study including cancer onset, cancer coping and survival, importance of social interaction and spirituality.

### ***Psychosocial and Spiritual Cancer Research: Spontaneous Remission - Early Research***

Most of the major medical studies of spontaneous remission in the 20<sup>th</sup> century have failed to record the concomitant psychosocial correlates of behavior (Boyd, 1966; Everson & Cole, 1966; Rhodenburg, 1918). Hirshberg and Barasch (1995) speculate that the lack of physician reporting is probably due to the fact that psychosocial research on spontaneous remission does not lend itself to inquiry under the positivist biomedical paradigm in which it is difficult to build linear predictive therapeutic models on elusive mind-body connections for a phenomenon that is spontaneous.

### ***Psychosocial and Spiritual Cancer Research: Spontaneous Remission - Recent Studies***

Kent et al. (1989) designed one of the first medical studies to look at the totality of biological, psychological and emotional factors and their impact on the immune system promoting disease resistance. But qualitative studies also emerged to address the void that was not being met through the medical literature. These studies usually employ semi-structured interviews and are of necessity retrospective due to the impossibility of predicting a spontaneous remission. From the mid 1980s through the 1990s many spontaneous remission studies evolved from dissertation research (Berland, 1994; Blu-Wagner, 1998; Hawley, 1989; Huebscher, 1992; Roud, 1985). As has been suggested previously, the dissertation literature has helped fill a void in the dominant post-positivistic research prevalent in psycho-social and spiritual research. The dearth of research on spontaneous remission suggests this research is not well funded. The dissertation research has not only helped fill a void, but has provided some of the best research in the field.

Overall, the spontaneous remission literature illuminates the diverse paths that individuals follow to healing that belie the remarkable commonalities that exist just beneath the surface. Each person utilizes a wide range of personal and spiritual belief systems; pursues vastly different medical treatment as well as complementary treatment; and, exists in a unique context consisting of widely varying family, work and community systems. While specific paths taken to healing are unique, the commonalities that emerge are striking. Most studies, in varying degrees, indicate the importance of facing mortality. In addition, there is a constellation of behaviors evidenced and often referred to as an “existential shift” or “turning point” in behavior. (Berland, 1994; Blu-Wagner, 1998; Roud, 1985; Hawley, 1989; Hirshberg & Barash, 1995; Huebscher, 1992; Ikemi et al., 1975, Ikemi & Ikemi, 1986; Schilder, 1992). Most of the individuals in these studies experienced this existential shift, although a few did not.

A number of behavioral and attitudinal behaviors characterized the existential shift: willingness to take responsibility for one’s life and recovery; living life congruent with one’s personal values with less regard for societal concerns; greater assertiveness in expressing these values; increased meaning and spirituality, a sense of universal connectedness; deepened relationships and a need to give something back to others.

Many of these studies also indicate that some part of this constellation of behaviors is frequently initiated by the individual early in their recovery which continues to develop into a full range of behavior just prior to remission. This has prompted some debate about whether or not the individual’s active pursuit of psycho/social/spiritual changes initiates the recovery process; or whether the process occur largely outside of conscious control, perhaps impelled by the emotional trauma of diagnosis. Some studies have indicated that this “shift” occurs after a period of despair.

The present study presents a theory that will explain the nature of this existential/spiritual shift, what likely precipitates such a shift and why it may be delayed or appear not to occur in some cases. The results of this study will offer a comprehensive model to describe not only the nature of the existential/spiritual shift but also illuminate the issue of whether and/or not it is rationally initiated or occurs as part of an emotionally laden unconscious process.

Schilder (1992) used semi-structured interviews with seven spontaneous remitters to discern a connection between psychosocial processes and spontaneous remission. His research supports the idea that spontaneous remitters have undergone an existential and/or spiritual shift,

resulting in a movement from helplessness to greater autonomy in pursuing and accessing life experiences previously believed to be inaccessible. Schilder found that participants made important life changes and evidenced significant autonomy prior to remission. The actual "shift" was not brought about by willful choice, but rather occurred spontaneously on an unconscious level brought about from previous despair and/or anger.

Hawley (1989) reported on 16 spontaneous remitters who experienced a turning point initiated by the impact of the terminal diagnosis resulting in either full recovery or a stabilization of the disease. The turning point was preceded by a significant spiritual insight, a secret revelation based on an inner knowing that all would be well; or a deep belief that God would care for them regardless of their condition. Hawley's participants did not view themselves as victims of a fatal illness, but instead, saw themselves as normal people with a challenge to overcome. They were motivated to take control of their lives and bring about profound changes. Curiously, Hawley seemed to abandon the significance of her findings by dismissing her participant's attributions that their healing was not due to medical treatment but a result of their spiritual insights. Hawley regarded her participants' responses as irrational due to difficulty coping with the anxiety of their terminal diagnoses.

In an investigation of psychosocial correlates of spontaneous remissions Van Baalen and DeVries (1987) found that six spontaneous remitters experienced an existential shift or turning point in their attitudes toward life. Even though participants went through periods of depression, as well as hope, their shift was evidenced in movement from dependency and helplessness to greater autonomy. The work of Ikemi et al. (1975) also highlighted the importance of an existential shift after five participants accepted responsibility for their recovery and the crisis in their lives that contributed to their cancer. They took an active role in their recovery, accepting the will of God for their outcome and feeling gratitude for the time remaining to them. The researchers postulated that their release of life to a higher power facilitated healing capabilities similar to what occurs in autogenic and meditative states. In later work Ikemi and Ikemi (1986) found in 27 cases of spontaneous remission that the existential shift that occurred preceded recovery or remission.

In other dissertation research, Berland (1994) conducted semi-structured interviews with 23 female and 10 male cancer survivors who did not necessarily have spontaneous remissions but rather "unexpected recoveries," having had less than a 20% chance of recovery. Berland's

purpose was to assess the participants' attributions for recovery. He found that three healing styles emerged: the "determined fighters," the attitudinally/behaviorally focused and those with a "spiritually/existential orientation." The five men who comprised the group of determined fighters were described as psychologically unsophisticated and strong-willed. While they accepted the reality of their diagnosis, they denied the impact of it and were determined to live their lives as if nothing had happened. They appeared to evidence a "positive avoidance" (Greer, Morris, Pettingale, & Haybittle, 1985) which appeared to enhance their fighting spirit by putting aside fears of death. Berland believed that the responses of the men were appropriate given the psychological profile of the participants. In this group, no one attributed their healing to psychological insights, attitudinal shifts, behavioral changes, existential and/or spiritual experience.

Berland's second group also demonstrated fighting spirit, but was distinguished by taking an active role in their own recovery process by maintaining a positive attitude and pursuing complementary activities such as meditation, visualization and prayer to promote healing. Unlike the first group, they believed medical treatment alone would not save them, that healing had to be augmented through changing their lives and learning all they could to promote continued growth and development.

The third group of participants demonstrated spiritual, religious, or existential changes which manifested as a transcendent relatedness and connection to something beyond the self. Over half of Berland's participant (18 of 33) experienced a spiritual/existential shift for which they attributed their recovery. This group also exhibited the characteristics of the first two groups: they had fighting spirit and believed attitudinal change to be important. Blu-Wagner (1998) performed research that focused on existential and spiritual factors of spontaneous remissions and remarkable recoveries (this study discussed in the gap section of this paper). She described Berland's third group of participants as having evidenced transpersonal awareness typical of the higher stages of Ken Wilber's model of consciousness development.

This group expressed a belief that their health was dependent on living more congruently with their inner natures and being true to their deeper beliefs and less concerned with pleasing others. Most thought that this change or shift they experienced arose out of the emotional despair of dealing with a terminal illness. The new spiritual awareness made them less inclined to return to their previous ego driven concerns or attend to the "shoulds" of life.

Berland concluded that individuals' coping strategies were not static but moved through anger and depression to a position of hopefulness. He further postulated that it was likely the terminal diagnosis set in motion some change in each individual's psyche that loosened personal identity structures. He particularly felt it important that individuals should not be viewed as a homogeneous group with only one coping style.

### ***Psychosocial and Spiritual Cancer Research: Type C Behavior and Temoshok's Process Model***

Type C personality refers to a composite of personality traits that is thought to characterize the cancer patient and presumably predisposed them to getting the disease. This research followed along similar research on the Type A personality which has been very successful in predicting those likely to be predisposed to heart disease. The research on Type A personality and heart disease has reinforced the idea that progression of this disease is controllable. This theory (Friedman & Rosenman, 1981) characterizes the Type A personality as impatient, hard driving and hostile. Williams (1990) found that the most lethal of these characteristics are anger and hostility. Type A's are frequently compared to Type B's, who are more relaxed, patient and not particularly hostile. It has been shown that type A's can be trained to be more like Type B's. With heart disease there seems to be something patients can do to counteract the problems that led to the disease (Spiegel, 1993).

Spiegel (1993) indicates that there is a significant difference in how cancer patients view their diagnosis compared to those with heart disease. Heart disease survivors are likely to have an unrealistically optimistic point of view compared to cancer survivors, who are far more likely to have a fatalistic outlook. For heart patients survival seems to be a well charted path: lose weight, reduce cholesterol, exercise and reduce stress.

The path to recovery is not so well conceived for those with cancer. Mostly doctors can only recommend the usual treatment regimens of chemotherapy, radiation and surgery; a diet low in fat and high in fiber is also recommended. The literature on personality variables and cancer, unlike that of heart disease, is far more disputable, resulting in significant controversy and debate in the medical community (Spiegel, 1993).

Morris and Greer (1980) and Temoshok and Heller (1981) concomitantly developed a "Type C" behavior pattern to describe cancer patients who suppress negative emotions, especially anger and appease and over focus on the needs of others. Temoshok (1985) found that

this self-effacing style, typical of cancer patients, predicted exacerbation of malignant melanoma, a skin cancer. The women in the study with histrionic and narcissistic personality styles who demonstrated active expression of their emotions developed a stronger immune response, resulting in tumors that grew more slowly.

Temoshok (1987) presented a "process model" designed to integrate many previous findings into a unified theory and reconcile apparent contradictions in psycho-oncology literature. She explained that the "Type C" individual learned to repress emotions in order to cope with early psychosocial conditions. The person who abnegates his/her own feelings in order to accommodate and appease others develops an underlying and unexpressed hopelessness about ever getting needs met or achieving one's goals.

Eventually a breaking point occurs, usually the cancer diagnosis itself or events that have led up to the diagnosis. Temoshok (1987) describes that at this stage the individual often goes in one of three directions. The first group undergoes a "transformation" of their personality, adopting a style antithetical to their previous personality. Realizing that their past coping style has been inadequate, they become more assertive and active in pursuing their own goals. These patients frequently develop a "take charge" attitude regarding their medical treatment, which is reflective of changing their Type C style and thereby stimulating and strengthening their immune system defenses.

The second group of patients maintains the status quo, maintaining their Type C style, which imposes yet more strain on their internal defenses. Finally, in the third group their previously hidden feelings of hopelessness overwhelms them resulting in an escalation of their disease (Temoshok, 1987). Temoshok and Dreher (1992) found that many patients who have recovered from cancer transformed their Type C personality to one of flexibility, assertiveness and full emotional expression, thus, bringing a new sense of meaning to their life.

Support has also been found for the findings concerning the third group whose cancer diagnosis serves to surface hidden hopelessness causing a precarious slide into physical deterioration. Leigh (1987) discovered that three-year cancer survivors receiving radiation treatment exhibited a healthier adaptive form of anxiety in comparison to nonsurvivors. Having administered and analyzed various psychological inventories, Leigh determined that nonsurvivors experience a "massive defensive failure" not unlike and certainly comparable to Temoshok's third group of patients who became overwhelmed by helpless/hopeless feelings.

Many other studies have lent support to Temoshok's (1987) work on the Type C pattern and associated constructs (Cox & McKay, 1982; Eysenck, 1985, 1987; Jensen, 1987; Morris & Greer, 1980; Pettingale, 1984). The characteristic of unexpressed anger as seen in Type C patients has found resonance in many other studies (Harburg & Schork, 1991; Jensen & Muenz, 1984; Julius, 1991; Le Shan, 1980). Stoic acceptance of the disease, depression and helplessness/hopelessness are frequently associated with disease progression and death (DiClemente & Temoshok, 1985; Greer, 1985; Levy et al., 1985; Shekelle et al., 1981). In Jensen's (1987) longitudinal study of breast cancer patients, a repressive personality style, chronic stress, helplessness, suppressed emotions and daydreaming were found to be correlated to disease progression.

Psychologist, Lawrence Le Shan (1980), whose career has spanned decades of working with cancer patients, developed a cancer profile which parallels Temoshok's Type C profile. He found that cancer patients appeared to have suppressed their anger in order to please others and maintain a façade of goodness. Underneath they seethed with self-hatred and unfulfillment, rarely acknowledging their own achievements. In addition, his cancer patients reported feeling a sense of despair most of their lives and learned in childhood that intimate relationships could be dangerousness. His therapeutic work has been an effort to reverse the pathological attitudes of repression of feeling, depression and helplessness/hopelessness as characterized by Temoshok's Type C personality. Le Shan (1980, 1989) considered it a goal to restore a sense of "enthusiasm" in his patients and encourage them to take control and change their lives.

While there is substantial literature to support the assertion that personality variables influence the course of cancer; however, the debate continues due to some large-scale studies that have failed to demonstrate such a relationship. Cassileth et al. (1985) administered personality tests to a large group of cancer patients relating scores to disease progression and survival time. The study revealed no relationship between personality measures and the course of cancer.

Researchers at Vanderbilt University (Jamison et al., 1987) tested 49 women with breast cancer to determine their sense of self-esteem, well-being, likeliness of experiencing hostility and sense of having control over their health. They determined that none of these factors had any predictive value in determining how long these women survived with cancer. There was no difference in scores between those who survived less than 16 months and those who went on to

live considerably longer. Spiegle (1993) also indicated that he never found personality variables that were predictive of the course of the disease. While his findings indicated prevalence of anger suppression in cancer patients, he cautioned that this kind of thinking can result in adding to the patient's burden by blaming them for their problem.

Comparison of studies both pro and con, regarding the effect of personality factors and course of disease, are difficult to make. Different populations are used, methods of inquiry vary and controversy has been generated by the disparate use of objective measures, subjective verbal report measures and interviews. Additionally, the accusation is often leveled that control groups are inappropriate and measurement of psychological factors is often vague (Cooper, 1984). Despite controversies regarding research design and measurement, support has been growing for a connection between psychological variables and cancer (Anderson, 1994; Lerner, 1994).

### ***Psychosocial and Spiritual Cancer Research: Psychosocial Factors in Cancer Onset***

Prior to the 19<sup>th</sup> century, medical opinion generally supported the importance of psychological factors in the causation of cancer (Le Shan, 1989). Dating back to early Greece, the physician, Galen, in 537 B. C. described that “sanguine women” were less likely to get cancer than "melancholy women" (Pelletier, 1977). Twentieth century research had seen a convergence in animal studies linking stress and tumor growth in clinical trials and personality studies (Cunningham, 1991).

Many studies support the concept that personality factors moderate resistance to disease. Carl and Stephanie Simonton delineated a clear connection between emotions and malignancy (1975). As previously described in Temoshok's process model (1987), cancer patients had frequently experienced underlying hopelessness and despair prior to cancer initiation. Temoshok (1985) suggested that the despair and hopelessness is often not assessed in standard clinical instruments because it is denied or remains unconscious. Dattore, et al. (1980) compared the psychological assessments of 200 disease-free patients at a Virginia hospital, seventy-five who went on to contract cancer. Findings indicated that those who developed cancer scored higher on indicators of repression but lower on depression and sadness. Zonderman et al. (1989) explained that retrospective investigators were able to determine that those with cancer had experienced an underlying despair prior to cancer onset, while prospective researchers using self-report instruments were unable to correlate depression to later cancer.

Cancer onset has also been linked to other psychosocial factors: depression (Shekelle et al., 1981); feelings of hopelessness (Greer et al., 1979; LeShan, 1966) and stress (Schmale & Iker, 1964, 1966; Selye, 1979; Taylor et al., 1985). Many studies have shown a relationship between depression and loss and cancer onset. LeShan (1959, 1966; LeShan & Worthington, 1955; Simonton et al. 1978) established that a significant number of cancer patients, prior to the onset of their cancer, had experienced the loss of an important person in their life.

Stress has frequently been implicated in cancer onset. Taylor, et al. (1985) administered a checklist of factors to women with breast cancer to assess the causal attributions of their disease. Results indicated that forty-one percent of patients believed stress to be a major factor. Kobasa et al.'s (1982) research on hardiness is also supportive of stress and coping style as important factors in cancer onset. She determined that "high stress/low illness" executives had developed positive coping strategies, which enabled them to handle stressful situations more positively, maintaining improved health. The key to that successful orientation appeared to be a focused sense of meaningfulness, established goals and priorities based on a life plan and active involvement in their environment. However, Thomas and colleagues (Thomas et al., 1979; Thomas & McCabe, 1980) found no correlation between stress and cancer in a longitudinal thirty year study of medical students, but did find a relationship between perceived lack of closeness and cancer initiation.

### ***Psychosocial and Spiritual Cancer Research: Coping Styles, Survival and Cancer***

Some researchers have turned their attention to investigating personality factors that aid an individual in coping with cancer. Greer et al. (1979, Greer & Watson, 1985, 1987) in a longitudinal study classified into four categories the responses of 69 women diagnosed with breast cancer:

1. Fighting spirit - These were women who were accepting of their diagnosis, optimistically realistic about the outcome and determined to fight it.
2. Denial - This group totally denied they had cancer or if they acknowledged it, minimized any threats to their health.
3. Stoic acceptance - These individuals accepted their fate believing there was little or nothing they could do to change the outcome.

4. Helplessness/hopelessness - Those in this group were engulfed by the diagnosis, preoccupied with survival, which resulted in an inability to cope and ultimately giving up.

Researchers followed these women for a number of years and found that those in the category of "fighting spirit" and "denial" were twice as likely to survive the following five years than those demonstrating "stoic acceptance" or "helplessness". Fifteen years later, the original findings were still supported. The women who were defined by "fighting spirit" had the highest survival rate as opposed to the group responding with "helplessness/hopelessness" who had the lowest.

DiClemente and Temoshok (1985) replicated Greer's work using malignant melanoma patients who were followed for up to 29 months. Greer's findings were partially confirmed. Women who demonstrated stoic acceptance and men who had high scores for helplessness/hopelessness were more likely to evidence disease progression. These psychosocial predictors were found to be independent important biological factors. Perhaps the most striking factor was that 71% of the stoic acceptors had died after follow-up.

Temoshok (1987) considered Greer's category of stoic acceptance to be remarkably similar to her Type C personality style, descriptive of the mind-state of helplessness/hopelessness undergirding Type C behavior; and fighting spirit, a description of behavior antithetical to Type C personality style. Studies of dispositional optimism in psychosocial adaptation to cancer strongly suggest that optimism is positively related to an adaptive coping mode; such as making active efforts to handle and deal with stressful events as opposed to active avoidance of such situations (Carver et al., 1989; Friedman et al., 1992). While optimism was found to have an inverse relationship to psychosocial distress (Stanton & Snider, 1993), it has also been suggested that various coping strategies (e. g., denial or acceptance) can mediate the effect of optimism on distress (Carver et al., 1993). In studies of women with breast cancer, an optimistic outlook has also been related to improved psychosocial adjustment, sense of well-being and increased vigor (Miller et al., 1996; Stanton & Snider, 1993).

As stated earlier in this chapter, psychosocial variables related to cancer and other causative factors are less well defined than in heart disease, therefore it is harder for people to get a sense of control regarding disease progression. However, several studies have addressed the effects of locus of control on psychosocial adaptation to cancer (Galbraith et al., 1993; Taylor et

al., 1984; Timko & Janoff-Bulman, 1985). These studies revealed two salient perceptions that indicate control over cancer: the first is that the individual believes he/she is capable of controlling cancer (internal or personal locus of control) and, secondly, the individual perceives that medical personnel (powerful others) are capable of controlling the disease.

Both optimism and personal locus of control are related to Greer's "fighting spirit". "Fighting spirit" is generally defined as realistically accepting the cancer diagnosis, while optimistically tackling the challenges presented by cancer in order to bring about recovery (Greer, 1991; Nelson et al., 1989). This quality is associated with extended survival in cancer patients (Greer, 1991; Greer et al., 1990; Greer et al., 1985).

### ***Psychosocial and Spiritual Cancer Research: Importance of Social Support in Cancer Treatment***

Probably some of the strongest findings in the literature on cancer are those that emphasize the role of social support (Berkman & Syme, 1979). Social support can include everything from confiding in a single person or several people to being married or attending a support group from the myriad offerings for cancer patients. House et al. (1988) stated that the strength of the relationship between social isolation and mortality is comparable to that of high cholesterol and smoking to mortality. Encouraging cancer patients to attend support groups is now a widely accepted part of current cancer treatment. Spiegel et al. (1989) found that metastatic breast cancer patients participating in group therapy revealed that they had doubled their survival time over the control group. Results also indicated a 'dose response', the more therapy received, the longer they lived. Spiegel et al. (1989) believed the salient effect of this group was due to social support. The study has been viewed as one of the most important for demonstrating the efficacy of psychosocial intervention, not only did the group therapy lead to better patient adjustment, but incredibly prolonged longevity.

Kiecolt-Glaser et al. (1993) concluded their study by saying, "The link between personal relationships and immune function ... is one of the most robust findings in psychoneuroimmunology." Kennedy et al. (1988) found that interpersonal relationships significantly mediated the role of acute and chronic stressors. Perhaps most striking in this research was the discovery that the elevation and activation of lymphocytes depended in large part on the quality of interpersonal bonds. Goodwin et al. (1987) studied 27,000 cancer cases and

found that married persons lived longer with far less mortality than single, widowed, separated, or divorced people.

Maunsell, Brisson, and Deschenes (1995) studied 224 Canadian women who had recently had surgery for breast cancer. A specially trained nurse was asked to perform in-depth interviews on the women to ascertain a variety of psychosocial factors, most importantly whether they had shared their feelings and discussed personal problems with one or more confidant in the ensuing months following hospitalization. Confidants could be a variety of individuals from family members, friends or colleagues to medical, psychological or religious personnel.

Survival data for the 224 women were analyzed seven years later. Results indicated that women without any confidants had a 56.3 percent survival rate after seven years. Those that had confided in one person had a seven-year survival rate of 66.2 percent; women indicating two or more confidants increased to an impressive 76 percent. While the statistical significance was only borderline, the differences in their survival could not be accounted for by any other variables. Results also indicated that improvement was unaffected by what type of confidant the women used. The salient point seemed to be the sense of being heard and receiving support by another human being.

Support groups, educational and therapy groups have been widely used with mixed findings in cancer research. Spiegel et al. (1989) described his surprise at the results of his seminal research on the efficacy of support groups. The original intent of this research was to study the impact of support group intervention on the women's quality of life during the course of their treatment. Eighty-six women diagnosed with metastatic breast cancer were divided into two groups: A control group received only standard quality medical care; the treatment group received, in addition to standard quality medical treatment, 90 minutes of group therapy a week for a year. Those who participated in the support group reported an overall sense of well-being, improved communication with their doctors and families and less depression, pain and anxiety.

The results of the study supporting improved quality of life were expected by Dr. Spiegel (1993). However, 10 years later he decided to do an analysis and follow-up to determine the course of cancer progression in the original participants. What he found was startling: All patients in the control group were deceased with one third of those in the treatment group still living. Patients who had received the group therapy intervention lived twice as long as the

control group. Dr. Spiegel's results held up even when controlling for the effects of stages of disease, amounts of surgery and other treatment intervention.

Other studies have demonstrated the efficacy of support groups and group therapy. Fawzy et al. (1990a) divided patients into two groups with malignant melanoma. Half of this group received normal medical care and the other half were assigned to a very structured series of six weekly support groups. The work done in these groups was far more structured than in Spiegel's groups, but still used similar topics and themes. The results showed that the treatment group utilized more active coping strategies and exhibited less mood disturbance.

In another report published at the same time as a companion piece to the first (Fawzy et al., 1990b), the researchers found significant differences in immune functioning at the six-year follow-up. The natural killer cells, a form of white blood cells, had been stimulated (elevated) in those who received the group therapy suggesting a positive effect of group support on immune function. After six years from the start of his original study, Fawzy et al. (1990b) found results supportive of Dr. Spiegel's work suggesting that patients receiving group support survived a longer period of time before their disease recurred and had least mortality.

Other studies have not demonstrated the benefits of support groups/group therapy. Maxwell et al. (1993) and Morgenstern et al. (1984) found no statistically significant differences in survival time in a long-term follow-up of 34 cancer patients. Participants in this program received peer support and family therapy, individual counseling and training in the use of positive mental imagery on a weekly basis. Patients used for this study were a group of patients in Dr. Bernie Siegel's (1989) *Exceptional Cancer Patient Program*. This study had one significant flaw in that there was no randomly selected control group, instead, the treatment group results were compared to that of a matched group of 102 patients.

### ***Psychosocial and Spiritual Cancer Research: Spirituality***

Spirituality and religion are often confused in everyday conversation as well as in the scientific literature. Increasingly studies are delineating these differences. Legere (1984) described, "Spirituality is not a religion. Spirituality has to do with experience, religion has to do with the conceptualization of that experience. Spirituality focuses on what happens in the heart, religion tries to codify and capture that experience in a system" (p. 376). Gilchrest (1992) differentiated between spirituality and religion, describing that many find less structured routes to their experience of spirituality, while for others, spirituality is inclusive of a religious system.

(p. 10) Spirituality is frequently described in the research as incorporating elements of connectedness and transcendence, as in a relationship an individual has with the universe or a higher being (Coward & Reed, 1996; Haase et al., 1992; Stoll, 1989).

Blu-Wagner's (1998) is one of the first studies to carefully distinguish between existential and spiritual issues. She defined existential issues as meaning and purpose in life, personal responsibility for creating a fulfilling life, aloneness in life and facing death. Religious and spiritual experience were described as a lessening of attachment to personal thoughts and emotions and corresponding increase in a sense of connectedness or at oneness with the universe or a Higher Power. Some also may have experiences of greater love and compassion for others or describe having experienced a major shift in consciousness which changes self-perception and understanding of the Divine. Kinnier et al. (2001) found that people who had faced death found increased meaning from the experience, believed they had learned important lessons about life and were eager to share their new found wisdom. They also expressed less interest in materialism, increased interest in spirituality and a need to care for and serve others.

The nexus of existential, spiritual and religious concerns constitute significant presenting issues to those faced with terminal diseases such as AIDS and cancer, especially in the late stages (Holt et al., 1999). Three issues identified by Yalom (1980) have particular resonance for those with life threatening diseases: fear of death, finding meaning in life and the importance of hope.

For Yalom's (1980) first issue there is much support in the research literature for the idea that through the necessity of confronting death, the terminally ill often find comfort and resolution of painful issues through spirituality (Ingersoll, 1994; Smith, Stefanek, Joseph, Verdieck, Zabora, & Fetting, 1993). People confronted with life threatening chronic illness can face a crisis of well-being, bringing about spiritual distress as they confront issues of death, body image and pain (Hastings, 1992). Even Stage 1 and 2 cancer patients know that their diagnosis brings with it the possibility of eventual death. An inadequate spiritual orientation can leave the individual open to experience the raw emotions of distress in coping with the possibility of death.

The second issue according to Yalom (1980) is the need of terminally ill patients to construct life meaning by facing the inevitability of their own death. Murphy (1986) indicated that everybody has doubts and fears about their relationships with significant others and to God, which only become magnified for those who are dying. Challenged by such painful realities,

issues of spirituality, meaning and purpose in life become central concerns for those with chronic illness (Burkhardt & Nagai-Jacobsen, 1985). Resolution of these issues not only encompasses deep existential questioning but frequently finds resolution for many people in religious beliefs and spirituality. Burkhardt (1993) defined spirituality as the force that pervades all aspects of our being, giving meaning to our existence and resulting in connection with nature, others or a Higher Power.

The third issue Yalom (1980) considered important for those facing death was the need to find hope. For many patients, hope and spiritual issues are integrally connected (Kylma & Venvilainer-Julkenan, 1997). In a study by Kendall et al. (1989), AIDS patients regained a sense of psychological balance by pursuing a spiritual/existential journey to gain further understanding of themselves with the disease. Spirituality provided them with a path leading to hope, not only for a cure for the disease, but to find a positive life even with the disease. Herth (1990) found that hope was fostered in terminally ill patients who exhibited characteristics of spirituality, such as interpersonal connectedness and purpose in life, along with religious practice.

Much has been written about spiritual well-being as a clearly defined indicator of spiritual health, which can be described as possessing a sense of inner peace, reverence for life, appreciation and gratitude for both unity and diversity and compassion for others (Vaughan, 1986). Hunglemann et al. (1996) identified harmonious interconnectedness as the single unifying theoretical construct comprising the concept of spiritual well-being. Burns (1991) found interconnectedness among self, others and the Infinite as essential to the lived experience of spirituality, which frequently resulted from personal crisis. Mickley and colleagues (1992) discovered in a sample of 175 women with breast cancer that those who were intrinsically religious demonstrated a significantly higher level of spiritual well-being.

As previously mentioned, Blu-Wagner's (1998) study of spontaneous remitters specifically focused on existential and spiritual aspects of the healing process. She defined spontaneous remitters as those who experienced regression of their tumors without having received allopathic treatment. Remarkable recoveries were those that had been given 20% chance of survival and a fixed period of time to live, received traditional medical treatment, but had survived 5 years past all expectations.

Blu-Wagner (1998) found that all participants, except one, reported spiritual and existential experiences. These experiences found expression in several prominent themes. All

participants reported viewing their pre-cancer lives as circumscribed by high stress, many made direct attributions of stress as causative of their diagnosis of cancer. All found that reduction of stress was essential to the recovery process. All participants also seemed to experience their recovery as a learning experience, which manifested idiosyncratically in each participant. Behavior change included challenging conventional medical wisdom and employing non-traditional healing methods.

All participants, except one, experienced augmented spiritual and religious experiences variously described as heightened compassion, inner peace and harmony and union with a life force or energy. Some spoke of cancer as the ultimate learning experience of their lives, helping them to shift from negative emotions of anger and fear and to turn adversity into personal growth and inner wisdom. Existential changes could be seen in expressions of increased meaning and purpose in life, reduced fear and greater acceptance of death as a natural consequence of life. This increased sense of union with the Divine manifested in positive attitude and behavioral shifts resulting in lessened fear and emotional stress, improved personal relationships and an overall sense of heightened awareness, consciousness and intuitive wisdom.

### **Conclusions**

The review of the psycho/social/spiritual literature reveals a relatively nascent field devoid of the deep debates that often characterize more established fields with multiple schools of thought. The field emerged as researchers eager to augment the biomedical paradigm began to search for variables that could account for the behaviors exhibited by cancer patients describing various facets of the cancer patient's experience such as onset, survival and coping behaviors. Survivor's voices demanded to be heard forcing the accommodations manifested in postpositivistic research that currently prevails.

Research in this field demonstrates the need for a major paradigm shift. Temoshok (1987) became aware of the inadequacies of her own research paradigm when she recognized that her earlier work characterizing the Type C personality portrayed a static picture of the characteristics usually seen in cancer patients. She developed her process model to describe the evolving characteristics demonstrated by survivors over time.

What is still missing from the research are constructivist approaches which seek to understand the lived experience of the cancer survivor and identify a process. In psycho/social/spiritual research the literature on spontaneous remission is more heavily

dominated by qualitative research, although semi-structured interviews seem to prevail, rather than in-depth studies of lived experience. Only one study attempted to look at the process manifested in spontaneous remission. This study and one other study presenting a model of transformation in cancer patients, but using the literature of post trauma survival, informed and influenced the present study on terminal diagnosis.

This study will present a model of terminal diagnosis survivorship and extended cancer survival that will extend theory by illuminating the nature of the existential/spiritual shift in behavior described in the literature of spontaneous remission. This shift is often characterized by a proliferation of positive behaviors that some researchers indicate occur before the remission. The literature indicates substantial debate as to whether this phenomenon occurs as a result of conscious effort or is brought about by emotional despair. The model in this study will explicate the phenomenon of the shift and how it occurs.

In addition, this model will extend theory by synthesizing disparate bodies of literature including psycho/social/spiritual cancer research and adult learning as described in this chapter, along with two other bodies of literature in the conclusions, post trauma survival and adult development. The work of Mezirow and Boyd provide the perfect frame for a holistic approach to terminal diagnosis survivorship. Both rational and emotional processes are accounted for and in addition, the role of extrarational processes in cancer recovery has been defined.

## **CHAPTER 3**

### **METHOD**

The purpose of this chapter is to describe the method used in this study of psychosocial process in three cases of terminal diagnosis survivorship. A case study approach was used to examine the lived experience, meaning, learning process and consequent changes made in the individuals' lives. From this research, a model was developed explicating a process that has implications for terminal diagnosis survival and extended cancer survival. This chapter details the research design, philosophical assumptions employed, participant criteria, data collection and data analysis of this study.

#### **Research Design**

Grounded theory, as developed by Glaser and Strauss (1967), was used as the method for this multiple case study research. As previously presented in this paper psychosocial research on cancer has become more prominent in the last 20 years. Previous studies on transformation of cancer survivors have reported and emphasized the different paths taken to recovery by each person. All studies have delineated the importance of mortality and described various attitudinal, affective and behavioral changes that are characteristic of this recovery. However, very little effort has been made to describe or ascertain an underlying process to the various behaviors delineated in these studies. Given the topic for this research has received little prior study, grounded theory was selected to help develop theory in this area. Grounded theory has been defined (Chenitz & Swanson, 1986) as a "systematic research approach for collection and analysis of qualitative data for the purpose of generating explanatory theory that furthers the understanding of social and psychological phenomena." (p. 3)

#### **Research Questions**

The research questions that guided this study are as follows:

1. What are the components (e.g., coping strategies, problem solving techniques, emotion management) of the learning process employed by three cancer patients who have experienced a terminal diagnosis?

2. In what ways did the phenomenal meaning of their lives change as they coped with the trauma of a terminal diagnosis followed by remission persisting a significant time past doctor's predictions?
3. What changes did they make in their lives, viewed from a holistic perspective, including thought processes, healthcare, emotion, spirituality and changes in their social lives?

### **Philosophical Assumptions and Background of the Researcher**

Some considerations of internal validity are important for the full understanding of the significance of the two following sections on Philosophical Assumptions and Background of the Researcher. A full discussion of evaluation criteria appears at the end of this chapter.

Internal validity concerns "factors which affect the degree to which the research procedure measures what it purports to measure" (Merriam & Simpson, 1995, p. 59). The researcher in qualitative research is the primary instrument for collection of data and analyses. As with positivistic approaches to validity of test instruments, it is important to know, does the test really measure what it is intended to measure? In qualitative research, when the researcher becomes the test instrument, it is important to know something about this "instrument". Denzin and Lincoln (1994) emphasize that in ethnographic research it is important to remember that knowledge is perspectival, therefore, it is essential in research to provide the reader with an explicit statement describing the author's intentions. This author believes that the reader should have sufficient information about the researcher to judge the "instrument" in order to fully comprehend the researcher's final constructions or conclusions. It is with this intent that the next two sections are offered.

#### ***Philosophical Assumptions***

Merriam and Simpson (1995) have described the importance of explicating one's theoretical perspective, which they define as, "the underlying structure orientation and viewpoint of your research study." They further elaborate that the topic selected, problem identified and purpose of the study, reflect the researcher's unique orientation to the world. This orientation may reflect a particular discipline such as sociology or psychology, or a particular theory or philosophy such as phenomenology or behaviorism. They emphasize the importance of making

this orientation explicit and demonstrating how the research is situated within the chosen theoretical perspective.

The researcher's approach to this study is framed within two related paradigms: the Quantum paradigm and constructivism. The researcher has long been interested in the power and influence that scientific paradigms have on our world. Kuhn (1962) first introduced the concept of a scientific paradigm, as a "constellation of achievements, concepts and values shared by the scientific community and used to shape the direction of work in the field". The differences between the Quantum and Newtonian paradigms as delineated by Capra (1975), Casti (1990) and Zohar (1990), each reflect prevailing scientific research of our times. Newton's work brought about quantitative and positivistic approaches that have constituted the prevailing dominant paradigm of scientific thought. The dominant belief here is that the world is a completely causal and deterministic machine and stands apart from us as an entirely orderly and predictable universe.

The Quantum paradigm based on research into the subatomic world revealed a world that could not be explained by Newtonian physics that predicted subatomic particles would have both a finite location and definite measurable motion. Subatomic particles anomalously demonstrated existence as either a particle or wave state but never both simultaneously; even more mysterious was the fact that whether a particle or wave state manifests depended on the scientist or observer who set the conditions for the experiment. The Quantum paradigm demonstrates a new epistemology that eliminates the idea that there is a reality separate from the observer. Prigogine (Prigogine & Stengers, 1984), from the world of chemistry, indicated: "Whatever we call reality is revealed to us through an active construction in which we participate."(p.24)

As positivism best represents the epistemology of the Newtonian paradigm, so constructivism parallels the Quantum paradigm. Denzin and Lincoln (1994) describe that constructivism is one of several paradigms of qualitative research as well as a part of the lexicon of philosophers and social science methodologists. Blumer (1954) asserts that this paradigm is less well defined and represents the new frontier for research, that the descriptors for this paradigm are best regarded as "sensitizing concepts only suggesting directions in which to look but not providing ideas of what to see " (as cited in Denzin & Lincoln, 1994).

Lincoln and Guba (1985) suggest that researchers are guided by abstract principles that include beliefs about ontology (What is the nature of being or reality?), epistemology (What is

the nature of human knowing?) and methodology (How do we gain knowledge of the world?). The constellation of answers to these questions represents the researcher's paradigm or beliefs that guide action. Denzin and Lincoln (1994) describe that the "constructivist paradigm assumes a relativist ontology (there are multiple realities), a subjective epistemology (knower and subject create understandings) and a naturalistic (in the natural world) set of methodological procedures. Findings are usually presented in terms of grounded theory . . ." (p. 13).

The constructivist researcher believes that any approach to understanding the lived experience of individuals must be holistic, looking not only at physical, cognitive, emotional and spiritual but also the construction of meaning. The person must also be viewed in the larger context involving historical, social, cultural, ethnic, economic and gender issues (Denzin & Lincoln, 1994). The assumptions of this paradigm lace the researcher's selection of context appropriate research as well as methodological approaches.

### ***Background of the Researcher***

The researcher had originally decided on the broad topic area of optimism for her dissertation research. She was pursuing research on this topic in an effort to narrow down the topic when in the Fall of 2000 a cousin she was lunching with shared his remarkable story of surviving a terminal diagnosis from cancer. Describing how he had already lived several years past the six months doctors gave him to live, he recounted his story of a transformation in his life in which he emerged from his cancer experience with amazing resilience and optimism. The researcher immediately decided to change the focus of her dissertation research to looking at the quality of optimism in survivors of terminal diagnoses.

In January of 2001, the researcher went to the doctor, reporting a large lump under her arm and was subsequently diagnosed with third stage breast cancer. Once again, the dissertation research topic took another turn. The researcher, through experiencing her own cancer process, decided that optimism was probably only one piece of a puzzle to be looked at in the spontaneous remission process. After hearing her relative's story and experiencing the cancer experience firsthand, she decided to look at the broader aspect of the psychosocial process for her dissertation. Later, in consultation with her dissertation chairman, a further refinement was made to specifically focus on psychosocial process of terminal diagnosis as a form of learning.

The researcher not only brings to this study her own sensitivity to the cancer process but also 20 years of counseling experience, first in alcohol and drug counseling, also in employee

assistance work with corporations and government. As a former employee assistance professional, the researcher assisted clients with a wide range of psychological concerns. Particularly relevant to this study, the researcher has counseled many individuals who were diagnosed with terminal diseases or had family members with such diagnoses. She also counseled young mothers who had lost a child due to SIDS or due to street violence. The researcher believes this experience provides her with a certain "comfort" level in questioning individuals regarding death and dying issues.

### **Selection of Cases and Theoretical Sampling**

The unit of analysis for this multiple case study is the psychosocial learning process as seen in several cases of survivors of terminal diagnosis from cancer. Investigation in grounded theory is not achieved by generating propositions (hypotheses) a priori for future testing; rather, Strauss and Corbin (1990/1998) state that it is,

. . . inductively derived from the study of the phenomenon it represents. That is, discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis and theory should stand in reciprocal relationship with each other (p. 23).

As quantitative research begins with hypothesis testing, qualitative research ends in hypothesis development. Propositions represent how ideas about phenomena are related to each other. Propositions specify relationships between categories and its concepts and permit deductions, which can guide data collection leading to further induction and testing of propositions.

Qualitative case study research is not comparable to sampling research, results are not generalized to a population, but rather the goal of this research is a thorough nuanced understanding of the uniqueness of the phenomenon studied. Stake (1995) described that qualitative case selection is not sampling by attributes; and while achieving balance and variety is important, the opportunity for learning should be regarded as of primary importance.

Selection of the first case flows logically from the research question. Additional cases are selected based on theoretical relevance of developing theory (theoretical sampling) and proceed from an "intimate relationship with data, with researchers fully aware of themselves as instruments for developing grounded theory" (Strauss, 1987, p. 6). The process of theoretical sensitivity (discussed later in this paper) is based on the unique qualities that researchers bring to their work, past experience, familiarity with theoretically relevant research and creativity. The

more theoretically sensitive the researcher, the more likely s/he will recognize theoretical relevance in the data, thereby improving theoretical sampling for case selection and development of propositions.

### **Interview Rationale**

As reviewed in Chapter Two, there is much research that becomes context for viewing the phenomenon of terminal diagnosis survival. In developing a framework for an interview protocol, the researcher must utilize several sources. Grounded theory tells us that proposition development (inclusive of all coding procedures) is an interactive process between the theoretical sensitivity of the researcher, including familiarity with multi-disciplinary research literature and personal and professional experience and the actual data collected. This was also true in the development of a first interviewing protocol that early considerations, questions and areas of focus morphed as the researcher made the rounds among interviews, data, research literature and personal understandings and insights.

The interviewer started the interview by engaging the participant in some small talk about weather, the surroundings and other innocuous topics. After explaining the purpose of the interview, data collection and confidentiality issues, the participant was asked to talk about his/her diagnosis and its impact. It is important to understand how this diagnosis was received in the context of the individual's life - in other words, was this person having a good life and perhaps now feels cheated, crushed or filled with rage against God or fate?? Or was the person having a sad, unpleasant, stressful life, one in which the diagnosis could be seen as either more of the same or perhaps a welcomed, blessed relief - a possible way out of pain?

Whatever their interpretation of this event, how did the individual feel prepared to deal with it? What personal resources (internal, such as optimism, strong spirituality, etc.) did the person possess to cope; what external resources ( e.g., family, friends, doctors) did they utilize? Most importantly, how did they come to terms with death or did they? Assessing the individual in terms of Elizabeth Kubler-Ross' (1969) stages of grief was considered important here; obviously the possibility exists that some individuals may stay in denial until their reprieve later on. And ultimately, from the new construction of their life and the time they have left, how are they now - the timeframe from diagnosis to expected death -living their lives?

Basically, the interviewer wanted to get a holistic sense of how they lived their lives prior to the diagnosis and how they are now living their lives: i.e., questioning ascertained their

thinking (cognitive), emotions, social life, physical (how they take care of themselves), spirituality and meaning construction. The next major concern became what happened when they were first aware that they have lived past the timeframe for death? What was the impact? Finally, when it was recognized that they have a reprieve - did they conceive it this way?

This researcher was particularly interested in looking at the death/reprieve nexus - after coming to terms with the imminent death realization, how did the meaning of life change once again upon the realization that the individual had a reprieve; during this time how did they experience the passage of time, i.e., one day at a time, week, etc? Once again this impact was assessed holistically as described above. From their current perspective how was an assessment made to view both terminal diagnosis and reprieve? Did the impact of having faced death prepare them to live in a better way, or did they prepare for death so well, that the additional life is a problem? Most importantly it was important to learn how they are they living today - what is truly different? If they feel good about their life, to what do they attribute this - personal resources, external resources or a combination? If they don't feel good about their life, what do they perceive themselves as being in need of? From this holistic questioning of participants regarding their confrontation with a terminal diagnosis and ultimately a reprieve on life, what did they learn, how do they construct new meaning and how did this manifest in their lives? Of course, grounded theory required supporting the evolving theory with the rich detail of their stories.

### **Criteria for Selection of Cases**

The researcher initially considered seeking participants who had evidenced a spontaneous remission. However, studies on spontaneous remission seem to have at least an implicit goal of demonstrating or suggesting that a mind/body connection may be responsible for the remission. Many spontaneous remission cases are individuals who have received no allopathic treatment, yet evidenced regression of tumors. Researchers of this phenomenon are hopeful of demonstrating to the medical community that they should be looking at these cases to learn more about how psycho/social/spiritual factors could account for these spectacular recoveries.

This researcher is interested in describing the learning or transformative process of the individual's lived experience of surviving a terminal diagnosis. It is the opinion of this researcher that once qualitative researchers have developed sufficient theory in this area, establishment of mind/body connections can be developed by other research better suited for this discovery.

This researcher also avoided the mine field of definitions of confusing definitions of spontaneous remission, remarkable recoveries and unexpected recoveries. Everson and Cole (1966) defined spontaneous remission as the partial or total disappearance of a malignant tumor without sufficient medical treatment, not to be equated with a cure. Ikemi et al. (1975) broadened this definition to include long-term survival even in the presence of continued malignancy. Even though Hirshberg and Barash (1995) found the original meaning and original definition of spontaneous remission to be most appropriate, they nevertheless proposed the term “remarkable recovery” as an alternative. This author found in pursuing her research, that spontaneous remission or unexpected recovery seemed to be more prevalent in the literature, but definitions were often confusing.

Whatever term is used to describe this phenomenon, careful definition is certainly required. Hirshberg and Barash (1995) discovered that querying doctors as to whether they had ever seen a case of spontaneous remission, met with little response. But, when they elaborated -- a cancer patient "who did extraordinarily well-- a terminal patient unexpectedly recovering after only palliative<sup>2</sup> cure; a person living past all statistical expectation or unexpected tumor regression" (p. 18), doctors often replied that of course they had seen one of those.

Hirshberg and Barash (1995) described six categories for remarkable recovery. The participants in this study could be considered spontaneous remitters, remarkable recoveries or unexpected recoveries depending on which definition one chooses. Hirshberg and Barash’s definition of remarkable recovery, which is the term they suggested in preference to spontaneous remission is defined below: Their six definitions are as follows:

1. No treatment: those cases where patients were properly diagnosed via X-rays, biopsies, or other medical tests, had no medical intervention and their disease just went away;
2. Inadequate Treatment: cases where diagnosis is followed by conventional medical treatment considered insufficient to produce either a cure or a remission -- the physician gives up, yet the patient returns one or five or ten years later free of disease;
3. Equilibrium (or Delayed Progression): those people who show either a partial regression of cancer or who live with their disease in reasonably good health for long periods of time.

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<sup>2</sup> Palliative care is designed to ease pain only and is not intended as a cure.

4. Long Survival: in which people undergo conventional treatment, yet survive for longer than the statistics for their type of cancer and treatment would mandate;
5. Complementary Treatment: where patients have resorted to an often motley combination of traditional and so-called "alternative" treatments to get well;
6. "Miracles": so-called spiritual cures, such as the healing documented by the Lourdes International Medical Commission.

Two of the cases from this study (Barbara and Donna) fit the number four definition above. However, other studies have used all the other definitions (1, 2, 3, 5, and 6) to refer to spontaneous remissions and the number four definition to refer to unexpected recovery or remarkable recovery. For example, Blu-Wagner (1998) categorized spontaneous remitters according to the other five definitions and a definition comparable to number four to describe remarkable recoveries in her study. In an effort to avoid this confusion of definitions, this study focuses on the phenomenon of the process resulting from the terminal diagnosis.

While both Barbara and Donna fit the number four definition above, Jim was originally given a diagnosis by several doctors that indicated he had six months to live. Soon he was told that this was a misdiagnosis. Thus, the term of terminal diagnosis survival includes his case as he truly believed and acted as if he was going to die.

### **Participant Selection**

In order to find participants for this study the researcher had originally planned to contact local area hospitals, cancer centers and oncologists' offices. However, in discussing her dissertation with family and friends, numerous leads were developed. Jim was the first participant selected. Jim was the first case interviewed for the study. Details of his story were passed along to this researcher from friends. The researcher interviewed him at his modest home that he built for himself in a small Midwestern city. He had been described as an individual who had been told by doctors that he only had six months to live after receiving a diagnosis of lung cancer. Everybody who had talked to him regarded him as being positively transformed by the experience. His case was considered the pilot study. The purpose of the pilot study was to assess the quality of questions and probes designed to elicit the lived experience of the participants' story. Upon completion of this interview the research professor and the committee chairman received the transcription and provided feedback. The researcher also presented the case in a

research coding class. Because the pilot interview yielded rich data the research professor and committee chairman recommended retaining it as a permanent case.

Jim, aged 64, is a divorced white male with three adult children, two sons and a daughter. He resides in the Midwest in a small town and lives in a little house he built. Although, he is now retired, he has a high school education and worked most of his life as a welder.

Since the first participant was a white male, the researcher sought a black female for a second participant, but due to time constraints, finally decided to interview Donna, a white, 52 year old divorced woman with two teenaged children. Donna's story is unusual because she was the only person to survive an experimental clinical trial after being told she only had six months to live. Even though she is now 52, at the time of her diagnosis she was 38 and her two children were aged two and four. Donna now has a college degree and following her cancer experience, went to work for an association with a cancer cause.

The number of clients selected was determined after each interview. Theoretically sensitive sampling proceeded after the analysis of each case. When it was time to select a third participant, the researcher found that the previous cases yielded rich data resulting in near code saturation. Since both participants had constructed their experience around a God centered spirituality and religious beliefs, the researcher was now seeking an atheist or agnostic to determine information about how meaning would be constructed given this orientation. The researcher placed an ad in the health section of the Washington Post newspaper that ran for two weeks and yielded only one response, the third case used, Barbara. Participant selection was terminated when all categories were saturated which occurred after analysis of Barbara's case.

Barbara, an agnostic, is now 60, having survived 17 years past her original diagnosis, which at that time was an elevated protein level, a condition that is a precursor to Multiple Myeloma, a rare blood cancer. She was officially diagnosed with Multiple Myeloma in 1994. Barbara's case added additional dimensions due to her non-theistic belief system; but also surprisingly, her case also demonstrated some unique aspects in terms of her use of denial as positive avoidance and the fact that she came to her own death acceptance by dealing with the death of the love of her life, not because of a need to come to terms with her own cancer.

### **Role of Participants**

Reinharz (1992) has elaborated the traditional role of the interviewee as an extension of the prevailing male dominated positivistic approach. She expressed how participants, under the

scientific paradigm, are regarded as impersonal objects of inquiry. She emphasized the importance of regarding the participant as a person of equal intelligence and experience to the researcher. The role of the participants in this study includes the following:

1. Participants were interviewed once for two hours. The participants were asked to tell their story based on identified topics and probes. The researcher used an entirely different style of interviewing for the latter half of the interview (see Interviewing Method in this chapter).
2. Participants reviewed for accuracy either the original transcript and/or the written narrative of their experience.
3. Participants also provided feedback on their narratives in a phone interview.

## **Data Collection and Analysis**

### ***Data Collection Procedures***

The primary data collection method utilized was tape-recorded face-to-face interviews. Transcripts of interviews were prepared after each interview. The committee chairman, doctoral committee research professor and members of a coding class reviewed transcripts and provided feedback. Feedback was also provided for interviewing method and for interview probes after each interview.

### ***Data Analysis***

Strauss and Corbin (1994, 1990/1998,) provide systematic procedures for analysis and development of grounded theory. Grounded theory, sometimes called the constant comparison method, an iterative process, was applied to understand the phenomenon of this study. Data analysis starts with the process of open coding in which concepts are selected and described in terms of properties and dimensions. Next, axial coding was used which required developing a paradigm model built on linking categories at the level of properties and dimensions. The categories are further developed in relation to causal conditions, consequences, context, action and interaction strategies and intervening factors (Strauss & Corbin, 1998). Finally, selective coding is used to consolidate and integrate categories in order to develop a larger theoretical scheme and relate it to other categories (Strauss & Corbin, 1990).

Strauss and Corbin (1998) suggest several methods to use for coding: line by line, sentences or paragraphs, or by comparison of documents. This researcher began coding by using

line-by-line coding but rapidly abandoned this in favor of coding by sentences and paragraphs. Approximately thirty to thirty-five categories were identified from the data. The researcher soon learned that most people have far more categories to start. However, the researcher believed the more limited number of codes worked very well in that twice as many categories would have been unwieldy to work with. Even though some codes would have to be broken down again, this distributed the data into more manageable categories. The important realization for researchers is to be aware that the relative broadness of the initial categories could obscure identification of certain elements. Establishing this awareness early on helped foreclose this possibility.

Printing out the coded segments on ETHNOGRAPH, a software tool for analysis of qualitative data, allowed the researcher to better understand and manage the data. The major benefit of coding appears to be slicing a large amount of data into manageable segments. Each segment can be analyzed and deconstructed if the researcher believes the smaller categories need separate recognition. One example of this was discerning the very important category of Meaning Making. In the coding of the first two cases, this was not identified as a separate category. Rather the researcher discovered that this category was embedded in other categories, particularly in spirituality (SPIRITUAL) or TWILITZONE, a category used to describe the extrarational processes identified. Meaning making (MEANINGMAK) activity by participants was particularly evidenced when they were considering issues of spirituality (SPIRITUAL) and extrarational processes (TWILITZONE).

After axial coding there emerged from the data four to six categories for each person. The commonalities of the process that were identified were striking. Each person had a turning point (TURNPOINT), a time when they accepted death and evidenced a constellation of behavioral change. The turning point was used to describe this phenomenon in the first two cases but was changed to low point with Barbara's case. As Barbara's was the last case coded it became apparent that the turning point was what each person described as the lowest point in their experience. Paradoxically, what emerged from this low point was a constellation of positive attitudinal and behavioral change.

The category of emotional coping (EMOTCOPE) became important at this time even though it is a stand alone category. The researcher could have subsumed this category under death acceptance but was unable to do so as this category was important throughout the participant's cancer experience.

Once again what became important after the low point was the movement toward death acceptance. Meaning making activity accelerated as the individual incorporated spiritual and extrarational events (TWILITZONE) as well as used altered states (prayer, mediation, music) to calm emotional states. Letting go was a category used with Jim and Donna to describe the individual's letting go of certain desires and unproductive ways of thinking as well as grieving these losses. This category was changed to GRIEFWORK with Barbara.

Appendix A shows the family trees of each participant. They illustrate the importance of the low point and the activity, previously described behavioral change, that occurred at that time. Other important segments are the diagnostic reaction (DIAGREACT) , the importance of emotions (EMOTCOPE), the life of the individual as a result of their transformation (NEWLIFE) and spirituality (SPIRITUAL).

### **Theoretical Sensitivity**

According to Strauss and Corbin (1990) theoretical sensitivity is a personal quality of the researcher that facilitates understanding of and insight to the subtleties of meaning inherent in the data. They indicate that it is not only important to realize what is important in the data but also to determine its meaning.

Strauss and Corbin (1990) cite several sources of theoretical sensitivity: (a) One source is the literature which includes readings on research theory as well as various documents. Familiarity with this material sensitizes the researcher to important issues concerned with the phenomenon studied; (b & c) professional and personal experience can provide additional background for interpretation of data but can also obscure vision; and (d) Analytical process is another source for theoretical sensitivity, as the researcher interacts with the data, repeatedly asking questions, making comparisons and forming hypotheses, developing theoretical frameworks regarding concepts and their relationships, then returning once again to the data and repeating the cycle.

Theoretical sensitivity is best served when an essential tension can be maintained between the researcher's creativity and imagination and the reality of the phenomenon (Strauss & Corbin, 1990). They offer several suggestions to ensure this balance:

- Frequently step back and assess how what is going on fits the observed data.
- Be skeptical of theoretical explanations, hypotheses and categories; regard them as provisional requiring constant checking out against data.

- Maintain rigor in the study by following all analytic and data collection procedures.

### **Interviewing Method**

Participants were interviewed twice. The first interview was structured with minimal topic areas and probes to allow full and complete opportunity for participants to disclose their full narrative. The purpose of the first part of the interview was to allow the participant to present his/her story with minimal commentary from the researcher. In the second half of the interview the researcher felt free to share her story when the participant indicated sufficient interest. All indicated that they wanted to know something about the researcher's story. The researcher regards this as a constructionist approach that allows the researcher to step outside or perhaps, alongside the researcher role and share with the participant an "insider view" as can only be experienced by those who have the cancer experience.

The purpose of this approach is to allow another "voice" to emerge from the participant; the voice of an individual that realizes they are sharing with one who is an "insider" to their experience. The researcher is not a total insider from the standpoint of having experienced a terminal diagnosis (at least not an immediate terminal diagnosis), but is an insider to the cancer experience. As a former counselor, the researcher understands that as with alcoholics, drug addicts, AIDs patients and many others, these people often feel best served and understood by those who have experienced and/or are recovering from such afflictions themselves. The change in focus for the second half of the interview was an effort to leverage this background for a different view or understanding of the participant. Upon completion of all the interviews all data were coded using ETHNOGRAPH. A second interview was conducted several months later. Each participant was sent copies of the narrative as well as the transcript. Interviews lasted between 20 minutes and one hour. All were asked if the narrative was accurate in all respects. Participants verified all major aspects of the narratives and suggested only minor changes.

### **Evaluation of Qualitative Studies**

The terms "validity" and reliability" have been thoroughly examined by many researchers (Denzin & Lincoln, 1994; Merriam & Simpson, 1995), but probably one of the most useful conceptualizations of validity for qualitative research was Lincoln and Guba's (1985) concept of trustworthiness explicated into four elements: credibility, transferability, dependability and

confirmability. These elements parallel and are analogous to conventional positivist criteria of "internal validity," "external validity," "reliability" and "objectivity".

Credibility is analogous to "internal validity." Merriam & Simpson (1995) state that internal validity as defined by conventional criteria, answers the question, "How congruent are one's findings with reality?" The authors elaborate this as, "Are we observing or measuring what we think we are observing or measuring?"(p. 101) Applying or adapting this criterion for qualitative studies must assume the differing ontological and epistemological assumptions accounting for a worldview of multiple changing realities as constructed by and understood by individuals. Lincoln & Guba (1985) suggest that credibility can be established by a variety of techniques, several of which were used in this study:

1. Prolonged engagement requires the investment of substantial time in order to accomplish several objectives, "learning the culture, testing for misinformation introduced by distortions either of the self or of the respondents and building trust." (Lincoln & Guba , 1985). This researcher knows well the culture of the respondents in this study. In fact, it could be leveled that this researcher is "embedded" in this culture and as such, would have to be mindful of "assumptions" in regard to understanding respondent's stories. This was considered as part of testing for misinformation of self and respondents. This author has in a prior section detailed her philosophical preferences and delineated experiential background to help bring to light personal preferences or attributes that will bear on the interpretation and construction of data.

Prolonged engagement also provides an opportunity to build trust with the respondents. According to Lincoln and Guba (1985) the trust building process is developmental in nature and must be demonstrated by not violating the confidences of respondents. The researcher must honor promises of anonymity, respect the interests of respondents and provide them mutual power and respect in the inquiry process.

Triangulation is another important mode for improving credibility. As Lincoln and Guba (1985) suggest, this can be accomplished by the use of multiple and different resources. They suggest that multiple sources may include "multiple copies of one type of source" which includes different interview respondents as used in this study. The researcher also attempted to triangulate by asking respondents to provide additional written materials, diaries, journals, letters,

newspaper articles or significant others that may be interviewed to add additional light to their stories. Finally, peer debriefing, as described by Lincoln and Guba (1985), was incorporated by the researcher's participation in a peer based coding group which provided an opportunity to test working hypotheses as well as have biases probed, meanings explored and interpretations validated.

2. Lincoln and Guba's (1985) transferability correlates to external validity in traditional scientific research and refers to the utility of research found in one context and applied to another. They indicated that this can be achieved by the investigator providing "thick description" or sufficient descriptive data to make possible similarity judgments.
3. Dependability is the qualitative researchers' equivalent of the traditional scientific research term of reliability. Reliability answers the question of what the likelihood would be of duplicating one's findings. When dealing with qualitative research or social science, replicating human behavior is problematic because it is never static. Qualitative studies can not be replicated with identical results; it is generally recognized that data can have numerous interpretations. Qualitative researchers need to consider the more overriding question of whether data collected are consistent with the results. Guba and Lincoln (1981, Lincoln & Guba, 1985) suggest an audit trail, establishing firm linkage between findings, assertions and interpretations. The audit trail can be traced through recorded materials such as interview transcripts, tapes, interviewing probes or guidelines, coding categories and memorizing regarding theoretical sampling, hypotheses formed, methodology and research procedures.
4. Confirmability is the qualitative equivalent of the traditional research term of objectivity. The audit trail and triangulation as described above constitute the major ways to establish confirmability, particular emphasis being placed on ascertaining whether the results are grounded in the data.

### **Summary**

The aim of this study was to explore the psychosocial learning process of several individuals who have experienced a terminal diagnosis from cancer. Although research literature on psychosocial aspects of cancer has only become prevalent in the last 20 years, research to identify psychosocial or learning process in cases of terminal diagnosis are scant. Therefore, the

selection of grounded theory methodology was appropriate for generating explanatory theory, given the dearth of research in this area. The primary data collection approach utilized was tape-recorded face-to-face interviews. Analytic methods developed by Strauss and Corbin (1990/1998) provided the structure for organization and interpretation of data. Results of this study delineated the elements of the phenomenon of terminal diagnosis survival and yielded a process model grounded in the data.

## CHAPTER 4

### NARRATIVES

#### Introduction

Chapter four presents the detailed stories of the three terminal diagnosis survivors. Two of the cases, Jim and Donna, actually heard from doctors that they only had six months to live. In Jim's case, this was a likely misdiagnosis. For three months he prepared in every possible way for his death. After learning she had six months to live, Donna had one last desperate chance for life by participating in an experimental clinical trial for a new drug. She ended up being the only person to survive. When Barbara was diagnosed with a rare blood cancer, she had only a 20% chance to live two or three years. This chapter portrays their stories as a totality without any headings or divisions, just as if someone was telling their story. This is the stories of three survivors who were positively transformed by confronting the reality of their own death.

It should be noted that some may find excessive the inclusion of the three narratives in this chapter and the extensive discussion of the cases presented in Chapter 5. This author has deliberately chosen to include both. The narratives are included so readers can better understand how and when death acceptance occurred. Too often narratives are chopped into pieces in other dissertations, making it difficult for the serious student to understand how this process occurred in the flow of events and in what context.

#### Jim's Narrative

Jim was diagnosed with lung cancer in May of 1999 at the age of 59. He lives in a very small rural town in the Midwest in a little wood house he built and describes as "shack". For the better part of a decade and prior to his diagnosis with cancer, Jim made several major efforts to simplify his life in order to pursue what seems to be a theme in his life, "peace of mind." He recalls,

*Yeah it was in '91. And I was after peace of mind. Whenever the kids were little, it was great raising my kids, but my wife...my ex wife, she was so insecure. Back in '65, I worked a lot of overtime at the steel mill...I had four kids, needed the money. Worked a lot of overtime and well she somehow or other she felt like she was neglected, so she had an affair starting in '66...maybe a couple, I don't know. So with the kids and everything, we went to marriage counseling, get it all lined out but then she went into this terrible*

*insecurity thing. If I get home 5 minutes late from work, she'd accuse me of having...and I never...I didn't have time. But anyhow I didn't and I don't believe in that. But I was after peace of mind and plus it was getting bad.*

They pursued counseling which failed to resolve their problems. Shortly before his divorce he retired, stating that his work life was also very stressful as he had harsh supervisors who came down hard on people for making mistakes. Because his wife received half of his pension, he resolved that he would live very frugally building a little house for himself far out in a remote area of the state. Soon after his retirement and divorce, he stopped taking “nerve pills” and took good care of himself by regularly visiting the doctor, eating well (because he liked to cook) and taking vitamins. While he had made great efforts to de-stress his life, he still felt something was missing and wondered why he could not feel better.

Because Jim had worked around asbestos a lot in his career, a good friend and attorney competency doctor connected to his previous work recommended he get a chest X-ray. He indicated that Jim would receive his results in 6 to 8 weeks. However, only one week later on a Tuesday night Jim was awakened around midnight by a phone call from the doctor informing him that he had cancer. He slept fitfully for the next several nights, agonizing over this news. He recalled crying and sweating profusely as he feared what all this would ultimately mean to him and his family. On Wednesday, in an effort to cope, he began praying. On Thursday he had an appointment with his own doctor who sent him to another radiologist for a chest X-ray and CAT scan. His doctor received the results and confirmed his worst fears:

*I went back and the doctor was waiting for me. And he told me...this doctor is blunt. He told me...he said it's inoperable. It's in the lymph nodes. I said, I feel great. He said in 2 weeks you are going to be sicker than hell. That is exactly what he said to me. If you don't have chemo intervention of some type. I said, Doc with what I have...give me some kind of time... He said 6 months to 2 years...I can't tell you for sure depends on which one it is. He said, 'tell you what I'm going to do. I'm going to give you 2 weeks. For 2 weeks, do whatever you want...take a vacation...do whatever...and then we are going to start the tests.'*

Jim didn't remember much about the following Friday, but he was very clear about Saturday, which was the beginning of a major turning point for him. Jim decided that he had to

start preparing for death. Since he is a Catholic he decided to go to church to pray and attend confession.

*That Saturday the priest in C\*\*\*ville hears confessions in the morning. So I went to C\*\*\*ville and I went through confessing my whole life again...to make sure if I had missed something. I told him...Father, I've given this a lot of thought and I told him the whole story and I said I'm prepping...I'm getting ready to make the big trip<sup>3</sup>. Okay, here is the way I talked about it...I'm getting my fire insurance<sup>4</sup> and all in order. Okay? I'm serious. That's right.*

That same day he went to an early mass and after mass talked to the priest about making funeral arrangements. Amazingly for Jim the priest just happened to have a better idea.

*Went to mass, told him the story and I said I want you to bury me. He said that's not a problem, but you look great. You sure you are sick? I said the doctor says that I've got a few weeks before I get the symptoms. He said it's ironic you came to me tonight. He said I'm getting ready to...I'm going to take you to the "miracle man" and I was kind of...I guess I was in a daze...so I said tell me more. He said there is a healing priest that comes to mass in S\*\*\* once a month...it's Saturday. It's ironic that you are doing this tonight. This is the night he is that he is here. We just have time to make it.*

Since the healing priest was saying mass in a nearby city, they both had to leave quickly in order to make it there in time. The healing priest was described as a charismatic, eighty year old, half-blind, Irish priest who had been known to help reverse the course of diseases or help those in wheelchairs walk again. Subsequently, Jim attended many of these healing masses, noticing that the old priest seemed to have an unerring ability to recognize who could be healed. While Jim appreciated the miracles he sometimes saw with others, he admitted that he did not feel anything extraordinary in himself as a result of that mass or the priest praying over him that night. He realized that many people got the same thing he got that night – an inner sense of peace and a quiet acceptance for whatever would befall him.

*Until this Saturday and then after that I had no trouble accepting whatever was going to happen. It was like it was automatic. And... it's like...God's gift. That's like now, before I had certain fears about dying, but not anymore. In fact I'm looking forward to the*

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<sup>3</sup> Making the big trip refers to dying.

<sup>4</sup> Fire insurance refers to making all the essential preparations for death such as wills, insurance arrangements and funeral preparations.

*destination...I'm a little worried about the trip. I got to eventually where I talked to my doctor and I decided not to take chemo and just have him take care of the suffering I was going to go through.*

As a result of that Saturday's events, praying, confessing, making funeral arrangements, the two masses and the meeting with the "healing father," Jim experienced significant changes in his perception and feelings. No longer was he sweating at night, flooded with anxiety or crying as much. He continued his plans to prepare fully for his death.

He promptly set about giving family members the power of attorney and obtaining a living will. He asked his sister, who is a nurse, to make sure he would not suffer. He even cancelled his 6 month dental cleaning, telling them he would not need any more appointments. He told his children to take whatever they wanted of his possessions, something they appropriately chastised him for and when he visited them he would give them things. One son bluntly told him, "Hey, old man, quit trying to give away your stuff." Plans were even made to have a final meeting or "ceremony" with the family, to say goodbye in case he later became too incapacitated later to be able to do this. His brother arranged the meeting to include Jim's three adult children, who live out of the area, his mother and sister.

After that eventful Saturday Jim spent almost another three months getting more tests and seeing more doctors. His case turned out to be quite controversial and he eventually started receiving conflicting reports on his diagnosis, causing him to pursue additional tests and opinions including consultations with a pulmonologist and oncologist and several biopsies. He was told by one doctor, "not to get his hopes up, he had cancer." Finally, after some biopsies came back negative, his oncologist declared that it probably was not cancer. He recalled that day:

*My sister went with me so she...and that's when he told me... 'You don't have cancer.' But he said, 'We don't know what it is'. That is when he recommended that I go to this surgeon and get a biopsy, but when I came out that day, that's when I knew for certain I didn't have cancer.*

Jim's sense of certainty would soon be tested because his next visit to the surgeon that specialized in the chest was hardly reassuring:

*I went to Dr. M. and he looked at all my papers and I said, tell me doc, what your opinion is because he is a chest specialist. He said it's either cancer or a fungus...either one will take your life. He gave me the percentage. He said 80% cancer. That was after both tests*

*back already came back negative. He was still saying 80% and this guy is no lightweight. But he told me...he said, 'what you did for a living, your lungs are probably adhered to your chest. I'm going to tear you up pretty good getting in there' and I said how long will you take me out of commission? He said, 'a couple of months'. I said if I'm going to die, I feel good right now, there is no use ripping me open...he said, 'I agree with you'.*

Overall, Jim received confusing reports on his diagnosis ranging from possible explanations of asbestosis and fungus to cancer. Even though the surgeon told him it was either cancer or fungus, either of which could kill him, Jim felt confident it was not cancer. Because he had prepared so well to accept death, he was mentally and emotionally prepared either way.

What was certain was that a chest x-ray he had in 1993 when he retired was clear and in May of 1999 the X-ray showed his lungs were filled with a growth that was expanding. Recent reports show that this growth has now been stationary for a couple of years. Jim recalled that if he had totally listened to some of his doctors in 1999, who were basing their opinions on the X-ray, he would have had exploratory surgeries, chemotherapy and radiation. Other people might not have felt as confident that they would be okay based on one doctor's report, even an oncologist's, but Jim had an inner sense of conviction and a sense that he would be all right. He explained that in 2003 he did not go back for an X-ray. Once again, he demonstrated a sense of certainty that he will be well based on knowing he can handle whatever comes his way.

For three months Jim prepared for death and coped with endless tests and diverging opinions by attending daily mass and praying intensely. He explained it this way:

*This is the amazing part. Once I had a long talk with our Lord, I was able to joke about it and everything else. For 90 days I thought I was going to die. They didn't have to give me anything to make me sleep. The doctor kept asking me...sleeping all right? The power of what God would do for you is absolutely unbelievable because it wasn't me. It was not me. It was amazing. I was ready to make the big trip and...*

It is interesting that Jim who had taken "nerve pills" for years took nothing during the most difficult period of his life. He really credits God with giving him the strength to cope with this experience. In the above statement he is also indicating that this new found ability occurred after he had thoroughly prepared himself for death, "making the big trip." Jim felt that God had responded to him through his prayers. Jim described what prayer means and how he prays:

*If I'm asking for something I just plainly talk to him as I was talking to you. Most times I make my statement and then I just shut up and go blank and see if he'll tell me what he wants or there are some thoughts come to me or whatever. Mainly when I'm going to ask something, mainly when I'm going to make a request or something that is real important, I always do it at mass with a consecration because to me that is the biggie. I firmly believe there is miracle that takes place at consecration and at mass. I never ever...the only thing I asked him was...I didn't ever ask him not to let me die or whatever, I just asked him don't make it too rough. But I've always felt that whatever God wants you to do, that's what it's about.*

Even after the oncologist told him he did not have cancer, the realization that he was not going to die did not really hit him until the testing and doctor consultations ended in early September, three months after his initial diagnosis. The family farewell meeting arranged by his brother was cancelled. It would be natural to assume that a person would be joyous upon learning he was not going to die, but for Jim this was almost as hard to accept as the initial diagnosis. He stated,

*That was the deal right there. It was like...in one way...it was like a sense of relief that I'm not sick and the other thing was I had myself so prepped to go to heaven that I had mixed feelings. I actually didn't sleep well for about 3 days until I get myself back in the mode to work. I continued to go to daily mass and pray intently and tell him...I tell him thanks for and help me do whatever he plans for me to do. I guess. I don't know. That's all I can say.*

Talking about this was not comfortable for him. He only briefly alluded to having imagined Heaven and being in God's presence. Because he had prepared himself mentally and spiritually as thoroughly as he had prepared physically (fire insurance) for his death, having his appointment with Heaven snatched away from him was traumatic.

While he does not seem to credit what could be called the "remission" part of his experience as being as important as his coming to terms with death, it seems that the gift of life had to be reconstrued in the light of his new understanding and ability to cope with death. He coped with this new trauma in the same way he had coped with the first – he prayed intently. Once Jim got over the shock that he was not Heaven bound, turning back to his life was made easier by the fact that he was different and had created a new life.

Paradoxically, Jim's thorough preparation for death intensified his involvement with life. As Jim increased his involvement in his church, he found himself embraced by a community of support. As his story spread throughout the church and the community, he found people continually coming up to him to tell him that he was in their prayers. He was amazed to find that he was on prayer lists all over the country including some Baptist churches.

Prior to his cancer scare, Jim went to church on Sundays and prayed occasionally, but had little personal sense of God in his life. He now had a more personal relationship with God, a sense that God had changed his life for a reason. He had often talked of a feeling that something was missing in his life, of being depressed, stressed and taking nerve pills for years. He talked about many years of searching for "peace of mind." He reported that the "psychological piece" is the biggest difference for him, not feeling stressed or worrying as much. Part of what he tries to express seems to be at an ineffable level.

*I don't know. I always loved nature because I grew up on a farm. I liked the changing seasons and I go walk a lot and stuff, but when I walk now, I feel differently than I used to. Used to just walk by...sit out there and watch the sunset. I just feel different. It's just better. It's just like an extreme peace. All I can tell you is that it's peace of mind. It's like satisfaction. Peace, satisfaction. Life is great! It doesn't get any better than this.*

To say that Jim's life had changed is probably an understatement. What he had experienced was deeply transformative. He had stared into the face of death and yet survived an experience most of us want to hopefully avoid as long as possible. Jim was born into a milieu of a small rural town of the Midwest, son of a farmer in a devoutly Catholic family. Although Jim had drifted somewhat away from his Catholic roots, the fundamental teachings of his Catholic upbringing were drawn on again when he was confronted with death. In this Christian society and other spiritual societies as well, his is a story that is almost biblical in nature and offers comfort to anyone struggling in life. It is a special status that confers wisdom on those who have been afflicted, survived and come back to inform the rest of us. This is what Jim came to represent to his community.

Jim was embedded in a community of support in such a way that he was not only a recipient of spiritual support, but also a benefactor. Other people going through similar struggles or with loved ones, beseeched him to offer advice and testimony on how he handled his situation. Some of these experiences are as follows:

*Yeah. Then what is amazing and this I wasn't prepared for, after mass one Sunday in \*\*\*\*\*ville, when I still thought I was terminal, of course the word got around. One of the guys I was going to church with, he was going...he always went to daily mass...he's a little older than I am. He came up with prostate cancer diagnosis. We spent a lot of time talking because it really shook him up. I told him...just pray. One day they had like a Sunday dinner to raise money and I'm getting ready to go and so the lady...I knew her sister, but I didn't know her...I didn't know who she was. She came out of the crowd...tears running down her cheeks and she grabs me and she tells me...I ain't ready to die, please talk to me. My God! So she had been diagnosed with lymphoma or something. She had a teenage daughter...I'd say she's probably in her 50's. The only thing that I could tell her was just ask God for strength to handle it. He'll give you what it takes; I can assure you because I'm there right now. Then I would say, because I tell this guy too...with the prostate deal and he doesn't like to hear...but I say, we just might go together. Because I was still in the mode of going.*

When asked what he thought about having such obviously distraught people approaching him for help, he remembered the woman from church:

*Whenever I can...because I asked her later see. Later after she...because she started all these healing masses. She didn't get a cure, but they treated it and she got to where she could live with it where it was. But anyhow later I asked her...did I say the right thing to you? She said you said exactly the right thing to me. That made me feel good that you could help somebody like that.*

The support given by Jim helped a number of people connect with the “healing priest” and attend healing masses. All of this has given Jim a level of importance and involvement with people he never had before in his life. He is clearly enjoying giving back to others in his life. This newly acquired role is part of his current life, but he was thrust into this role even when he still thought he would die. While initially Jim felt shaken and startled, especially in the previously mentioned experience of the crying woman approaching him regarding her recent diagnosis with cancer, his deep spirituality and thorough preparation for death allowed him to offer the example of strength he had derived from his own experience.

During an exchange when the researcher was in the “sharing” mode<sup>5</sup> of questioning, there was a discussion regarding reaching out and relating to others. He explained,

*That's a big one. You see, I'm an introvert. I'm a loner. But yes, it's easier for me to relate to people than it used to be. I don't like crowds and things like that. But it is. It's easier.*

What has helped Jim become more outgoing is having repeated opportunities to tell his story. He described how his dentist asked him to get up in church and give his testimony about his experience in front of the congregation:

*She goes up front and she said, some months ago I heard this absolutely amazing story from one of my patients and then she had me...I don't like attention a lot...to get up and give my testimony was very difficult. I get up in front of the church and gave my testimony. I would never dream of doing something like that. Something just drove me and I had to do it. I surprised myself even doing that. But I don't know. Like you said I reach out to people more and I'm starting a new relationship with a nice lady and I think that is part of it too.*

There is a strange sense of coincidence and irony that informs his story. Several different experiences contributed to this perception. Jim recalled that first Saturday what an incredible coincidence it was to learn that the “healing priest” was going to be in a nearby city that very night. This was the very day Jim went to his local church to confess and make funeral arrangements. After praying all day and attending an early evening mass, his priest informed him about the rare appearance of the “healing priest.” Jim expresses a sense of awe and admiration for the “healing priest.” Since the first night he went to the father’s mass, he has heard many people tell of the amazing healings this man has performed.

*Father went over there to that baby...that baby was diagnosed with some kind of cancer and they said...nah this is no game...there were 8 doctors involved. By the time it was over with, it was a small benign tumor that they could treat.*

*There was another guy over there that had leukemia...old guy like me. The blood tests and everything keep showing and he's had it for like 3 years...he ought to be dead...not even sick and they wanted to make a documentary on him. But you see it's not everyone. It's just certain ones. That old priest was - just like knows. It's intense. It's really intense.*

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<sup>5</sup> Sharing mode refers to a more intimate form of interviewing (discussed in Chapter 3) used by the researcher when she discusses her cancer experience in order to bring about a different level of communication and exchange.

Jim's Catholic theology allows for the possibility of miracles and Jim is clearly wondering what role this might have played in his own situation. Jim believes his own experience has been so special that he questions whether or not he has experienced a miracle. He returned to his oncologist one more time to ask:

*I went back to the oncologist one more time. I told him. Doc, can you say it was a miracle? Can you say it was cancer? He said if I didn't have a positive biopsy I can't say anything for sure.*

He also mused about a strange mishap in 1998, when he had cataract surgery. As part of this procedure he should have gotten an X-ray, but through some error it was overlooked. He reflected,

*Yeah. If I would have gotten a chest x-ray in '98, I wondered if it would have been ugly or not. It's just the way it happened...when I stop and think it through. The way it happened is kind of amazing, so I don't know. Your guess is as good as mine. I don't know if I had cancer and it was cured or if this just happened. But whatever happened, God had something to do with it. He was changing me around for something. I'm convinced of that, but I don't know what how he did it.*

Another event that added to Jim's sense of awe and his perception that something almost miraculous was occurring in his life occurred that Saturday when he attended two masses, including the special mass with the "healing priest." That night he did not get back to his home until around 11 pm. He found that his two sons and his brother had been trying to reach him earlier that evening. He remembered:

*The oldest and the youngest son. Bobby was taking it real hard. This mass was 5:00 this Saturday evening and then we went over to that mass at St. N\*\*\* and I didn't get home until 11:00. They had been trying to call me. So the next morning, Bobby gets me up early... "hey old man, what happened last night?" That's what he said exactly. What happened last night? I told him what happened and he said, along between 5 and 7:00 I can't tell you when I just...a peace came over me where I could...I wasn't tortured like I was. I could accept it. Same thing happened to David and same thing happened to John. John even went up and told mom about that time. He said, 'Mom, I'm feeling a lot better about this. I can handle this.' Amazing. Three of them that night.*

The researcher believed it was important to question Jim very carefully regarding this experience to ascertain that he had not in some way communicated his own good feelings about the experience to them that Saturday. After repeated questioning by the interviewer, who was sure that the calm they experienced must have come after talking with Jim, he clarified:

*No it just came out of nowhere. It was the Saturday night I went to that healing mass. When it happened, just listening to them, it happened to them somewhere in the time I went to mass in B\*\*\* and us going over there, because his mass starts at 7:00 and all three of them had sensed some relief by 7:00. Because Danny told me, "Pop, I knew something was happening and I tried to call. I'm wondered what was going on."*

### **Summary**

Jim coped with the trauma of a terminal diagnosis of cancer head-on with a remarkable absence of denial. A man of faith, born into a deeply religious Catholic family, he naturally turned to his church for support at that time. Immersing himself in intense prayer helped to relax the intense anxiety reaction he initially experienced. A turning point for him occurred just a few days after hearing the diagnosis. After going to church to confess his sins, make funeral arrangements and attend an early mass, he was informed he would just have time to attend mass with the "healing priest" in another nearby city.

While attending the mass with the "healing priest" was significant, he does not believe he experienced anything miraculous, but acknowledged that he did leave with a greater sense of peace of mind. Through three months of confusing diagnoses that would have left many traumatized, Jim accepted the process with equilibrium and continued his preparations for death. In the meantime, he had become embedded in a community of spiritual and social support, in which he was not only a recipient but also a benefactor.

Jim's "remission" phase, or when he learned he probably did not have cancer, had an anomalous effect of not producing joy but rather causing distress. So thoroughly had he prepared for Heaven that he now faced a new trauma as he realized this would not happen. Once again, he coped through prayer.

It is somewhat paradoxical that Jim's intense preparations for death actually resulted in his creating a new life. Because people knew what he had faced, he became a role model with people coming to him for advice. A quiet, shy man was forced out of his comfort zone to speak about his experience.

### Donna's Narrative

Donna was 38 when she was first diagnosed with cancer in January of 1990. The summer before her diagnosis she and her husband felt that they were financially stable enough that she could quit her job to be at home with her two young sons, ages 2 and 4. She was looking forward to this time, a chance to work on building the kind of family life of which she had always dreamed. Coming from a family with two alcoholic parents and two alcoholic brothers, one with AIDs, she was only too familiar with problems and strife. Her first marriage at age 20 to an alcoholic resulted in divorce two years later. She had been single for ten years before marrying Eddie, her current husband of six years. Although she had little awareness of this at the time, she now recognizes that he also had a drinking problem.

She remembered the summer of 1990, just prior to her diagnosis, as one of the most promising times of her life. As Donna described herself, she was just a "simple girl" who wanted nothing more than to have a husband and children and be a stay-at-home mom. That summer was her first opportunity to have that life. Little did she know that she was embarking on a three year fight for her life that would transform her forever.

That summer she had started working out at the gym to lose some weight when she encountered the first sign of a problem:

*I was going to the gym to work off all these pounds from these babies and I noticed this lump in my groin area when I was drying myself and I thought...that's odd...I wonder what that is? And I didn't feel it anyway I was mentioning it to a group of girlfriends when we all got together for lunch. I said...we get those things...its hernia...it's from dragging these big kids around. And I was having...the only side effects I was having at the time were night sweats, but I was 38 so I was close to 40 and my mother was early menopause so that could explain that, plus I was just so tired.*

Visits to the doctor and talks with her friends reassured her that this really wasn't a serious problem. Even though the problem persisted, with Christmas coming she figured another visit could be postponed until after that time. In January her physician referred her to a surgeon who immediately saw the lump as problematic and recommended a biopsy. Even though cancer now loomed as a possibility, Donna still hoped it would be otherwise:

*It just didn't dawn...I was convinced it was hernia. And so I went in and when they opened me up the doctor knew right away. He said it was really big and had grown into*

*the leg area and he pulled it out and it fell apart. He said it was just...surgeons have seen it enough to know when it's a good gland or bad gland...this was a bad gland. He came out and told my husband...I was still knocked out, but he said 'I believe it's going to be some type of cancer. I believe it's going to be some type of Hodgkin's cancer, but whether it's Non-Hodgkins or regular Hodgkins I don't know. It's a lymphoma. We'll know more by Friday when we get the biopsy back.'*

The anesthesia she received for the biopsy made her sick making it necessary for her to spend the night in the hospital. The next morning when her husband came to pick her up, he promptly informed her:

*'I have something to tell you' and he told me what the doctor was thinking that it was cancer. I said...it can't be! You just don't want to believe it and I remember just being numb at that point. Totally numb! I was just like...I can't believe this. Then we got in the car and we both looked at each other and then we started crying. Eddie promised all this stuff and he would never drink again and all this stuff that you do. But we went to the library...we came here to this library and we asked for anything on Hodgkin's or non-Hodgkin's lymphoma or whatever and we got all this material...back then...it's so much better nowadays. So much more directed to the patient that the patient can read...layman's terms. But we were reading these textbook things, but the best thing we could figure out is that I wanted Hodgkin's and not Non-Hodgkins. Because Non-Hodgkin's lymphoma is not as easy to go into remission as Hodgkin's is. Hodgkin's has a better survival rate. So we already figured out if I've got to have one of them, I'll do the Hodgkin's.*

Unfortunately for Donna, the diagnosis was the more malignant of the two diagnoses, Non-Hodgkin's Lymphoma, Stage II (of a possible 4 stages), or at least that was the diagnosis at her local hospital. When her results were sent to a premier and noted specialist at National Institute for Health (NIH), the results were determined to be non-cancerous. Her local hospital deferred to the experts at NIH and decided to check her again in 6 weeks.

*I came back in another 6 weeks and it was now in my neck area which started swelling. They said they would have to do another biopsy and they did another biopsy and again NIH said no signs of cancer and Arlington said now a Stage III because it had crossed over from below to upper and my doctors would not treat me yet. They said no, we're still*

*going by what \*\*\*\*\* [NIH expert] said and they also sent it to Stanford University. Stanford University said we are not sure and I don't know how somebody cannot be sure. I never did understand that prognosis there.*

The contradictory diagnoses continued through most of the summer. What helped her cope were some friendships she had made earlier in the summer when she joined Mary Kay cosmetics. She described this company as a Christian organization where she met two women Pentecostals who exposed her to a very charismatic religious approach, explaining concepts of Holy Spirit and talking in tongues. When she was diagnosed with cancer, they took her to “prayer groups” and exposed her to every type of spiritual treatment. She remembered them fondly:

*I was open to it. I said to Eddie... 'Why not?' It was a little odd I have to admit, I'm not one of...I'm not a tongue person. I'm not into that stuff, but these were good people.*

At that time she asked the pastor of her church what he thought about the Holy Spirit and tongues. She recalled his response:

*He pooh-poohed it. This was the original [Methodist] church I was in. They weren't there for me. When I got diagnosed with cancer, my kid was going to the pre-school at the church I'm currently going to, F\*\*\*\*\* Methodist and they told me... 'why don't you join our church?' And I'm thinking...it's sort of modern and I'm like these old ones that were in DC. But then I met several people and they were all so nice there and then I got sick and I thought I can't go back and forth and they at my old church was not there for me.*

Feeling little connection to the people at her old church, she joined F\*\*\*\*\* Methodist. The new minister later came to visit her in the hospital. She told the minister about her Pentecostal friend's beliefs and asked her what she thought:

*She said, we don't believe in the tongues and all like they do, but it's perfectly acceptable for some people. She didn't give me this vague answer that the other people did or anything. She listened to me and she said there is something to all of that. Everybody has a different way of expressing it. But I just really liked her from the beginning and they were so good to us.*

This behavior is characteristic of Donna and informs and delineates the movement of her story: The two prime motivators of her life have been relationships with others and an inner quest for

spiritual knowledge. Her movement in and out of churches was often based on friendships she formed with both ministers and members. She would later describe this movement into this new church as an extremely fortuitous event because of the wonderful support she received from both her minister and church members during her cancer experience.

These friendships were just forming as the summer was passing and still Donna had no clear answers regarding the status of her cancer. She was feeling very tired and began itching violently. The itching was also a symptom of Non-Hodgkin's Lymphoma, but still she was sent to Johns Hopkins to a skin specialist. At this point, perhaps a sense of exasperation and intuition kicked in, prompting this response to the skin specialist:

*There they asked me what kind of soap I'm using...I said...oh please...it's not that stuff. I'm telling you I know my body and this is like...I've never had this and it's just not something I'm eating; it's not the dog, it's not...they were running all these tests on me.*

This would be the first of several times in Donna's experience when a sense of intuition guides her to express a sense of knowing contrary to the doctor's opinion and to make decisions contrary to the wishes of the doctors. She correctly intuited that this was no skin condition. In a couple of weeks her leg started to swell which resulted in a blood clot. She was immediately hospitalized. From her gurney she had to call friends to pick up one child at the park and another from daycare. In early September the cancer had definitely spread to several areas of her body – this time all hospitals agreed that it was Non-Hodgkin's lymphoma, although now it was Stage III. It had now been six months since her original diagnosis in February of 1991.

She went through six months of chemotherapy and in January of 1992, she was deemed to be in remission. However, there was no time for celebration. Two months later it was back and upgraded to a Stage IV; another 6 months of chemotherapy ensued.

*So we were now up to September of '92 and I was out of remission and they had upgraded it to a Stage IV and they said that there was no...they couldn't do anymore chemo on me or anything...they were going to give me chemo once to just knock the heck out of it, so it would go into remission - they hoped and they were going to do a bone marrow transplant on me.*

As she was completing her second round of chemotherapy and just before they told her that she would have to have the bone marrow transplant, her mother died. The relationship with her mother had been a turbulent one, but one that had ended in reconciliation the year before her

mother's death. Her mother, who had been a violent and abusive alcoholic, finally stopped drinking that year giving Donna an extraordinary opportunity to reconcile her angry feelings for her mother. Donna recalled all the painful years she had endured before that final year of reconciliation, how she had frequently fled the violent arguments at home seeking refuge with the minister and his family:

*I remember he tried to protect me from mom and dad sometimes. Not dad...dad was very kind when he drank. Mom was very mean when she drank, so dad would be able to control her, but it was just hard. I would run away...run down to Georgetown or something. We grew up in DC. So I'd run to Georgetown and then call my minister from like M street on the telephone or something and he would say, 'Ok, I'm going to come down and get you Donna...don't move where you are.' I said...I just want to stay... 'No, I'm going to come get you and we'll talk this out.'*

Donna had learned that her mother was an alcoholic many years earlier from drug and alcohol instruction in her high school health classes. The family had tried to get her mother to stop drinking and smoking, but without proper treatment intervention, she eventually ended up emaciated, "old before her time," suffering from medical complications of the disease and other health problems such as osteoporosis. Her mother had finally been placed in a home but pleaded with the family to allow her to come home. They stipulated that this would be allowed only on condition she not drink. This is how she came to be sober the last year of her life. Donna remembered the changes in her mother:

*She changed so much that year...just in the 12 months time. I was diagnosed during that year and she was there for me. She would call me every day. She would get out...she was in a wheelchair at that point, but she'd make this lady that would help her come by and pick her up in the wheelchair and she'd go to the shop and get me all these turbans for my head because I was going bald and she got little bangs...they are hideous things, but she was trying so hard to do something for me and this was more than she'd done for me my whole life. She never was very 'motherly' as such. Not a hugger; not a kisser; never said I love you. That type of stuff. I remember the first time I was in the hospital, I got this huge thing of beautiful yellow roses and it said 'Love Mom'...I just burst out crying. My god, she's never said that to me, so that was a wonderful, powerful healing year for us and that really made me feel good.*

Donna was very happy to have had the opportunity to learn what a wonderful person her mother was when she was sober. Because she knew that her mother had been struggling to stay alive long enough to see her get well, she did not have the heart to tell her mother that her cancer had returned.

*And she...actually Mom died that summer that it kept...she thought I was in remission and I never told her that it had come back. Because I didn't want her...I knew she was hanging on for me. She was ready to die the year before and she hung on because she knew I had the cancer and so I just wanted to let her go and she said are you alright? And I said yes, I'm fine now mom. I'm going to be alright. And so she died within a month of hearing that. It was a difficult time...it really was.*

Not only did she have to grieve the loss of her mother but she had to prepare to go to the hospital for a bone marrow transplant. Bone marrow transplants are performed to replace damaged marrow that occurs with certain forms of cancer such as lymphoma or results from different types of treatment such as radiation and particularly high-dose chemotherapy. Healthy bone marrow is necessary for fighting cancer because it fights infections, replenishes red blood cells and clots blood. There was initially much discussion about who could be a donor in her family. She recalled a conversation with others, laughing about finding good bone marrow from her own family, given a most difficult health history:

*So they said and I was laughing with them because alcoholism does run in the family. My mother and father both had trouble with drinking and my brothers do it and so I was just kidding and said that the only brother that I could get it from would be...I have two older brothers. The oldest one has HIV/Aids and he's out in California. So we knew that we couldn't use him and so I could use Chucky. But Chucky...I said...oh god can't use my brother, I'd wake up with a beer in one hand and a cigarette in the other because that is what he does...he just drinks beer and lights a cigarette all the time. So I said...I don't think...and he said...oh that doesn't go through on a bone marrow.*

The doctors determined that she did not have cancer in her marrow but needed the transplant due to damage from chemotherapy. She received an autologous transplant, which is when they collect bone marrow from the patient. This is how she ushered in her fortieth birthday – with a bone marrow transplant – as she recalls today, the lowest point in a three year ordeal of treatment:

*I had a very difficult time during that time. It was...you were locked away basically...the hospital was not done up real pretty, it was very dark colors in the room and you were in that room sealed off from everything, everybody...you had your own air system, food was cooked in a separate kitchen from the hospital, because it was so sterile because after they do the bone marrow, you are just lying there...you are like a shell. They've taken everything out of you and you just have to wait for the counts to come back, so you sort of lay there like a shell and it's really difficult.*

During this long stay in the hospital, she endured a rigorous battery of therapeutic procedures and more chemotherapy and radiation to clear out damaged bone marrow. Precautions that are taken to guard against infection during this process can leave a patient feeling cut off from normal human contact. The patient is placed in a private room with special air-filtering equipment to purify the air. Visitors are restricted and asked to wear protective clothing such as gloves and masks to prevent the spread of bacteria and virus. She recalled:

*Isolation. I was there. You are supposed to be there like months...I was there 2 months because my counts...after they do the bone marrow, they took out the bone marrow from me and they chemo it and all and they chemo your body as if that is not enough, then they chemo you again to get rid of everything in your body, so at that point you are just like this rag doll and then you go through a week...I had to go through total body radiation. Three times a day, it would be eight in the morning, noon and five in the afternoon and total body radiation and this was like you'd have to stand like in this chamber thing, hold onto two things and you are completely naked except for these casts things on your to protect your lungs or something and this thing would just have to slowly go down you and you just have to stand there for a half hour and you are so weak. By the end of the week, I didn't think I could do it and half the time I'd throw up in the middle of it and they'd have to start again. It was hell! The worst thing.*

What sustained her during these dark and trying days was a network of support provided by family, friends and her minister. Her husband was allowed to come in for very short periods of time and he would have to completely dress down and disinfect even then he couldn't touch her. Her minister also came to see her twice a week. Donna described her feelings about their visits saying, "I swear that if I didn't see them I don't know what I would have done. It was just...you felt like you were in jail."

A woman she met in the hospital suggested an idea to help keep her spirits up during this period of isolation. She was to have an answering machine to record her calls, because there would be days she would be too weak and tired to even pick up the phone. The woman emphasized the importance of keeping in touch with the outside world, urging Donna to tell her friends to call and not feel obligated to be cheery and upbeat. It was important for them to understand that it was enough for her to just hear their voices describing the ordinary everyday events of their day - to just tell her anything. She prepared her friends this way:

*I said, please call me. Let me know what the weather is like. Let me know if you are having a bad day. I don't care. It doesn't matter; I just got to be able to hear voices. Lovely I have quite a few that did that and that was great. My friend Mary would call and 'hey Donna...I've got the' ...she had boys the same age. She'd say, 'I've got the boys in the car, in the car seats, all the things hooked together and it's pouring down rain out here, the umbrella won't open...' she said 'oh my god it is just a nightmare,' so she is going on and on... Yeah. I'd just sit there and just smile. I remember that day. So it was good for me to have that and I encourage people that are going through it to do something like that.*

However, as the weeks passed Donna's spirits began to fall. She remembered having eleven lines going in and out of her body for various functions including food and chemotherapy. She had to be fed intravenously because all the chemotherapy and radiation had resulted in sores down her esophagus and through her stomach. Getting down a little applesauce would be a good day for her. Her white blood cell counts, so important in determining the general functioning of the immune system, were poor. She could feel herself growing weaker, her fever was still 105 and they had placed her on a bed of ice. Thoughts of death began to come during this time and yet no one had broached the topic with her. When they called her husband to return from his business trip in another city, she knew what they were thinking, although she did not learn until much later that they did not expect her to make it through the weekend. Finally her minister came to speak with her and dared to ask the unspoken question:

*Then you wait for your counts to come back, but mine weren't coming back and so I was on this ice bed and all and I remember my minister coming in and I was hallucinating because of the morphine they put you on for the pain, but my minister came in and she's a very sweet person and she said, 'Donna I'm going to ask you something, you don't have*

*to tell me if you don't want to, if you don't want to talk about it, that's fine, but I sort of need to ask you as your pastor, do you want to plan your funeral?' And I started crying. She said, 'I didn't mean to upset you' and I said no, no, no it's a relief. I wanted to tell you that, but I'm afraid people would think I gave up and I'm not giving up, but I'm being realistic...I'm not coming back. Look at me. I said I'm getting worse every day and I know that and so...but my husband's like... 'She's fine.' ...telling everybody I'm fine and stuff...he just had this veil...he just didn't see it all and so I was afraid I'd look negative if I actually said I was scared and actually said I wanted to plan. So we went over songs I liked and Psalms I liked.*

Donna's fear of looking negative if she talked about her real feelings is a characteristic dynamic of Adult Children of Alcoholics (ACOA). Also, her husband's telling people that she is "fine" fits the family pattern. Discussion of real feelings in these families threatens the tenuous family structure built around trying to manage and control the alcoholic. The family's denial of feelings mirrors the alcoholic's denial of a drinking problem. It is not surprising that with all she was going through and knowing that she was close to death, it was an enormous relief to have someone finally talk to her about these feelings.

Talking about her death, which was beginning to seem inevitable, provided the first real comfort she had experienced during her bone marrow ordeal. No doctors had ever mentioned this to her, not even the psychiatrist provided by the hospital. She recalled feeling particularly uncomfortable talking to the psychiatrist, joking that to bring up the topic with him would probably result in her being put on a deathwatch. Many patients find that they are unable to discuss the possibility of their death with hospital personnel. As Elizabeth Kubler-Ross pointed out in her research on dying patients, hospitals are geared to keep people alive and death is regarded as failure on their part.

The talk with her minister started her on a path to what she would later describe as a turning point in her cancer experience. She explained,

*My minister just took all the notes down and she said that's covered and so I felt a great sense of relief when she left and it also opened me up that night to where I prayed and I really got into prayer a lot during...I've always thought of myself as somewhat spiritual, but nothing until I was diagnosed with the cancer did it really sink in a lot more and I read a lot. What I did was read a lot of books and they in turn would lead me to other*

*books and then I started opening up more of a spiritual life and I had music...wonderful music by me and I would read my bible and I would...she would tape the sermons for me and our whole church service, she would tape it and I'd listen to them and follow along in there like I was there sitting. I'd pretend like I was in church. You have to do whatever you can when you are like that. And, so I did all that.*

*So that night I cried and I sat in the middle of the bed and I said, Lord I'm ready to go now. If you want me to go, then this is it, I'm ready because I'm tired of fighting. I was still very confused over this holy trinity...the three people up there...so I said, look, I want you God, Jesus and the Host...all three of you guys down here right now and it was weird because I said that and all of a sudden there was a heaviness on my bed...this is weird and I don't always tell everybody this because some people think...I know I was on morphine, but this was not one of my hallucinations, this was a heaviness on the bed and I felt a warmth all around me and right away I said, you're here and I just hugged the air.*

*I'm sure if anyone was watching would think...I was just hugging the air and said...oh my god you are here and I said thank you and I laid down and I went into an extremely peaceful sleep and during that sleep my fever broke, my counts went up the next morning, the fever was gone...it broke. This was something they had wrestled with for four to five days...105 on an ice bed and it was breaking and it had gone down and down and they were like...they were like...I don't know what happened last night and I was like I can tell you what happened...you won't believe me.*

This experience was Donna's death acceptance. She described later that this was the lowest point in her whole experience, even though there was still at this point one more ordeal to endure. Her minister facilitated this process that started her grieving, letting go of the things of this world which opened her up to a wonderful spiritual experience. It's important to note here that her spiritual experience comes after having made death preparations. It was at this point that she began intense praying which can produce an altered state from which such a spiritual experience might spring.

The next day when the doctor remarked how her blood counts had improved, she told him about her experience. She described how her doctor and some others reacted:

*I told the doctor. I said, well you know, I was praying last night and I really think that...I told him what I said and ...he goes, 'You know what? Doesn't surprise me at all. He said whatever it takes. I'm glad that you are starting to show signs of recovery here.' He didn't mock it or anything. He said he wasn't surprised, so I guess he's heard something like that before. I don't know.*

*I didn't tell my husband because he wouldn't have...he would have just chalked it off to wacky or something. But I told my minister and she believed it right away. And she has had me share that with other people in the church.*

How doctors talk about spirituality is still left up to the preferences of the individual doctor. Mostly there is little training around these issues. Donna was fortunate to have a doctor that did not deliberately or unintentionally negate the importance of this experience for her. By not acting surprised he normalized the experience for her by allowing her to speculate that perhaps he had seen this in others. Her reluctance to mention this issue to her husband again suggests the difficulties with communication in their relationship. However, her minister also helped Donna to appreciate the importance of this amazing spiritual experience she had at the hospital.

Even though she had dramatically improved, the doctors did not want to release her. But Donna was back in a fighting mode, with a new sense of taking charge of her recovery. Once again she had a strong intuition that she would not get well in the hospital. Because she hated both the environment and the food, she left the hospital in January of 1993. She reflected on how doctors including the psychiatrist did not want her to leave:

*Then I thought by January that I just needed to get out...I was very depressed. Of course by then the shrink said...oh she's depressed...duh...you know...I said I'm only depressed because I'm in here. I have to get around people. I wasn't allowed to see anybody. This is ridiculous. So they finally let me out and from that...I made much better progress once I got out of the hospital. Much better on my own.*

Her insistence paid off and they released her, but only if certain conditions were honored: The house had to be scrubbed down, she had to wear a mask, carry machines around that she was attached to and, perhaps the hardest part, she could not let her two young sons hug her. She remembered how they would sit across the room from her and blow kisses at her.

After completing her bone marrow treatment, she returned to the clinic several times a week for the next two months. Unfortunately for Donna, this sense of feeling better and improving didn't last long; there was still more bad news ahead. In March she returned to the clinic with a bad cold, reporting lumps in her neck.

*I remember coming back this time and I had a cold and there were lumps in my neck and I told them so he felt them and all and he just sat back and said... 'it's back' and I said, No, it can't be. I had a bone marrow transplant...it can't be back. He said, 'Its back'. I said...no and I just burst out crying. I can't stand this; I'm trying so hard, why is this happening. Well, I said, what are we going to do? He said, 'Well, you go back to your oncologist you had before you came here and he'll make you comfortable for the time you have left.' My husband said, 'What does that mean? I want to know what you mean for the time she has left...what time are you talking about?' And he said, 'I would say a year normally, but not with her because she has just gone through this bone marrow and we can't do chemo because there had been no counts, so he said, I would say 6 months.'*

Donna had now been going through treatment for two years, exhausting all forms of available treatment to the point that her body was worn out. During her bone marrow transplant, she faced the possibility of death. However, this time was different. This was the first time she had received a terminal diagnosis. In this she heard a message of no hope which she struggled to come to terms with:

*It was bad and so I went back to Dr. \_\_\_\_\_, my original oncologist and I walked into his office and just sat down and cried. Eddie was with me and I said, They told me there is no hope. You've always told me there is hope and they say there is no hope. He said, 'You know what, I don't believe that. You're not dying yet'. He was just exceptional and he said, 'I'm going to tell you something, this is weird. God works in funny ways, but I just went to a luncheon two weeks ago and sat next to this doctor from Texas who is doing a clinical trial. He is doing it on non-Hodgkin's lymphoma patients that have not responded to regular therapy and he said, that's not just chemo, that's chemo, radiation and a bone marrow transplant and you've done all.' So he said, 'I think you might be a candidate, so you stay right there and I'm going to call him on the phone right now' and he called him right from his desk.*

This was a very important meeting for Donna. Not only did this doctor restore her sense of hope, but he talked to her in a way that reinforced her belief system when he spoke of God working in mysterious ways. By picking up the phone and immediately calling to inquire about this treatment, he communicated a positive, “can do” attitude and demonstrated that as a doctor he was going to fight for his patient.

In May of 1993 Donna began this experimental clinical trial program, her last opportunity for treatment that might save her life. For six months she received an experimental regimen using a new drug, Interleukin II, administered intravenously. She would fly to San Antonio and receive therapy for a week, return home for three weeks and then fly back again. She had to use a wheel chair to get around because the drugs she had been given caused her hips to lock up making it difficult for her to walk, but perhaps the hardest part was knowing that this represented her last chance for survival. When asked what this second brush with death did to her faith, she answered:

*It's interesting. It never wavered my faith and that's what Dreama {her minister} was always surprised at is how I kept so faithful. I never yelled at God. I don't ever remember being mad at him. I would cry out to him to help me, but I never got mad at him. I never thought of it as his fault or anything and I don't know why or where that came from or why I didn't...I think it would be natural to get mad, but I didn't. Of course I had my bible down there...I did lots of different spiritual work when I was down there by myself.*

To help her through these difficult periods, she took devotions down and read the bible and listened to calming music. Due to receiving chemotherapy so many times, she suffered from “chemo brain,” a term cancer patients use to describe the fuzzy, unfocused state of the brain that frequently follows chemotherapy. She described how she coped with this state:

*...I had no brain cells at that point. We always laugh about chemo...chemo brain and I definitely had that and all I could do was look at pretty magazines. I could hardly read. I could read the bible, but passages and stuff, but don't give me a novel...I couldn't do that. I definitely just liked to look at pictures and little articles...I could do devotions...little snippets...that kind of thing...I was reading that type of stuff. Some of my friends were wonderful. They'd send me videos...like I Love Lucy videos...laughter...they said laughter is always good and so I'd try to keep it as light as I could. I took care of myself. As much as I didn't want to...when you are a mom, you want to take care of your*

*kids...but I realized I had to be selfish finally and worry about myself and I didn't...but that was just a necessity and out of all the books I read said that...you have to think about yourself right now.*

During this time Donna sometimes received support from surprising sources, like so many helping hands reaching out to assist her. Because she was participating in a clinical trial which insurance programs regard as experimental, none of the expenses would be covered. However, her doctors from her HMO arranged an agreement with the doctor in San Antonio to have him offer his services free of charge, avoiding using the hospital there which would have demanded they follow hospital procedures for reimbursement and insurance. Instead, the procedures were performed at the doctor's office. The drug company, eager to have patients test their drugs, provided the drugs at no cost and the American Cancer Society paid her motel bill. Because her mother had died the year before and left her an inheritance, there was money to pay her air fare back and forth.

This treatment, like all the others, would also not go smoothly. Once again Donna would have to fight with her doctors for what she wanted based on her own intuition and internal truth. Halfway through the study she turned yellow, indicating that the liver had shut down from all the chemicals going through her body.

*I felt like... I started to lose hope when I turned yellow or whatever color I happened to be. Because they said they were going to stop the study and I remember a panicked feeling saying I don't want to stop it... It's working... I know its working. They were like... 'I know its working too Donna, but it's gotten too caustic for you and it's hurt your liver. We've got to give you some time out here and they said now they want to stop it because the drug company doesn't want any liability, but I'm going to talk to them because I'm going to tell them as a doctor and I've seen a lot of these people...it's working on you... I know it is, but we need to give you a break.'*

So instead of coming back in 3 weeks, she skipped a treatment and came back in 6 weeks. After skipping one treatment at her doctor's recommendation, she never turned yellow again and never again experienced the bad side effects. At the completion of this treatment, she actually felt good again. She recalled, "After that I was renting cars after treatment and I'd go around San Antonio and do sightseeing...I had a blast and enjoyed life. I was just enjoying it." She was able to

continue to successfully complete her participation in the study, but subsequently learned that she was in a unique category:

*I was in the last leg of the study and there were 6 or 8 of us around getting this treatment...a couple died during that year and the others have died several years afterwards. I have found out since then that I'm the only survivor out of that group down there that this stuff worked on.*

She theorizes that because she suffered more side effects than others in the study, frequently returning to her room shaking and feverish, that somehow the medication had more effect on her. In addition, she offered another thought:

*I'm trying to think of logical reason why I'm the only one it worked on and I'm thinking that one I had just come out of bone marrow. They [the other study subjects] were out like 5 years from the bone marrow, so they probably already had bad cells working. I probably had very few bad cells...I didn't have any cells...I didn't have hardly any good cells, so I was so new from it that it must have reacted more on me or something.*

In October of 1993 Donna was deemed to be in remission once again. When asked how they determined this she explained:

*They judged it by the fact that there was no sign of the cancer anywhere. I was feeling good. They were doing blood counts...everything was going good. I still had a low blood count, but I always will because of what I went through, but it was all right...it was okay and I remember they had a big cake for me.*

Donna had been told she was in remission several times before, so it might have been perfectly reasonable for her to expect that remission really didn't mean anything. However, she seemed to have a feeling everything would be all right. "That was...I think I just gradually slipped back into life. But it would have been when I left Texas in October I felt like I had accomplished something. That this was going to work."

When she returned home and visited her oncologist, he informed her that her first benchmark would be to make it to the two year mark. If she then made it to the five year mark, she could be considered cured.

For the next year and a half her life began to return to normal. Even though she was now back home, feeling good and ready to get back to the good life of being a wife and mother,

something was not right. She noticed that her husband seemed to be acting distant. When queried if this is a retrospective observation she replied,

*I was noticing it at the time and I was panicking, but I didn't know what to do about it? I'd say, why? 'I'm working a lot.' Why do you have to work? Can't you be home with us? We'd love for you to be home. Or I'd have dinner and then he would never show...and so the boys and I would eat and then he would call. I could tell he was at a restaurant or bar or something. He would say, 'Well, I've had to work late and we're just going out afterwards for a drink.' It would be 10:00 or so or if he did come home early, he went downstairs and drank and watched TV. Just totally separated himself - didn't want a bunch of noise upstairs. I'd get the kids all quiet. It was very stressful. I waited all day for him because I wasn't working...I really wanted to talk to him.*

Her comments reveal not only his distancing in their relationship, but drinking as a prominent feature in his life. Interestingly, Donna does not comment on this, leaving open the question of whether or not she realized or perceived his drinking as a problem.

Donna was now a year and a half past her last treatment when the storm clouds that had been gathering in her marriage finally burst. She remembered,

*So I was really trying to make it to that 2 year mark and probably about a year and a half I had only about 6 months to go before 2 years was when my husband left and he just walked out one day...he just couldn't take it. I was like...we just been through all this...this is nothing now. So that was really devastating and the doctors were a little bit worried that I might do something...the stress of it might put me back into... And there are a lot of reasons...I don't know, but it took me by surprise and it really upset me. And I thought to myself...if Eddie left me during treatment I would not be here...I would have given up. I kept fighting not only for the children...it wasn't just for the children, it was "for the marriage"...the whole thing. I thought I had a dream world because I thought he was the perfect person and then I thought here I have this beautiful life...I've got to fight for this. I remember just being so grateful for my life and fighting for that reason...one of the reasons I was fighting, but and after all that he left.*

Donna believes that another woman came into her husband's life when she was sick and provided solace to her husband during this time. Her husband has since gotten married to this woman and lives in the area. She says it would have been easier if he had moved somewhere

else, but he didn't and they have to communicate for the kids' sake. It seems ironic that the very thing that Donna wanted most in life, a good marriage and family, the thing that kept her going and motivated through the darkest days of her treatment, dissolved in the end. When Donna looks back now and reviews her marriage there appears to be some awareness that, perhaps, the marriage wasn't really so good after all. Now she wishes she had kept her job, which she really enjoyed, because ultimately that would have helped her in her marriage:

*I enjoyed my job and in some ways I wish I had kept it only because...but I wouldn't have been able to with the cancer because I had gotten so sick, but in some ways I sort of wish I was working because what happened is when I quit, I sort of lost my identity. I didn't realize that with Eddie. Eddie started to control and I lost my identity. Especially with being sick like that...I relied on him so much and I think I totally became like a little puppet or whatever I was just afraid of anything or getting him upset or anything. Before when I worked and all that I was independent and I blew it off. You are not going to talk to me like that, but I just allowed it to happen. It got really bad, so it was really a blessing that he left, but I didn't see it that way at the time. Yeah, because I would not have been strong enough to leave, I would have never left. So I would have been under that oppression as such...which wouldn't have been good.*

This remark is also very typical of the ACOA pattern. ACOAs are very loyal. They tend to not leave relationships because of low self-esteem, shame and the tendency to blame themselves for everything. They frequently take physical and/or verbal abuse believing that they can change the person. The “oppression” she refers to seems to suggest an element of verbal abuse. Donna demonstrates some good awareness when she states that she now knows that she never would have left this relationship.

About the time her husband left Donna still wasn't working because her doctors had ordered her not to work due to the weakened condition of her immune system. The loss of her marriage and ultimately her dream of a “perfect” home life, the fact that she was not working and the physical complications as a result of her chemotherapy and radiation treatment, contributed to a loss of confidence and identity. But even as one door was closing in Donna's life, another started to open. About this time, shortly after her divorce, Donna's minister suggested she become a Steven Minister, a lay person specially trained to minister to troubled and suffering church members. She described what this experience entailed:

*So the Steven ministers and they are through all denominations...all Christian denominations. They are Catholic, Baptist, Lutheran, Presbyterian, Methodist and you are trained as a Steven minister and you go through a 9 month training every week for 2 or 3 hours. It's pretty intense and you learn care giving and it's just care giving. It's caring for people. Listening.*

The opportunity to help others brought about a growing awareness that she now had something to give others. Having survived her own ordeal gave her a special credibility in working with others. Not only did she have a greater compassion for the problems of others, she had her own special story to share. Eventually she got a new job doing cancer related work for an association. She indicates that she is happier and more confident about herself than ever before. Her lawyer, who remembered what she was like at the time of her divorce, shared with her recently an impression of how she has changed:

*My lawyer says that she just can't get over. What I was like when I first walked into her office. Of course I'm working now and that helps a lot too. But I couldn't work at first and when he left, I still couldn't work...they didn't want me to work. So I went to an attorney and she said...you just sat in the corner and you were all huddled up and you were just this mess...you looked awful. When he left and he...just when I went and saw her and she said since then, I've grown so much. The cancer made me stronger.*

Donna reflected on her process of growth and development of strength coming from such a dysfunctional family. Since she never drank or smoked, Donna was the anomaly. She neither smoked nor drank. She described:

*My parents had cancer, but theirs was lifestyle cancer. They smoked, they drank...and they had lung cancer and throat cancer and mouth cancer...things that you would associate, so I would never have thought that, plus I didn't smoke or drink...I was the healthy one in the whole family...I thought. So it took me by surprise.*

Even though she had tried to avoid their mistakes, she still got cancer. The legacy from her family was not only addiction and related cancers, but also a home life filled with crises and turmoil, a skewed relationship to normality.

But it was this boiling cauldron of family strife that gave rise to the dream that sustained her through the bleakest days of her cancer treatment which was to one day have a “perfect” marriage and family life. This dream was finally burst when her husband left her for another

woman one year and a half after her final treatment. However, perhaps she got something unexpected from her turbulent family origin -- a resilience and durability that would serve her well through a grueling cancer treatment regime that many may have never survived. "I've always had a lot of crisis...ever since I can remember as a little child and so I just looked at it as another crisis. I guess that taught me how to roll with the punches."

Looking back on her situation, it seemed to Donna that many things had just fallen into place, as if God were preparing her for events. She felt that she switched churches just at the right time, just before her cancer. She also recalled:

*But I can't help but think that the Lord was asking...preparing me for this adventure that I was going to go on...journey I was going on with this cancer because putting me in touch in these girls that really explained a lot of the basics to me; had me going to these different churches and stuff, but at least I got an idea and I realized that really wasn't mine...but I realized that this voice and I've always had this inside of me - was my holy spirit and I said I didn't know that. Always had the little voice, but the little voice is my spirit. That's what it really... People struggle with it in our church and we have classes. We had little small group classes and stuff we do. And I'm probably the only one in there that can honestly say I feel like I have that. None of them feel they do.*

She indicates here that the experience of cancer has greatly enhanced the development of a spirituality that has always been a part of her. But what is different now is that she has the confidence to express this. This is now a part of who she is, that she shares by giving back to others through her work as a lay minister.

Recently Donna was assigned a young woman who just showed up at the church crying after being diagnosed with cancer. Donna talked to the woman who was most grateful for her help. As Donna recalled her response, she mused about a possible meaning to her cancer ordeal:

*You have made a big difference and so, I wrote that down. I thought this is why you do it. It just makes you feel good that you maybe helped someone. Yeah. I was just so thrilled when she said this made such a difference. I can face this now. I can see you and I know I've got hope and I've had a lot of people tell me that, so that makes me feel good. That makes me feel real good. So, I said, maybe this is why I went through it. I was trying to figure out the reason I was going through all this.*

## **Summary**

Donna came from an extremely dysfunctional family, having two alcoholic parents and two alcoholic brothers. After a turbulent childhood and an equally disastrous first marriage to an alcoholic, Donna was embarking on the best period of her life. Her husband was doing very well in his work so he suggested she stay home with their two young children. This had always been her dream to be a stay-at-home mom. However, this was not to be. Originally diagnosed with a Stage II cancer, she went on to experience incredible misdiagnoses, contradictory opinions, grueling treatment regimes and brief remissions over a period of a couple of years. Finally, a last ditch effort had to be made to save her life through the experimental use of a new drug. She survived this treatment even though no one else who received the same drug did.

Through all of this she worked at developing her spirituality and read everything she could to learn how to best deal with her experience. She came to an acceptance of her death through discussion with the minister when she was in the hospital and believed that death was imminent. At that time she had an amazing spiritual experience that became a turning point for her.

She returned home after all of her treatment to learn that her husband had met another woman and soon left her. The spiritual and psychological strength she gained from her cancer experience helped her survive this as well. Like the other two cases in this study, she has found a deeper meaning to life and connection to the universe through spirituality. Even though she was pronounced “cured” she also lives her life one day at a time. While, like all of us, she prefers to stay among the living, she does not fear death like before. Her profound gratitude for life has resulted in a need to give back to others, which she does by working as a lay minister for her church, often helping others cope with their diagnoses of cancer.

## **Barbara’s Narrative**

Barbara was 45 when she was diagnosed with multiple myeloma in March of 1992. This diagnosis did not stand out as a singular trauma in a relatively normal life, but rather became just another problem, following so many others through the years. Her marriage to Mac had been on the rocks since 1984 when he moved into the basement of their house. She dealt with his depression and suicide threats for years before they divorced and he moved out in 1990. She had also experienced the loss of her father in 1987 and her mother in 1989. Her own health issues

had been looming since 1987 when she was told that she had elevated protein levels in her blood, a prelude to the subsequent diagnosis of multiple myeloma.

Perhaps the most traumatic of all the events prior to and including Barbara's diagnosis was the fact that Rob, the love-of-her-life, walked out on her. Rob was the man she almost married and to this day occupies a permanent room in her mind. He had an unfailing ability to always come crashing back into her life, to once again dangle before her the promise of a fulfilled relationship and to ultimately snatch it away before she could grab it. She explained their early relationship and the night he called her just before his wedding.

*He is the man that I almost married. We were together most of my college days. We almost...we were getting married, we weren't getting married, we were getting married. This went on for a long time until I finally said, shit or get off the pot. He said I'm not ready yet and I said, well, I don't know how much longer I can wait. I was...this was like '68-69 and we'd been farting around since '64. It was like let's just...*

*So after that ended eight or nine months later, I met Mac and we began courting and Rob called the night before he got married and we both knew that he was making a huge mistake. You could tell. Everything we said to each other that night. I said, why are you calling me? You are getting married tomorrow. He said, 'well I guess that's why I'm calling you.' It was just...*

Rob calling her the night before his wedding would not be the only occasion that he would demonstrate his unfailing skill for creating tortuous emotional pain. There would be more to follow. However, at this time he and his new wife moved across the country to Colorado. Barbara got married just eight or nine months later. Perhaps in fatal resignation to the fact that she would not find another Rob, she married Mac, a quiet, retiring, accountant with whom she had two children, John and Katie. Her marriage was never good. His appealing, shy, retiring ways turned out to be indicative of a deeper problem of depression although she would not learn that until many years later. At the time it just seemed as if he was always angry and did not care. Eventually she realized he needed help. She recalled:

*I had begged Mac to get counseling. Mac was severely depressed and simply was not part of our family. I'm raising the 2 kids basically on my own. Once in a while he would drive them to something. Once in a while we'd all go to a movie or we'd go out to dinner, but he wasn't very pleasant to any of us and he slept in the downstairs. I live in a 4 level*

*split and one of the levels is a bedroom and full bath and that was his lair and he just retreated there and after dinner went down there and was not a part of our life. We had maybe sex like twice a year.*

It was after many years of this unhappy relationship with her husband that Rob came back into town when his wife left him in 1986. Although more than fifteen years had passed since she saw him last, he had never left her mind:

*At this point- here comes Robert coming into town, the man I had this huge passion for. It had never really died. I remember waking up at night, dreaming of him and screaming. Will you find me? I don't know where you are. You have to find me, and I knew that we weren't through with each other. There was something in my gut that said that we are not through. So sure enough, he comes waltzing back into my life. Here he is on the phone. I said, nah it's not Rob, he said 'yes, it is.' It can't be. And I was in the middle of playing poker with Mac and the kids and I said, excuse me, I have to take this call. I'm in our family room...it was so weird. The tears are coming down as I'm listening to him and I said, come over for brunch on Sunday and Mac says, 'I'm going fishing, have a nice brunch.' But anyhow, Mac did eventually come back while Rob was still there and the three of us sat around talking about life insurance policies and I'm going...this isn't happening. This is not Rob and my husband together talking about government benefits, because they both worked for the federal government. This is not how this is supposed to play out.*

She remembered following Rob out to the car and hoping her husband would not follow her. He did not and they both talked about how they wished they had met five years earlier. He told her how his wife had left him and taken the kids back to this area and how he was hoping to convince the kids to go back and live with him in Colorado. Barbara sent him a Christmas card that year in 1986. The day he got the card he called her and they talked and both knew they had a deep connection.

*He was hoping to convince the kids to go back and live with him in Colorado because his ex-wife was an alcoholic...was a tramp, was really doing ugly things and not taking care of the kids. But what happened is that he ended up having to come back here because the kids didn't want to live in Colorado and he knew he had to get them away from their mother, so he moved back here and he got back in late '87, early '88. We had sent letters*

*back and forth during that time. Not big time stuff, but little stuff. But he wrote at one point, he said, 'oh it's so beautiful up here in the mountains, gee I wish you were here to see it,' and then he said, 'whoops, that wouldn't be a good idea, we'd probably get into trouble.' Yeah the flames stilled burned.*

While Rob was out in Colorado in 1987 Barbara had been diagnosed with elevated protein levels, a condition that is a possible precursor to multiple myeloma, the cancer she was finally diagnosed with in 1992. Multiple myeloma is a rare hematological cancer, meaning that it develops in the blood. This cancer accounts for 1% of all cancers diagnosed in the U.S. It eventually weakens the immune system because it is a cancer of the plasma cell, an important part of the immune system producing antibodies that fight infection and disease. Later on, as the disease progresses, bones become weakened due to damage of the bone marrow, resulting in bone pain and possible fractures.

This did not seem to make much of an impression on her at the time: He [the doctor] told me in '87 something, I didn't know what he was saying - there was an elevated protein level and that was what he said about it. Mostly this was a condition with enormous potential to develop into cancer and as such required her to have her blood checked every few months. Timing is critically important for treatment of multiple myeloma: It is postponed to the last possible minute to avoid unnecessary side effects and delay resistance to chemotherapy. As is so characteristic of Barbara, if it was not a major problem now, then do not worry about it. So she did not really dwell on it and moved ahead with her life.

When Rob returned again in 1988, Barbara had already made it clear to her husband that the marriage was basically dead. She had described conditions for them to work it out, primarily that they both go to counseling, but to no avail. Later, she told Jim she was having lunch with Rob and he told her, 'Have a good lunch.'

*We had a three hour lunch, he told me more of the details about what had happened and then he looks at me and I'll never forget this. This was the one water shed moment in my life. He looks at me and he had some tears in his eyes and he looks at me and he says, asks me, 'are you happy?' Now I know I couldn't lie to him because he always knew...but I knew if I told him the truth, we were headed into trouble. But I told him the truth. I said I don't have a marriage. I have a man living in my house, but I don't have a marriage.*

*And so we kind of...we knew what we shouldn't do and we didn't for a while, but then about six months later, we just...there was nothing. We just did.*

Rob came back into her life in 1988, just prior to her mother being diagnosed with cancer. Both Barbara's mother and father had been heavy smokers, a fact that caused Barbara to give up smoking years before. At this time her mother depended on Barbara for emotional support, as she was still grieving the death of her husband who had died two years before of lung cancer. Barbara remembered:

*I could not have gotten through what happened to her without Rob. He's the one. Not my husband. He knew my parents. Oh yeah, he adored my parents. He really wanted to see my mom, but she had already deteriorated to a point where she didn't want...she knew I was with him and she was very happy for me and actually I told her how bad my marriage was - my mother said, 'Thank God. Your father and I couldn't understand how you could live with that man [Mac].' We hated it when we were all together when we went out to dinner...we picked the wrong restaurant. Mac would just pout and sulk and he was very controlling. So my mother was so glad to hear that...she was so glad to hear.*

Barbara had been working part-time before her mother died, but decided now to get a full time job. Her background had been in teaching and working with mental health programs. She quickly found a full-time job as program coordinator for a non-profit program that brought together seniors and elementary school children to interact in meaningful ways. For many years she had only done occasional part-time work, but now she had a full-time job and an inheritance from her mother and father that enabled her to take an action she had been contemplating for a long time. Finally she would divorce Mac. For the first time she was free to pursue a more meaningful relationship with Rob.

*So I had a job and so the day before I was to start my new job, I informed Mac that the marriage is over and he should just get his ass out of there...that I'd had it. I was done. The marriage was more than done. I had a job, I had my parent's inheritance that would help me very nicely, didn't need him, didn't need his money except for child support and he was to get out. So he finally moved out in February of '90, because it took him a little while to get it together. Poor man. One night his therapist called me. This is way off subject, but one night after he has more or less fallen apart, his therapist calls me and he says, you know...this was after I had said get out. 'You know, Mac is going through a*

*really hard time now. What he really needs from you is some hugs.’ I said to the psychiatrist, what about my needs? I don't care about his anymore. Just fuck off! And I hung up on him. So two days later I saw his therapist who wasn't the psychiatrist, he said, ‘I understand you weren't too please[d] with doctor so and so’ and I said no. And she told Mac you have to quit threatening your wife because he was saying if I leave, I'm going to kill myself. He was threatening suicide. He was just off the wall. And finally, he got it together and moved out in '90.*

Barbara continued to see Rob through most of 1991. They lived in separate houses and saw each other occasionally at this time, making an effort to keep the exact nature of their relationship from their children. Because he was talented at building and renovating houses, Rob would spend a lot of time at her house working on various projects which allowed them to spend more time together. It was about this time that her doctor called with more distressing news about her cancer. Once again, her protein levels, which they had been closely monitoring, were elevated. When this condition becomes serious the patient is referred to a hematologist/oncologist who specializes in this particular cancer of the blood.

*And 4 years later in 1991 when I was doing my blood work, he called one Sunday night and he said ‘now I don't want you to be worried, you don't have leukemia and you don't have bone cancer, but this elevated protein level is beginning to concern me and I want you to see a hematologist.’ He didn't use the word cancer. I didn't know what the hell he was talking about. I was pretty frantic at that point and became even more frantic when I got there and found it was hematology/oncology.*

*But on the day I went for my appointment I had been called at work and informed that my ex-husband had been rushed to the hospital. We didn't know if he had a heart attack or not. I was the only family he had. His family is in Texas and he didn't have very many friends and so I went ahead with my doctor appointment and I walked into this guy and I said, look I am told my ex-husband now is in the hospital with what might be a heart attack, I have two teenagers, I'm single parenting, so don't bullshit me and that is how I sat down to the oncologist. And he preceded to bullshit me for several years and...he said, ‘well, we can't give you a definitive diagnosis at this point.’ He said you might have something called ‘Smolder Multi Melanoma’ and he said, ‘ don't look it up anywhere because you'll be very worried by what you read and all this stuff is old.’ I*

*said, are you talking about cancer? And he said, 'well, myeloma is cancer, but I can't tell you that you have it. I can tell you that you might be developing it.' So, I don't know. There was nobody with me going to this appointment. I was alone and I was pretty hysterical.*

She learned that her ex-husband, Mac, did not really have a heart attack, but she still had to cope with her own bad news that day. She went home and waited for Rob. At that time he had been working on her kitchen, so when he came that day she remembered their conversation.

*I forget whether my kids were at home that night, but my friend Rob was coming over. He had done a lot of home improvements on my house. He had the avocation to build houses and putter around and build things and so we were in the process of designing a kitchen and I'm three sheets to the wind when he shows up. And I told him what was going on and he said, well what do you want to do? I said I want to redecorate my kitchen.*

This reaction, denial, as she would often explain, became her characteristic way of dealing with her cancer. Hers was not a blanket denial in which she denied having the disease, but rather it reflected an element of choice. She would always be vigilant about her medical care because she had a major goal to see her two children through college. However, she avoided the deeply personal issues involved in considering the real possibility of her death.

Smoldering multiple myeloma is an early stage of the disease not requiring treatment but, like her elevated protein level, it required frequent monitoring so that eventual treatment could be undertaken at the best time. But what happened in the fall of 1991 with Rob superceded the impact of her cancer. They had an argument that forever changed their relationship.

*So it was one morning he had come over to do some work and that's when we had this argument...I thought it was a minor thing and he turned it into a big thing and he stormed out of the house, shaking his fist at me and drove off. And got home and called me and said I can't do this...blah, blah, blah...you're suffocating me...I told you I couldn't do it...so I'm walking away and he left.*

After the breakup with Rob she continued to have her blood checked until she received the diagnosis of Smoldering Multiple Myeloma in March, 1992. Doctors told her the "smoldering" part was like a diagnosis of HIV+. At some point it would get very bad, but at the present time it was untreatable. She learned that the expected life prognosis at that time was two to three years.

*In '91 I found a few things that said two to three years. But it was really scary and this doctor that I had was really not very good. We went to one visit and my ex-husband who did not have a heart attack actually came with me and the doctor was hiding stuff as he was telling me what was going on and I walked over and I said, you don't need to hide it, I've already read this article. I know that it says two to three years. Again, don't bullshit me! And so we went on until finally that March '92 he finally said yes definitely you have...so it was interesting because there wasn't a moment when I was told you had cancer. It was kind of spread out over six months and did I, what did I have, what was this...it was all very confusing to me.*

So, now she was left to face her cancer without the company of the most important person in her life: I kept waiting for him to call back because he always had and in March when I was diagnosed and he hadn't come back, that is when I totally fell apart. She continued to see the therapist who had been helping her cope with the loss of her mother and her own depression. Barbara expected at this time that Rob would soon return like he always did before. But several months passed and there was still no word from Rob. She recalled this time:

*Very tough time. I was in therapy. I'd been in therapy since after my mom died and I started taking antidepressants and stuff then and I'd been on sleeping medication. The kids didn't know, I just went every three months for blood work. There was no treatment. So I'm working full time, I'm balancing kids, I'm active in the PTA, Mac's finally out...Mac sees the kids on the weekend and I'm just coping and it really was just coping. I mean it was just part of what was in my mind, but a very little part. Really I was consumed with living. I've always been and that's part of what I continue to do. I'm consumed with living. So I don't have a whole lot of time to focus on dying. Just consumed with living.*

Barbara still was not receiving any treatment for her cancer. Her condition continued to be monitored by regular visits to her oncologist every three months. Late in 1993 her protein levels had begun to climb and still her oncologist was not recommending any treatment. She decided to pursue a consultation elsewhere and found to her shock that this doctor recommended a bone marrow transplant. Torn between these extreme recommendations, she decided to pursue a new oncologist.

*So finally I get the oncologist I have today, who is wonderful. He is just terrific. And I saw him maybe three weeks after the \*\*\*\*\* consult and he goes over everything and he says, 'well, we definitely need to start treatment, but I wouldn't jump in right away with a transplant, let's see how you do on regular chemotherapy' and this was the winter I started...this was February '94 and again we are talking about all the statistics if you were to look at statistics back in that point of time, two to three years. That's what they are giving me.*

Through the years Barbara had managed to avoid telling her children that she had cancer. In May of 1994, her doctor informed her that she was doing so well with the chemotherapy that it was time to consider a bone marrow transplant while she was still young and strong enough for the procedure. For the first time she had to tell her children the reality of her situation. She recalled part of this discussion.

*I simply said to them. Look, your lives really suck. I'm going to be really honest with you. You both have had a terrible few years. You've lost both of your grandparents. They adored my parents. I said, you've got a choice. You've lost your grandparents, your parents are divorced and now your mom has cancer. You guys have a choice. You can do one of two things. You can go screw up because life is terrible, but if you do that, don't ever blame it on me. It's not my fault if you make that decision, I don't ever want to hear you say, it's because my mother this or my mother that. I don't want to hear it. It's your choice to make. If you decide to go that way because life sucks, or you can take this experience and let it help you be more compassionate for other people and you can use it to learn. It's your choice. And fortunately they both chose to become even more compassionate and incredible people. My children are incredible people.*

Barbara's transplant did not happen immediately. In August she took her son, John, to help him move in at college and then she started chemotherapy to get ready for the transplant. She, like Donna (previous case), also had a bone marrow transplant and full body radiation. Unlike Donna, she offered very little description of her experience. This fits her pattern at this time of either denying or pushing this negative part of this experience out of her mind.

*Lost my hair, timed my transplant so I could go down to parent's weekend in North Carolina with my wig on and so we did. I'm sitting in the stands on a glorious fall day*

*with my son and his roommate watching a football game with my wig on having a blast. Then I had the transplant at the end of October, early November '94.*

The individual undergoing a bone marrow transplant endures a rigorous battery of therapeutic procedures and more chemotherapy and radiation to clear out damaged bone marrow. The patient has to be placed in isolation with special air-filtering equipment to purify the air. Visitors must be restricted and must wear protective clothing such as gloves and masks in order to prevent the spread of bacteria and virus. This experience often leaves patients feeling cut off from normal human contact as it goes on for anywhere from two weeks to a month. But Barbara offered little description of this experience. Either once again she used denial to get her through this situation, or this time the reality that she might die came crashing into her awareness.

*I think the way I survived was by total denial. I just really...it was the only when one day...one of the days after I had gotten heavy...I had full body radiation and more chemo and then had both the stem cells and bone marrow replaced and then you have to wait for your counts to come up for your new immune system because at that point, you have absolutely no immune system, so I was in isolation. I guess it was as soon as I was out of isolation one day and I'm walking the halls and one of the doctor's said, 'what are you doing?' I said, I'm taking my walk. He said, 'don't you know you almost died last night?' The only way I survived I was having a platelet crisis and the platelets weren't working and so they called my brother-in-law to donate platelets and that was what turned me around. He said, 'don't you know that we almost called your family in last night?'*

*I was still acting like...bone marrow transplant...big deal. That was when it struck me, holy shit...I'm really sick. That is when it became real to me. It's interesting that that is when it finally really became real, that this was serious stuff and I could die. I did very well. I was out of the hospital after 23 days, came home the day before Thanksgiving and slowly recovered.*

This is an important point for Barbara. This is the impact of death awareness. For the first time the real seriousness of her situation impacts her consciousness. When asked what kind of thoughts she had at that time about death, she replied:

*My mom and I had some really good conversations about life and death and what it's all about and I was a believer at that point and of course having my parents die made me*

*more of a believer that when we die, we still go on. In one way or another, our energy, spirit, soul goes on after we die. My only concern when we were debating about doing a transplant...I was talking with the transplant doctors at \*\*\*\*\* and I asked the doctor...the night before. I said, look my son wants to be a lawyer so that's four years of college and then three years, I want to be there and he said, 'without the transplant, you probably won't make it. With it there is a good chance.' And my son delayed law school for two years and I still made it. I made it! I made it! So my concern, I think, wasn't so much with death, it was that I couldn't die yet. I had too much to do. My kids needed me. Their dad wasn't much good for anything. I mean...he knew nothing about money, nothing about organizing a life, he was just out there and I was just too stubborn. I really think I knew I couldn't die. It was not an option. It simply was not an option.*

This is a conscious decision that Barbara is making, reminiscent of Robert Frost's poem where the person muses, "The woods are lovely, dark and deep, but I have promises to keep and miles to go before I sleep." She has acknowledged that she is really facing death, which is what is required to come to death acceptance, but she does not have time to dwell on it. She has children she needs to get through school. She went on to explain the background of her belief in her ability to survive, that this is part of her spirituality, a spirituality that does not include a belief in a God.

*I do not...I have no belief in a God that has anything to do with what happens to my life. I believe in myself. That is where my spirituality comes from. It comes from a belief in myself and through all I've been through learning how and learning that I can survive. I can survive. The only thing that better not be thrown at me is the death of one of my kids. My belief was always that I had me. And that's where my strength had to come from. It had to come from me. It never came from there. It had to come from within me. That I had...my mother's belief had always been that if there was any sort of divine spirit then, what this divine spirit has done is someone says that doctor saved my life...it was God's doing, my mother's take on it would be, no. Whatever spirit there was...she did use the word God, but she didn't...what she said was God's only intervention is that by giving man the intelligence...that if man chose to use that intelligence, they could then come across ways to save people's lives, but it wasn't God doing it. It was that these people had chosen to use what God had given them to the betterment of other people, but that God*

*himself, is not the one that saved that person on the operating table. It was the skill of surgeons and that skill came from within the surgeons and so that is where it came to me it's within me.*

Barbara's spirituality, at that time, was based on a lot of her mother's thinking, even though her mother believed in God. Barbara is agnostic so she at least entertains the possibility of a God. Barbara indicates that the spirituality that she has today really developed as a result of her search for meaning after the death of Rob. In general, her experience of cancer is ultimately subsumed by the greater story of her experience with Rob. About this time she got a note from Rob.

*In '95 the letter simply said 'just wanted to let you know that I'm out of here, going back to Colorado. Don't try to figure out what happened, just accept it and move on.' I tracked him down right away to make sure I knew where he was in Colorado...that didn't take much time. I could be a private detective...I just had to know where he was.*

*But anyhow about six months later, I get another letter from him with a picture in it of him standing in front of this house that he had built with the mountains in the background and he said, 'now you know why I had to come out here.' That was the end of that communication.*

Time passed and in 1996 Barbara's son was now away at college and her daughter had just graduated high school and was living on her own. Barbara was feeling well, except for her pain issues. After the bone marrow transplant Barbara had been doing well, but later developed shingles which is not uncommon when a person has a weakened immune system after cancer treatment. Permanent neurological damage ensued causing chronic pain in her back. She blames doctors who did not refer her to a pain specialist in time to prevent the pain from becoming chronic. But generally she felt well enough to pursue, like the proverbial moth driven to the flame, some closure to her relationship with Rob.

*Once my daughter goes, I'd always said we were going to settle this on his mountain. I've a cousin who lives in Denver and she has always wanted me to come out there. So I send him a letter and I said [I was] going to be visiting Joanne...he knew her...he knew my whole family. Said I was going to be visiting Joanne later in October/November and wondered if there is any chance of seeing first hand this house that you built? Three days*

*later I get a phone call. All he says is 'yeah it's me.' We picked up where we left off five years ago.*

Rob was now divorced, so the possibility once again loomed of developing a relationship. Barbara had asked to meet him for lunch but he proposed she stay with him. When they met again they immediately fell into each others arms, but their long dreamed of relationship was not to be. Their relationship had always been a passionate one, but this time Barbara's pain issues were bothering her. Their efforts to rekindle their sexual relationship ended in failure. Rob grew colder and more taciturn. Barbara remembered their last day together, the cruel ending to a tumultuous relationship.

*I'm trying to figure out...oh and Friday night when I went to bed, we had sex...or he had sex...it was whatever and so I had no reason...so suddenly the next day, he wouldn't even talk during dinner. I wanted to throw something...my drink at him. He had parked the car as far away as he possibly could have...down about four flights of steps...stairs and all this. I don't move real fast anymore. So when we leave the restaurant, he is high tailing it up and I'm dragging along up these stairs wishing we had parked...not knowing why we hadn't parked any closer. Finally I make it up to the top level...and he is heading to the car and finally I stand there and no one else is around and I scream at him God damn it, I'm not making up this shit and I threw my handicap parking permit at him. Then we really got into it. He is yelling at me. He said, 'you are not trying hard enough, you got a rough time, but you need to be doing more than you are doing' ...yada, yada, yada...I said, Most people respect and admire how I've handled my life. They think I'm a role model. He said, 'You should do this and you should do that.' And I said, Well what would happen if something would happen to you? He said, 'Oh, nothing is going to happen!' I said what if you broke a leg? 'Oh, I'd still manage...nothing is going to happen!' Meanwhile he is a two pack a day smoker. And he even gets up in the middle of the night to smoke. But nothing is going to happen to him.*

*So we get home. It's 7:30 on a Saturday night. I'm leaving the next day...he walks in the front door and says, 'I'm going to bed!' Storms upstairs and I'm left there absolutely devastated. I'd been crying the whole time we were driving back from Vail. There were any number of things in hindsight I wish I had done...I did none of them. I called my best friend and ran up his phone bill and talked to her for two hours and finally*

*went up to bed and I didn't know whether...I thought maybe I should sleep in the guest room...I didn't know what, but I crawled in next to him. He moved as far away as he could, he gets up the next morning at three, stalks out of the room and that is the last I ever saw him. That was it.*

Barbara, in describing some of her early incidents with Rob, never used the word cruel. Yet his behavior to her has very cruel aspects, starting from the time he called her on his wedding night. However, when Barbara later comes to accept her own death by trying to understand his, she finally describes his behavior as cruel.

Barbara tried to call him a couple of times. He would ask her if anything is wrong and she would say no, so he would hang up. He would never discuss the problems in their relationship in Colorado and never talked to her again. She is today still furious with him, but at that time she coped largely by crying and talking to her therapist.

Her pain problems and her relationship with Rob were not the only problems Barbara had at that time. Her life was beginning to go into a negative spiral. She had been the heir apparent to run the Interagency she had been working for. Her boss was retiring and wanted her to replace him, but because of the pain she could not do it.

*Shortly thereafter my boss at this Interagency announced that he was going to retire. I had been the heir apparent to run the agency, but because of the damn pain and the cancer, I couldn't do it. So that added to my devastation. The new person who came in was terrible. She worked me like a dog and she eventually...my pain became so severe and had radiated up my entire spine, down my arm. My pain doctor said, 'I won't treat you if you won't quit working.' This was 1999. June of 1999 and I had to retire on disability. I had to leave a job that I had loved...an agency that had it not been for my illness would have been mine to run, which had been my goal. Three months later, Robert dies.*

Barbara had seen the obituary in the newspaper here. She had thought her life could not get any worse, but here it was, the man who occupied the home in her heart was gone. She recalled,

*I knew in my heart that if I were the one that was going to die...before I died, I would get a hold of him and I would say, God damn it, before I die we got to settle this. But I had a*

*feeling that he would never...I would never know if something happened to him. And there it is in the obituaries.*

*He's in Colorado. At least I figured he was. I scream. I mean...I just and I called my best friend and I'm sobbing and I say, Gail, get your newspaper...tell me it's not true! Tell me it's not in your paper. Tell me I'm hallucinating. She picks it up and goes, Oh my God! I'm on my way. I call my therapist and she goes...she can't believe this has happened.*

The next day Barbara called Rob's brother and learned that Rob, who scoffed at her own illness and denied that such a possibility could happen to him, had been diagnosed with esophageal cancer eight months before his death in September of 1999. Barbara did not go to his funeral because she knew she would never make it through. However, she recalled a conversation with Rob's daughter after the funeral.

*And all she could say was what a terrible man he was and she and her brother had gone to Colorado and told him what they thought of him and that he needed to be nicer to people and he was a terrible father...telling this to him when he died and this is a man who had given up his life in Colorado to come back to get them away from their mother and anyhow we had a really long talk and a year later I got a note from Andrea saying how much she had treasured our conversation and she was beginning to see the good in her Dad...anyhow she had told me how much she remembered our talk...she sent me the note and it had helped her understand her dad better and she was beginning to remember the good times and all that. And I'm saying...see what I did...after all you did to me...see what I'm doing for you...you...I was so angry at him in my grief. I was furious.*

Barbara remembered this time as the lowest point in her life – losing Rob and the job she most loved, having to work under an abusive boss and dealing with her own physical pain. The six months after his death left Barbara with nothing to do except grieve. Barbara had always kept moving through life using denial to push aside troublesome issues and applying herself to the things that needed to be done for her kids, but finally she had been forced to confront her grief.

*You couldn't go any lower. And I had already realized that suicide wasn't a choice. I had worked through that in my previous crisis. But I knew and I read, that there was finally nothing to stop me from grieving. I had nothing. I couldn't run from it and it was like I grieved my parent's death and his death. It was finally...there was nothing for me to do*

*but grieve. So that was my job for six months...was to grieve and to come to some sort of meaning.*

From the depths of this period she started to come to grips with all that had happened to her and began to weave a new spirituality from the tangled threads of her life. She began a personal search to understand what death was all about. She started attending a group for people who have had or are interested in near death experiences.

*I read this group advertisement in the newspaper and I went to that group a couple of times. I also began walking. Taking really spiritual walks and connecting with nature and realizing to everything there is a season and watching the leaves change color and watching them fall off and die, but then you know they are going to bloom again in the spring and incorporating that into my grief work. I swam and I would swim lap after lap, slapping the water, saying, you bastard, you bastard, you bastard with each stroke and sometimes it would be at my job and I would just kind of bend and pound out the grief...pound it out...just pound it out. And I knew finally that the only way to move on was to forgive him. I had to. And that following Easter...Easter has always been symbolic to me because the way it is approached in the Unitarian Church is a rebirth. And I've also...Mac and I had talked a lot about reincarnation and that is also a belief that I explore and I'm curious about. I don't know...I don't have a sense that is what happens, but I don't discard that as a possibility. But after this near death group experience fully led me to believe that absolutely we do go on. There is more. There is more to life. And there is a reason for what happened.*

Barbara, like the other two cases in this study, experienced some extrarational events at their lowest points which became very important, contributing to their construction of meaning. She described attending this near death group and an incredible chance encounter with Rob's brother's wife as a couple of miraculous things that happened at that time.

*About a month and half later, usually I saw Gail, my best friend for lunch on Saturday and I couldn't...some reason on Saturday she couldn't and I was wondering around trying just to do something and I saw they were having a craft fair at the local recreation center...I thought what the hell, I like to look at crafts. So I went to do that. And one of the women at the booths had a name tag on that read Linda \*\*\*\*\*. Well that is Robert's last name and his brother Phil, the one I had talked to has a wife named Linda who had*

*had cancer. I said, I'm an old friend of his brother Rob...I'm Barbara. And she screams... 'you are Robert's Barbara,' and gave me a hug like you wouldn't believe.*

*Linda, when we had lunch, filled in so many of the blanks of what had happened when Robert was sick and how bad it had and how much he had suffered and his kids left him alone and the whole bit.*

*And I came to believe...there is no reason for me to have gone to that craft fair. I believe he sent me there. This is when I began believing in ghosts and angels. Really believing! I believe he sent me there. That he knew I had to heal somehow and that by sending me to Linda she would help fill in the missing pieces and she did...and the near death experiences.*

Shortly after her experience of meeting Linda at the craft fair, there were a couple of instances in her life that provided her with some "messages" about her life. For example, she had a problem of an odd odor at her house. The gas company came out and discovered that her house was slowly filling up with carbon monoxide. They turned her furnace off, so she found a repairman to come out and fix it.

*A little Hispanic guy and he looks at me and he says... 'you very lucky...is not your time yet.' I believed that was a message. Its not your time yet. A month later I was driving over to Virginia to a conference and as I was pulling into the conference I was hearing a thud, thud, thud while I was driving, but I'm going 80 miles an hour...what do I know. I pull off and I get into this conference and when I parked the car, the valet parking...the guy says, 'madam, do you know you had a flat tire?' He said, 'you are very lucky. It could have blown on the beltway...you could be dead.' So I took those two messages...it somehow...it's not your time yet, you've got to get on with the living.*

This tendency to read the environment for messages also occurred in Jim's case. For both it happened at their low points when they were seeking meaning to their life. The messages appeared to be morale boosters indicating they would live. For Barbara, pieces were fitting together. She was finally coming to an acceptance of Rob's death and her own as well. When Rob was alive they had often talked of planting azaleas in a section of her garden -- now this area had simply gone to weed. She recalled:

*I finally said - it's time. I've got to plant our azaleas and I have to sit here until I can forgive him. So I sat out there on that Easter Sunday crying my heart out. I was...that six*

*months is the most devastating...I kept saying is this the bottom? No. Those six months were the most devastating and the best most important months of my life. Because it was through all of that that I really came to finally find some inner peace. Yeah I believe in ghosts. I absolutely believe in ghosts. He has visited me. I know he has. Sometimes it's a dream, I know it's a dream, but he has visited me. My father has visited me.*

When asked how she distinguished between the dreams and the “visits,” she replied:

*Because it is too vivid. It's too vivid. In one dream shortly after my father died I saw him standing on the top of a hill bathed in bright lights dressed in his suit and smiling with this warm light surrounding him and I woke up and that morning I knew that he was telling me he was okay. His spirit lives on and he is okay. I just believe it. With Rob the difference between when I dream about him and when we visit...I actually feel his presence. We actually had sex one night. Don't think I'm nuts. We had sex one night. I know we did. It was physical. I woke up literally feeling it. It wasn't a dream. I have dreams, but this wasn't a dream. There is a physical quality to this where it is so real that I believe...there is no doubt in my mind that we do go on after we die. And if I'm wrong, I'm not going to find out until I die.*

Barbara is beginning to have a sense that she will survive even as she is working through her grief and anger at Rob. Those six months after Rob's death, Barbara began to find some meaning not only in his loss, but in all the loss she had experienced:

*He sent me Linda so that I would begin to deal with the baggage he left me holding. I have forgiven him for everything, but the last night in Colorado. I will never forgive that because I don't understand it. It was cruel. He had never been cruel to me before. I will never forgive him that, but I have forgiven him for being a jackass...for being...I don't understand why we kept throwing it away. Parts of me do, parts of me don't, but I don't worry about that anymore because it doesn't matter. I've forgiven him...he is here. He'll always be here. I can talk to him if I want. But he is here. My parents are here and I do believe that - not in a God, but in the energy of spirits and souls, to in some way, help us get through. We kind of have to learn to decipher the messages, but they are there if we choose to hear them. I heard that little Hispanic man...it is not your time yet. It resonated with me in a way it might not have with other people, but it sure as hell resonated with me. Living in the present, knowing that we have today and that's it. This is my day. This is*

*my experience today; this is your experience today. And I have in my own mind, what is today's problem? I don't have a problem today. I may in another month if the doctor says I'm relapsing, but right now my counts are good. My pain is under control...this moment, I don't have any problems. Yeah, I'm moving, I have to do this and this, but it's a very simple...I have found a very simple way of living each day.*

Barbara's statement indicates that she has done a lot of work on reconstructing her world. For the first time she can describe Rob's behavior toward her in Colorado as cruel, although whether or not she sees a pattern of this behavior is unclear. Her ability to now describe his behavior this way indicates that she has a better perspective on this relationship than she had before. She also realizes the importance of letting go and forgiving him. She has refashioned her world with a vibrant spirituality, one in which spirits and souls aid people in their journey and important messages can be read for the one who has eyes to see. She also feels connected and able to communicate right now with those who have passed on. Her walk on the cusp of life and death has resulted in an ability to truly live one day at a time.

When asked about remission, she replied that she had been told that if her bone marrow transplant worked she could expect remission for about two years. She did have a second two year remission, but in 1999 her blood was once again showing the protein buildup that signaled the end of remission.

*When I first started relapsing in the fall of '99, we just kept watching, the numbers were yet high enough. We knew I was out of remission, but it wasn't yet time to treat the cancer, so we waited for almost a year...more than a year of just kind of watching it until finally in March of 2002...I get my dates confused...when I finally did have to start treatment. I went on the drug which wasn't an option when I had relapsed in '99 and my doctor said at that time...well you know... 'how do you feel about another transplant?' and I said, fine if you want me to have one. I'm not interested, but if you want...that may be what we are going to do. By the time we got around to treating it, he took it off the table. He said there is new drug now. It knocked my counts down, it knocked me back into remission.*

One of the side effects of this drug was neuropathy (numbing tingling sensation in her feet) so she eventually had the doctor take her off of this. Barbara's disease is considered to be incurable, although some people do live 10 years. She has now been living with the disease for twelve years

and expects her cancer to keep recurring, but this does not bother her. She has learned to appreciate each day.

*What is important to me now certainly is enjoying my kids as adults. I'm having the time of my life with these two. I never thought I'd get to see it. You have to understand that I was told when I was 48 years old that I might not live for three years. I might not live for seven years. And I have fought that every step of the way. I have refused to ever accept. I acknowledge that I have an incurable illness...I acknowledge that...treatable at this point...not curable, but treatable. Every day there are new things. My oncologist says every six months of remission, you gain a new treatment and that's exactly what's been true.*

She reports that she has been off of this drug for a year and a half and is still in remission. Recently she spoke with an expert on multiple myeloma and he indicated that of the patients who have stopped taking the drug, one and a half years is usually the maximum before they relapse. Most relapsed immediately. She considers herself lucky that she has not had the bone lesions that so many multiple myeloma patients get. She shared again some of her thought on spirituality.

*What you will see on x-rays and MRI's is ... you will literally see holes in people's skin or in their skulls where the myeloma has eaten through and sometimes people actually get the myeloma cells clustering attached to one of their organs and that's pretty serious. I have not had any of that happen. I don't know why. But just like I never said why me, I never said that about why me God because there is no God to say that to. It's a crapshoot, that's what my mother believed...that's why I believe I got this illness and someone else didn't...I don't know. It would have been nice if... Bin Laden got it instead and died...that would have been very nice. But that's not what happened. I got it.*

*Every day is a miracle that I'm still in remission. What is there to be upset about? Am I thinking about when I relapse and when I die? No. Not really because that is not today's problem. When it happens, I'll deal with it. And when I do think about okay, what happens when it's over and you are dying? I don't know. I can't...I don't know how I'm going to handle that because I do believe the soul goes on. I think that a part of me will be eager to reconnect with Rob, but I do have this sense that we are already connected and so why will that end when I die? That we will in some way...I will with my parents in some way...I don't know that*

*they are going to be standing at the pearly gates to greet me. I don't know. That's a vision that you know...it's not too bad to think about. I don't know. I ask my dad when he was dying...I asked him...Dad, how do you feel about dying? I was really curious to know. How do you feel about it? He said, well I'm worried about how your mom will do...I'm really worried, but he said that to tell you the truth, I'm looking forward to it. I want to see what it's all about.*

For Barbara, the development of her spirituality has been an important comfort for her, but she is very clear that her spirituality is not a result of her cancer. Barbara did not come to death acceptance as a result of her cancer, but because of a need to understand Rob's death. She needed to know she would be connected to him in some way again.

*What is interesting is as we've been talking...what you've picked up on is we are not talking about cancer. Cancer has always been a sidebar. What has forced me to explore my own spirituality has been Rob. Not the cancer. Cancer has been a day at the beach compared to the emotional pain that I've gone through, through him. In terms of the cancer, again I think I've always been focused on living and not dying with it. (okay... now you talk about spirituality and Rob... you mention this earlier and don't talk about it)*

She recalled the words to a country western song which seemed to reflect that lovers separated by death will find each other again:

*It just to me is a very logical explanation that we are all of us part of some energy force and that energy doesn't go away. There is a wonderful song...I'm into country music. There is this wonderful song and it actually says that...it's about a guy that is obviously grieving the loss of a woman...says every now and then I feel a soft breeze upon my skin and I know you've come back again. It goes on to...I believe when we are gone there is a light in each of us that goes on and the light never ends and it's always with us and if I'm right, our love can even reach across eternity and then he even says, the people who don't see the most see that I believe in ghosts and if that makes me crazy, then I am, but I believe. I love that song.*

An important part of Barbara's spirituality is now to give back and help others. Her work had always been developing intergenerational programs for kids and the elderly. Although she no longer works, she still has a passion to help kids and especially immigrant kids. Since 1999 she

has been performing volunteer work with a young girl from Haiti. This girl asked her to help a young girlfriend of hers from Cameroon. Barbara is helping to mentor them to get their high school degrees and to help them adjust to life in this country. In addition Barbara also helps counsel individuals newly diagnosed with cancer, writes a column for a cancer journal, has contributed to a book that was published and paid her for writing her cancer story. Presently she also participates in an on-line support group for people with multiple myeloma. There are scientists who answer all the technical problems, but she is considered the 'emotional soul' who answers the feeling questions.

*So there are some people who are very scientific and I'm the emotional soul on that list. I will write...if someone says help, my mother's diagnosed and she has been told this and this and this...and I'm really confused, the scientists on the line will take care of what it means and I'll get on and I say I can imagine that you are really scared and confused. Moms aren't supposed to get sick and I go at...and then everyone...you don't know how much your words helped me...I'm a healer because I'm healed.*

*I don't ask why I'm in remission...I just accept this is what is and that is another biggie. What is, just is? Play the ball where it lies. That's what is. And so that is right. We are all connected in ways that at some point we will understand. But for now, it's comforting for me to know and to feel and to believe first of all my purpose in life is clearly to help others along the best I can: To love my children, to be kind to people and to have fun. That's why I'm here. And, when I die that energy will go on. It will go on.*

### **Summary**

Barbara's case is somewhat different from the other two cases in that the trauma of her diagnosis did not become the central focus of her concerns. Her love for Rob and her motivation to see her children through their college years were the central focus of her life even after her diagnosis. Barbara's case illustrates the use of denial as positive avoidance. Mostly, she always had an awareness of the seriousness of her diagnosis but rather than seriously face this issue, she chose to put it on the back burner of her mind and focus on more immediate concerns of pursuing the best treatment, taking care of her children and pursuing her relationship with Rob.

For the other two cases, it was issues of facing their own mortality that brought them to a turning point of working through the issues that would bring death acceptance. Barbara finally began to work toward death acceptance, not because of the seriousness of her own cancer, but

due to learning of the death of Rob, the love of her life. This occurred at a time when she also learned she was out of remission. In addition, she lost the job she had most wanted to have. All of these events, but most particularly the loss of Rob, propelled her to grieve and ultimately face her own mortality.

She worked toward death acceptance through serious grief work, attending a group for those who have had or are interested in near death experiences, taking “spiritual walks” in nature and contemplating her life and her relationship to the universe. She had a couple of extrarational events “miraculous thing that happened at that time” which helped her derive meaning from both the loss of Rob and her cancer experience. She like the others, lives her life one day at a time, grateful to have achieved her goal of seeing her children finish college. She found and evolved for herself a deeper more meaningful connection to the universe which she happily shares by performing volunteer work with immigrant youth, contributing to an on-line support group and counseling newly diagnosed cancer patients.

## **CHAPTER 5**

### **RESULTS**

#### **Introduction**

This chapter presents the findings derived from coding and analysis of tape-recorded interviews with three terminal diagnosis survivors. Grounded theory, as developed by Glaser and Strauss (1967), was used as the methodology for this multiple case study research. Grounded theory provides a systematic basis from which qualitative data can be collected and analyzed to generate theory that furthers knowledge and understanding of psychological and social phenomena (Chenitz & Swanson, 1986). The results are presented and discussed using a 5-phase model of terminal diagnosis survivorship that was constructed from the data of this study and is used to organize the findings. The model provides a framework from which to understand eight themes that emerged from the data and inform and represent aspects of the phenomenon under study.

The model developed for this study presents five phases that characterize frames or passages that are descriptive of the individuals' lifespan from their pre-cancer days until the present time. (see Figure 1) The model provides a map for the largely uncharted landscape describing the lived experience of those surviving a terminal diagnosis. Progression through the model is largely sequential; however, there is always the possibility of recycling back to the diagnostic phase from succeeding phases. Elizabeth Kubler-Ross received a great deal of criticism for her model of the stages of death acceptance because people believed that one stage led to another in a linear fashion. But, as she later acknowledged, people cycle through several stages in many different ways and sometimes run through the gamut in a day. In her model this process of cycling from denial, bargaining, anger and depression can go on for a year or two (or more in some cases) before the person reaches death acceptance.

The model presented in this study has similar aspects to Kubler-Ross's (1969) as the person can return to the diagnostic phase from the remission or new life phase in many repetitions. In this study both Donna's and Barbara's case illustrated this. Donna had a number of short remissions until she received her final treatment that resulted in a ten-year remission and possible cure she enjoys today. Because of the nature of Barbara's cancer, she knows that she will continue to experience reoccurrences of her cancer. Even after a person reaches many years

## STAGES OF TERMINAL DIAGNOSIS SURVIVAL

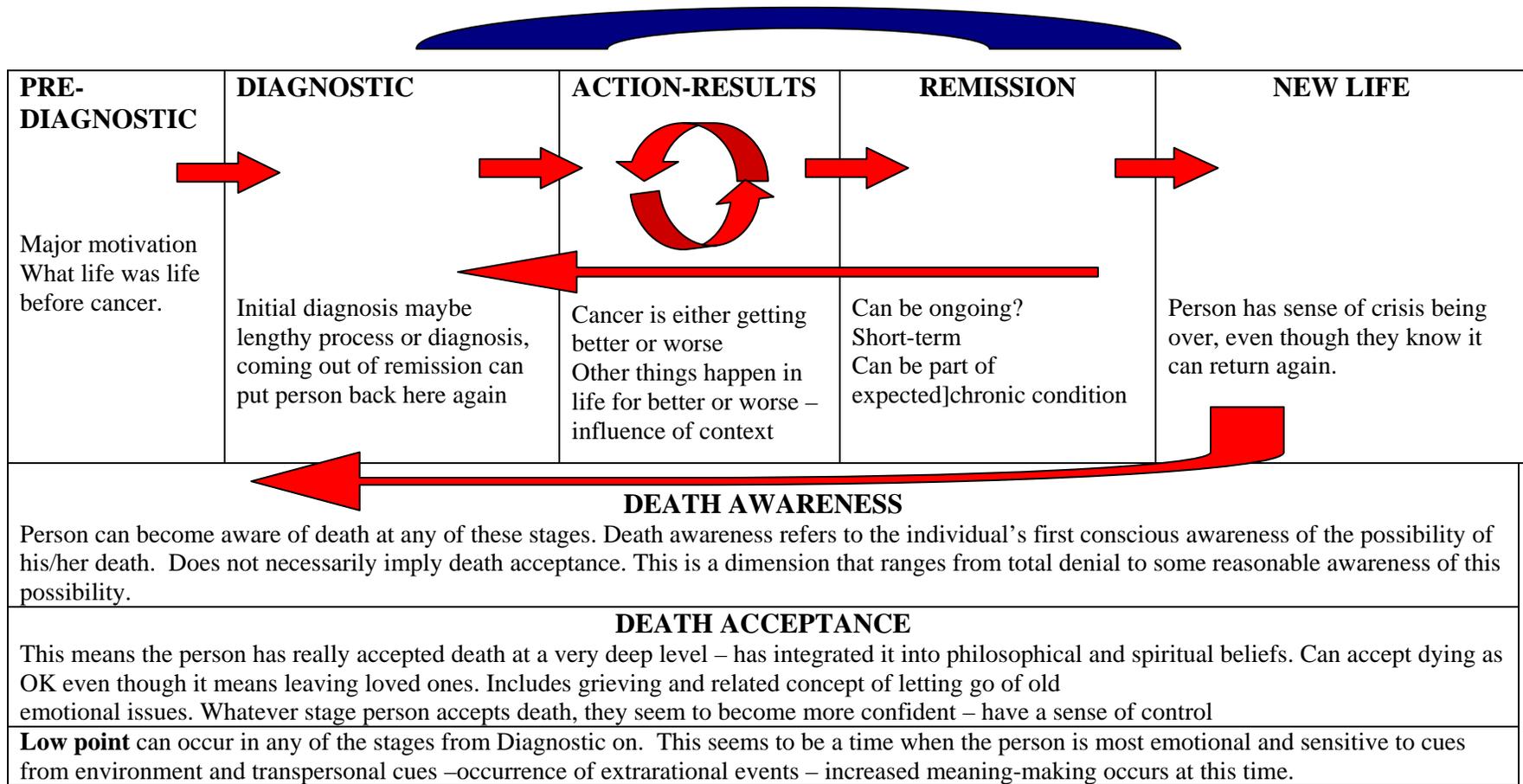


Figure 1. Stages of terminal diagnosis survival.

of stability in the new life phase, the possibility of a reoccurrence can throw him/her back into another cycle starting at the diagnostic.

The model resulting from this study is different from Kubler-Ross's because it outlines five phases that provide frames for activities taking place during the cancer journey. The five phases of this model are: precancer, diagnostic, action-results, remission and new life. These phases are descriptive of the basic experiences of any cancer survivor. Each person was shocked out of his/her pre-cancer life by a diagnosis, has taken a series of action-steps providing certain results and has moved on to remission and ultimately to a new life that is forever changed.

What gives this model its unique character and reflects the lived experience of terminal diagnosis survivors is the occurrence of eight themes that appear in varying degrees throughout the phases of the model. The eight themes weave throughout the phases of the model characterizing and describing the individual's reactions that form the process of terminal diagnosis survivorship. The next section will describe the themes in further detail, followed by an overview of the model and then the presentation of the model.

### **Themes**

The themes are briefly described here to orient the reader to recognizing and understanding their meaning in the model. As mentioned in the overview section, these themes emerged from the coding process and represent the internal dynamics, thinking, emotional and spiritual processes of the three cases used in the study. The themes weave through the phases of the model and are expressed in the findings of each individual's story which gives definition to the phenomenon of terminal diagnosis survivorship.

The salient theme that emerged is death acceptance. When the individual reaches a point of acceptance of his/her death, many themes converge at this point reflecting multiple internal changes reflected in a constellation of activity such as a greater sense of meaning and appreciation of life, stronger sense of self, increased spirituality and willingness to give back to others.

#### **Themes: Death Acceptance/ Death Awareness/ Denial**

Death awareness refers to the individual's first awareness of the possibility of death. The individual eventually moves in a process of approach/avoidance toward death acceptance. If the individual uses denial extensively to avoid death awareness s/he may never experience death acceptance. Death acceptance occurs when the individual has done some existential and spiritual

questioning and has come to a deep acceptance of death. This process entails a related concept of “letting go” which means releasing, at some level, all that one considers important in life. Each person has to come to terms with and answer questions such as the following: What is death? What will it mean to have the physical body die? Is there a soul? Where will the essence be upon dying? In addition to spiritual questioning, death acceptance often involves physical preparations for death such as funeral arrangements, taking care of insurance and saying goodbyes.

### **Themes: Low Point**

This was the point that all participants described as the worst part of their experience. Low points were brought about by considerations of death or after the occurrence of a number of negative events and resulted in death acceptance. Low points stimulate greater efforts at meaning making and open the individual to greater intuitiveness, synchronicity, increased sensitivity to reading meaning from the environment and a tendency to experience spiritual, paranormal, or transpersonal events.

### **Themes: Meaning Making**

Meaning making refers to the individual’s construal of meaning from his/her cancer experience. In this study each person believed that cancer happened to him/her for a reason. Meaning-making becomes a particularly pronounced effort when the person struggles with the issues presented by the low point resulting in death acceptance.

### **Themes: Spirituality**

Each person described significant development of spirituality as a result of his/her cancer experience. Spirituality, as evinced by each of these participants, seemed to help him/her identify away from the materialistic world and find a deeper connection to God, nature, other people and the universe. Spirituality does not necessarily mean a belief in God. Barbara was selected for this study based on the fact that she did not profess a belief in God and thus would use other organizing constructs for her experience.

### **Themes: Major Motivation**

Major motivation is the dominant motivation or orientation of the individual’s life, under which all other motivations are subsumed. In this study each person’s motivation prior to the cancer and how it changes with the unfolding experience.

### **Themes: Emotional Calming/Coping**

This theme highlights the importance of emotions that is central to the phenomenon. A distinction is made between emotional calming and coping. Coping is a means, technique or behavior that can be functional or dysfunctional and is used by the individual to defend against anxiety. Emotional calming is used to describe a deeper level of calmness that occurs after death acceptance. The individual can now face the possibility of death with emotional equanimity due to having found meaning in the experience of death deriving from a spiritual realization of connecting to something greater than himself/herself. This does not imply that the individual will never experience fear or depression or anxiety again; however, s/he can now better cope with these feelings and move away from them.

### **Themes: Altered States**

Altered states are generally described as pertaining to different levels of consciousness characterized by brain wave levels<sup>6</sup> that are different from the normal beta brain wave state of everyday consciousness. These states are induced through practices which bring about relaxation, such as prayer, meditation, or music. Each person in this study utilized practices inducing altered states that related to the enhancement and development of his/her spirituality and/or calming of emotional states. Some of these practices were prayer, mediation, recordings of church services, music and nature walks.

### **Themes: Extrarational Experiences**

In this study individuals evidenced a number of extrarational experiences which included heightened intuitiveness, visitations from spiritual beings or the dead, synchronicity and a tendency to read “messages” from their environment. Transpersonal experiences generally occurred with greater frequency during low points when individuals were coming to death acceptance and actively seeking meaning in their experience.

Throughout this chapter certain themes appear in all the phases while other themes appear only once or sporadically. For example, the low point occurs only once as a theme. Of course, each individual endures many low points in his/her cancer history, but the low point in this study refers to what each individual would recall as the very worst experience of all. For

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<sup>6</sup> Different brain wave states correlate with certain states of consciousness. Beta waves describe our normal waking state. Alpha waves indicate a relaxed state such as meditation or prayer. Theta is associated with daydreaming and delta deep sleep.

each of these participants, death acceptance occurred following the low point. Death acceptance always appeared with a confluence of themes, usually spirituality, meaning-making, emotional calming, altered states and intuition/synchronicity. These occurred together as the person tried to find meaning and calm the emotions of his/her low point. Participants sought to calm their emotions in ways conducive to promoting altered states of consciousness such as prayer, meditation and music. During times when individuals were grappling with death acceptance, incidents of increased intuition, synchronicity and scanning the environment for “signs” for meaning became prevalent.

An overview of the phases of the process model used in this study is presented below. This overview discusses the characteristics and significance of each phase, as well as provides a framework from which to understand eight themes that emerged from the data and inform and represent aspects of the phenomenon under study. The five phases describe frames or passages that are descriptive of the individuals’ lifespan from their pre-cancer days until the present time. (see Figure 1)

### **Overview of the Process Model**

In the pre-diagnostic phase, a general description of the individuals’ lives is presented to serve as a reference point from which to consider the impact of the diagnoses and the significance of future action taken in the course of their cancer experience. In the pre-cancer phase, the individuals’ lives are described holistically to provide a basic understanding of what their lives were like prior to cancer. The theme that emerged as most important at this time is major motivation, a dominant orientation or motivation in the person’s life under which all other motivations can be subsumed. Delineating this motivation in the pre-cancer history provides an important reference point for assessing change in the cancer experience.

The diagnostic phase describes the impact of the diagnosis, a life altering event that forever changes the person’s life. Not always just a moment in time, this can be a recurring event to which people return from subsequent phases. The theme that has particular importance at this time is death acknowledgment/death acceptance. An important part of meaning making for each person is the choice of an orientation to or perception of death, ranging from denial to total death acceptance. Death acceptance is achieved when the individual totally confronts the possibility of his/her death which includes answering deep existential and spiritual questions, recognizing

without denial how one's death will impact loved ones and being able to discuss this impact with them.

Some can come to total death acceptance in the diagnostic phase, as Jim's case illustrated in this study, or denial can be used in different ways. Denial can be negative, in that the person refuses to deal with reality, or it can have a positive usage in the cancer patient's life, allowing the person to postpone considerations of death in order to take care of urgent needs and responsibilities.

Both emotion and motivation are important aspects of the diagnostic phase that must be accounted for. Once the individual has chosen an orientation to death, then a decision is made about what is worth living and fighting for. Individuals reassess the major motivation that had been guiding their lives and either decide to keep fighting for this or try something new. Perhaps one of the most important tasks for each person is to discover some way to calm their emotions. The theme of emotional calming is expressed either through use of denial or some practice involving altered states such as praying, meditating, or listening to music.

The action-result phase delineates all the actions taken by individuals to respond to the consequences of their diagnosis. This includes all standard medical treatment, alternative therapies and efforts to learn about the medical aspect of their disease, as well as how to understand related psychological, social, emotional and spiritual issues. Each individual experienced both an initial reaction cycle and subsequent major action cycles. Initial reaction cycles were actions impulsively taken by each participant that were driven by the inflamed emotions resulting from diagnosis and proved to be a characteristic of the individual's major action cycles. The actions undertaken in this phase either bring success or plunge the individual into a new set of action-result cycles.

Remission is not always an endpoint, but often a passage to recurrence. Those unfamiliar with cancer may think remission is the only pronouncement that could bring peace of mind. The reality for each person in this study is that remission was anticlimactic. By the time they reached a remission that lasted and was not simply a transitory remission of short duration, they had found their own equilibrium by coming to a deep acceptance of death. From this acceptance, the participants came to a deeper appreciation of their lives and a renewed energy and confidence to deal with their cancer, even in the face of possible relapse.

New life represents a phase in which the individual has survived a few years past the date offered by his/her diagnosis. This phase occurs after full death acceptance is achieved. During this phase, participants believed that life is more precious and they become more deeply spiritual as a result of this experience. They feel grateful for the experience and have a deep desire to give something back to others. This is perhaps the most significant part of their meaning-making; that this experience happened for a reason and now they have a story to share with others, one of surviving the darkest adversity to emerge stronger and happier than before.

### ***Results: Pre-Diagnostic Phase - Introduction***

This phase provides important background information that becomes a baseline from which to assess the dynamics of change in the life of the person, starting with the cancer diagnosis. The individual's cancer experience cannot be assessed without reference to the quality of his/her pre-cancer existence. Naturally, everyone expects that getting cancer is a horrific occurrence. However, it is not hard to imagine a scenario in which a person with suicidal ideation may actually experience some relief with such a diagnosis. While this represents one extreme possibility, a whole range of possible scenarios is probable depending on the existing conditions and circumstances of the individual's life at the time of diagnosis.

Some people in their sixties or seventies, upon being diagnosed, may feel that they have largely lived a good life and thus may be able to handle the impact of the diagnosis with more equanimity. However, a mother with two young children naturally wants to live to see her children grow up and is likely to be totally devastated by a terminal diagnosis. When cancer occurs in the course of a stressful and generally unhappy life, does it simply become one more depressing event in a series of misfortunes; or, conversely, could it serve as a catalyst for change? If a person is having a generally successful and satisfying life and cancer occurs, does this destroy his/her continuing hopes for a good life? Will the person fight all the harder to conquer the cancer in order to preserve that good life; or is it possible that the cancer could set him/her on a new course for growth and development never before dreamed possible? By assessing the individual's pre-cancer life as a standard for comparison to his/her life after cancer, the answers to these questions may be developed.

This section will explore the pre-cancer period of the individual's life from several aspects: (a) physical and psychological concerns; (b) social support systems; (c) existential questioning and spirituality; and (d) the major motivation guiding the individual's life prior to

diagnosis. Examining these aspects of the individual's experience will provide a holistic (physical, psychological, spiritual and social) view of the pre-cancer life that will serve as a basis and background for understanding the impact of cancer on his/her life.

***Results: Pre-Diagnostic Phase - Physical and Psychological Concerns***

For the participants in this study, their lives prior to cancer ranged from satisfaction and relative happiness to dissatisfaction and unhappiness. For Barbara the cancer came at a relatively unhappy point in her life. She started taking anti-depressants about the time of her mother's death. This tragic event was then shortly followed by her father's death and her own diagnosis with cancer. In addition, she had just recently left an unhappy and stressful marriage. Her husband had been an extremely depressed man who left the raising of their children to her. For many years he had slept in a bedroom on another level of the house and, as she described, the couple had sex about twice a year. All the while, Barbara had continued to harbor love for another man, Rob, whom she almost married years ago.

Psychologically, all three participants had experienced significant to severe stress in their lives. However, at the time of diagnosis Donna was at the other end of the spectrum from Barbara. She described the pre-cancer period as the happiest and most promising time of her life. Her husband was doing so well that she decided to quit her job and stay home with her two young children. While Donna had enjoyed her work life, she much preferred to stay home and take care of her kids and be a homemaker. Having come from a family where both her parents and brothers were alcoholics, she had never experienced a normal family life. Even in her first marriage she had chosen an alcoholic husband, continuing the pattern she had known since childhood. When she was diagnosed with cancer she had been married for a few relatively "happy" years to her second husband, Eddie, with whom she had two young boys, ages three and five.

A close examination of Donna's story (see Donna's narrative) indicates that her recollection of this being a happy time may have been somewhat illusory. Today she realizes that her husband was too controlling and "oppressive"; however, at the time of her diagnosis and treatment, she did not recognize this characteristic. Although Donna never came out and said this directly, from her description of his drinking there are indications that he may have had a drinking problem as well.

Cancer entered Donna's life at what she perceived as the best time of her life and entered

Barbara's at a mostly unhappy time. For Jim, cancer came at a time when things had begun to get better for him after a depressing and unhappy adult life. Jim, like Barbara, also had an unhappy marriage. Over the years Jim had also found his work life to be stressful because of having too many responsibilities and harsh supervision. In addition, his work environment was not healthy as he worked around asbestos much of the time. He even recalled sometimes working at midnight and taking naps at work under an asbestos blanket. It was the fact that he worked around so much asbestos that caused a friend of his, who was a doctor, to suggest that he get a chest x-ray. This suggestion led to his diagnosis of cancer.

To cope with a stressful work life and an unhappy marriage Jim had been taking "nerve pills" for years. Now he began to reduce the stress in his life by getting divorced and retiring. In the divorce, his wife received half of his very small pension, leaving him very little to live on. But even this did not upset him; he simply moved to a very rural location and built himself a little house. He was just beginning to turn his life around when he was diagnosed with cancer.

None of the participants in this study had any outstanding health issues prior to getting cancer. Jim knew that he worked around a lot of asbestos in his welding career and many of the doctors he consulted, after he was initially informed of his diagnosis, suggested that his condition could be Asbestosis. However, he never received a definitive diagnosis of asbestosis at any time either prior to or after his cancer. Neither Donna nor Barbara expressed any concerns about health issues prior to their cancer.

### ***Results: Pre-Diagnostic Phase - Social and Community Support***

Each of the participants in this study generally had good support systems both before and after his/her cancer experience. Lack of social support did not seem to be an issue in any of their lives. When cancer occurred, none had to face dealing with their cancer totally alone. Barbara had a severe jolt to her support network when Rob left her in 1991. It was during this time when she had been told that her blood proteins were elevating to a critical level resulting in her definitive diagnosis of Multiple Myeloma in 1992. Rob left after a fight about some unrelated personal dispute they had; however, Barbara believed that in all probability he could not cope with her cancer since he had little capacity to deal with emotional issues.

It appears that Barbara spent most of her time prior to diagnosis involved with her children's lives by supporting them in their goals and making sure they were successful in school. She never revealed to her two teenage children that she had cancer until she was faced

with a bone marrow transfusion. Interestingly, efforts to keep them from knowing added some additional stress due to this emotion work. Her strained relationship with her husband also offered her little support. Mostly, they did not socialize with other couples because of her husband's reclusive behavior of isolating himself from both family and friends. However, she did have the support of friends that she utilized more after her divorce.

Barbara indicated she had friends to support her, but she never described in any detail how they helped her after her cancer. She remembered having to handle some of these critical moments of her diagnosis with no one there to support her. Because she did not believe in God, she chose to attend the Unitarian Church, but she never indicated that she had the active involvement or support that both Jim and Donna had from their churches. It appears that prior to her cancer her attendance at this church was only occasional and after her cancer she did not use this as a source of support.

Jim and Donna both had excellent support networks through their churches, both prior to and after their cancer. Jim had received much support from several priests and many church members. Jim also had a mother, brother and three adult children who were very supportive of him. His relationship with his family had been mostly positive prior to his cancer and remained so afterward. Donna had an excellent support network made up of her husband, friends, church members and her minister. Friendships and a relationship to her church had always been a primary motivating force in Donna's life.

The community in which people live is likely to impact how they will experience their cancer. Certainly, where people live influences not only quality of medical care, but also access to information and exposure to new ways of thinking. For instance, it could be assumed that Jim living in a small rural community may have had some limitations on getting the best medical care. This seems to be a possibility considering how he received confusing and contradictory diagnostic information. However, Donna also received confusing information in a major city. Ultimately, she learned that her local community hospital's diagnosis was the correct one, as opposed to an incorrect diagnosis offered by the National Institute for Health (NIH). This misdiagnosis resulted in her cancer progressing from stage II to stage III.

Living in a small community was actually helpful for Jim because he was constantly meeting people who had heard of his situation and expressed good wishes for his recovery. Even people he did not know came up to him to ask advice about their own situation or to wish him

well. The others in this study who lived in large cities seemed to have received sufficient support from the community as well, although Barbara often lamented that she was alone when she received her diagnoses.

Generally, it could be assumed that those who live in larger cities have greater exposure to new ideas through bookstores, TV, internet and diverse self-help groups. Perhaps the modern era ameliorates those differences more today. Even Jim, who lives in what he termed his own self-built “shack,” has a computer with internet access. He recalled the importance of reading about near death experiences and how very helpful this was for his understanding and acceptance of death. Barbara, who lives in a large metropolitan area, recalled a similar impact from attending a group for people who had near death experiences or were interested in them.

### ***Results: Pre-Diagnostic Phase - Existential Questioning and Spirituality***

Prior to his/her cancer experience each of the participants had clearly done some basic thinking about the meaning of life, what it is all about and his/her role in the larger universe. Both Jim and Donna believed in God and found a religious/spiritual orientation within an established church. Jim came from a very devout Catholic family where his mother worked actively with nuns in the community. Coming from a parochial and traditional view of Catholicism, considerations for divorce were very difficult for him. He actually contemplated divorce for decades before pursuing that course of action. Jim had stayed active in the church to the extent that he attended mass every Sunday. This was partly because he wanted to, but family pressure also played a role. Church had become a duty more than a heartfelt need. Jim’s relationship to God and church would change after his cancer. This experience allowed him to form a personal relationship with God. Today he feels that God had “turned him around for some reason.”

Donna’s background also contained a connection to an established church. She had been brought up in the \*\*\*\*\* church as a child, but at age thirteen her parents became angry at the church and stopped attending. For two years Donna did not attend church. Later, she met some friends at a \*\*\*\*\* teen group and decided to join their church. Donna’s attraction to churches, based on her impressions and feelings about the people in them, became a characteristic orientation of her experience with organized religion. Donna did not, however, base her involvement in a church solely on whether she liked people; she was always seeking knowledge about spirituality as well.

Prior to her cancer, Barbara had clearly done some thinking about spiritual issues, particularly in discussions with her mother, but did not go out of her way to learn and explore these issues as she did after the death of Rob, the love of her life. Barbara's parents were Jewish, but were not very strict and even accepted her break with the religion when she was in her late teens. Barbara came to believe that all religions were filled with hypocrisy and eventually she stopped believing in God and considered herself an agnostic. She had not continued to develop her spiritual beliefs in any depth until she reached her low point and eventual death acceptance.

***Results: Pre-Diagnostic Phase - Major Motivation***

The theme of major motivation is important in order to describe each person's movement throughout the phases in this model. It is important to understand what the major motivation was in each person's life prior to diagnosis and how it changed with the cancer experience. Major motivation is the dominant theme operating in each person's life and under which all other motivations can be subsumed. As one progresses through the phases of the model, each participant will continue to reassess this motivation.

Prior to diagnosis, Jim had been seeking for years what he termed "peace of mind." The stress he had suffered as a result of his marriage and in his work career, had motivated him to seek a quieter, simpler and less complicated way of living. However, he remarked that he still felt that something was missing in his life and he wondered why he could not feel better more of the time. Donna's major motivation in life prior to cancer was her desire to be a stay-at-home mother and homemaker. She had quit her job, knowing that her husband now made a salary sufficient to support them both, in order to pursue this dream of a happy life - the one she never had as a child. For Barbara, her motivation prior to cancer was to have an ongoing relationship with Rob, the man she termed the love of her life. Another part of her motivation was to see both of her children get good educations before she died.

Establishing what the major motivation or driving force in the individual's life was prior to the onset of cancer is critical as an organizing construct for assessing future thoughts, feelings and action taken through the subsequent phases of this model. Jim's original motivation of seeking "peace of mind" comes to fruition in an unexpected way as a result of his cancer experience. While Donna's motivation for the perfect family life and Barbara's motivation to always be with Rob were never fulfilled, they eventually changed in a way that was beneficial to both.

### **Results: Diagnostic Phase - Not Just a Moment in Time**

The Diagnostic Phase is launched from the moment the individual is confronted with the diagnosis of cancer given by a medical doctor. This is a life-altering moment that defines life from that point on and is impossible to ignore. The diagnostic period is a time of absorbing the shock of diagnosis to cope with such issues as death, altered body image and impact on job, finances and family life.

Diagnosis does not always come in one neat moment. Getting to a definitive diagnosis can be difficult and strung out over a long period of time. For example, Jim spent three months talking to multiple doctors, taking endless tests and receiving contradictory results. Diagnosis can also change every few months, growing progressively worse, as it did for Donna when she went from stage II to stage III to stage IV of non-Hodgkin's lymphoma all within months of each other. Cancer can also keep recurring through the years either as an expected part of a particular cancer or because of recurrence, as in Barbara's case. For each individual the process of diagnosis is different and inevitably helps to shape the person's overall experience with cancer.

Barbara was told in 1987 that she had elevated proteins which had to be monitored. It was not until 1991 that she was told her condition could be cancer. After careful monitoring for another six months, in 1992 she finally received a definitive diagnosis of Multiple Myeloma. Today she lives with the knowledge that her cancer is like a chronic condition and that she can expect her cancer to keep recurring. This throws Barbara into new periods of diagnosis, treatment and remission. Her hope is that surviving each period may ultimately keep her alive for a possible cure.

Donna has also suffered protracted diagnostic periods due in part to the initial misdiagnosis and vastly different conclusions from various prominent institutions. Her local hospital had originally diagnosed her with stage II, non-Hodgkin's lymphoma but a second opinion from the National Institute of Health (NIH) determined that she did not have cancer. By the time all institutions finally agreed on her diagnosis, the cancer had advanced from a stage II to stage IV, Lymphoma (Non-Hodgkin's). She had several treatments which only gave her a few months of remission before the cancer was back again. Even after chemotherapy, full body radiation and a bone marrow transplant, she only had a couple months of remission before she had to try an experimental clinical trial, which was ultimately successful. She has currently been enjoying remission for over ten years, but during this earlier period of her life with cancer, an

extended period of diagnosis was characteristic.

Jim also had an extended period of diagnosis lasting three months. Eventually he learned that he most likely did not have cancer. Some of the first doctors Jim consulted informed him he had six months to two years to live. While he continued to be sent to other specialists for opinions, Jim heard his diagnosis as a death sentence and prepared himself accordingly. Jim's focus after his diagnosis was not trying to rethink his life or establish a new identity, but was purely on preparing for death in all possible ways from spirituality to the mundane preparations of wills, a funeral and distributing possessions.

### ***Results: Diagnostic Phase - Acknowledging Death/Death Acceptance***

The challenge of the diagnostic phase is that everyone must simultaneously make sense of new shocking and negative information about the course of their life, as well as quiet the raging emotions that accompany a cancer diagnosis. The individuals in this study each received terminal diagnoses of varying lengths. Each came to terms with death and survived past indicated terminations for their lives. They had to choose, as all cancer patients must, a perception of what they believe the diagnosis meant to them. Is it a death sentence or is it just an illness that can be treated and they will eventually get well? Today, a stage I cancer diagnosis has cure rates as high as 95%, yet no one can afford to be oblivious to the possibility of death when he/she knows that 5% are likely to die.

Popular magazines and newspapers create a public perception suggesting the possibility of death in connection with cancer and AIDS more than other diseases. When diagnosed, each person processes this awareness of death at some level resulting in a reaction somewhere between denial at one extreme and death acceptance at the other. In this study, each person chose as an essential element of his/her meaning making, an orientation to or perception of death. This choice of perception can be viewed as a dimension ranging from denial to total death acceptance. For this study, denial is defined as a protective mechanism that shields the individual from stressful awareness that ranges from a semi-conscious process on one end of the continuum to total refusal to face reality impelled by unconscious impulse. As defined earlier in this paper, death acknowledgement means the individual knows at some level that death is a possibility, but s/he has not come to a deep acceptance of death.

Both denial and death acceptance can be viewed as having positive and negative aspects. Denial could be seen as (a) negative denial - the individual chooses to believe s/he does not have

cancer and requires no treatment; and (b) positive denial – the individual acknowledges the reality of the disease, possibility of death and pursues treatment but otherwise operates as if nothing were wrong by plunging back into the activities of his/her life. Data from this study suggest that denial should not be totally viewed in the classic psychoanalytic sense, but rather as Elizabeth Kubler-Ross indicated; that people can positively use denial at many different stages. They can consider death for a while but then must put it aside in order to pursue life. Life drives them on with the necessities of taking care of loved ones and having to support themselves and others.

Death acceptance can also be viewed on a dimension from positive to negative: (a) negative death acceptance – the person believes s/he will die so he/she gives up, take no treatment and waits for the inevitable death; and (b) positive death acceptance - the person perceives the possibility that s/he could die and so pursues new learning to understand what death is, who he/she is and how he/she fits in the universe and what death really means in this world view?

### ***Results: Diagnostic Phase - The Role of Denial***

Jim's case is a remarkable illustration of an individual who appeared to demonstrate no denial. He described how he spent several sleepless nights after being diagnosed, filled with crying, sweating and praying. He was diagnosed on a Tuesday and that weekend he met with the priest to make his funeral preparations, attend masses and meet the healing priest. By the end of that weekend, he had reached death acceptance. He did not sit around and wait to die but continued to pursue whatever the medical establishment could offer him and sought to prepare for death in every possible way.

Donna went through her cancer experience with very little denial, but only came to a deep acceptance of death when she was in the hospital receiving her bone marrow transplant that almost resulted in her death. From the time she was diagnosed with stage II Lymphoma, she rapidly progressed to new diagnoses of graver consequence and a series of endless treatments leaving her little time to contemplate anything other than what her next treatment would be.

In the psychological literature, denial is frequently presented in a negative light, suggesting a failure of the individual to face reality. Barbara's case illustrates how a person can use denial in a somewhat positive and nondestructive way that helps to further immediate goals. Barbara, when diagnosed and even after years of treatment, was not ready to seriously consider

death in a deeper philosophical and spiritual sense that might have brought about death acceptance. While she acknowledged the possibility of her death given her diagnosis, she really wanted to live to see her children through their college years so she used denial to avoid the deeper considerations of her situation.

Barbara may have had some denial when she was diagnosed with an elevated protein level in 1987. It is hard to believe the doctor did not mention the possibility of this eventually resulting in a cancer. Barbara did not seem to worry about this condition for the next four years. She stated, "He told me in '87 something ... I didn't know what he was saying, there was an elevated protein level and that was what he said about it."

It is quite possible that this was a patient/doctor collusion in which the patient does not want to push to understand the possible grim consequences of a condition and the doctor wants to spare the patient, as well as himself/herself, of mentioning cancer until absolutely necessary. Her next exchange with her doctor suggests that this was so, as he omitted the oncology part of her referral and minimized the possibility of cancer:

*...in 1991 when I was doing my blood work, he called one Sunday night and he said "now I don't want you to be worried, you don't have leukemia and you don't have bone cancer, but this elevated protein level is beginning to concern me and I want you to see a hematologist. He didn't use the word cancer. I didn't know what the hell he was talking about. I was pretty frantic at that point and became even more frantic when I got there and found it was [an} hematologist/ oncologist...*

When she went for her appointment with the hematologist/oncologist she became very assertive, perhaps because she felt deceived by her previous doctor. She explained how she entered this situation with a more determined mindset to learn the truth of her diagnosis:

*I walked into this guy and I said, 'look, I am told my ex-husband now is in the hospital with what might be a heart attack, I have two teenagers I'm single parenting, so don't bullshit me' and that is how I sat down to the oncologist. And he proceeded to bullshit me for several years .....and he gave me...he said, well, we can't give you a definitive diagnosis at this point. He said you might have something called "smolder multi melanoma " and he said, don't look it up anywhere because you'll be very worried by what you read and all this stuff is old. There is newer stuff out there and so knowing this is hematologist, I said are you talking about cancer? And he said, well, melanoma is*

*cancer, but I can't tell you that you have it. I can tell you that you might be developing it. So I don't know. There was nobody with me going to this appointment. I was alone and I was pretty hysterical.*

As is evidenced by the data presented above, Barbara alternated between periods of denial and periods of great assertiveness with doctors. She also was actively researching various resources to learn new information regarding her condition. However, after this last meeting with her hematologist/oncologist, she apparently slipped back into a period of denial. When she got home, she was waiting for Rob to come over and finish work on her house. She had been drinking (she described being “three sheets to the wind”) when he walked in. After she told him about her appointment with the doctor, he said, “What do you want to do?” She replied, “Decorate my kitchen.”

This response is typical of Barbara’s use of denial. It is also reflected in the way she answered questions by this interviewer regarding her feelings at various times during her cancer treatment. It was difficult for the interviewer to get answers about how she reacted to her cancer. Frequently, Barbara would abruptly explain other issues in her life. An example of this is the following questioning regarding how she dealt with Rob leaving shortly after she was diagnosed.

*Alice: How were you handling all this during this time? Here you are deserted by the love of your life at a time when you are very worried about what is happening to you.*

*Barbara: I think I was partly in denial as we all are. I had two teenagers, I was working.*

*Alice: Were they at home?*

*Barbara: Yeah. At that point, maybe one...Scott would have been. He was born in '76, so he would have been 15 and Debbie was 13. So I was running them to this and that and hither and yon, working full time. I didn't have time to deal with it. Now, I hadn't had time. My father had died of lung cancer in 1987 and my mother was diagnosed a year later with lung cancer. They both had been smokers.*

She goes from explaining that she had been in denial, to demonstrating this by suddenly referring back to her parent’s death which occurred several years earlier. While this does not answer the question, it does explain that she never really grieved her parent’s death, illustrating a pattern of denial in highly emotional situations.

Later in my interview with Barbara, she finally indicated how she reacted to her definitive diagnosis in 1992:

*Very tough time. I was in therapy. I'd been in therapy since after my mom died, I started therapy. I have a wonderful therapist and I started taking antidepressants and stuff then and I'd been on sleeping medication, but that continued, so life went on and I was coping, but there was nothing to cope with. The kids didn't know, I just went every three months for blood work. There was no treatment. So I'm working full time, I'm balancing kids, I'm active in the PTA, Mac's finally out...Mac sees the kids on the weekend and I'm just coping and it really was just coping. I mean it was just part of what was in my mind, but a very little part. Really I was consumed with living. I've always been and that's part of what I continue to do. I'm consumed with living. So I don't have a whole lot of time to focus on dying. Just consumed with living.*

Once again we see how her answering of questions was diverted with information on other aspects of her life, for example the importance of getting her kids through college. However, in this statement she acknowledges the possibility of dying – she simply does not have time to focus on it.

We can see diversion and denial in another segment of the interview presented below:

*Alice: We were kind of trailing along there where you had gotten your cancer. You were beginning to go ahead and move with it. You told your kids that now you are going to have....*

*Barbara: Probably have the transplant, but I remained relatively healthy. I was still working full time. We went down in August to move my son into college. At that point, he [her husband] hadn't been remarried and we had stayed close friends. We both agreed the divorce is much better than the marriage.*

Once again she diverted a discussion of the cancer by talking about her husband. Barbara has been in therapy for over ten years and probably understands herself pretty well when she describes that she dealt with much of her experience with denial. Barbara was certainly not in total denial to the point where she refused to accept and deal with her condition. Rather, she made a semi-conscious decision to focus on the issues of life because there were simply too many things to do.

### ***Results: Diagnostic Phase - Changing Motivations***

Once the individual has chosen an orientation to death, he/she will take steps to come to terms with death or make decisions about what exactly is worth living and fighting for. The

major motivation that was guiding his/her life prior to the cancer is reassessed and a decision made to hang on and fight for this or try something new based on this new reevaluation.

Barbara and Donna did not deny the possibility of their death but chose to put aside considerations of death in order to fight for their lives, for the men that they loved and to be with their children. The major motivation that was driving their lives did not change as a result of their diagnosis, but rather became the driving force to continue to live. Jim was divorced and had no significant other in his life at that time. His children were grown and out on their own, so he turned to death preparation and acceptance because he was at a different developmental phase.

Diagnosis presents the individual with an opportunity to find meaning and reframe the old life by existential and spiritual questioning and making decisions about what is really important in one's life. But not everybody immediately leaps into deep questions about the nature of existence and afterlife or questioning his/her own identity.

Jim, unlike Barbara and Donna, immediately set about trying to come to terms with the reality of his likely death which at that time was projected to be as early as six months. Even though Jim chose to seriously contemplate and prepare for his death, he was still doing all that he could to live. He continued to pursue and receive standard medical treatment.

Some people might wonder why he was so accepting of his doctor's early diagnoses. Why did he not wait until he had more doctors' reports and opinions? Perhaps a person with more education who lived in a large metropolitan center might have thought differently and immediately pursued a second opinion. It is likely that his old fashioned religious upbringing and relative lack of education made him inclined to respect and heed the word of authority figures. Jim was very trusting of both his priests and his doctors. When told by his first doctor that he would probably be dead in six months, he did not pursue a second opinion. He simply followed that doctor's recommendations.

Donna's response to diagnosis was similar to Barbara's, except with less denial. Donna had the same motivation; fight to live to take care of her children and be with her husband. Unlike Barbara, Donna felt she was having a very good life prior to her diagnosis. She wanted to survive to live the dream she had started by quitting work to stay home with her children and be a homemaker. Both Barbara and Donna were aware of the possibility of death related to their diagnosis (death awareness) but were not ready to begin to seriously contemplate the reality of death (death acceptance). This basic choice orientation to death sets the stage for other choices

about what is worth living for (major motivation) and what will be required to achieve desired goals. For those who made the decision to actively fight for life, they decided to “table” considerations of death in much the same manner as the person in Robert Frost’s poem who realizes “the woods are lovely, dark and deep, but I have promises to keep.” As in the Frost poem, the woods represent death, which the person has stopped to consider, but realizes he still has things to live for.

### **Results: Action-Result Cycle Phase - Introduction**

Because each phase in the model used for this study is not an absolute entity but rather a series of fluid events that are often intimately connected to other phases, placement in one or the other often can be somewhat arbitrary. For instance, on one level the diagnostic phase can seem for many people as a solid period of time prior to treatment being taken (action steps). On the other hand we know that people are taking action steps from the moment they are diagnosed.

For the purpose of this study, the action-result phase begins when the person has made some deliberate decisions about a course of action to be taken. Each person’s action steps are unique, reflecting the total context of his/her life, including such things as where he/she lives, marital status and children, family support and friends, or whether or not he/she belongs to a spiritual or religious group.

Even though the overall pattern of action steps for all participants is unique, there is a basic thread of commonalities that connects their efforts. The commonalities can be organized around several dimensionalized themes, described at the beginning of this chapter. But even more basic, all have chosen to do something. In other words, no one elected to just continue the same pattern of their life. All felt that they had cancer for a reason and they all ascribed meaning to the event. They may not have been able to express this at the action-result phase, but by the time they reached remission or new life they could articulate a cohesive story and a construction of meaning that set them on a new course for life. Meaning-making at the action-result phase can be very dramatic, as for Donna and Jim who came to a total acceptance of death. Or the action-result phase can be more about denial or partial denial, as with Barbara, who fully understood the implications of her diagnosis and the possibility for death, but frequently used denial to carry on with the activities of life.

### ***Results: Action-Result Cycle Phase - Initial Action-Result Cycle***

For each person an initial action-result cycle was undertaken shortly after diagnosis. This act was not given a lot of thought, having almost an impulsive emotion-driven quality that had a temporary calming effect. This initial action-result cycle established the pattern that would be followed by the individual in future action-result cycles. It is most likely that each person probably had several of these before he/she started major action cycles, but in this study only one emerged from the data for each person.

#### ***Results: action-result cycle phase - Jim's initial action-result cycle***

After receiving his diagnosis Jim, was in a state of great mental and emotional anguish. Unlike Donna or Barbara, Jim was told he might be dead as soon as six months. Both Barbara and Donna had expectations of several years when first diagnosed. Jim had sleepless nights, sweating, tossing and turning. His thoughts were mostly on the impact this would have on his family, not only mother and sister but particularly his three children. Jim was in a panicked state and unlike Donna and Barbara, had no one living at home with him to help support him at that time.

In order to cope with his agitated state as a result of his diagnosis, the next day Jim went to church to pray and “talk with the Lord.” This was Jim’s initial action-result cycle undertaken to help cope with his painful emotional state. Praying and going to church became characteristic of his future major action-result cycle.

#### ***Results: action-result cycle phase - Donna's initial action-result cycle***

After her first visit to a doctor, from whom she received a biopsy but still had not received the results, Donna learned from her husband that the doctor was concerned she might have cancer. The doctors were uncertain which kind of cancer she had, either Hodgkin’s or non-Hodgkin’s lymphoma. She remembered her initial reaction as being numb. She and her husband both panicked and started crying. Shortly after this they took immediate action.

Donna and her husband promptly went to the library to research both of these cancers. They learned that Hodgkin’s was less lethal than non-Hodgkin’s and they hoped that if she had to have cancer it would be non-Hodgkin’s. Eventually she learned that she did have the more serious diagnosis of the two, non-Hodgkin’s. Taking this simple action that night helped calm her and gave her at least a temporary sense of control. This initial reaction would characterize

her future action steps. She would continue to fight for her life and learn all that she could about her disease and how to take care of herself physically, psychologically, emotionally and spiritually.

***Results: action-result cycle phase - Barbara's initial action-result cycle***

As discussed earlier in this chapter, Barbara reacted with periods of alternating denial and assertiveness that allowed her to focus on taking care of the business of her life. This pattern of denial was established right from the beginning in her initial action-result cycle and would be followed through most of her treatment. Barbara did not worry about her diagnosed elevated protein levels in 1987. Not until the protein reached critical levels in 1991 did she began to panic. Her action step upon panicking was to get drunk and wait for Rob to visit so she could explain her situation. Using alcohol to escape the reality of her situation was later reflected in her use of denial to avoid facing certain aspects of her cancer experience.

***Results: Action-Result Cycle Phase - Major Action-Result Cycles***

Major action-result cycles occur after the individual has chosen a death orientation and made decisions about future motivations. Major action plans for the people in this study always included treatment choices, both within the medical establishment as well as alternative treatments. This section describes the major action-result cycles that occurred for each participant in this study. Some immediate remissions will be included in the section because of the close connection of action-results and some remissions. The transformative changes for each case brought about by death acceptance are described in the following section.

***Results: Action-Result Cycle Phase - Major Action-Result Cycles and Death Acceptance***

All participants in this study reached a deep level of death acceptance, not entirely as a result of an active pursuit but mostly after being confronted by events resulting in a low point of despair or near death which sent them searching for answers. Each felt it necessary to face death by coming to terms with it; seeking answers to important existential and spiritual questions that would help him/her understand the nature of death. Coming to terms with death became the ultimate motivation for the discovery of meaning in each individual's life.

The period of death acceptance was inevitably brought on by a time of deep despair which would be described by each person as his/her lowest point. Low points were characterized as periods of great emotional pain, a point where meaning-making efforts accelerated and were

accompanied by altered states and events characterized by intuition, synchronicity and receptivity to reading messages from the environment.

The period of the low point came about for different reasons. Jim thought he was going to die in a few months. Donna reached a low point in her treatment when she was told she only had a few months to live. Barbara was motivated to understand what happens to people when they die when Rob, the love of her life, passed away. This prompted her to mourn not only his death, but also her parents. She ultimately found answers that would help her confront the reality of her own possible death. Each participant came to this acceptance at different phases. For Jim, the initial diagnosis was his lowest point. For Donna it occurred in the action-result phase. For Barbara after her first remission and onset of relapse provided the context for her acceptance of death.

***Results: action-result cycle phase – Jim’s major action-result cycles and death acceptance***

Jim’s case illustrates how phases can run together and blur in distinction. His situation is different from the others in that his diagnostic phase and action-result phase merge. The major difference delineated in this study between these two phases is that individuals can be distinguished as being in the action-result phase due to the fact that they have reestablished motivation based on reevaluation of their goals after the impact of diagnosis. They may pursue their previously established goals if these are still achievable or strive for other goals based on a newly developed major motivation.

Jim quickly extended his initial action-result cycle into major action-result cycles. Jim came to death acceptance, which was not intentional on his part, just four days after his initial diagnosis. This reflected a change in motivation from “peace of mind” to preparation for death. He had been told that he only had a few months to live. The shock of this diagnosis was the worst experience he had ever had.

The Saturday of the week he was diagnosed, Jim went to church all day, prayed intently, confessed his life, made funeral preparations and went to mass with the healing priest. This eventful day resulted in his acceptance of death. What Jim did worked for him, for it brought him to a place where he found peace of mind that has stayed with him to this day:

*This is the amazing part. Once I had a long talk with our Lord, I was able to joke about it and everything else. For 90 days I thought I was going to die. They didn't have to give me*

*anything to make me sleep. The doctor kept asking me...sleeping all right? The power of what God would do for you is absolutely unbelievable, because it wasn't me. It was not me. It was amazing.*

This provided Jim something he had never experienced before, a sense of God's presence in his life. Jim's case provides an example of a person whose emotion-based actions lead his meaning making and future decision making strategies.

In the darkest moment of Jim's life, he sought comfort, solace, peace of mind and some meaning in the fact of his impending death. He pursued this understanding in the only universal meaning system he had ever known, the Catholic Church. Since he believed he would soon die, he had to learn more about death and prepare himself to leave this earth and meet God in the afterlife. He did this by having long talks with the priests, attending masses and by praying. He sought help through the Catholic Church and it worked for him. Jim never prayed to ask God to let him live, but rather he prayed for the ability to accept his death, which he received. He got an unexpected bonus, however. He got to live.

On the Saturday that resulted in Jim's death acceptance, he recalled two unusual events that ultimately had deep meaning for him. The first event occurred while he was at church that first Saturday evening. One brother and his two sons, who were in an entirely different city and did not know what he was doing that day, simultaneously had a feeling that something very good was happening to Jim. They tried to reach him at his home to find out how he was. The next day they spoke to Jim and learned that he had been at the mass with the healing priest when they got this impression.

Additionally on this day, there was a simple event that occurred at mass that evening that made a deep, meaningful and lasting impression on Jim. At one point during mass, everyone in the church, including Jim, wrote down their prayer requests on a piece of paper and placed it in a basket that was passed around. Each person then took a paper out of the basket and whatever was written on it was their prayer request. Jim picked one out that said, "For Jim, his tests come out good." When asked what he thought about this, tears welled up in his eyes and he said, "I took it as a message". Since he was in another church in another town, he could not understand how anyone he knew could have been there to write the message. Even if one person was there to write it the odds that he would select that one out of all the names would be rare. This seemed to have the effect of making Jim feel very hopeful at a time when he was at his lowest point.

After that Saturday, Jim continued his preparations for death. During this time he also took care of all the mundane aspects of death preparation such as preparing a will, giving or trying to give away some of his things in advance to his adult children, funeral preparations, insurance matters and even canceling his six month dental check-up. He also asked his sister, who is a nurse, to make sure he would not suffer. Plans were made to have a final meeting or ceremony with the family, to say goodbyes in case he became too incapacitated later on to be able to do this. His brother had arranged a meeting for Jim to say his farewells to his family including Jim's three adult children, his mother and sister.

Jim also continued to pursue more medical testing and continued his daily mass attendance and intense prayer life. He read books about dying and near death experiences and he shared his story widely in his church circle and offered comfort to others who had their stories to tell. During this time, with his strong religious and spiritual involvement, Jim began to feel an inner sense of peace that felt better in some ways to the way he felt prior to cancer.

*I was prepared. Whatever happened, happened. As I would go to mass daily, it was like a strengthening thing. It's amazing! It was a strengthening experience. It got to the point where...and you know what is amazing that...and I was on prayer lists all over the country...this is from a Baptist Church from \_\_\_\_\_. I'm on their prayer list.*

The knowledge that people were praying for him at different churches in various parts of the country was most encouraging.

Along with the increased recognition he was getting from church members who had heard what he was going through and offered support, Jim's church involvement was offering him earthly benefits in addition to the spiritual. In order to cope with his cancer diagnosis, Jim increased his church participation which resulted in an unexpected benefit of being more socially connected. This connection gave him a new important role of being one who had "walked the walk" and could give advice to others. The support given by Jim helped a number of people connect with the "healing priest" and attend special masses.

More and more Jim found that people were coming to him for advice about how to deal with their own diagnosis. Sometimes he would be asked to get up at church and tell his story to the congregation. At first he felt ill-at-ease and inadequate to give this advice, so he would frequently go back to people and ask them later if what he said helped. He soon learned it was just enough to tell his story. For a shy man this was a new and different experience:

*You see I'm an introvert. I'm a loner. But yes it's easier for me to relate to people than it used to be. I don't like crowds and things like that. But it is. It's easier.*

*That's like when I give my testimony; I get up in front of the church and gave my testimony. I would never dream of doing something like that. Something just drove me and I had to do it. I surprised myself even doing that. But I don't know... I reach out to people more and I'm starting a new relationship with a nice lady and I think that is part of it too.*

Jim has since married the woman he reported meeting at that time.

For someone who has been shy and retiring, preferring to stay on the sidelines all his life, Jim is describing an important change in his character. He is surprised at this quality of being driven to get up in church and tell his story. As one who has suffered and faced death, he knows he has something important to say and therefore reaches out to people more.

***Results: action-result cycle phase- Donna's major action-result cycles and death acceptance***

To receive a definitive diagnosis Donna had to go through an extended diagnostic period involving contradictory diagnoses from various prominent institutions. She was originally given a diagnosis of non-Hodgkin's lymphoma, stage II, by her local hospital. This diagnosis was soon refuted by a prominent national institution. The smaller hospital acquiesced to the larger institution and held off treatment. When the larger institution finally agreed she had cancer it had advanced to stage III and soon progressed to stage IV.

Donna's action steps included treatments such as two chemotherapies in which she had short remissions lasting only a couple of months. From the time she was first diagnosed, Donna went from one treatment to the next in fairly quick order as each treatment failed. Since the chemotherapies did not work for her, she was scheduled to have full body radiation and a bone marrow transplant.

Donna considered her bone marrow treatment and full body radiation to be the lowest point in her experience. She had to be in the hospital for a couple of months in a room she described as dark and dismal, a sterile room sealed off from everything and everyone. What she had to sustain herself during these dark days was a good support network including family, friends and her minister. Several months earlier, before she went to the hospital, she had all her friends come over for pizza and wine one night for the purpose of wrapping all her children's

Christmas gifts. She knew she would be in the hospital a long time and wanted to make sure they would have as normal a Christmas as possible. On the advice of a woman she met at the hospital, Donna kept an answering machine by her phone, because there would be days she would be too tired to pick up the phone and she encouraged her friends to leave messages on her answering machine describing the small details of how their day was going.

These actions reflect her continuing motivation to have things as perfect as she could for her family by making sure her children would be taken care of at Christmas time. She knew the importance of having social support and actively seeking assistance from family, friends and her minister as well as soliciting advice from other cancer patients to learn all she could to make her experience better.

Donna read and opened herself to advice from a variety of resources to learn all she could about her cancer, alternative treatment sources and spirituality. She read books on all of these topics, as well as bible readings and listening to self-help tapes, recordings of her church services and beautiful music. All of this provided her much comfort when she was incapacitated and could barely move. All of these action steps are an expanded version of her initial action steps immediately undertaken after diagnosis and provided a number of benefits. These efforts helped her to learn about all aspects of her experience in order to assess all her options, manage her emotions and restore some sense of control in a situation that is basically beyond her control.

But even with all her preparation, things got much worse. The doctors had her on a bed of ice due to a high fever and her immune system was showing signs of weakening. She could only eat a few tablespoons of applesauce a day. They called her husband back from a business trip in another city and she knew what they were thinking. Thoughts of death filled her mind, but there was no one she felt comfortable talking to about this issue. Fortunately, her minister broached this topic and asked her if she wanted to plan for her funeral. This laid the groundwork for her deep acceptance of the reality of death.

Her minister was the first to bring up this topic and Donna was relieved to finally be able to talk about it. It was at this point that she made preparations for her funeral, including requests for all her favorite songs and Psalms to be used in the service. That night after her minister left, Donna opened herself up to spirituality by reading, listening to music and praying a lot. This led to an altered state and a special spiritual experience.

*So that night I cried and I sat in the middle of the bed and I said, Lord I'm ready to go*

*now. If you want me to go, then this is it; I'm ready because I'm tired of fighting. I was still very confused over this holy trinity...the 3 people up there...so I said, look, I want you God, Jesus and the Host...all three of you guys down here right now and it was weird, because I said that and all of a sudden, there was a heaviness on my bed...this is weird and I don't always tell everybody this because some people think...I know I was on morphine, but this was not one of my hallucinations, this was a heaviness on the bed and I felt a warmth all around me and right away I said, you're here and I just hugged the air.*

*I'm sure if anyone was watching would think...I was just hugging the air and said...oh my god you are here and I said thank you and I laid down and I went into an extremely peaceful sleep and during that sleep my fever broke, my counts went up the next morning, the fever was gone...it broke.*

Donna had been on an ice bed for days with a high fever, but after her spiritual experience her fever had broken and her blood counts had greatly improved. The doctors did not want to release her, but Donna was back in a fighting mode and ready to take charge of her recovery. There were several times in Donna's experience when she demonstrated a strong sense of intuition about what would ultimately benefit her that ran contrary to the opinions of her doctors. This was one of those times. Her insistence paid off and the doctors released her early in January 1993. Like Jim, Donna had now gone through a period of deep death acceptance which gave her a boost of energy, a new confidence to face her ordeals. This would prove to be important because Donna still had so much more to endure.

After a short remission following the bone marrow transplant, Donna returned to the hospital with what she thought was a cold, only to be told her cancer had returned. This time Donna was given a message of no hope from one of her doctors. She promptly went back to her original oncologist asking what she could do since she had never before been given such a message. Her efforts paid off because he just happened to have met another doctor at a recent conference who was running a clinical trial in which she could participate. She then flew to San Antonio to participate in this study for a new cancer treatment drug.

When Donna completed her treatment in San Antonio, she was feeling good again. In October of 1993 she was deemed to be in remission because the doctors found no sign of cancer anywhere in her body. Since she had been in remission many times before, it could have been

possible for her to think that this remission would not last any longer than the other ones. Donna, however, seemed to have an inner intuitive sense that she was out of trouble and things would be better. Donna had this feeling at the end of her treatment in San Antonio. She remembered, "That was...I think I just gradually slipped back into life. But it would have been when I left Texas in October I felt like I had accomplished something. That this was going to work." She knew she would be all right.

***Results: action-result cycle phase - Barbara's major action-result cycles and death acceptance***

When Barbara received her diagnosis of elevated protein levels in 1987, she continued to have her blood checked until she received her definitive diagnosis in 1992. Rob had walked out on her in 1991 shortly after learning that she most likely had cancer. At this time, denial, therapy, sleep and antidepressant medications were her main coping mechanisms. Every three months she would return to the doctors for blood tests to determine when it would be necessary for treatment. In 1993 when her protein levels still continued to rise and her doctor was still recommending no treatment, she once again powerfully asserted herself and sought consultations elsewhere which resulted in her getting an oncologist that she was happy with. In February of 1994 her new oncologist started her on chemotherapy and then recommended the bone marrow transplant "while she was still young."

Barbara's only consideration regarding death at this time was whether she could see her son through his completion of law school. As with Donna, her major motivation was to live for her children and the man in her life.

*My only concern when we were debating about doing a transplant...I was talking with the transplant doctors at G\*\*\*\*\* and I asked the doctor...the night before. I said, look my son wants to be a lawyer, so that's 4 years of college and then 3 years, I want to be there and he said without the transplant, you probably won't make it. With it there is a good chance. And my son delayed law school for 2 years and I still made it. I made it! I made it! So my concern I think wasn't so much with death, it was that I couldn't die yet. I had too much to do. My kids needed me. Their dad wasn't much good for anything. I mean...he knew nothing about money, nothing about organizing a life, he was just out there and I was just too stubborn. I really think I knew I couldn't die. It was not an option. It simply was not an option.*

As previously discussed, Barbara's use of denial meant she did not spend a great deal of time thinking about herself during her periods of treatment. However, she did have an underlying spiritual development based on thinking she had done all her life. The core of this belief system was that she was not to wait around for any magical help in life; she had to make things happen herself:

*I do not...I have no belief in a God that has anything to do with what happens to my life. I believe in myself. That is where my spirituality comes from. It comes from a belief in myself and through all I've been through learning how and learning that I can survive. I can survive. The only thing that better not be thrown at me is the death of one of my kids. My belief was always that I had me. And that's where my strength had to come from. It had to come from me. It never came from there. It had to come from within me. That I had...my mother's belief had always been that if there was any sort of divine spirit then, what this divine spirit has done is someone says that doctor saved my life...it was God's doing, my mother's take on it would be, no. Whatever spirit there was...she did use the word God, but she didn't...what she said was God's only intervention in that is by giving man the intelligence...that if man chose to use that intelligence, they could then come across ways to save people's lives, but it wasn't God doing it. It was that these people had chosen to use what God had given them to the betterment of other people, but that God himself, is not the one that saved that person on the operating table. It was the skill of surgeons and that skill came from within the surgeons and so that is where it came to me it's within me.*

This belief in herself, along with her motivation to be with her children, always propelled her to challenge her doctors to get best answers about her condition in order to get the best care. This strong assertiveness that came through, even though alternating with periods of denial, kept her focused and emotionally under control during the most difficult periods of her treatment. It is only later when she experienced a series of setbacks in many areas of her life that she accelerated into a period of deep existential questioning and acceptance of death and spiritual growth.

***Results: special case – Barbara's major action-result cycles, death acceptance and remission***

A discussion of Barbara's first remission is included here instead of in the Remission section because Barbara came to death acceptance in her first remission phase. As mentioned

previously, the action-result cycles and remission are difficult to separate and need to be maintained in their integrity of occurrence rather than arbitrarily separated.

Barbara has had two periods of remission with her cancer. The first occurred after her full body radiation and bone marrow transplant in 1994 and lasted for approximately seven years. The fact that she has lived long past expectations and realized her goal of getting her son through seven years of schooling is greater success than she ever thought possible. At the end of this remission period her protein levels started elevating for a couple of years requiring treatment with a new drug in late 2001. But before she reached her second remission and the period of equilibrium she enjoys today, she hit a low-point at the end of her first remission in 2000.

Around this time she had some residual pain issues after the bone marrow transplant. She was beginning to feel well and started turning her attention once again to finding Rob. After the disastrous visit with him in Colorado, which was the last time she was ever to see him, her life once again began to grow problematic. In 1999 Barbara's protein levels had begun to elevate, indicating that she was going out of remission and would require treatment for the second time. She was offered the job of director of the organization she had been working for, but had to turn it down because of residual pain issues from the effects of her cancer. She now had to deal with the new director who treated her abusively. At this time, Rob died, leaving her to deal with the baggage of their unfinished and psychologically abusive relationship.

Barbara characterized this time as, simultaneously, the best and worst time of her life. Finally, all the issues of her parents' death, Rob's death, the loss of her job and her cancer could no longer be avoided by denial but had to be faced head on:

*You couldn't go any lower. And I had already realized that suicide wasn't a choice. I had worked through that in my previous crisis. But I knew and I read and I knew that there was finally nothing to stop me from grieving. I had nothing. I couldn't run from it and it was like I grieved my parent's death and his death. It was finally...there was nothing for me to do but grieve. So that was my job for 6 months...was to grieve and to come to some sort of meaning ...*

Like Jim and Donna, Barbara finally faced the issue of her death, as well as all her other unresolved grief. Like both of them she did this when things in her life had hit a particularly low point. Unlike both of them, her low point was not just about her cancer but involved trying to understand and find meaning in a relationship with a man whom she never married, but was the

love of her life. All of this propelled her into a period of great activity, a new motivation to grieve all of her loss, but perhaps most importantly, to try to understand Rob, forgive his cruelty to her and grieve his death.

This period in Barbara's life propelled her on a quest to understand life after death and caused her to question the existence of God and the workings of the universe. During this time, Barbara worked very hard to translate the adversity of her life into some deeper understanding and meaning. She began attending a group for those who have had or were interested in near death experiences. She described some of the things she did:

*I read this group advertisement in the newspaper and I went to that group a couple of times. I also began walking. Taking really spiritual walks and connecting with nature and realizing to everything there is a season and watching the leaves change color and watching them fall off and die, but then you know they are going to bloom again in the spring and incorporating that into my grief work. I swam and I would swim lap after lap, slapping the water, saying, "you bastard, you bastard, you bastard" with each stroke and sometimes it would be at my job and I would just kind of bend and pound out the grief...pound it out...just pound it out. And I knew finally that the only way to move on was to forgive him. ... but after this near death group experience fully led me to believe that absolutely we do go on. There is more. There is more to life. And there is a reason for what happened.*

She also planted a section of her garden with azaleas as she and Rob had often talked of doing. This was one of her final efforts of forgiveness and finding peace with his memory. She used this period to put together some understanding and forgiveness for Rob's often cruel treatment of her. She also grieved her parents and discovered some deep answers on spirituality from her walks in nature, participation in a near death group, meditation and reflections on discussions about these issues with her mother and father.

During her period of seeking meaning to understand and resolve the issues of her low point, Barbara had a number of events occur in which she found great meaning. She met Rob's brother's wife, Linda, at a craft fair that she had attended only by accident due to a friend canceling a lunch date with her, leaving her to wander around looking for something to do. One of the women selling crafts had the same last name as Rob. Although she did not recognize Barbara, when she learned of her connection to Rob she was thrilled:

*I said, I'm an old friend of his brother Rob...I'm Barbara. And she screams...you are Robert's Barbara and gave me a hug like you wouldn't believe. Linda when we had lunch filled in so many of the blanks of what had happened when Robert was sick and how bad it had and how much he had suffered and his kids left him alone and the whole bit.*

*And I came to believe...there is no reason for me to have gone to that craft fair. I believe he sent me there. This is when I began believing in ghosts and angels. Really believing! I believe he sent me there. That he knew I had to heal somehow and that by sending me to Linda she would help fill in the missing pieces and she did....and the near death experiences.*

Shortly after her experience of meeting Linda at the craft fair, there were a couple of other instances in her life that provided her with some “messages” about her life. She had a problem of an odd odor at her house. The gas company came out and discovered that her house was slowly filling up with carbon monoxide.

*A little Hispanic guy and he looks at me and he says...you very lucky...is not your time yet. I believed that was a message. Is not your time yet. A month later I was driving over to Virginia to a conference and as I was pulling into the conference I was hearing a thud, thud, thud while I was driving, but I'm going 80 miles an hour...what do I know. I pull off and I get into this conference and when I parked the car, the valet parking...the guy says, madam, do you know you had a flat tire? He said you are very lucky. It could have blown on the beltway...you could be dead. So I took those two messages...it somehow...it's not your time yet, you've got to get on with the living.*

Both Barbara and Jim had experiences of feeling like they were getting messages in unexpected ways that they would get well. In Barbara’s case two messages that it was not her time and Jim’s message at church that he would get well. This apparently heightened sensitivity to the environment seems to have an impact on the individuals finding meaning in their experiences. Barbara also found meaning in the incident of meeting Linda at a fair she unexpectedly attended. She believed that Rob had sent her there, so she could ultimately heal by learning more about what happened to him in his last years.

It was during this difficult period after Rob’s death that Barbara finally resolved all the unfinished emotional issues associated with Rob and her parents’ deaths. She also developed a strong and enduring sense of spirituality which she continues to develop today and which has

helped her deal with her cancer as well. In the fall of 2001 Barbara was deemed out of remission and received a new experimental drug. To date, she is still in remission. Discussion of Barbara's life since the remission is presented in the new life section.

### **Results: Remission - Introduction**

Remission is a word that describes a state that can be stable or static, as when a doctor pronounces the individual cancer free, or it can pertain to a much more fluid state, a temporary state or respite that the individual may be passing through until it is determined the malignancy has returned. With cancer some people are occasionally deemed in remission and stay that way the rest of their lives. For most, the popular conception is "You never know." For some, periods of remission interspersed with periods of treatment become the norm.

### **Results: Remission - Donna**

After her two chemotherapies Donna also experienced some very transient remissions which lasted a couple of months each time. This did not allow her to experience remission as a lasting phase. There was no time to feel a sense that she would be well. She barely had time to recover from one ordeal when doctors were calling her back for more treatment. Unfortunately, even after her full body radiation and bone marrow transplant, she returned to the hospital reporting a cold, only to learn that the cancer was back again. However, in October of 1993 after her experimental treatment in San Antonio, Donna was finally deemed to be in remission once again. The doctors told her it was based on the fact that they found no cancer in her body. She was feeling good and her blood counts and other indicators were now normal. Donna remembered how the doctors had a party for her at the hospital and she spent several wonderful days exploring and celebrating in San Antonio.

Since Donna had experienced a number of unsuccessful remissions, one might have expected a certain amount of skepticism on her part about this remission. However, she, like Jim, had a strong intuitive sense, different from previous experiences that everything would be alright:

*That was...I think I just gradually slipped back into life. But it would have been when I left Texas in October I felt like I had accomplished something. That this was going to work.*

Rationally, both Jim and Donna had reasons to expect their remissions to be short-lived. Jim had

been told by several doctors that he had cancer. However, when he was told by one oncologist he did not have cancer, he left that day believing he would be fine even though that doctor recommended he go to another doctor. The commonality between the two is their deep sense of intuition and the fact they both previously had experiences of death acceptance.

The process of experiencing the low point leading to death acceptance seems to bring with it a heightened sense of intuition and confidence that those who experience this phenomenon learn to trust. Donna also demonstrated this deep intuitiveness which informed her decision making a couple of other times. It started after her spiritual experience in the hospital which brought about her death acceptance. The next morning, she fought with the doctors to be released from the hospital. They resisted strongly and only agreed after much debate. But in this instance, Donna had a strong sense that her recovery would be better at home. Also, when she received her last treatment in San Antonio, her liver was exhausted and she had turned yellow. Once again, the doctors wanted to give her a long break, but she insisted on a shorter break because she “knew” that the treatment was working. Finally, Donna demonstrated this same sense of knowing that Jim did when she completed treatment in San Antonio.

This confidence occurred as a result of fully facing all the existential and spiritual issues related to death and knowing that no matter what happens – life or death – there is a sense of spiritual survival, connection and continuity with the universe that brings great comfort. It is probably somewhat in this sense that both Jim and Donna “knew” they would be well.

When Donna returned home from San Antonio, her oncologist informed her that her first benchmark would be to make it to the two year mark. Then if she made it to the five year mark she could be considered cured. She has long passed that five year mark and while she was certainly pleased, it was not the benchmark most people tend to think it would be. This was true for all the people in this study once they had passed the point where they came to terms with death. Somehow they took their remissions in stride, perhaps knowing that life really is a walk on the cusp of life and death. It is also possible the business of life simply takes over and all the ordinary everyday issues begin to take up the focus of attention again.

Donna returned home eager to get back to the home and family life she so loved, but it was not to be. Her husband was acting distant, spending as much time away from home as he could or retiring to another room in her house to drink when he came home. This was particularly painful for her because she was not working and looked forward to his getting home

each day. She recalled that time:

*So I was really trying to make it to that 2 year mark and probably about a year and a half I had only about 6 months to go before 2 years was, when my husband left and he just walked out one day...he just couldn't take it. I was like...we just been through all this...this is nothing now. So that was really devastating and the doctors were a little bit worried that I might do something...the stress of it might put me back into...*

The irony of this situation was not lost on Donna, fighting for her husband and children were what kept her alive through her cancer ordeals and now that she was well, her husband left her.

*And I thought to myself...if Eddie left me during treatment I would not be here...I would have given up. I kept fighting not only for the children...it wasn't just for the children, it was "for the marriage"...the whole thing. I thought I had a dream world because I thought he was the perfect person and then I thought here I have this beautiful life...I've got to fight for this. I remember just being so grateful for my life and fighting for that reason...one of the reasons I was fighting, but and after all that he left.*

Donna realizes now that her dream of having the perfect home life was one that probably would have crumbled even if she never had cancer. However, it still served an important purpose in her life because it kept her alive during the darkest days of her treatment. Looking back, Donna realizes that it was a blessing that her husband left, because at the time she did not see how controlling he was and she never would have been strong enough to leave the marriage.

*I enjoyed my job and in some ways I wish I had kept it only because...but I wouldn't have been able to with the cancer because I had gotten so sick, but in some ways I sort of wish I was working because what happened is when I quit, I sort of lost my identity. I didn't realize that with Eddie. Eddie started to control and I lost my identity. Especially with being sick like that...I relied on him so much and I think I totally became like a little puppet or whatever, I was just afraid of anything or getting him upset or anything. Before, when I worked and all that, I was independent and I blew it off. You are not going to talk to me like that, but I just allowed it to happen. It got really bad, so it was really a blessing that he left, but I didn't see it that way at the time. Yeah, because I would not have been strong enough to leave, I would have never left. So, I would have been under that oppression as such...which wouldn't have been good.*

This remark suggests that recovery from cancer had forced a dependent role on her in which she did not feel she could assert herself in her relationship with her husband. Donna, of course, thought that she was coming home to a perfect family life and marriage. She appears to be trying too hard to make it work by holding back her real feelings. Since she previously described that he met the woman he ultimately married while she was away in San Antonio, it is likely he already had lost a sense of investment in the relationship.

Her failing relationship with her husband, physical complications as a result of chemotherapy and radiation and the fact she was unable to work, contributed to a loss of confidence and identity. Donna recalled how when her husband left, she went to a divorce lawyer who also gave her some feedback about how she appeared at the time.

*My lawyer says that she just can't get over. What I was like when I first walked into her office. Of course, I'm working now and that helps a lot too. But I couldn't work at first and when he left, I still couldn't work...they didn't want me to work. So, I went to an attorney and she said...you just sat in the corner and you were all huddled up and you were just this mess...you looked awful. When he left and he...just when I went and saw her and she said since then, I've grown so much. The cancer made me stronger...*

The cancer experience eventually did make Donna stronger, but at the time of her husband leaving her, she had not processed all of that and was mainly experiencing the loss of her dream of the perfect family life.

During this period, Donna coped by involvement with her church. As usual, her minister was instrumental in giving her solace. She also got Donna involved in training to become a Steven minister, a special lay person who can assist others who are in need. Donna also credited the young Ethiopian woman, whom she employed to take care of her children before she got her cancer, for offering her emotional and spiritual support at this time. The first few years after her remission were fraught with problems, but eventually Donna improved physically, got a new job and moved onto a new life described in the next section.

### ***Results: Remission - Jim***

Even though Jim in all probability did not have cancer, the dynamic in his case is very much like someone who was diagnosed and either successfully treated or had a spontaneous remission. For three months, Jim's infliction with cancer was totally real to him, since he had been told by several doctors that he could die as soon as six months. That was all Jim heard – six

months. So with a total absence of denial, he prepared himself for three months for death, until he was told he did not have cancer. He recalled that meeting with the oncologist:

*My sister went with me, so she...and that's when he told me...you don't have cancer. But he said we don't know what it is. That is when he recommended that I go to this surgeon and get a biopsy, but when I came out that day, that's when I knew for certain I didn't have cancer.*

Because he had prepared so well for death and had focused so intently on going to heaven, Jim found it hard in many ways to deal with the reality that he would live.

He pointed out the ambiguity of his response:

*That was the deal right there. It was like...in one way...it was like a sense of relief that I'm not sick and the other thing was I had myself so prepped to go to heaven that I had mixed feelings. I actually didn't sleep well for about 3 days until I get myself back in the mode to work. I continued to go to daily mass and pray intently and tell him...I tell him thanks for and help me do whatever he plans for me to do. I guess. I don't know. That's all I can say.*

Once Jim got over his initial shock of not dying and going to heaven, he had to come to terms with his life after an amazing experience. The remission part of his experience was not important to him in coming to terms with death, but certainly he had to reconstruct the gift of life in light of his new understanding and ability to cope with death. Turning back to his new life was made easier by the fact that he had been changed by this experience and had even created a new life for himself by becoming more involved in his church and having a special role as someone who coped and survived cancer. In his small town and Catholic Church environment, Jim achieved considerable stature by having gone through such an experience. Some even believe that he may have experienced a miracle. Jim does not believe this himself; however, he did question the doctor about it and was told that unless a biopsy had come back positive it would be impossible to say.

While the confrontation Jim had with death resulted in him preparing on all levels of his being for death, almost inadvertently and paradoxically, he had intensified his involvement with life. As Jim increased his involvement in his church, he found himself embedded in a community of support. As his story spread throughout the church and the community, he found people continually coming up to him to tell him that he was in their prayers. He was amazed to find that

he was on prayer lists all over the country including some Baptist churches.

Prior to his cancer scare, Jim went to church on Sundays, prayed occasionally, but had little personal sense of God in his life. He now had more of a personal relationship with God, a sense that God had changed his life for a reason. He had often talked of a feeling that something was missing in his life, of being depressed, stressed and taking nerve pills for years. He talked about many years of searching for “peace of mind”. Jim reported that the “psychological piece” is the biggest difference for him, not feeling stressed or worrying as much.

### **Results: New Life**

There eventually comes a point when life begins to stabilize, the person begins to understand what to expect from remission and has reconceptualized the impact of cancer on his/her life and feels stronger for having had the experience. Each person was transformed by his/her experience and knew there was no old life to go back to. Their lives are forever changed. When exactly each person crossed the line and got to a point of feeling stable in a new life can be difficult to pinpoint. Jim and Donna both had an intuitive “sense” that things were going to be better. Jim had this sense when he went to his oncologist and was told he did not have cancer. Even though many doctors had told him previously that he had cancer, he left that day feeling confident about not having cancer and that confidence persisted even when future doctors would tell him again that he did have cancer. Donna “knew” when she left San Antonio that she was going to be all right even though all her previous remissions never lasted more than a couple of months.

Donna also had a couple of important benchmarks. The first was to make it for two years and then, if she made it to five, she could be considered cured. She has survived now over ten years, but does not really talk about being cured, preferring to acknowledge that it is always possible cancer could return. However, she does not worry about it, but rather focuses on the present, a one-day-at-a-time philosophy espoused by the other two as well. Barbara’s thoughts on this seem to reflect the others’ thoughts as well:

*Every day is a miracle that I'm still in remission. What is there to be upset about? Am I thinking about when I relapse and when I die? No. Not really because that is not today's problem. When it happens, I'll deal with it. And when I do think about okay, what happens when it's over and you are dying? I don't know. I can't...I don't know how I'm going to handle that because I do believe the soul goes on.*

Even though Jim was told that he did not have cancer, he was still clearly puzzled about the many confusing diagnoses he received. He, like the others, seemed to acknowledge that if sometime in the future he did get cancer, he could deal with it because of having come to an acceptance of death. None of the individuals seem to be counting each day of their survival, rather they are so focused on and grateful for each day that they are still here. From time-to-time, they then have an awareness that a certain amount of time has passed. Even though Barbara knows that her cancer will recur, she does not sit around dwelling on this, but has moved on to filling her days with the things that are important to her.

Donna feels that it is important to give back, so she now participates at her church as a Steven minister, a lay person specially trained to minister to troubled and suffering church members. Jim does not actively seek out participation to give back; however, he is frequently called upon to talk to others who have received a life threatening diagnosis. Often times he helps connect people to the healing priest's masses.

Each of these participants chose to weave for themselves, from threads of despair, a new and meaningful pattern to their lives. Their stories are not tales of unbridled optimism but rather the stories of individuals that have grappled with the depths of despair and emerged stronger and wiser for having visited the dark places.

Today Jim feels that he no longer searches for peace of mind, he has it.

*I don't know. I always loved nature because I grew up on a farm. I liked the changing seasons and I go walk a lot and stuff, but when I walk now, I feel differently than I used to. Used to just walk by...sit out there and watch the sunset. I just feel different. It's just better. It's just like an extreme peace. All I can tell you is that it's peace of mind. It's like satisfaction. Peace, satisfaction. Life is great! It doesn't get any better than this.*

Currently, Jim is still trying to derive all the meaning he can from his experience. He knows he does not have all the answers, but he is sure that he is better for the experience and that God touched his life for a reason.

*I don't know if I had cancer and it was cured or if this just happened. But whatever happened, God had something to do with it. He was changing me around for something. I'm convinced of that, but I don't know what how he did it.*

Donna never got to realize her dream of a happy family life, but seems very content to use her life to give something back to others. In addition to working a fulltime job in administration for an association, she loves her role as a Steven minister. She explained:

*So, the Steven ministers and they are through all denominations...all Christian denominations. They are Catholic, Baptist, Lutheran, Presbyterian, Methodist and you are trained as a Steven minister and you go through a 9 month training every week for 2 or 3 hours. It's pretty intense and you learn care giving and it's just care giving. It's caring for people. Listening.*

Recently Donna was assigned a young woman who showed up at the church crying after being diagnosed with cancer. Donna talked to the woman who was most grateful for her help. She, like the others, clearly enjoys being able to reach out and help others as a result of having survived her own incredible ordeal. As Donna recalled her response, she also mused about a possible meaning to her cancer ordeal:

*You have made a big difference and so I wrote that down. I thought this is why you do it. It just makes you feel good that you maybe helped someone.*

*Yeah. I was just so thrilled when she said this made such a difference. I can face this now. I can see you and I know I've got hope and I've had a lot of people tell me that, so that makes me feel good. That makes me feel real good. So I said, maybe this is why I went through it. I was trying to figure out the reason I was going through all this.*

For Jim and Donna cancer is clearly the transformative element in their lives. Barbara through an on and off semiconscious use of denial had always given cancer a secondary role in her life. Her careful working through and understanding issues of spirituality came about due to several events breaking down her denial and resistance to finally grieve past losses and find meaning to the events of her life. Her lowest point occurred after a confluence of events, Rob's death, loss of an important job and the return of her cancer. Barbara makes it clear what she considered the most important of these.

*What is interesting is as we've been talking...what you've picked up on is we are not talking about cancer. Cancer has always been a sidebar. What has forced me to explore my own spirituality has been Rob. Not the cancer. Cancer has been a day at the beach compared to the emotional pain that I've gone through, through him. In terms of the cancer, again I think I've always been focused on living and not dying with it.*

From this, Barbara worked to develop her spirituality, to find answers to life's deepest questions. Today the meaning she found informs how she lives her life. No longer does she feel the need to question, "Why me?" She has made peace with her "sword of Damocles" existence and seems content to just enjoy each day, knowing that when the end comes she will be all right. She, like the other participants, also feels a sense of being grateful and wanting to give back.

*I don't ask why I'm in remission...I just accept this is what is and that is another biggie. What is, just is? Play the ball where it lies. That's what is. And so that is right. We are all connected in ways that at some point we will understand. But for now, it's comforting for me to know and to feel and to believe first of all my purpose in life is clearly to help others along the best I can: To love my children, to be kind to people and to have fun. That's why I'm here. And, when I die that energy will go on. It will go on.*

Her work had always been developing intergenerational programs for kids and the elderly. Now that she no longer works, she still has a passion to help kids, especially immigrant kids. Since 1999, Barbara has been working with a young girl from Haiti. This girl asked her to help a young girlfriend of hers from Cameroon. Barbara is helping to mentor them to get their high school degrees and to help them adjust to life in this country. In addition she also helps counsel individuals newly diagnosed with cancer, writes a column for a cancer journal, contributed to a book that was published and was paid for writing her cancer story. Presently, Barbara participates in an on-line support group for people with Multiple Myeloma. There are scientists who answer all the technical problems, but Barbara is considered the "emotional soul" who answers the feeling questions. She, like the others, seems to have reached a deeper level of understanding and peace with her life.

### **Conclusion**

This chapter has described the findings derived from coding and analysis of the interview with three survivors of terminal diagnosis. The results were presented as a five phase model of terminal diagnosis survivorship. The model presented a framework that described eight themes derived from the data describing aspects of the phenomenon under study. The five phases represent the activities taking place during the survivors' journey: precancer, diagnostic, action-results, remission and new life. The themes occur in varying degrees throughout the five phases describing the individuals' reactions forming the process of terminal diagnosis survivorship. The

reader desiring to read a summary of the model is referred to the section, Overview of the Process Model, located at the beginning of this chapter.

## **CHAPTER 6**

### **CONCLUSIONS**

#### **Introduction**

Chapter six will describe the conclusions resulting from analysis of the data and development of a model of terminal diagnosis survivorship and extended survival. The theory presented here is more nuanced and comprehensive because it extends psychosocial and spiritual cancer research and challenges the heavily rational and cognitive based theories of adult learning and post trauma survival. One of the strengths of this model is that it synthesizes disparate bodies of literature including psycho/social/spiritual cancer research, post trauma survival research, adult learning and adult development. Conclusions will be presented in five sections: Centrality of Death Awareness/Death Acceptance; Comparisons to Other Models of Process; Transformative Change; Recommendations for Future Research and Implications for Future Research.

#### **Centrality of Death Awareness/Death Acceptance**

The salient factor that emerges as a central organizing construct from this study is death awareness/death acceptance. How the individual deals with this issue will determine the extent of transformative changes evidenced. Death acceptance is the key transformative element of a survivor's experience from which a constellation of other positive transformative behavioral changes flow. Other studies of long-term or extraordinary survival of cancer (Berland, 1994; Blu-Wagner, 1998; Huebscher, 1992; Roud, 1985) reveal many commonalties including the importance of facing mortality issues, exploring meaning and purpose to life, assuming responsibility for life, transcending ego and finding meaning to life through transpersonal levels of consciousness, altered states and spirituality.

While there is a wide variance in the unique path each individual takes to recovery, all of these studies reveal a similar pattern of attitudinal, affective and behavioral change as a result of a terminal diagnosis of cancer. What has never been delineated in any of these studies is an explanatory process that would account for the constellation of behavioral change experienced by the survivors in these studies. Too often this research has relied on the attributions made by survivors as explanation for behavioral change rather than viewing these attributions in a broader context of total process, which includes the unique qualities of the individual and concomitant

opportunities available in their respective environments.

In some studies, participants have indicated a myriad of behavioral changes that they explain with such attributions as “right attitude,” “took up Qi Gong” or “became more assertive.” Roud (1985) found that existential changes and spiritual changes occurred in his participants (spontaneous remitters) prior to recovery, although their attributions did not reflect this process. Berland (1994) reports a personal correspondence with Huebscher (1992) who studied nine spontaneous remitters that all evidenced spiritual and/or existential shifts in behavior, but did not always attribute their recovery to these changes.

The present research describes an organizing construct of death awareness/death acceptance from which individuals take an approach/avoidance orientation. The more individuals move toward death acceptance the greater the transformative change. Extreme use of denial or avoidance is likely to result in physical deterioration and pathology. However, this model allows for a role of positive avoidance or denial which can be very functional, providing the individual with time to take care of more pressing issues in life, postponing confrontation with death acceptance until later.

What was observed in this study was that each person at the moment of diagnosis chose an orientation or perception of death. This perception ranged from denial to total death acceptance. Jim moved quickly to death acceptance within a few days of his diagnosis with remarkably little denial. Barbara used an avoidance or semi-conscious denial to put off considerations of death and focus only on her treatment and care of her children. Donna was originally given a stage II diagnosis. She realized the seriousness of this, but had little time to reflect; confusing diagnoses continued and were followed by one treatment after another. She came to death acceptance when she was finally told she had six months to live after her bone marrow transplant.

Death awareness must be distinguished from death acceptance. Death awareness refers to the individual’s conscious recognition of death as a possibility given his/her diagnosis. Death acceptance occurs after serious existential and spiritual questioning resulting in answers to such questions as, what is death, is there a soul and what does it mean when the physical body dies? This concept also includes an emotional grieving process comprised of the resolution of emotional issues unique to the individual and a letting go of the people and things of this world one loves. When a person can answer such questions, find emotional resolution to important

issues and is able to concomitantly say goodbyes to loved ones, then he or she has reached a deep acceptance of death.

This study presents a model of terminal diagnosis survival that challenges and extends theory in adult learning and post traumatic survival. These fields of research are dominated by heavily rational and cognitive models of transformation that do not sufficiently delineate the role of emotions in facilitating behavioral change; nor do they describe the role that extrarational processes, altered states and spirituality have in furthering meaning-making in the transformational learning process. Additionally, this model highlights the importance of holding environments, in both sustaining and eliciting developmental change.

### ***Centrality of Death Awareness/Death Acceptance: Death as Fundamental Ground of Existence***

Yalom (1980) postulated that the primary existential concern most denied by Western societies is the inevitability of death. He described that, “life and death are interdependent; they exist simultaneously, not consecutively; death whirs continuously beneath the membrane of life and exerts a vast influence upon experience and conduct” (p. 29). While the biological life-death boundary is unmistakably definitive, the psychological boundaries between life and death are permeable and yet must be confronted by the individual in order to live a meaningful life. Yalom states,

*Death is a fact of life; a moment’s reflection tells us that death is not simply the last moment of life. ‘Even in birth we die; the end is there from the start,’ Manilius said. Montaigne, in his penetrating essay on death, asked, ‘Why do you fear your last day: It contributes no more to your death than each of the others. The last step does not cause the fatigue, but reveals it.’*

*Virtually every great thinker (generally early in life or toward its end) has thought deeply and written about death; and many have concluded that death is inextricably a part of life and that lifelong consideration of death enriches rather than impoverishes life. Although the physicality of death destroys man, the idea of death saves him. (p. 185)*

Yalom (1980, 1989) bases his idea of how death saves man on the work of Heidegger. Heidegger (1962) postulated two fundamental states of being in the world: (a) a state of forgetfulness of being; and (b) a state of mindfulness of being. The first state pertains to the life

most people have of being immersed in everyday reality, concerned with the “way things are,” trying to please others and often lost in “idle chatter” or “entangled everydayness.” In this state, the individual engages in uncritical participation in the world described as an inauthentic existence. The other state of mindfulness of being is portrayed as an authentic existence characterized by self-analysis that frees the individual from the anonymous forces of the culture in which s/he lives. One is aware not only of the fragility of being, but of responsibility for one’s own being. Yalom (1980) states that “one becomes fully self-aware – aware of oneself as a transcendental (constituting ego) as well as an empirical (constituted) ego; one embraces one’s possibilities and limits; one faces absolute freedom and nothingness – and is anxious in the face of them” (p. 31).

Facing these considerations of death can be terrifying to most people embedded in the ordinary, but unthreatening, concerns of everyday life. Most people do not live in a state of mindfulness of being. The reality is most people plunge themselves into the everyday existence as defined by assumptions, values and beliefs of the culture in which they live. Western society, in particular, worships youth, obsessively focuses on the material and eschews reverence for the elderly that is central to many other cultures. All of this makes for a materialistic, death denying culture (Kubler-Ross, 1969; Yalom, 1980) and exacerbates the natural tendency to exist comfortably in the illusory bubble of invulnerability to mortality.

However, one does not move to a more authentic state of being by mere contemplation alone, but only through certain jolting events Yalom (1980) described as boundary situations. The boundary event is defined as an urgent experience, jolting the individual out of the state of forgetfulness of being and into mindfulness of being. He described that of all these boundary situations, “death is the nonpareil” (p. 31). The other boundary experiences have power, because to some extent they evoke aspects of death. Divorce, loss of a job and awareness of aging are all boundary situations confronting us with the limitations to our existence, bringing sorrow and change.

Counselors frequently extend Elizabeth Kubler-Ross’s (1969) stages of grief to help people cope with other losses in their life mentioned above. Once again, these losses conjure the ultimate loss: death. The individual is jolted by the boundary situation into mindfulness of being or what Yalom (1980) described as the “ontological mode.” The “ontological mode” is a way of operating in which one accepts responsibility for one’s own being, acknowledging the capacity

for self-creation. Most importantly, Yalom indicates that it is only in this mode that the individual can deeply understand the power to change oneself.

The moment of diagnosis forever destroys the old order of one's existence. Perhaps there are those who receive a stage I diagnosis who are treated and quickly move back to their pre-cancer life, regarding it as no more than a critical health issue akin to having a gall bladder removed. One seeks treatment and ostensibly is cured and returns back to his/her normal experience. His/her current meaning structures or schemas have assimilated the experience.

The individuals in this study all received either a definitive terminal diagnosis or indications that they only had a finite period of time to live. As discussed earlier in this paper, a diagnosis of cancer brings with it the specter of death. Certainly confronting death, more than any experience, has the power to shatter all our assumptions about life. They could not have avoided eventual confrontation with their mortality except through pathological use of denial which is relatively rare. Elizabeth Kubler Ross (1969), who worked with dying patients for years, only reported seeing a few people who died without accepting the fact they were dying. In our country, for the general public, there are probably no diagnoses that conjure up the specter of death more than cancer and AIDS. It is this shock that initiates the shattering of the individual's world and the assumptions upon which it has rested. It is from these seeds of despair that transformation takes root.

Naturally, with a diagnosis of a life threatening disease such as cancer, one becomes catapulted out of his or her assumptive world and must face the challenge of reconstructing a new life. Mezirow's (1991) transformational learning theory helps to elaborate Heidegger's (1962) transition from "forgetfulness of being" or embeddedness in everyday realities to a state of mindfulness of being and greater responsibility and control for one's existence. Mezirow's perspective transformation is a process whereby adults change their meaning perspectives, expanding consciousness through greater inclusivity.

### ***Centrality of Death Awareness/Death Acceptance: The Existential/Spiritual Shift***

As was described in the literature review, the spontaneous remission literature describes the diverse paths that individuals pursue for healing and that, despite the diversity, there are also remarkable commonalities between individual stories. Each person utilizes a wide range of personal and spiritual belief systems; pursues vastly different medical treatment as well as

complementary treatment; and exists in a unique context consisting of widely varying family, work and community systems.

Most studies, in varying degrees, indicate the importance of facing mortality. In addition, there is a constellation of behaviors evidenced and often referred to as an “existential shift” or “turning point” in behavior. (Berland, 1994; Blu-Wagner, 1998; Hawley, 1989; Hirshberg & Barash, 1995; Huebscher, 1992; Ikemi et al., 1975; Roud, 1985; Schilder, 1992). A number of attitudinal and behavioral changes characterized the existential shift: willingness to take responsibility for one’s life and recovery; living life congruent with one’s personal values with less regard for societal concerns; greater assertiveness in expressing these values; increased meaning and spirituality, a sense of universal connectedness; deepened relationships and need to give something back to others.

The results of this study help illuminate the nature of the existential/spiritual shift. All participants in this study demonstrated this shift as manifested by a constellation of attitudinal and behavioral change. This shift was evidenced at the lowest point in their experience. This low point arrived at different times for each person. Jim’s low point was his diagnosis, in which he totally believed doctors who had informed him, that he only had six months to live. Donna’s low point came after a grueling regime of treatment including a bone marrow transplant and full body radiation. One might have thought, objectively looking at her case, that it would have been even worse when later her doctor told her she only had six months to live. What is important is her subjective experience, so it is not possible to recognize a low point except as it is subjectively experienced.

The low point does not necessarily correspond to receiving a terminal diagnosis. Barbara’s case is unique because her low point did not occur as a result of her cancer experience; but rather, it was the result of the death of Rob, the love of her life. (Although in coming to terms with his death, she also came to her own after having used denial for years.) But the salient point for all cases was that the low point initiated and resulted in complete death acceptance. As a result of this experience, each participant exhibited increased energy and exuberance for life followed by the constellation of attitudinal and behavior change so often described in the literature.

Many of these studies also indicate that some part of this constellation of behaviors is frequently initiated by the individual early in his/her recovery which continues to develop into a

full range of behavior just prior to remission. This has prompted some debate about whether or not the individual's active pursuit of psycho/social/spiritual changes initiates the recovery process; or does this process occur largely outside of conscious control, perhaps impelled by the emotional trauma of diagnosis.

The results of this study support the role of emotions in initiating conditions favorable to transformation. However, this is not to say one totally precludes the other. Donna had actively pursued psychosocial and spiritual changes early in her cancer treatment when she was still considered a Stage II or III, long before her eventual low point.

### **Comparisons to Other Models of Process**

Tower (2000) asserted that literature on growth after traumatic events reveals "static" descriptions of changes such as "improved relationship" or "new possibilities" (p. 248). He illustrates that these concepts do not allow for the possibility of evolutionary change in the journey of the survivor. This parallels the previous discussion that attributions by the survivor do not constitute a bottom line on the individual's experience. To account for this evolutionary growth Tower introduced a model of a dynamic change process occurring over several stages.

In Tower's (2000) model he asserts that growth in the cancer survivor's journey evolves as a result of a significant existential insight which occurs at the time of diagnosis. This immediate insight expands consciousness resulting in the individual's reprioritization of life, initiating a constellation of changes frequently described by his study, as well as research from extended survival and spontaneous remission studies previously mentioned. These changes include the development of important relationships, greater appreciation of life and new possibilities and increased spirituality. He describes that these core changes evolve throughout the cancer survivor's journey, augmented by "critical self-reflection and a dynamic ongoing struggle with the trauma and stress caused by the illness, into higher levels of wisdom, consciousness, meaning, congruency and time urgency" (p. 249).

Tower (2000) further describes that at the moment of diagnosis the survivors experience an immediate disconnect from their sense of immortality and strength. The individual faced with the possibility of death experiences an immediate insight which produces behavioral change which is "sudden and automatic;" although feelings of terror and grief may make conscious realization take weeks or months. This is further described as a turning point, the start of a dynamic and evolutionary change process which will continue for several years.

This study differs from Tower's (2000) by describing the salient change factor as death acceptance rather than an existential insight at the time of diagnosis. Certainly, the moment of diagnosis which shatters the assumptions and illusions of the individual's previous existence is dramatic and undoubtedly launches changes that will eventually lead to transformation or psychological dissolution and pathology. However, in this study none of the participants exhibited an existential insight that forever set their course of action.

However, the question must be asked, what is the essence of the "existential insight" except death awareness? What is this insight based upon? This insight becomes powerful due to the impact of death awareness. Tower (2000) certainly understands this as he describes the impact of his own diagnosis of cancer, "All I could feel at that moment was the terror of nothingness." This is a perfect expression of the emotion-laden response to death awareness – the realization that "I" could die. He goes on to indicate, "The diagnosis of cancer is almost always a complete surprise, a moment that has no preparation because it is inconceivable to think of oneself with cancer until actually diagnosed. Cancer is death. It is the hidden face of the Grim Reaper" (p. 174)

Towers' (2000) research has multiple references to the importance of the impact of mortality, but like so many other researchers, this important finding gets subsumed under other headings or curiously minimized or omitted from major conclusions. For instance, Tower discusses the importance of mortality in his conclusions under a section called "Post Cancer Stress." In the chart of his model, there is no reference to the impact of mortality. Existential insight is characterized as strengthening the "I" vs. "Me." Several core changes are listed, but not one encompasses the mortality issue (p. 185).

While Tower (2000) alludes to the importance of the impact of mortality, his concept of the existential insight encompasses a broad range of considerations that he believes occurs immediately to the individual. He suggested that this insight produces an immediate "shift in priorities concerning the importance of relationships, appreciation for life, new possibilities for action and perhaps even into his own spiritual nature" (p. 246). He describes these core changes as transformational and as a turning point or "course correction," the beginning of an evolutionary change process.

This is probably an excellent characterization of what happens to a percentage of people after a shocking life threatening diagnosis, but it lacks comprehensiveness in that it does not

account for those who use denial either extensively or moderately (as illustrated by Barbara's case in the current study) to turn away from the direct gaze of death. It also does not account for those who ultimately go on to come to a full acceptance of the possibility of their death, but gain their insights incrementally or all at once during a later phase.

Tower (2000) sees the initial diagnosis as the impetus or turning point for a variety of behavior changes. This study focuses on death acceptance as the focal point of change which can occur at many different points in the survivor's experience. What is consistent through all the cases in the present study is that death acceptance was preceded by the lowest point in their experience. As demonstrated by Jim's case, death acceptance came only a few days after diagnosis. For Donna, death acceptance came after her worst experience of her treatment, a time when she received her bone marrow transplant and full body radiation. At this time of greatest desperation, she had an extraordinary spiritual experience as she wrestled with the issues of her own mortality. Barbara faced death acceptance after surviving many years using denial to avoid issues of her mortality so that she could focus on her treatment and survive to see her children through until adulthood. The major insights gained by the participants came with death acceptance and occurred at completely different times for each. None of these participants exhibited an immediate insight upon diagnosis.

Huebscher's (1992) grounded research study also sought to determine a process of recovery and transformation in spontaneous remission. After accounting for the shock of the diagnosis, her participants fought the medical system, a phase she entitled *Bucking the System*, by seeking alternative care and refusing medical treatment recommended by their doctors. The participants in this study did not have to pursue treatments outside of standard medical care. Donna, after receiving a bone marrow transplant and full body radiation, was given six months to live. Her doctor, however, located for her an experimental clinical trial as a last desperate effort at therapy. Ostensibly, this treatment worked for her, although everyone else in her cohort died. Jim was also told he most likely had six months to live. Within three months of his diagnosis, however, he had learned that this was likely a misdiagnosis. Barbara, when diagnosed had a twenty percent chance of living two or three years. As the years have progressed new treatments have been developed which have kept her going for years past her diagnosis.

Huebscher's (1992) identification of process parallels this study in many respects. She identified a category entitled *Deciding on Life* which was further broken down into three sub-

categories: (a) Existential Questioning; (b) Letting Go; and (c) Abiding Faith. The existential questioning appears to be the part of the process that would parallel this study's death acceptance. Existential Questioning referred to the questioning of life and death issues that occurred after diagnosis. After this questioning, the individual "made a decision, that is, formed an opinion of what life was about and decided where to go and what to do" (p. 115).

Her other two categories Letting Go and Abiding Faith have related components in this study. She defined Letting Go as releasing goals that are now viewed as unrealistic or the process by which someone lets go of a build up of emotions over previous unresolved issues. This corresponds to the grieving process of death acceptance in this research. For Barbara it meant grieving the loss of Rob, forgiving his abusive treatment of her and grieving the loss of her parents who died many years earlier. Jim grieved the fact that he would no longer be in his children's lives and Donna had to let go of her dream of a happy married life.

Huebscher's (1992), Abiding Faith category, corresponds to the process of death acceptance that results when individuals see themselves as connected to something greater in the universe. This idea of connection to something greater than oneself is a central part of coming to peace with death, according to the findings of this study and the literature of spontaneous remissions. Studies frequently describe remission as anticlimactic because by the time a person reaches remission she/he has often come to death acceptance or established a pattern of denial that is working for her/him that appears to allow remission to occur in a remarkably uneventful manner.

While Huebscher's (1992) descriptions of these categories parallel the process of this study, it does not stress the importance of death acceptance as a central organizing construct. Once again, as happens frequently in these studies, recognition of the importance of dealing with mortality is a part of the findings, but curiously subsumed under other categories, minimizing the importance of this issue. To subsume this important consideration under Existential Questioning minimizes the importance of this critical concern.

Another study by Courtenay et al. (1998) investigated the role of meaning-making in HIV-positive adults. They also described an emotion-laden initial response similar to that presented in the diagnosis section of this model. Central to their findings is the role of a "catalytic event" that facilitates change in the participants' lives helping them to view their diagnosis from a new perspective. Courtenay's findings are different from this study on terminal

diagnosis which delineates death awareness/death acceptance as the salient agent for change. This is supported by Yalom's (1980, 1998) work and is a core concept of existential philosophy and psychology. Heidegger (1962) described an important insight that awareness of death can initiate a shift to a higher mode of existence. This shift is a movement from the state of "forgetfulness of being" to "mindfulness of being" as described earlier in the chapter.

Courtenay et al.'s (1998) description of the catalytic event is a good insight, but more particularly with reference to Yalom's (1980, 1998) concept of the boundary event. The boundary event is defined as an urgent experience that jolts the individual to the state of "mindfulness of being." What Yalom suggests is that the boundary event is powerful because it carries some of the same power of death, jolting us back to facing the issues of life that are really important to our experience: love, achievement of our potential, making the most of the time we have in this world and perhaps contributing to the betterment of the world in small everyday ways. Pursuing activities such as these contribute to our authenticity as opposed to endless pursuits for material goods, status, power or trying to please others to the exclusion of our own needs.

Courtenay et al. (1998) further describes that these catalysts could be of an external or internal variety. External catalysts occurred more frequently and included such events as the initial diagnosis or input of other people. Internal catalysts involved making decisions such as "to commit one's life to an external and perceptibly stronger source, a decline in health, or awareness that there is no other alternative but to make a change in life" (p. 72).

To ascribe such potency of change to a "catalytic event" is to once again minimize the impact of the central galvanizing event of death awareness/death acceptance. These researchers cited the diagnosis as an example of a catalytic event. There is probably no greater catalytic event than a life threatening diagnosis of AIDS or cancer which brings with it the central awareness of the possibility of death. Their description of catalytic events is useful when one compares it to Yalom's (1980, 1998) boundary situations. But as Yalom indicated, death is the ultimate boundary situation from which all the others take their meaning.

They also cited the example of how another person can be a catalytic event. They described Jamie's case, one of their respondents, who had a friend who came to his house, grabbed him and threw him on the floor. She threatened to kick him to death, all the while exhorting him to get up and fight his disease:

*And she just kept screaming. And she said, 'Do you want to die? Just lay there and I'll kick you to death right now and if you don't want to die then get up and live.' ...And it just clicked and I said, 'That's right; you know that's the answer.' That was the real turning point for me, when I realized that death was easy and anybody can do it; everybody's gonna do it. Living life well isn't something that everybody does. And so I just made up my mind that day that living life well is what I wanted to do...*

This person helped Jamie recognize that he had allowed his paralysis with the diagnosis to cause him to give up and do nothing. By throwing him off the bed, this individual made him face the possibility of his death or death awareness. We do not have enough information to know whether he carried this thought process forward to an eventual death acceptance or if he made a decision to plunge into life by ultimately denying this reality. This catalytic event helped him develop a new perspective on dealing with the possibility of his death.

What these authors have not accounted for is that all the catalytic events described reflect a central quality of either facilitating death awareness or are a result of death acceptance. The previous descriptions of the external catalysts facilitated death awareness. An awareness of a decline in health could be an insight related to death awareness or could be part of the consideration of death acceptance. The other two internal catalysts, the “decision to commit oneself to an external and perceptibly stronger source” and “there is no other alternative but to make a change in life” appear to be indications of thinking that would characterize death acceptance. In short, Courtenay’s catalysts are boundary events that precipitate death awareness/death acceptance. The present study describes this concept as the central organizing construct for the individuals’ experience. The catalyst, as described by Courtenay, are given new meaning with reference to this construct.

Courtenay et al. (1998) describe that the catalytic event helps the individual acknowledge the inability of the old assumptions to assimilate the new experiences. They further argue that the catalytic event helps move individuals beyond the initial reaction to make meaning of their situation. The authors mentioned that spirituality played a role in nearly all of the participants’ lives. However, they do not describe why this became important and did not seem to observe or account for the impact of mortality on their respondents, particularly as it related to development of spirituality.

What distinguishes the present study from those described in this section is the centrality

accorded the impact of death on the transformation process. Huebscher (1992) subsumes issues of death acceptance under a category entitled Deciding on Life. Tower (2000) refers to the central defining construct as an existential insight and Courtenay (1998) refers to the catalytic event as a prime mover. All of these studies miss or minimize the impact of death as the central element.

Yalom (1980) argues that Freud missed the importance of death that lay beneath his castration, separation and abandonment concepts. Yalom believed that scientific researchers have continued to miss the implications and importance of this central concept for years due to their own repression which he describes this way:

*The omission of death fear from dynamic theory is obviously not oversight. Nor, as we have seen, is there substantial reason to justify translating this fear into other concepts. There is, I believe, an active repressive process at work – a process that stems from the universal tendency of mankind (including behavioral researchers and theoreticians) to deny death – to deny it both personally and in life work. Others who have studied the fear of death have arrived at a similar conclusion (p. 103).*

### **Transformative Change**

Transformative change in terminal diagnosis survival is initiated with the diagnosis that has implications for death. This creates a perception in the individual that is the awareness of death – the first startling awareness that one’s existence is finite. One either deals with this by consciously facing death and resolving the issues or coping by various means of denial. This is the process that will be described in the following section.

#### ***Transformative Change: Shattered Assumptions***

Meaning perspectives are collections of meaning schemas or general frames of reference made up of “higher order schemata, theories, propositions, beliefs, prototypes, goals, orientations and evaluations” (Mezirow, 1990, p. 2). These meaning perspectives are acquired through uncritical socialization and acculturation with parents, teachers and mentors. They constitute our everyday existence and provide useful paradigms for understanding the world. However, they also constrain our perceptions by bounding our view of reality in cultural and psychological assumptions. Our meaning perspectives become the lenses through which we view each new experience. They cannot be transformed during routine experience, but only through rare and

dramatic events of disorienting dilemmas, such as diagnosis with a potentially terminal disease.

McCann and Pearlman (1990) also describe schemas, a construct similar to Mezirow's meaning perspectives, as cognitive manifestations of psychological needs or as personal constructs that provide organization for reality. Janoff-Bulman (1985, 1989a) describes a similar concept as "assumptions" and Epstein (1985) uses the term "postulates." All describe these concepts as organizing structures which become disrupted by traumatic events which present disorienting information which must be integrated by either of two processes called assimilation or accommodation first described by Piaget's cognitive development theory (1970, 1971, Piaget & Barbel, 1969).

Most information in our everyday lives can be incorporated into our schemas by the process of assimilation. Cognitive schemas must be changed or modified through a process of accommodation when more difficult information is presented, such as that which occurs with a traumatic event that cannot be assimilated under existing schemas. Individuals tend to be conservative when it comes to changing schemas; that which is anomalous tends to become squeezed into existing schemas whenever possible due to the need for coherence and stability of organizational and conceptual systems.

### ***Transformative Change: Inadequacies of Existing Theories***

The literature on post traumatic survival (Janoff-Bulman, 1989a, 1989b, 1992; McCann & Pearlman, 1990) describes how traumatic negative events which include criminal victimizations, disasters, severe accidents and illnesses cannot be easily ignored due to the vivid, emotionally intense nature of the experiences. After a traumatic life event, the individual must confront anomalous data that renders his/her basic assumptions unviable. The new data must be made to fit existing assumptions if these assumptions are to be retained, or extensive revisions of assumptions must be made in a way that allows them to preserve a non-threatening worldview (Janoff-Bulman, 1989a).

Janoff-Bulman (1992) describes traumatic events as "those that are most apt to produce a traumatic response – are out of the ordinary and are directly experienced as threats to survival and self-preservation." Lifton (1967, 1980, 1988) describes, as key to all traumatic experiences, the fact that survivors experience a jarring confrontation with mortality. Kushner (1975) described that the salient concern of women newly diagnosed is survival and psychologically adjusting to a chronic and possibly fatal disease.

It is this quality of a life threatening disease, the fact that it brings with it a shocking and stabbing intrusion of mortality, which forever impacts the fundamental assumptions of the survivor's world. Our natural tendencies in learning are to preserve knowledge structures and subordinate new data to these structures. Both Janoff-Bulman (1992, 1989a, 1994) and McCann and Pearlman (1990) elucidate the illusory nature of fundamental assumptions about our self-worth and the general benevolence and meaningfulness of the world. These assumptions formed in early childhood and derived from positive interactions with caregivers at an early age have become over generalized through different developmental periods. These over generalized experiences lead to abstract characterizations or representations of the world providing some degree of insularity from reality (Janoff-Bulman, 1992; McCann & Pearlman, 1990).

The confrontation with mortality provided the central organizing construct for the transformations of the survivors in this study. Their lives are instructive not only because they successfully coped with the confrontation with death, but also because they transformed their lives in ways they believe are now better. They each chose different ways to find new meaning in their world, understand the Ultimate Reality to which they connect, use the support systems available to them and ultimately reach out to the larger world and give back. What these survivors demonstrated is that the very nature of trauma or terminal disease is paradoxical - what is considered one of the worst experiences offers an opportunity for a new level of development.

How this level of development can be attained can be partially explained by current theory (Janoff-Bulman, 1992; McCann & Pearlman, 1990; Mezirow, 1991) in which there is an emphasis on rational thought or cognition, but the role of emotions requires additional elaboration. Their theories do not sufficiently account for the role of emotions, altered states, or extrarational processes. Survivors in this study experienced powerful emotions at various points, but never more so than at what each of them described as their lowest point. The low point was brought about by the confrontation with mortality or came about by a series of negative events or what Yalom (1980) would characterize as boundary events. Barbara's case in this study illustrates that other events in the individual's life, besides the cancer, can bring about death acceptance (in her case the loss of her parents and Rob). The survivors coped with their powerful emotions at these low points through pursuits which are known to bring about altered states.

### ***Transformative Change: Role of Extrarational Processes and Altered States***

Altered states indicate different brain wave states and are reflective of different and

usually more relaxed states of consciousness. Participants used prayer, mediation, music and nature walks to help manage and calm emotions. Also observed in the participants were increased development of intuition, tendencies to read and interpret messages from the environment and incidents suggestive of synchronicity.

Every person in this study evidenced one or more of these extrarational processes. Donna had a spiritual “visitation” at her lowest moment, when she had just completed her bone marrow and full body radiation treatment. Jim’s brother and his two sons called the night Jim was at the mass with the healing priest. They had a “sense” that he would be all right and left messages on Jim’s answering machine that they had called. That day, Jim was attending mass in a different city and they had no direct knowledge of what he was doing. Their sense of knowing he was going to be all right appears to be an example of synchronicity as described by Carl Jung (1960). Barbara had powerful dreams that she felt were real visits from Rob after his death. She also experienced some events, like Jim did, of “messages” from her environment telling her she would be all right. (See narratives for full descriptions of these events.)

None of the post trauma survival cognitive theories mentioned earlier or Mezirow’s (1991) transformational theory incorporates or accounts for these experiences. Boyd’s theory of transformation (1989, 1991; Boyd & Myers, 1988) presents some balancing counterpoints to Mezirow’s, emphasizing that the individual’s internal experience is comprised of both rational and extrarational (emotions, symbols and images) thinking. He describes transformation as a process of discernment or a dialectical movement between both forms of understanding. Central to this process is the role of grieving as an emotional crisis forming the core of discernment.

In this study grieving is certainly a central concept related to death acceptance. There can be no death acceptance without grieving (Kubler-Ross, 1969). For the person who has had a good life, it is grieving for lost happiness and lost assumptions that have provided a sense of invulnerability and immortality. For the individual who has had a largely unhappy life, the diagnosis may bring some sense of relief, but still there is grieving to do for the possibilities that might have been. Grieving provides an important function, for it allows the individual to let go of old issues and emotions, releasing concern for what was and what might have been. This opens the door for development of spirituality in which a transpersonal connection is made, allowing for a glimpse of immortality that diminishes the haunting and terrifying power of death. The meaning of one’s life that was shattered with the diagnosis has not been restored but rather

transformed, providing new developmental opportunities. Whether or not these opportunities come to fruition depends to a large extent on how well they are supported by the environment.

### ***Transformative Change: Relevance to Developmental Theory***

The development literature was not reviewed in Chapter Two, but must now be introduced because of the relevance to the findings. The impact of a terminal diagnosis will be received differently by individuals depending on their developmental stage. Erikson (1963) described how individuals at midlife and beyond begin to turn away from deriving identity from relationships and professional pursuits to what he called a stage of generativity. At this stage there is a turning inward to find meaning in self-transcendent endeavors. Therefore, it is most likely that older individuals may be more able to move toward death acceptance than those who are younger. It is likely that Jim could come to death acceptance before Donna and Barbara because his children were grown while each of them still had children at home.

Kegan's (1982, 1994) constructive-developmental theory provides a good basis from which to assess other core transformative changes as seen in the participants of this study. Central to his theory of development is the concept that "personality development occurs in the context of interactions between the environment, rather than through the internal processes of maturation alone" (p.7). Kegan relates that the fundamental activity of personality is the gradual evolution of meaning negotiated through a series of subject-object balances, an emergence from embeddedness. Kegan describes five stages or Orders of Mind (1994). To understand how one moves through the Orders it is necessary to define Subject and Object. What is Subject to us cannot be seen by us and consists of various relationship issues, assumptions, attitudes, behaviors and emotions. These things are taken for granted and cannot be reflected upon. Objects are elements of our knowing, things that can be reflected on, things that can be internalized and acted upon.

For the purpose of this study, the movement from the Third Order to the Fourth Order has particular relevance. The Third Order can be described as the Socialized or Traditional Mind. This consists of older adolescents and the majority of adults. At this stage, others' feelings and emotions have been internalized. There is an eagerness to please certain people or institutions (e.g., church or political party). This Order is characterized by a particular limitation; when conflict arises between important others (e.g., spouse, institutions, or political party), the person feels incapacitated to make a decision. The key issue here is that the individual has no sense of

what s/he wants outside of others' expectations. The major limitation of this way of knowing is that relationship loss can be experienced as a loss of identity.

An example of change from Third Order to Fourth Order would be an individual who has decided s/he wants to be a doctor. In reality this is her/his parents' desires, but the individual believes it is really what s/he wants. When this person develops Fourth Order thinking he/she realizes this is really his/her parents' desire. Perhaps on serious reflection this person wants to rebel against this former control by the parents. Only on serious reflection, the individual realizes that s/he really loves science and to switch to another curriculum to spite the parents and assert authority would be foolish.

Kegan's (1994) Fourth Order is characterized by the "Self-authoring" or "Modern" Mind. Adults who have arrived at this stage of development now have a self that exists apart from its relationship to others. Others' opinions and desires, which had been previously internalized, no longer control them. They can take opinions and feelings of significant others as Object, putting this information in a realm where it can be further evaluated.

Kegan (1994) describes transformation as not just simple knowledge accretion or adding elements of knowledge to a container. With transformation the container itself must be changed. The individual can step back and reflect on past experience. This is the movement of things from Subject to Object. Kegan (1982) further describes that this kind of epistemological change can only be initiated and integrated through support from a "holding environment" which provides the individual with support for continued evolution while concomitantly confirming and contradicting his or her current meaning-system (Kegan, 1982).

### ***Transformative Change: The Holding Environment***

In describing this concept, Kegan (1994) states that development cannot take place without "a holding environment that provides both welcoming acknowledgement to exactly who the person is right now as he or she is and fosters the person's psychological evolution. As such, a holding environment is a tricky, transitional culture, an evolutionary bridge, a context for crossing over" (p. 43). Because development is a difficult process, people tend to regress to an earlier state which is familiar and more comfortable. Therefore, the holding environment becomes important to support growth. Some examples of environments that could serve as holding environments are self-help groups, schools, therapy groups and conversation, or reading groups.

The participants in this study evidenced behavioral changes illustrative of developmental evolution typical of movement from Third Order to Fourth Order as described in Kegan's (1982, 1994) theory. Donna came from a family where every member except her was an alcoholic, as well as her first husband and most likely her second husband. Coming from such a dysfunctional family life, she dreamed of a happy family life and blissfully pursuing her dream of being a stay-at-home mom and wife. This dream sustained her through a grueling treatment regimen. She heroically survived a multitude of different treatments and even a last desperate effort at life through participation in an experimental program. After making this heroic journey, she returned home and acted like a "little puppet" to appease her husband, clearly demonstrating Third Order thinking.

Her case illustrates the importance of the holding environment in sustaining and developing transformative change. Donna had already gone through her period of death acceptance and gained significant strength from that transformative experience. When she returned home she went back to her former behavior patterns. Her home was a stage three holding environment where she depended on her husband's approval for her definition of self. However, when she returned after treatment, he had already formed a relationship outside of the marriage, making every effort to avoid her and leaving her totally without self-esteem.

After her husband left she sought increased support from her friends and through her church. She became a lay minister which was congruent and supportive of the developmental changes she had experienced as a result of her death acceptance. This is who she is today. From this perspective (Fourth Order) she now sees how staying with him would have been extremely deleterious to the subsequent growth that she now sustains.

As a relatively uneducated man living in a small town, Jim seemed to take authority figures or representatives of society as the final arbiters of his situation. Jim accepted his initial diagnosis from one doctor with little questioning or doubt. However, a few months after he came to death acceptance, he was told by an oncologist that he probably did not have cancer. The doctor recommended another appointment for him. However, he was sure when he left that day that he did not have cancer and he never wavered on this again, even with his next appointment when once again the doctor expressed an opinion that he had cancer.

Barbara also seemed to be at a level three development demonstrated by her devotion and passion for a man who was psychologically abusive. After her cancer diagnosis, Barbara

survived for years using denial to avoid the deeper realities of her life. However, she still focused on pursuing effective treatment for herself in order to achieve her goals of seeing her children through to their adulthood and continuing her relationship with Rob. Her death acceptance involved grieving the loss of Rob and her parents, the loss of a job she loved and her cancer. In Barbara's grief she worked through her rage at Rob and came to see and describe his treatment of her as abusive. For the first time she could take a perspective on this relationship and process this experience as Object.

All of the participants in this study evidenced some elements of developmental movement and growth in meaning-making capabilities reflected by transitioning from Third Order to Fourth Order levels of development. Kegan's description of the transformative change of behavior from Third Order to Fourth Order parallels the movement from inauthentic to authentic existence as described by existential philosophers and psychologists. As previously described in this chapter, both Heidegger and Yalom delineated the importance of the authentic life over the inauthentic life.

The signature characteristic of the authentic life is the individual's growing awareness of the impact of the forces of acculturation due to the occurrence of a boundary event (the ultimate being death). This event jolts the individual into the "ontological mode" in which the individual develops the capacity for self-creation. This is the same basic process, once again, reflected in Mezirow's transformational process describing how meaning perspectives become transformed through rare and dramatic instances of "disorienting dilemmas."

### ***Transformative Change: Role of Denial***

The model introduced in this study demonstrates that the diagnosis of cancer brings with it an awareness of the possibility of death. This results in a range of possible reactions on a continuum of denial on one end to total death acceptance on the other. This is a fundamental choice on the individual's part to acknowledge the possibility of his/her death. A very small percentage might react with pathological denial and not acknowledge either the death or the cancer. The other extreme was demonstrated by Jim, who within a matter of a few days, not only made efforts to acknowledge death but came to full death acceptance.

The death acceptance described by the three cases in this study did not represent qualities of fatalism or giving up on the part of the survivors, but rather represented a change or expansion of meaning perspectives to accommodate the possibility of their death. True death acceptance

went beyond mere death awareness or acknowledgement. Survivors prepared themselves for death in various ways such as engaging in existential questioning leading to further development of their spirituality, saying good byes to loved ones and even engaging in preparations involving wills, insurance and funeral arrangements.

While orientation to death may range widely from denial to death acceptance, most people probably use both modes in dealing with the loss of their assumptive world. McCann and Pearlman (1990) describe reports by clinicians that depict approach-avoidance patterns used by victims to come to terms with traumatic memories. Roth and Cohen (1986) offer a synthesis of the literature in which they view approach-avoidance as a dialectic between emotion and cognition that characterizes the individual's progress either toward or away from awareness of threat. Krystal (1978, 1984, 1988) describes the overwhelming and paralyzing affect that is the corollary of traumatic states. Denial not only serves a protective function against engulfing emotions but also allows the individual time to assimilate disruption of schemas, assumptions and frames of reference (McCann & Pearlman, 1990).

Taylor (1990) describes how some individuals appear to derive healthy benefits by using "positive illusions" to shield themselves from unwanted aspects of their cancer experience in order to achieve certain desirable goals. Greer and colleagues (1985, 1990) discovered that patients who evidenced "fighting spirit" had the highest survival rates, fully accepted the reality of their cancer diagnosis and displayed an optimistic attitude with a determined orientation to fight their disease. However, perhaps even more surprising was the fact that the next highest survival group included those who used denial as a strategy of positive avoidance.

Janoff-Bulman (1992) in discussing the oscillation of movement between denial and intrusive recollection in trauma survivors, suggests that these have too often been regarded as abnormal responses to trauma, rather than as adaptive responses to abnormal occurrences. She explains how denial has all too often been over pathologized and not valued for its remarkable adaptive quality.

### **Recommendations for Future Research**

This study and a few others have identified some important elements of process concerning transformational change in cancer. Replication of this work could be made to assess more closely different elements identified in this study. The issue of death awareness/death acceptance needs to be pursued by researchers and efforts made to recognize and delineate how

this impacts consciousness. Researchers will need to be aware and vigilant in identifying their own resistance to look at his issue. Those that have not personally come to terms with these issues may have difficulty in questioning others. Endeavors should also be made to clearly elucidate the impact of mortality without subsuming the issue under other concepts or by using euphemistic terminology.

Additional work could be done to distinguish how personality characteristics of individuals relate to the quality of their environments. What environmental elements help foster transformative changes? Also, what is the role of the individual's holding environment in supporting transformative change? Researchers would benefit from use of more holistic approaches in assessing individuals that are inclusive of developmental changes taking place in the individual. Also, what other motivations besides the cancer have driven and are currently driving, the individual's life?

Berland's (1994) work takes on new meaning in light of this study. His work on attributions identified three groups with distinct healing styles: the determined fighters, the attitudinally/behaviorally focused and the spiritually/existentially oriented. These three distinctive styles may make more sense when assessed from a different paradigm of process. This researcher concludes from information he provided in his study that death acceptance was likely present in the latter two groups. The determined fighters, from the information provided, likely never reached death acceptance. Future studies that identify similar groups, such as this one, need to look more closely at process to see if in fact some did face death acceptance and how the process of avoidance or denial manifested itself in these individuals. Research investigating these issues could help clarify this process.

Also, most studies on remission seem to use individuals as participants who express concepts of spirituality. Spirituality, or connecting to something beyond the self, has been an important element identified in many studies to help people deal with issues of mortality. But what happens to atheists? Are there atheists who would construct their experience without concepts of spirituality, believing instead that when life is over there is nothing else? This researcher sought to find such a person for this study but was unable to locate someone in time. However Barbara, who is agnostic, was selected instead. She demonstrated spirituality that was not God centered. A study on atheists could be most useful in evaluating the dimensions of response to confronting mortality.

This research demonstrates that extrarational processes occurred with every case and particularly intensified during the low point where participants came to death acceptance. Often these elements are only obliquely referred to or likely overlooked in research. These extrarational experiences seem to play a significant role in participants' meaning making. Participants also all used practices that induced altered states that helped calm emotions throughout this experience. Much more research is needed on all of these elements that have often been overlooked due to the prevalence of largely cognitive and rational theories.

In addition, the importance to each individual's story of extrarational experiences which intensified the process of meaning making should also be further elaborated with reference to transpersonal literature. Each person derived significant meaning from his/her experience in facing mortality due to concepts of spirituality which connected them to greater wholes. The strong impact of transpersonal experiences evidenced by the participants in this study bears additional investigation.

Another finding in this study, which could use further examination, is the role denial can play in allowing the individual time for assimilation and accommodation of the impact to their assumptive world. Janoff-Bulman (1992) indicates that there is much debate in the psychological literature about whether or not denial is a conscious or unconscious process. Psychoanalytic literature emphasizes this process as psychopathological, but Barbara's case in this study and Janoff-Bulman's (1985, 1992, 1994) work indicate that this process can have positive and non-destructive uses. Some researchers would argue that the term avoidance best describes the deliberate refusal to think about stressful events. More research is needed on this issue in an effort to reach a greater clarity of terminology and understanding for researchers.

### **Implications for Future Research**

Implications from this study are applicable to a wide range of fields: adult learning, psycho/social/spiritual research, nursing psychology and post trauma survival. This work synthesizes literature from several fields including psycho/social/spiritual research, post traumatic survival, adult learning and adult development. The process model developed illuminates the learned experience of cancer survivors which extends theory of adult learning and post traumatic survival fields. This work ultimately has implications for workers in psychological, medical and nursing fields, those who are the caretakers of cancer survivors.

### ***Implications for Future Research: Adult Learning***

Mezirow's (1991) transformative learning theory has been central to understanding not only everyday learning but more importantly how people change their internal epistemologies in ways that reflect major personality change observed by all. Naturally, such seminal work has provided a major impetus to the field that has sparked significant criticism that his theory is too heavily cognitive, linear and does not fully account for emotional, spiritual and extrarational processes.

This study elucidates the need for a new meaning perspective as applied to transformative learning, one that combines components of Mezirow's theory with aspects of Boyd's theory and further elaborates transpersonal aspects as described by Boucouvalas (1997). Mezirow demonstrated how meaning perspectives become transformed through rarer and more dramatic events of disorienting dilemmas, such as death of a loved one, divorce, loss of a job, or other such events and result in a world-view shift. Boyd's theory is also supported as it more clearly emphasizes the role of the importance of emotions and the role of extrarational processes which includes increased intuition, synchronicity and transpersonal experiences.

### ***Implications for Future Research: Psychosocial/Spiritual Cancer Research and Nursing***

Psychosocial research is dominated by linear based post-positivist research which could be greatly augmented by more studies such as this one, which looked at the lived experience of cancer survivors in order to delineate the underlying dynamics of process. All terminal diseases require research to understand the deep transformative or, at the other extreme, pathological effects of a confrontation with death. This study has implications for research on spontaneous remission, long-term survival and everyone who has received a cancer diagnosis who has had to confront their mortality.

The use of denial in cancer requires additional research. This study illustrates a positive use of denial by one of the survivors. Trait research has demonstrated that those who use denial along with determined fighters tend to have higher survival rates. What type of denial is being measured in these studies is not always well defined. Understanding differences in use of denial will have important application for patient care.

### ***Implications for Future Research: Post-traumatic Survival***

This study expands the knowledge of process in cancer survivors who have confronted a

terminal diagnosis, a form of trauma researched by this field. It also delineates the developmental role in transformative change that has applicability among other aspects to psychology.

### **Summary**

This chapter described the salient conclusions resulting from analysis of the data and development of a model of terminal diagnosis survivorship and extended survival. This work synthesizes literature from several fields including psychosocial and spiritual research, post traumatic survival, adult learning and adult development. A comprehensive theory was presented extending psychosocial and spiritual cancer research and challenging the largely rational and cognitive based theories of adult learning and post trauma survival.

The process model presented describes how death awareness/death acceptance is the central organizing construct for the individual's cancer experience. How the individual deals with this issue determines the extent of transformative changes evidenced. Research on spontaneous remission has demonstrated the importance of facing mortality and has described a constellation of positive behaviors that occur often prior to the remission, termed the existential/spiritual shift. This model explains the occurrence of the existential/spiritual shift as due to the individuals fully accepting the possibility of their death which results in the manifestation of the constellation of positive behaviors.

In this process, emotions play an essential role in galvanizing the individuals' movement toward full death acceptance. The individuals each came to death acceptance as a result of experiencing what they described as the lowest time in their cancer experience. This theory is more comprehensive than others because it also incorporates the role of extrarational processes which included increased intuition, synchronicity and transpersonal experiences. This model also describes the role of denial which interplays with death awareness taking the individual toward total denial or toward death acceptance, or even postponing death acceptance to a time of the person's choosing.

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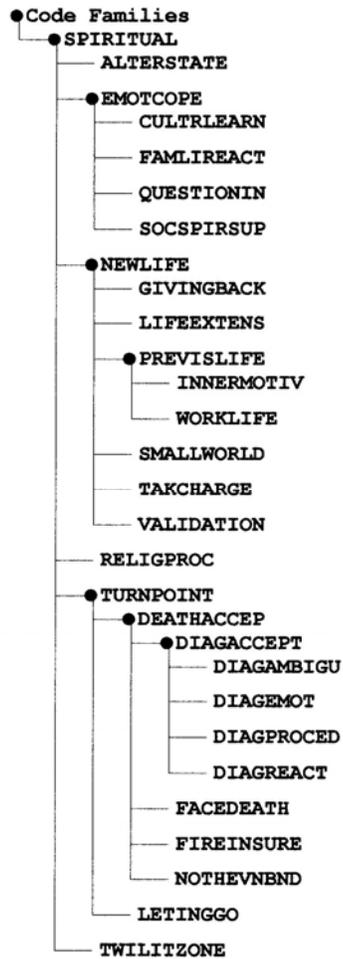
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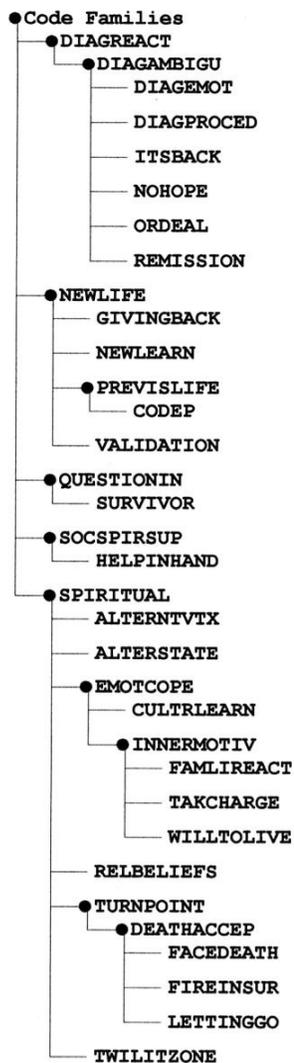
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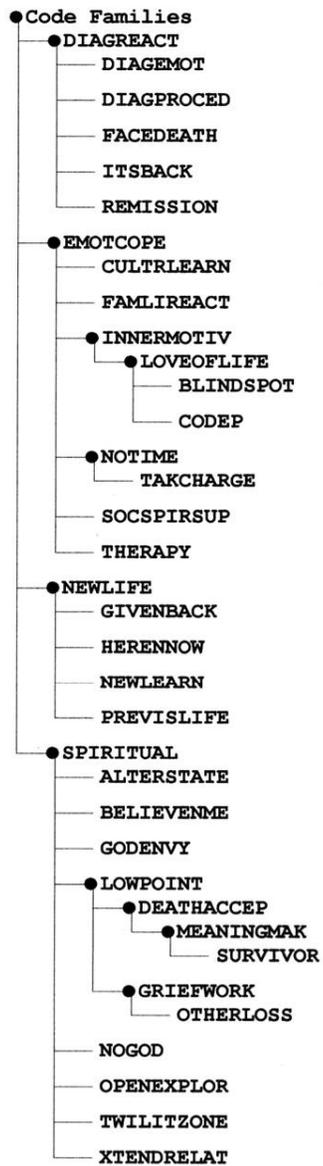
# APPENDIX A: CASE CODE TREES

JIM:Code Book--Family Tree

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## APPENDIX B: SAMPLE CODE BOOK

### JIM:Code Book-All Code Words

Page 1

Codeword	Parent	Text	Level	Added	Modified
ALTERSTATE	SPIRITUAL	Yes	2	02/13/03	05/14/04
		intentionally or unintentionally induced experiences resulting in altered states such as prayer, meditation, dreams, imagery, etc.			
CULTRLEAFN	EMOTCOPE	Yes	3	02/14/03	05/14/04
		reading material or things learned regarding ones experience from society, friends, media, etc.			
DEATHACCEP	TURNPOINT	Yes	3	02/14/03	05/14/04
		accepting without denial reality of death			
DIAGACCEPT	DEATHACCEP	Yes	4	02/13/03	05/14/04
		statements reflective of understanding and acceptance of diagnosis			
DIAGAMBIGU	DIAGACCEPT	Yes	5	02/14/03	02/20/03
		contradictory elements of diagnosis			
DIAGEMOT	DIAGACCEPT	Yes	5	02/13/03	02/20/03
		emotions experienced during diagnostic phase			
DIAGPROCED	DIAGACCEPT	Yes	5	02/13/03	02/20/03
		description of procedures related to the diagnosis			
DIAGREACT	DIAGACCEPT	Yes	5	02/13/03	02/20/03
		statements describing actions taken by participant to deal with diagnosis			
EMOTCOPE	SPIRITUAL	Yes	2	02/13/03	02/20/03
		statements reflective of participants emotional states			
FACEDEATH	DEATHACCEP	Yes	4	02/13/03	02/20/03
		includes being informed about death, reactions both cognitive and emotional			

**JIM:Code Book-All Code Words**

<b>Codeword</b>	<b>Parent</b>	<b>Text</b>	<b>Level</b>	<b>Added</b>	<b>Modified</b>
FAMLIREACT	EMDTCOPE	Yes	3	02/14/03	02/20/03
		Description of interactions of participant and family members or significant others			
FIREINSURE	DEATHACCEP	Yes	4	02/13/03	02/20/03
		taking care of business preparing to die			
GIVINGBACK	NEWLIFE	Yes	3	02/14/03	02/20/03
		something the individual has learned and can offer others - the desire to do so			
INNERMOTIV	PREVISLIFE	Yes	4	02/14/03	02/20/03
		themes that have motivated person throughout their life			
LETINGGO	TURNPOINT	Yes	3	02/14/03	05/14/04
		releasing old emotions or grieving for things lost ; e.g., often goes along with death acceptance where the person releases the fear of death			
LIFEEXTENS	NEWLIFE	Yes	3	02/13/03	02/20/03
		realization that even though death was expected - it's not happening may not happen			
NEWLIFE	SPIRITUAL	Yes	2	02/14/03	02/20/03
		life after remission - an understanding that life will probably go on			
NOTHEVNBND	DEATHACCEP	Yes	4	02/14/03	02/20/03
		after preparing for death intensely, realizing that you are still going on - not going to make the trip			
PREVISLIFE	NEWLIFE	Yes	3	02/14/03	02/20/03
		life before diagnosis			
QUESTIONIN	EMOTCOPE	Yes	3	02/15/03	02/20/03
		doubting or questioning one's beliefs			

Codeword	Parent	Text	Level	Added	Modified
RELIGPROC	SPIRITUAL	Yes	2	02/13/03	02/20/03
		practices of a particular faith used by participant			
SMALLWORLD	NEWLIFE	Yes	3	02/14/03	02/20/03
		other people who are hurting or who have illness want to make connection or share similar experience			
SOCSPIRSUP	EMOTCOPE	Yes	3	02/14/03	02/20/03
		church or spiritual group members support			
SPIRITUAL	None	Yes	1	02/13/03	02/18/03
		spirituality - spiritual/religious views of participant and actions taken based on them			
TAKCHARGE	NEWLIFE	Yes	3	02/14/03	02/20/03
		going against medical recommendations or following one's own inclinations against accepted societal norms			
TURNPOINT	SPIRITUAL	Yes	2	02/14/03	02/20/03
		as experienced by the individual - point where they feel they can handle anything - may or may not relate to diagnosis/remission -essential learning			
TWILITZONE	SPIRITUAL	Yes	2	02/13/03	02/20/03
		twilight zone/miracle - statements reflective of individual experiencing something extraordinary - almost magical			
VALIDATION	NEWLIFE	Yes	3	02/15/03	02/20/03
		Others commenting on your behavior in a way that validates your feelings, thoughts and reactions			
WORKLIFE	PREVISLIFE	Yes	4	02/15/03	02/20/03
		descriptions of work life			

## APPENDIX C: SAMPLE TRANSCRIPT DIALOGUE

### APPENDIX C: SAMPLE TRANSCRIPT DIALOGUE - DONNA'S CASE

Alice: So that 7 days that you were getting that full body radiation/chemo you are in the hospital all those days?

Donna: Yeah. I stayed in the hospital 2 months. Because what happened is normally within 10 days or so you start making counts and of course I had 2 ports put in me at that point. Usually I had a \_\_\_\_\_ and then I had a Hickman put in because with all the tubes coming in and out of you, I needed 11 lines and you can't do it out of one, so they had to put another one in, so you are sitting there with all these lines going in and out and they ended up having to feed me that way for a couple of months because the radiation and the chemo all put these sores all the way down and all the way through the stomach. So anything you had was just...if I got a teaspoon of applesauce down it was a big day. It was terrible and I wasn't making my counts back and so then things were going from bad to worse for me. It seemed...I was getting weaker and I knew that...I definitely knew it and I knew that they had called my husband...he had gone to a meeting in NY and they called him and asked him to come home...they didn't think I would make it through the weekend because of the way the body was just...I was collapsing and my fever now was up to 104.5...they put me on a ice bed.

Alice: Was this after the radiation?

Donna: Yes. After the radiation, after chemo.

Alice: After going through all that.

Donna: Then you wait for your counts to come back, but mine weren't coming back and so I was on this ice bed and all and I remember my minister coming in and I was hallucinating because of the morphine they put you on for the pain, but my minister came in and she's a very sweet person and she said, Donna I'm going to ask you something, you don't have to tell me if you don't want to, if you don't want to talk about it, that's fine, but I sort of need to ask you as your pastor, do you want to plan your funeral? And I started crying. She said I didn't mean to upset you and I said no, no, no it's a relief. I wanted to tell you that, but I'm afraid people would think I gave up and I'm not giving up, but I'm being realistic...I'm not coming back. Look at me. I said I'm getting worse every day and I know that and so...but my husband's like...she's fine...telling everybody I'm fine and stuff...he just had this veil...he just didn't see it all and so I was afraid I'd look negative if I actually said I was scared and actually said I wanted to plan. So we went over songs I liked and psalms I liked.

Alice: Was it kind of a relief to you then to have somebody say...?

Donna: Yes.

Alice: ...can we talk? In essence.

Donna: Yeah and so she very gently talked to me.

Alice: Was that the first one that broached that topic with you?

Donna: Yes. Including the doctors.

Alice: Of course the doctors.

Donna: Then you know, also...and then they'd send a shrink in, which I wanted to kill this guy. It was so idiotic. I'm like...pleassssse. I couldn't even remember what he said. I just remember sitting there thinking...oh geez! This is not what I need out of him.

Alice: Get this clown out of here.

Donna: I know. I'm all for therapy. I really believe in it, but he was just not coming from the right page. Considering the situation and just...what do you think? I said, what do you think I think? He just had no patience.

Anyway I guess.

Alice: Even with him you didn't bring up the topic of have you thought about or?

Donna: No. And I thought, God I can't tell him. I need to be...put her on death watch or something. Stupid.

My minister just took all the notes down and she said that's covered and so I felt a great sense of relief when she left and it also opened me up that night to where I prayed and I really got into prayer a lot during...I've always thought of myself as somewhat spiritual, but nothing until I was diagnosed with the cancer did it really sink in a lot more and I read a lot. What I did was read a lot of books and they in turn would lead me to other books and then I started opening up more of a spiritual life and I had music...wonderful music by me and I would read my bible and I would...she would tape the sermons for me and our whole church service, she would tape it and I'd listen to them and follow along in there like I was there sitting. I'd pretend like I was in church. You have to do whatever you can when you are like that. And, so I did all that.

So that night I cried and I sat in the middle of the bed and I said, Lord I'm ready to go now. If you want me to go, then this is it, I'm ready because I'm tired of fighting. I was still very confused over this holy trinity...the 3 people up there...so I said, look, I want you God, Jesus and the Host...all there of you guys down here right now and it was weird because I said that and all of a sudden there was a heaviness on my bed...this is weird and I don't always tell everybody this because some people think...I know I was on morphine, but this was not one of my hallucinations, this was a heaviness on the bed and I felt a warmness all around me and right away I said, you're here and I just hugged the air.

I'm sure if anyone was watching would think...I was just hugging the air and said...oh my god you are here and I said thank you and I laid down and I went into an extremely peaceful sleep and during that sleep my fever broke, my counts went up the next morning, the fever was gone...it broke. This was something they had wrestled with for 4-5 days...105 on an ice bed and it was breaking and it had gone down and down and they were like...they were like...I don't know what happened last night and I was like I can tell you what happened...you won't believe me.

Alice: I had the whole trinity sitting right here.

Donna: It was wild. And so from that point on I started making much better progress and I still was not well enough by January.

Alice: Did you tell anyone about that experience? Your husband? Minister?

Donna: I definitely told my minister and I've told people in my church.

Alice: I mean did you tell them at the time. Were you discussing it? Well you said, when they asked you what happened last night?

Donna: I told the doctor. I said, well you know, I was praying last night and I really think that...I told him what I said and I told them all three of them to get down here right now...he goes you know what? Doesn't surprise me at all. He said whatever it takes. I'm glad that you are starting to show signs of recovery here. He didn't mock it or anything. He said he wasn't surprised, so I guess he's heard something like that before. I don't know.

I didn't tell my husband because he wouldn't have...he would have just chalked it off to wacky or something. But I told my minister and she believed it right away. And she has had me share that with other people in the church.

Alice: Oh yeah.

Donna: But anyway, finally I told the doctor, I have to get out of here. This place is making me sick. I can't get well in here. I hate the food in here. If I got home I think I would do better, so they released me before my counts were up where they should have been. They released me under the condition...the whole house was scrubbed down and everything and I had to put a mask on, even in the house and I was still hooked up to all the machines, but I carried them around the house with me and the kids couldn't come up and hug me and that was really hard.

The first time I saw them was Christmas Eve, so that would have been over a month and a half...about a month they hadn't seen me and they let them in Christmas Eve. I remember I would sit in a chair because I didn't want to scare them, but they were so cute because they had these huge dressing gowns on and big...they are this little minute things....and they still couldn't touch me then, but Eddie would have to hold onto them to make sure they didn't break through, but that was hard. I had to fight back those tears not to...I kept blowing them kisses and they were blowing me kisses and stuff and it was just good to see them. They remember that. Little as they were. They were 3 and 5 I guess. But they remember that part of it.

Alice: That was kind of...in retrospect now, does that seem like a turning point for you of sorts? That night when you prayed like that? You had that sensation of spirits?

Donna: Yes it was a definite turning point for my road to recovery. Yeah.

Alice: Then the next day you wake up and you...

Donna: I'm not well, but I'm certainly in a lot better shape then I was and over the next few days they were tripling and quadrupling the counts where they were doing nothing before.

Alice: After that night...that special night, there had been several days that went by where you are still in the hospital and then you got to the point where you said I know that I need...I need to get out of here.

Donna: That was another 15 days.

Alice: Okay, you were there about another 15 days. Then you had the sensation of being ready to go?

Donna: Then I thought by January that I just needed to get out...I was very depressed. Of course by then the shrink said...oh she's depressed...duh...you know...I said I'm only depressed because I'm in here. I have to get around people. I wasn't allowed to see anybody. This is ridiculous. So they finally let me out and from that...I made much better progress once I got out of the hospital. Much better on my own. I ate more at home because it was my stuff I guess. And it was all very controlled; I couldn't eat any fresh vegetables. You had to eat all frozen or canned. You couldn't have any fresh.

Alice: Less germs or what?

Donna: Yeah. Because of the germs. I couldn't eat anything from restaurants. I remember when I was really sick in the hospital, my minister asked if I could...she said what could I bring you and I said, I'd love a frosty...just a chocolate frosty is all I want and she said I can do that. Well, she comes walking in the hospital with it and the nurses go excuse me...I'll take that no, she can't have it...we don't know what their machines are cleaned like and all...no way. They wouldn't let her bring it in. I was looking forward to that so much.

## APPENDIX D: SUGGESTED INTERVIEW QUESTIONS

### INTERVIEW QUESTIONS

These questions were not all used and were not taken into the interview but rather served to help me focus my thinking prior to the interview. The bold questions served as my personal frame for learning information and constituted the main probes. This allowed the participant to set the direction of the interview.

#### ***Describe your reaction to learning you had cancer and a terminal diagnosis?***

How did you discover you had cancer?

How did you learn the actual diagnosis?

- What was your reaction - thoughts, feelings?

Did you have times when you lost all hope - had thoughts of dying?

- How did you deal with this?
- What helped - what didn't?
- How did you handle these feelings?

Have you asked yourself questions about the meaning of life?

- How did this change as a result of this cancer experience?

How did you go about seeking information to help you deal with the diagnosis?

Was there anything you learned or did that gave you comfort during this time?

What support did you receive? Did you feel supported by those close to you?

What help did you get from the medical community (doctors, nurses, social workers, support groups) besides any treatment, if applicable, that was helpful?

- Did they say or do anything that was helpful/harmful?
- What was the extent of your involvement in treatment decisions?
- Did this ever change from being more involved or to less involved?

What did you decide to do as a result of having a terminal diagnosis?

- What approaches were most important to help you cope? (Mediation, yoga, alternative practices, diets, prayer etc.?)
- What sources of information did you use (books, tapes, support groups, hospital Staff, friends, family, other?)
- Given a limited time frame, what decisions did you make about how you would live the rest of your life?

## ***How would you describe your life before cancer?***

Single/Married/kids

Social life/friends

Work life

Physical or psychological problems/illnesses - exercise, eating, other health

- pursuits, bad habits, drinking, smoking alternative health pursuits

Spirituality/beliefs

Motivation - What did you consider most important in life?

Were you getting out of life what you wanted?

Had you thought about your purpose in life/meaning to life?

Did you have any suspicions about not being well prior to diagnosis?

Childhood/Teen/Young Adulthood

How would you describe your childhood?

- teen?

- young adult years?

Family life - parents, siblings

School

Illnesses

Significant events

How would you describe yourself as a child? Teen? Young adult?

- major characteristics
- What did you enjoy most/least about these years?

## ***Describe your life after you learned of the remission?***

What was your reaction to learning you had a spontaneous remission?

What do you think happened that caused your remission?

- Do you have any personal theories/intuitions that could explain this process?

Were there any turning points, unusual experiences or special moments you could describe?

Do you feel you changed more as a result of your diagnosis or remission?

How has this diagnosis changed your life?

In what ways are you a different person?

Did you experience any "weird experiences", altered states, visions or change in consciousness as part of your experience?

- Do you think any of this helped you get better?

What changes have you made in your life?

- career

- relationships
- health
- Do you believe any of these help sustain your remission?

How would you describe your current emotional state?

Is there any change in the way you express emotions?

How would you describe the main effect of cancer on the course of your life?

Are there any things you could discuss about your recovery that we have not talked about?

How would you advise someone else who has recently been given a terminal diagnosis? Recommendations?

## **APPENDIX E: STAGES OF TERMINAL DIAGNOSIS AND LONG TERM SURVIVAL: SUPPORT DOCUMENTS**

### **SUPPORT DOCUMENT FOR MODEL**

(STAGES OF SURVIVAL IN CANCER PATIENTS RECEIVING TERMINAL DIAGNOSIS)

#### **PRE-DIAGNOSTIC STAGE**

##### **Jim**

- Life had been improving after having had a bad divorce and terrible job.
- Major motivation: Reducing stress in his life.

##### **Donna**

- Describes this period as the best period of her life.
- Had quit work to be a stay-at-home mom and raise her two young children.
- Major motivation: Be stay-at-home mom and wife.

##### **Barbara**

- Unhappy marriage to a severely depressed man who threatened suicide.
- Pined for years for a man she almost married.
- Parents died.
- Major motivation: Establish permanent relationship with the love-of-her-life Rob.

#### **DIAGNOSTIC STAGE**

##### **CONCLUSIONS:**

- Each person experiences similar emotions of anxiety, fear and depression.
- Each person faces considerations of death on a dimension from denial to immediately grappling with realization of death or death awareness.
- Denial can be viewed as a positive adaptation strategy for those who feel they have to survive to take care of others and endure their own treatment process.
- Particularly for those with a stage III or IV cancer diagnosis, this is not just a passing stage but frequently a returning point. For some, must be viewed as part of chronic condition.
- This stage can be the beginning of a search to redefine self and relationship to others and existence; for some in denial this is just something to get through for survival.

### **Jim**

- Crying, night sweats, sleeplessness, anxiety
- Heard his diagnosis as the end. Prepared death acceptance immediately (in several days).
- Feared what this would mean for him and family.
- \*\*\*Lowest point

### **Donna**

- Shock, numb, crying with husband.
- Controversy over diagnosis.
- Several periods of “remission.”
- Only thought to survive to get back to husband and family.
- Some denial – focused on getting through extended diagnosis and treatments.

### **Barbara**

- High semi-conscious use of denial. Not pathological – did not deny disease – diligent about her treatment. When given her official diagnosis she got drunk.
- Lived with elevated protein levels for 4 years, a precursor to Multiple Myeloma – with little concern or awareness.
- Some initial panic in 1991 and in 1992, when protein levels were getting problematic and cancer was appearing to be inevitable.
- Went through much of same as Donna but did not describe in any detail – also indicates level of denial

## **ACTION-RESULT CYCLES**

### **CONCLUSIONS:**

Action steps are always unique to individual

Action-result cycles are performed until the individual gets desired results or comes to an acceptance that there is no more that can be done.

Action-result cycles not only include treatment, but efforts at growth and development and effort made to learn more in order to make meaning of the experience.

Context is extremely important. Includes:

- Socio-economic level which affects quality of medical care among others.
- social support systems
- access to resources libraries, internet and periodicals

There are action steps taken to calm emotions that bring about altered states.

Extrarational events tended to occur at low points often at emotional times and aided meaning-making.

Possibility cancer gets worse- sending person back to diagnosis.

Cancer is either getting better or worse.

Other things happen in life for better or worse – importance of context

For individual who has accepted death – that person has a sense of control – that s/he can handle anything.

Results at this point can be profound – See Barbara

Possibility of death acceptance

Life can begin to change (See Jim).

### **Jim – Actions**

- Three months of doctors appointments and medical testing.
- Attended mass daily
- First Saturday spent all day at church, funeral arrangements, confessions of life, fire insurance, prayer and healing mass.
- Turning point: Death awareness was immediate and death acceptance occurred a few days later.
- Extrarational processes: “message” at mass; Miracle man “ironic” that he just happened to be performing his healing mass in a nearby city the night Jim needed it; his children and a brother “knew” he would be well when he was at mass even though they were in another city and did not know what he was doing that day.

### **Jim – Results**

- Learned he did not have cancer, although he still has mysterious clouded areas on his lung today.
- Believed this experience was God’s “gift.”
- Easier to relate to people
- Sought after for words of wisdom
- In peoples’ prayers.
- Lives a day at a time with great joy in small things of life.

### **Donna-Actions**

- Driven by idea of being stay-at-home mom and wife.
- Confused diagnosis – long treatment process - first and second chemotherapy – Bone marrow transplant
- Read books – opened up a spiritual process with music, tapes of church services.
- Support from family, friends and minister
- \*\*\*Turning Point – Death acceptance when she hit her low point after bone marrow transplant - talk with minister- talk with “trinity - major extrarational event.
- Participated in last ditch effort to say her life – experimental clinical trial in San Antonio

### **Donna-Results**

- Had sense of having “summoned” God to talk
- After “accepting death” ready to leave this earth even husband and children.
- Took charge – insisted on getting out of hospital for her health.
- Finally pronounced cured after experimental treatment.

### **Barbara-Actions**

#### First Action Cycle

- Therapy, Medication: anti-depressants and sleep medication
- 1987 – elevated protein levels – not concerned – doctors say monitor
- 1991,1992 - doctors are concerned – considerations of treatment
- Gets second opinion – told she needs bone marrow transplant – discrepancy too great between nothing and bone marrow transplant
- Gets another oncologist – recommendation for chemo first, bone marrow next
- Told doctors she needs to live 7 years to get her son through law school

### **Barbara-Results**

#### First Action Cycle Results

- Chemotherapy
- Bone marrow transplant
- Full body radiation
- REMISSION - Barbara’s remissions are hardly noticed by her – she is “consumed with living as her ACTION STEPS
- Pain issues due to shingles a complication of her treatment
- Couldn’t take job as head of agency due to her physical limitation due to her dancer
- Pain gets worse – Rob dies -has to quit job \*\*\*\*\* LOW POINT

#### Second Action Cycle

- : Out of remission - elevated proteins – her action plan: grieve all the loss in her life- the death of Rob and her parents; loss of job she loved and her cancer returning
- Gets new treatment.

#### Second Action Cycle Results

- Another remission
- Forgives Rob begins to see him in more realistic way – can describe some of his behavior as cruel
- Develops her spirituality – comes to her own death acceptance through trying to come to terms with Rob’ death.
- Most devastating and most important time of her life.
- Extrarational events: Woman who helped her fill in all the pieces about Rob’s life –“sent to her from Rob”; “messages” – hispanic man who said “is not your time;”

carbon monoxide in house: told, “You could be dead;.” visitations from father and Rob – “different from dreams”.

## **REMISSION**

### **CONCLUSIONS:**

- For all of them once they pass death acceptance they take remission and possibility of future occurrence in stride.
- Sense of knowing when remission will be ongoing.
- Great hope is that it will be ongoing.
- Remission can be short-term or temporary as it was at different points for Donna and Barbara.
- Remission can also be part of expected chronic condition as it is for Barbara..

### **Jim**

- Realization he is not going to die – “knew it”
- Confusion – mixed emotions – had prepared so thoroughly to go to heaven.

### **Donna**

- Donna told after clinical trial that she was in “remission.” Additional bench marks were two and five year points.
- Glad to quietly pass these benchmarks but recognizes that it could always come back.
- “Knew “she was in remission (after previous remissions – after her final experimental therapy)
- Only one to survive clinical trial
- Enjoying life briefly in San Antonio but then came home to realize husband no longer loved her and was leaving.

### **Barbara**

- Too preoccupied with trying to understand Rob’ situation to pay attention to her first two remissions
- Third remission – is still in this now due to new drug treatment
- Came to death acceptance just before this last remission. Deepened spirituality – truly enjoys each day – gets the most out of each moment – is loving life even though Rob is gone.
- Understands that her situation is one of dealing with a chronic condition reoccurrence of cancer is expected
- Importance of giving back

## NEWLIFE

### CONCLUSIONS:

- Life is beginning to stabilize even though cancer return is possibility.
- Remission can be long term or recurring if cancer is a chronic condition
- Person continues work at meaning-making and developing his/.her story
- Story has meaning.
- Life seems better, richer.
- All this happened for a purpose.
- Importance of giving back.
- Major motivation may have been fulfilled or may have changed – but carried them through and kept them going through roughest times

### Jim

- “Life is better”
- “Peace of mind” – God turned him around for a reason.

### Donna

- Husband distancing.
- Husband leaves.
- She believes now it worked out for the best.
- But realizes she would have never made it without him.
- “Cancer made me stronger.”
- “God preparing me by sending me Pentecostals.”
- Awakened Holy Spirit in her.
- Giving back
- “So this is why I went through it.”

### Barbara

- Realizes extent of her denial in dealing with cancer.
- Story of her cancer is a “sidebar” in greater story of her relationship with Rob.
- Tremendous loss she experienced and need to continue the relationship with Rob helped her develop her spirituality which gives her great comfort today.
- “Spirits and souls help us get through”
- “We are all connected in ways that at some point we will understand.”

## **APPENDIX F: INFORMED CONSENT FORMS**

### **Outline for Protocol for IRB Request**

#### **Justification of Project**

This is a grounded theory study exploring the psychosocial process of spontaneous remission in cancer patients. Studies of spontaneous remission by the medical profession are very few and rarely include the psychosocial aspects of the process, which do not fit the prevailing biomedical paradigm. The last 20 years has produced very few studies of this phenomenon even in other disciplines. However, the progress that has been made in mind-body research during the 20<sup>th</sup> century and implications derived from current psychosocial research in cancer make a compelling case for additional research on psychosocial aspects of spontaneous remission. Subjects for this study will have received a terminal diagnosis with six months or less to live; they will have survived well past this prognosis. This study will examine the lived experience, meaning and consequent changes made in the individual's life. Particular emphasis will be given to explicating the internal process of learning.

#### **Procedures**

Participants will be asked to participate in two interviews each lasting from one to two hours. All interviews will be taped and transcribed. Tapes will immediately be transcribed and submitted to the participant for review. Upon completion of interviews with all participants, each person will be asked to participate in a focus group to review the results of the analyses. Tapes and transcripts will be handled according to the specifications described under the section on Confidentiality/Anonymity.

#### **Risks**

To the best of my knowledge there are no risks to participants in this study.

#### **Benefits**

Because very little research has been performed on this topic, your participation in this research is extremely valued. You have had to confront and survive a situation very few ever have to face in life. Your experience is unique, yet reflects an element of learning important for all to understand. This experience, as documented in this research, will provide an important contribution to research concerning psychosocial processes of spontaneous remission in cancer.

#### **Confidentiality/Anonymity**

Anonymity and confidentiality are promised to all participants in this study and will be provided for in the following procedures.

- Interviews will be audio-taped with participant permission to ensure greater accuracy.
- The name of the participant will be deleted from any written materials and replaced with a pseudonym.

- Tapes will be immediately transcribed by the researcher and identifying information excised.
- The participant will be asked to review the transcript of the interview for accuracy and anonymity.
- Tapes will be stored in a bank safe deposit box for a maximum of seven years and then destroyed. Transcripts will be destroyed upon completion of analyses.

### **Informed Consent**

Consent forms attached.

### **Biographical Sketch**

Alice is a doctoral candidate in the Department of Adult Learning and Human Resource Development at Virginia Tech in Northern Virginia. Having completed all coursework, she is currently working on her dissertation. She has 20 years consulting and mental health experience working with corporations, Federal and local governments, Washington law firms and law enforcement agencies

Having worked with Employee Assistance Programs (EAPs) as a Certified Employee Assistance Professional (CEAP), she has performed management consultations concerning various human resource issues: identification and referral of troubled employees, substance abusing or mentally ill employees; change management, workplace violence, trauma and morale issues. She has also counseled employees on full range of psychosocial issues as well as coping with various organizational problems: downsizing, lay-off, reorganization; and dealing with difficult co-workers and supervisors

## **INFORMED CONSENT FORM**

### **Virginia Polytechnic Institute and State University Informed Consent for Participants of Investigative Procedures**

**Title of Project: Spontaneous Remission:  
The Ultimate Life-long Learning Experience**

**Investigator: Alice E. McAndrew**

#### **I. The Purpose of this Research:**

This is a grounded theory study exploring the psychosocial process of spontaneous remission in cancer patients. Studies of spontaneous remission by the medical profession are very few and rarely include the psychosocial aspects of the process, which do not fit the prevailing biomedical paradigm. The last 20 years has produced very few studies of this phenomenon even in other disciplines. However, the progress that has been made in mind-body research during the 20<sup>th</sup> century and implications derived from current psychosocial research in cancer make a compelling case for additional research on psychosocial aspects of spontaneous remission. This study will examine the lived experience, meaning and consequent changes made in the individual's life. Particular emphasis will be given to explicating the internal process of learning.

#### **II. Procedures:**

Participants will be asked to participate in two interviews each lasting from one to two hours. All interviews will be taped and transcribed. Tapes will immediately be transcribed and submitted to the participant for review. Tapes and transcripts will be handled according to the specifications described under the section on Confidentiality/Anonymity.

#### **III. Risks:**

To the best of my knowledge there are no risks to participants in this study.

#### **IV. Benefits:**

Because very little research has been performed on this topic, your participation in this research is extremely valued. You have had to confront and survive a situation very few ever have to face in life. Your experience is unique, yet reflects an element of learning important for all to understand. This experience, as documented in this research, will provide an important contribution to research concerning psychosocial processes of spontaneous remission in cancer.

#### **V. Confidentiality/Anonymity:**

Anonymity and confidentiality are promised to all participants in this study and will be provided for in the following procedures.

- Interviews will be audiotaped with your permission to ensure greater accuracy.
- Your name will be deleted from any written materials and replaced with a pseudonym.

- Tapes will be immediately transcribed by the researcher and identifying information excised.
- You will be asked to review the transcript of the interview for accuracy and anonymity.
- Tapes will be stored in a bank safe deposit box for a maximum of seven years and then destroyed. Transcripts will be destroyed upon completion of analyses.

**VI. Compensation:**

No compensation will be provided for participating in this study.

**VII. Freedom to Withdraw:**

Participants have the right to refuse to answer any question, comment on any issue or withdraw at any time from the study.

**VIII. Approval of Research:**

This research project has been approved, as required, by the Institutional Review Board for Research Involving human subjects at Virginia Polytechnic Institute and State University, by the Department of Adult Learning and Human Resource Development.

**IX. Subject's Responsibilities:**

I voluntarily agree to participate in this study. I have the following responsibilities:

- Participate in two interviews of 1 or 2 hours duration.
- Phone follow-up as needed.

**X. Subject's Permission:**

- I have read and understand the Informed Consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.
- If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

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**Participant**

**Date**

**Alice E. McAndrew**

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**Researcher**

**Phone**

## VITA

### *Alice E. McAndrew*

Alice earned a BA degree in psychology from Seton Hill College in Greensburg, Pennsylvania and an MA in clinical psychology from Ball State University in Muncie, Indiana. In her early career she worked as an alcohol and drug counselor and later as a Certified Employee Assistance Professional (CEAP). As a counselor in these programs she counseled employees on a full range of individual and family mental health issues including depression, stress, marital, grief, trauma and work related issues.

In later positions as a manager in employee assistance programs she performed management consultations concerning various human resource issues: identification and referral of troubled employees; change management, workplace violence, trauma and morale issues. She also provided assistance to managers and employees coping with various organizational problems: downsizing, lay-off, reorganization; computerization and new management structures; and dealing with difficult co-workers and supervisors. In her last position she evaluated mental health programs for the District of Columbia government. She has over 25 years consulting and mental health experience working with corporations, *Federal* and local governments, law firms and law enforcement agencies.