To the Graduate Council:

I am submitting herewith a dissertation written by Meta Gustafson entitled "Quality of Life for Cancer Survivor Spouses". I have examined the final paper copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.

Dr. Marla Peterson, Major Professor

We have read this dissertation and recommend its acceptance:

Acceptance for the Council:

Vice Provost and Dean of Graduate Studies

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# QUALITY OF LIFE FOR CANCER SURVIVOR SPOUSES

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Meta H. Gustafson
August 2005

# DEDICATION

This dissertation is dedicated to the cancer patients and their families that I have had the privilege to work with. Their courage and honesty has been an inspiration for this dissertation and my life. In particular, I want to thank Pam Gildersleeve, Lisl Schick, and Marilyn Lewis. These women supported their spouses with cancer through many good and bad times. I admire them more than they could ever know.

# ACKNOWLEDGEMENTS

I wish to thank my wonderful family for all the support and patience they have given me throughout this process. In particular, my husband's belief in me allowed me to continue working when I felt like giving up. Without them this dissertation would not have existed.

I also want to express my appreciation to my friends and professors. Their support, guidance, and confidence in my abilities has helped me to achieve my goals.

ABSTRACT

In spite of increased consideration for cancer patients and their quality of life (QOL), very little attention has been given to their spouses. The intent of this study was to gain a greater understanding of what QOL means to spouses of cancer survivors. Within this framework, this study explored QOL domains and how QOL had changed since the cancer diagnosis.

A qualitative method using the grounded theory approach was used for this study. Five spouses were interviewed face-to-face about their QOL. Interviews were taped and transcribed verbatim. Responses were then analyzed by three psychology professionals using constant comparative analysis.

Results confirmed the complexity of the QOL concept; a subjective experience, influenced by numerous factors. For these subjects, QOL revolves around how their spouse was feeling, both physically and emotionally. Five categories that impact QOL emerged: personal issues, marital relationship, social support, finances, and motivation. All spouses reported changes in QOL. Findings suggest that spouses continue to live as if the survivor was still ill and undergoing treatment even though treatments had ended at least one to two years earlier.

The primary implications of this study include: (1) QOL for cancer survivor spouses is intimately connected to their partners' health; (2) QOL has changed since the cancer diagnosis; (3) more research is needed to better understand the spouses' experience; (4) increased attention must be given to the financial impact of cancer and its treatment; (5) spouses find meaning through personal belief systems that help them reframe what has happened; and (6) personal and marital issues are the most important domains for spouses when considering QOL.

TABLE OF CONTENTS

**CHAPTER 1: INTRODUCTION ..... 1**

*RESEARCH QUESTIONS ..... 3*

**CHAPTER 2: CONCEPTUAL CONTEXT ..... 6**

*QOL HISTORICAL PERSPECTIVE ..... 7*
*QOL THEORETICAL PERSPECTIVES ..... 8*
*QOL DISTINCTIONS AND DOMAINS ..... 12*
*CANCER ..... 19*
*RESEARCHER INTEREST AND EXPERIENCE ..... 20*

**CHAPTER 3: METHODS ..... 24**

*RESEARCH DESIGN ..... 24*
*DATA COLLECTION ..... 26*
*Researcher as Instrument ..... 26*
*Context ..... 28*
*Sampling ..... 30*
*Participants ..... 31*
*Sample Size ..... 33*
*Setting ..... 34*
*Interviewing ..... 34*
*DATA ANALYSIS ..... 36*
*Constant Comparative Method of Data Analysis ..... 39*
*Comparing Incidents Applicable to Each Category .. 39*
*Integrating Categories and Their Properties ..... 41*
*Delimiting the Theory ..... 42*
*Writing Theory ..... 43*
*VALIDITY ..... 44*

**CHAPTER 4: STORIES ABOUT QUALITY OF LIFE - FINDINGS ..... 47**

*PERSONAL ISSUES ..... 47*
*Life Satisfaction ..... 49*
*Self Concept ..... 51*
*Feelings ..... 54*
*Philosophical and Existential Beliefs ..... 55*
*SPOUSAL ISSUES ..... 57*
*Spousal Support ..... 58*
*Marital Relationship ..... 59*
*SOCIAL SUPPORT ..... 62*
*Helpful Support ..... 63*
*Damaging Support ..... 64*
*FINANCIAL BURDEN ..... 65*
*MOTIVATION ..... 67*

**CHAPTER 5: IMPLICATIONS ..... 68**

*SUMMARY ..... 76*
*LIMITATIONS ..... 83*
*CONCLUSIONS ..... 86*

**LIST OF REFERENCES ..... 87**

**APPENDIXES ..... 97**

**APPENDIX A ..... 98**

**APPENDIX B ..... 101**

**APPENDIX C ..... 102**

**APPENDIX D ..... 103**

**VITA ..... 104**

# Chapter 1

## Introduction

As I locked my office door for the last time, I reflected on all the individuals who had allowed me to share their lives. For the past seventeen years, I had counseled cancer survivors and their families. I was privileged to be a part of their lives during times of fear, sadness, joy, and even death. Their journeys through this process taught me lessons on living and lessons on dying. My experiences have had a profound effect on my life and how I interact with the world. Over time, I have become increasingly conscious of the fact that relatively little is known about the impact cancer has on cancer survivor families and, in particular, spouses. Through this study, I want to contribute to existing research by gaining a more profound understanding of the impact upon cancer survivor spouses.

The National Cancer Institute(http://www3.cancer.org/cancerinfo) estimates that over 8.4 million persons in the United States with a history of cancer are alive today. Trends in five-year relative survival rates for all races have increased from 50% to 59% between 1974 and 1995. In the year 2000, the National Cancer Institute estimated that

over 1.2 million cancer diagnoses would be made in the United States. Even though relative survival rates continue to improve, the general public continues to perceive cancer as a death sentence. Although cancer remains the second leading cause of death in the United States, survivors are living for much longer periods of time. Mortality rates are declining and remissions and cures are increasing. Consequently, understanding the experiences of living with cancer is gaining more attention.

Interestingly, psychologists have been actively involved in studying cancer survivors, but have failed to examine the impact a cancer diagnosis has on quality of life (QOL) for cancer survivor spouses. The issue of QOL for survivors has been documented through numerous studies, but very few address quality of life for spouses. My experience supports this phenomenon, in that spouses are often ignored or viewed as extensions of the survivor's life, disregarding the impact on the survivor's spouse. A spouse's ability to cope, support, and survive this experience should not be discounted or disregarded.

Therefore, my intention is to contribute to existing literature by improving the understanding of cancer survivor spouses' quality of life. I have chosen to use a

qualitative, grounded theory approach to gain insight into how participants make sense of what is happening, and what impact, if any, this situation has on their QOL. How individuals define QOL affects their behavior, thoughts, and emotions, which in turn, impacts others. As scientist-practioners, psychologists must begin to understand the nature of the QOL construct from the spouses' experience, and begin to generate substantive theory in order to work more effectively with this ever-increasing population.

### *Research Questions*

The distinctive characteristic of hypotheses in qualitative research is that they are generally formulated after the researcher has begun the study; they are grounded in the data and are developed and tested in interaction with it; rather than being prior ideas that are simply tested against data (Maxwell, 1996, p. 53).

The difference between a research hypothesis in quantitative research and research questions in qualitative research is a critical distinction. In qualitative research, the research questions identify what the researcher wants to understand, whereas, in quantitative research the hypotheses state what the researcher thinks is going on, which is then supported or not by the data.

The current research is designed to answer the following questions:

1. What does QOL mean to cancer survivor spouses?
2. How has the experience of cancer impacted their QOL?
3. Are there specific QOL domains that are most strongly affected in spouses of cancer survivors?
4. How do cancer survivor spouses make meaning of their experiences?

By applying inductive, qualitative methodology to these questions, I hope to increase the understanding of participants' reality and develop a descriptive, grounded, midrange theory for use in present psychological interventions and future research.(see Figure 1)

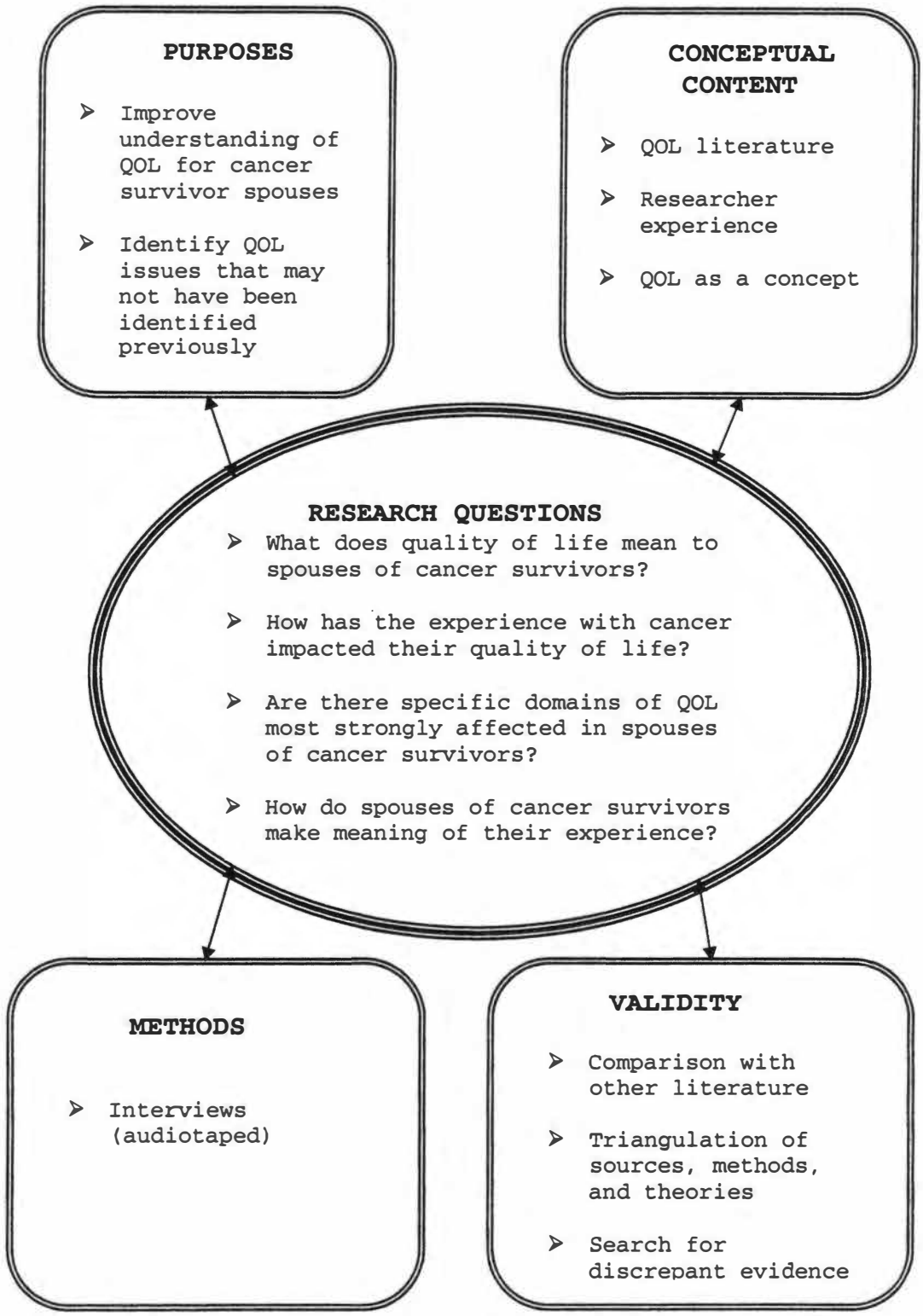



Figure 1. Research Design

# Chapter 2

## Conceptual Context

I intend to construct a conceptual framework from which to explain the key factors, concepts, and experiential knowledge that will provide the context for my research. Consequently, this section will discuss the QOL construct, briefly review previous studies on cancer survivor spouses, define cancer, and present my own experiential knowledge.

Qualitative researchers differ on when to begin reviewing previous literature. One extreme is Glaser's (1978, p. 31) recommendation that no use of prior literature be involved before conducting fieldwork. He justifies this position by pointing out that prior information may mislead the researcher's perception of what is occurring, thereby reducing the researcher's openness and ability to make accurate decisions. The opposite extreme, as presented by McCracken (1988) and Lincoln and Guba (1985), is for the researcher to begin with an exhaustive review of the literature. They support the use of a thorough literature review to define problems, become acquainted with the field, and then assess the data.

Thus, providing a literature review for qualitative

research can present a dilemma. However, Morse and Field (1995) propose a method that attends to some of the advantages and disadvantages of each extreme. They recommend that the researcher critically examine previous literature and utilize it selectively. Their method "provides a theoretical context for the study per se, but does not drive the study or provide an outline for analysis" (p. 50). Lincoln and Guba (1985) similarly suggest "that those things to which the inquirer can and should attend before getting the study under way [provide] - a *springboard* that assures 'getting off on the right track' and a *benchmark* against which later changes and developments can be assessed" (p.251). The crucial element for the effective use of any prior information entails critical analysis or deconstructive reading (Denzin, 1989; Glaser & Strauss, 1999; Lincoln & Guba, 1985; Maxwell, 1996; McCracken, 1988; Morse & Field 1995).

### *QOL Historical Perspective*

My objective in this section is not to list all the ambiguities of QOL, but rather provide an historical and judicious assessment of the QOL construct. Limiting the definition of QOL to a particular theoretical approach or domain is neither feasible nor adequate.

The phrase "quality of life" appears to be a concept developed in the 1960s as a social indicator driven by economics (Birnbacher, 1999; Gerson, 1976; Haas, 1999b; Ziller, 1974). In an attempt to answer the dilemma of increased violence and crime during a period of rising societal wealth in the United States, social scientists began to look at social indicators as a way of evaluating QOL (Haas, 1999b). These indicators focused on providing objective data in which public policy could be based. By collecting information on areas such as housing, crime, health, resources, and education, policy makers hoped to develop a tool for social and economic planning (Gehrmann, 1978). Ideally, governments could then measure current QOL issues and build on this information to improve society's future.

### *QOL Theoretical Perspectives*

By the 1970s, a plethora of articles and studies were published to expand upon the QOL concept. Research focused on subjective measures (Haas, 1999b). Approaches to defining QOL primarily vary on an objective to subjective continuum. McCall (1975) analytically discusses QOL in the context of perceived satisfaction (attainment versus expectation), happiness, Maslow's theory, and concludes

with his own theory of need-satisfaction. Ziller (1974) approaches QOL from a phenomenological approach derived from his theory of personal change. He offers a QOL theory based on a phenomenological approach that assumes that QOL is in the "eye of the experiencer". Using a framework of self-other orientation and personal meaning, his theory is based on his research with non-verbal subjects.

In his 1994 article on QOL as a concept, Parmenter reviews numerous conceptual approaches and various types of measurements to consider with specific populations. He supports the use of symbolic interactionism theory to provide a conceptual base. Using symbolic interactionism theory in which self is defined and maintained by interaction with the world, he suggests that QOL "represents the degree to which individuals have met their needs to create own meanings so they can establish and sustain a viable self in the social world" (p. 20). This theory can provide a framework for the variety of domains, as well as include the consideration of the individual's meaning of illness. Although my participants are not the cancer survivors, the meaning of illness may be a very important factor in their QOL. Gerson (1976) compares individual and transcendentalist approaches, and then

proposes a third approach, based on a continuing process of negotiation. Once again, this negotiation theory is based on symbolic interactionism.

Hayry (1991) reviews two other theories of QOL. The first is based on need. In this theory QOL is dependent on having certain basic needs met. The second theory involves Calman's gap theory. Both Hayry and Parmenter (1994) describe this theory as the gap between what one expects and what one achieves. In other words, for good QOL the individual gets what she wants.

Obviously, attempts to empirically measure QOL became difficult. Gehrmann (1978) affirms this in stating:

> An analysis of about 50 attempts at quantifying and measuring QOL on different spatial levels (such as national, state, regional, urban, city-district, neighborhood level) demonstrates that the results are highly influenced, among others; by the selection of indicators, by the aggregation of indicators to one 'element', by the weighting or non-weighting of the indicators, by employing various measurement techniques. This means that the results of quantifying QOL are subjectively influenced to a certain extent by the researcher. (p. 75)

Even though the concept of QOL has continued to be a source for theorizing and research, no significant definition or approach to measurement has evolved. In the 1990s QOL research began to focus on health care because of medical advances leading to increased life spans. (Haas, 1999a) Haas describes an increase in psychological research on QOL occurring as a result of this phenomenon. She did a comprehensive, multidisciplinary analysis that produced her definition of QOL as a "multidimensional evaluation of an individual's current life circumstances in the context of the culture in which they live and the values they hold. QOL is primarily a subjective sense of well-being encompassing physical, psychological, and spiritual dimensions" (p. 738). This definition clearly supports the subjective view and most succinctly encompasses the data I anticipate acquiring through interviews.

Nevertheless, I do acknowledge that QOL remains a concept originally driven by political and economic interests. I believe that QOL is indeed a construct and must be dealt with as such. Birnbacher (1999) captures the essence of these circumstances when he states:

> On the one hand, the concept is far too well established in the social sciences, in medicine, and

> even in everyday language, to be simply discarded; on the other hand, it is part of too many different discourses and is meant to fulfill too many different functions to have anything like a fixed and unitary meaning. The question, then, is: Is it possible to fix its meaning in a way that is theoretically and practically satisfactory and neutralizes, or at least diminishes, what is seen as dangerous in the concept? (p. 26)

I consider Haas's (1999a) definition to be a feasible answer to these questions for the current research. The nature of this study requires a subjective approach and Haas's definition will provide a satisfactory "springboard".

### *QOL Distinctions and Domains*

Even though QOL cannot be identified as a single entity, various distinctions and domains discussed in previous literature are worth examination. Happiness, life satisfaction, and personal well-being are all constructs frequently used interchangeably with QOL, as well as with each other. Musschenga (1997) and Shin and Johnson (1978) make distinctions between happiness and QOL.

Musschenga (1997) describes three components of happiness: enjoyment, satisfaction, and excellence. He also discusses three conditions that contribute to the realization of these happiness components: material, person-dependent, and good fortune. In the context of medicine and health care, Musschenga clearly contrasts the components and conditions of happiness with QOL. Shin and Johnson (1978) propose a model in which happiness is a concept relative to individuals' "unique needs and resources and to the culture and environment in which they function as social beings" (p. 491). Schwarz and Strack (1991) offer a similar model in their discussion of subjective well-being.

Life satisfaction is yet another term commonly interchanged with QOL. Diener, Emmons, Larsen, and Griffin (1985) refer to life satisfaction as a cognitive, judgmental process, centering on subjective well-being. Using this as background, they have developed a satisfaction with life scale that focuses on global life satisfaction.

The essential feature to consider for the present research is that participants may use similar terms to describe their personal meanings and experiences. As the

researcher, I had to be aware of the difficulty in conceptualizing QOL. I allowed my participants to inform me, rather than attempt to provide them with a singular definition or structure. Recognizing the subtleties enabled me to better explore responses with greater depth.

The domains in QOL are as varied as the definitions and approaches. Specific areas of exploration depend on the author's philosophical background, goal, and purpose. Given that I have chosen to use qualitative methodology, I reviewed QOL domains presented in the literature as subjective experiences. I was aware, however, that when using the constant comparative method of grounded theory, I must take into account all available information as part of the analysis process.

Ziller (1974) offers domains of attitudes, values, behavior, roles, and self-concept. He concludes by identifying the central features of his approach as: (a) stressing personal meaning; (b) being able to compare the personal meaning of events; and (c) facilitating the search for meaningful personal experiences. One of the most valuable aspects of his research is his use of a non-verbal cognitive approach, supporting the need to thoroughly attend to nonverbal cues when interviewing participants.

His theory also provides another method of getting information that may not be available by only verbal interaction.

Cella (1992) describes two components that need to be considered in the concept of QOL in healthcare. He supports the individual's subjective perspective in assessing QOL as one component. He further advocates asking the individual directly. The individual perspective is also defended by Taylor and Bogdan (1990) in their treatment of QOL when applied to mental retardation. They propose that inquiries into QOL be undertaken with the acknowledgment that QOL must be understood in terms of the person's subjective experience. Since individuals may define QOL differently, research in QOL requires in-depth knowledge of people and respect for their subjective accounts.

The second component Cella (1992) discusses is the multidimensional nature of QOL. He describes the elements of physical well-being, functional well-being, emotional well-being, social well-being, spirituality, and sexuality. Haas (1999b) also discusses QOL domains as being physical, psychological, social, and spiritual. Schalock (1990) emphasizes the importance of considering how the individual weighs each domain. He further suggests grounding these

domains in the culture, and how this relates to the individual.

Using grounded theory with leukemia survivors, Bertero, Eriksson, and Ek (1997) identified four domains for QOL. These include self-esteem, interpersonal relationships, performance ability, and social ability. With a different population of chronically ill survivors, Gerson (1976) proposes a theory of QOL as being a continuous process of negotiation. Outcomes of these negotiations affect QOL. Gerson then discusses the specific components of money, time, sentiment, and skill. In Spilker's text (1990) on assessing QOL in clinical trials, he states that the major QOL domains generally referred to include physical status and functional abilities, psychological status and well-being, social interactions, and economic status and factors. In the same book, Shumaker, Anderson, and Czajkowski present a model of QOL with six dimensions. They offer cognitive, social, physical, emotional, personal productivity, and intimacy domains.

Moberg and Brusek (1978), Mytko and Knight (1999), and Brady, Peterman, Fitchett, Mo, and Cella (1999) all advocate the inclusion of spirituality as a QOL domain.

Mytko and Knight, and Brady et al. studied QOL for cancer survivors, and presented valid arguments for the inclusion of spirituality as a core domain. Moberg and Brusek critically review QOL construct development and recognize its complexity. They proceed in demonstrating how spirituality has been neglected as an important component, and encourage future research to include this QOL indicator.

Reviewing professional literature on spouses of cancer survivors, Keller, Henrich, Sellschopp, and Beutel (1996) describe the impact of illness from the spouse's perspective. They include life domains such as demands of the illness, role changes and changes in daily living, communication and decision-making, spouse distress, perceived support, and impact on the relationship. Their research is focused on spousal distress, a component of QOL. Schachter (1992) also identifies similar factors in QOL for families of survivors with terminal cancer. Fuller and Swensen (1992) studied a similar population, but from an ego development viewpoint. They assessed marital quality and QOL for both survivor and spouses. Domains included in their study were interactional style, level of intimacy, coping ability, and stage of ego development.

At this point, I believe I have established that QOL is not a simple construct with limited domains and singular approaches. Growing out of an economic and social indicator to help determine cultural policy, it has become a term used to represent many different beliefs and ideas. QOL has been, and continues to be a challenging concept to grasp. With this understanding, the current research can provide an additional aspect to consider for a specific population.

Research on QOL for cancer survivor spouses has been neglected. In 1999, Suinn and Whitfield (eds.) published a bibliography of abstracts that appeared between 1990 and 1999 in psychological and behavioral literature on cancer. References were compiled using the PsycINFO database and a total of 3133 abstracts or references are cited in the bibliography. Except for spouses of survivors with advanced or terminal cancer, no article or book specifically examined QOL for cancer survivor spouses. My personal search of Medline, PsycINFO, and Dissertation Abstracts International databases yielded similar results. Studies of spouses exist, but are limited to adjustment, stress, support, and other possible domains of QOL. These articles were used in the theoretical triangulation for

this research. If I had used a quantitative method of investigation, I would be including this literature at this time. Since my approach was inductive and used emerging data through interviews, existing literature was more purposeful at the data analysis and validity stages.

*Cancer*

Given that cancer is a fundamental aspect of this research, defining cancer is essential. First and foremost, it is important to understand that cancer is a group of related diseases, not a single illness (http://cancernet.nci.nih.gov). Cancer, as a category, involves the out of control growth and spread of abnormal cells. Normally, body cells grow and divide only when the body needs them to, such as in childhood or in the healing process. However, cancer cells keep dividing even though the body does not require it. Some types of cancers form masses or tumors, which may spread to other parts of the body. These new sites are called metastasis. Other types of cancer do not usually form tumors, but rather circulate through the blood and blood forming organs. Cancer is classified by both the part of the body where it originates, and its microscopic appearance. Cancer is staged based on spread and cell type. Therefore, different

cancer types vary in growth rate, spread patterns, and treatment responses. Treatment decisions are based on the specific form of the disease.

The American Cancer Society reports that in America, one-half of all men and one-third of all women will develop cancer during their lifetime (http://www3.cancr.org). The types, treatments and responses vary. This study will not be limited to any particular type or stage of cancer, but rather, prognosis, since the research criterion is centered on cancer survivors and not specific disease.

*Researcher Interest and Experience*

My experience in healthcare began in the mid-1970s when I began a number of different jobs ranging from nursing to medical social work. I moved to Florida in 1978 and became one of the founders of a hospice that is currently one of the largest in the country. Upon receiving my master's degree in rehabilitation counseling in 1981, I began working exclusively with cancer survivors and families as an oncology counselor. A turning point for my approach to this population occurred during my interview for the position of oncology counselor. The physician who interviewed me asked me how I thought I would handle working with cancer survivors. My quick response was that

I believed I would be very comfortable because I had enjoyed working with dying individuals at hospice. Her reply was "What does death and dying have to do with cancer?"

Thankfully, I was hired, and I began to learn about the realm of cancer experiences. For the next six years, I made daily rounds with six oncologists, giving me valuable knowledge in both the medical and psychological aspects of the disease process. I counseled survivors, their families and friends while I became increasingly skilled at working with this population. In addition, I continued to be trained in more formal educational atmospheres such as Sloan Kettering Memorial Hospital, Yale University, and other professional conferences. I continued to work in oncology counseling at the same hospital and was fortunate in being permitted to develop and supervise a total support and education oncology program. Our department consisted of six master degree counselors who provided individual family and group counseling, as well as community and professional education. This program continues to date and has served over fifteen thousand survivors and families.

I had the privilege of being with survivors at the time of diagnosis, accompanying them in surgery and other treatments, and working with them throughout their journey. Through this, I became increasingly aware of the effects this process had on survivor spouses, and how little attention the medical community gave them. Frequently, spouses discussed feeling left out, superficial, angry, guilty, and confused. It appeared that both professional and community support centered on the survivor, neglecting the spouses' needs. In 1994, I left the hospital. I, then, designed and established a similar support program for a private oncology practice. I continued to work there until 1996. I have taught physicians, nurses, radiation therapists, and other healthcare professionals about the psychological and behavioral aspects of cancer survivors and families.

Consequently, I believe my professional experience and education qualify me to act as instrument for this study. The psychological interviewing skills I have learned added to my ability to be effective in the interview process. My formal graduate studies have included a number of supervised counseling practicum. I have also taken several research courses that include research design, quantitative

and qualitative research methods. Furthermore, being away from oncology counseling for the past five years affords me the distance needed to be more objective during both the interview process and the data analysis.

# Chapter 3

## Methods

### *Research Design*

As discussed previously, the concept of QOL and the impact of cancer upon spouses are both research areas requiring more depth and investigation. Accordingly, applying qualitative methodology to the research questions appears to be most well suited to this purpose. Qualitative research methods provide an emic perspective, examined in a naturalistic environment with the emphasis on theory construction (Morse & Field, 1995). Maxwell (1996) states, "The strengths of qualitative research derive primarily from its inductive approach, its focus on specific situations or people, and its emphasis on words rather than numbers" (p. 17). In this study, qualitative methods are particularly appropriate for understanding the meaning of QOL for these participants in this particular context. Morse and Field (1995) further support this method when conducting research to "explore problems about which relatively little is known" and when the "researcher's emphasis is on the construction of theory" (p. 2).

For this study, I have chosen the grounded theory approach as developed by Glaser and Strauss (1967). The

major themes of qualitative inquiry: naturalistic; inductive; holistic; context sensitivity; empathic neutrality; design flexibility; qualitative data; personal contact and insight; dynamic systems; unique case orientation (Patton, 1990, p. 40-41) remain consistent throughout all of the approaches to theory and research. However, the type of research question dictates the qualitative strategy. Glaser and Strauss (1967) formulated grounded theory to produce explanatory theories of human behavior. Glaser and Strauss have defined grounded theory as the "discovery of theory from data" (Glaser & Strauss, 1967, p. 1). Morse and Field (1995) state:

> The theoretical base for grounded theory is symbolic interactionism. Symbolic interactionism stresses that human behavior is developed through interaction with others, through continuous processes of negotiation and renegotiation. People construct their own realities from the symbols around them through interaction rather than through a static reaction to symbols. Therefore, individuals are active participants in creating meaning in a situation. The primary purpose of grounded theory is to generate explanatory theories of human behavior. (p. 27)

Symbolic interactionism suits the present research because it emphasizes the personal meaning an individual creates from social participation and human interaction (Greene & Ephross, 1991). Critical assumptions and basic concepts of symbolic interactionism include the belief that persons must be studied on their own level and that individuals interact with their environment, which is symbolically mediated. Through the use of symbols (principally language) individuals create meaning, roles, positions, role taking, self, and the importance of significant others (Stryker, 1972). Symbolic interactionism recognizes that the individual adjusts personal meaning as he or she internalizes messages received from others in their own environment. Applying these concepts to the participants in the present study demonstrate how they deal with the demands of their situation and with their own personal set of meanings.

## *Data Collection*

### *Researcher as Instrument*

In qualitative research, the researcher acts as the research instrument for data collection. Naturalistic methodology requires the research instrument to be adaptable, interactive, and responsive (Guba & Lincoln,

1981; Lincoln & Guba, 1985; Maxwell, 1996; McCracken, 1988; Morse & Field, 1995; Patton, 1990). Lincoln and Guba (1985) state, "the naturalist has no choice, because only the human instrument has the characteristics necessary to cope with an indeterminate situation" (p. 193). In other words, it is impossible to develop a priori, an instrument that is sufficiently adaptive to the diversity of responses anticipated. However, as with any instrument, researcher as instrument has both positive and negative aspects.

The idea of researcher-as-instrument appealed to me because it gave me "privileged access" (Lincoln & Guba, 1985) to my participants' experience. This method offers opportunities for clarification, responsiveness, adaptability, and exploration that are not available in other methods. I believe this enabled me to reach a depth of information that offered the "rich" data required for theory building.

Of primary concern in qualitative research is the researcher's credibility and trustworthiness which encompasses issues such as researcher experience, training, perspective, and the personal connection the researcher has to the people and topic being studied (Patton, 1990). For this study, I believe these concerns have been adequately

answered in the conceptual context section. I have summarized my personal and professional background and shared the salient elements with my participants. I had no personal connection with participants prior to this study. My ability to develop rapport and gain trust is an essential therapeutic skill and thus, was of benefit during interviews.

Evaluator effect is a possible threat to validity. I acknowledge my responsibility to be able to recognize that my presence and questions had an effect on participants' responses. This includes my awareness of changes that may have occurred in me during this process, my personal biases, and participant reactions. Reviewing transcripts and discussing responses with two other psychology professionals provided an objective monitor of evaluator effect.

*Context*

This study took place in Knoxville, Tennessee in 2002. Knoxville is a city with medical sophistication, having numerous major medical facilities including teaching hospitals. Cancer survivors have many choices among medical providers and can expect a high standard of care.

Support and psychoeducational groups are accessible through various community agencies such as the American Cancer Society, Wellness Community, and other public institutions. Survivors and families are encouraged to participate in these types of programs throughout their cancer experience.

In general, cancer continues to be viewed as a fatal disease by the general public. Accordingly, cancer survivors and their families are regarded as individuals preparing for death. As will be seen, this belief often interferes with the family's ability to adjust to living with a cancer survivor.

For the participants in this study, private insurance companies cover medical care cost. The extent of coverage varies significantly which can create a substantial financial burden. Although no one is refused treatment because of financial difficulties, families bear the responsibility of making ends meet. Further issues arise when the survivor has no disability income and is the primary provider. During early 2001, financial instability was a major problem for many Americans due to stock market fluxuations. Financial security became a chief concern for many individuals. My participants were all in their late

50s, an age usually associated with preparing for retirement. With the economic issues influencing society in general, cancer families are distinctly vulnerable.

*Sampling*

Qualitative research necessitates the use of purposeful sampling. Patton (1990) explains that purposeful sampling focuses on participants purposely selected to provide information rich cases for study in depth. He states, "Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research" (p. 169). Since this research's purpose is to increase the understanding of a select population about which little is known, purposeful sampling is appropriate. When discussing the differences between qualitative and quantitative techniques, McCracken (1988) believes that purposeful sampling is a lens that "looks for patterns of interrelationship between many categories rather than the sharply delineated relationship between a limited set of them" (p. 16). The participants are not chosen to characterize a part of the larger world, but rather, to offer a chance to view the nature and experience of their world. Participants characterize a criterion based, homogeneous group.

*Participants*

Glaser and Strauss (1999) define theoretical relevance as "the basic criterion governing the selection of comparison groups for discovering theory; for furthering the development of emerging categories" (p. 49). My participants are spouses of cancer survivors and met the following criteria: (a) participants were married to the cancer survivor at the time of diagnosis; (b) participants ranged in age from 25 to 65; and (c) the cancer survivors were either "in remission" or "cured" based on medical assessment. These criteria were selected because I wanted to ascertain whether the participants experienced a change in their QOL since the diagnosis was made. I also wanted my participants to be in an age group that is actively involved in society and planning for the future. My choice of survivors being in remission or cured is significant because I wished to limit my research to spouses of individuals who are not considered terminal. I believe that this prognosis may have a different effect on both the survivors' and spouses' QOL.

Participants were recruited through physician offices, and community contacts. All five participants were attending support groups at the Wellness Community,

a non-profit organization whose mission "is to help people with cancer and their families enhance their health and well-being by providing a professional program of emotional support, education and hope". Participants were fully informed of the purpose and confidentiality of the study (see Appendix A).

Table 1 presents the sociodemographic data of each subject. As can be seen, the sample was very homogeneous. Although this occurred by chance, I believe the homogeneity influenced the sample size and data. Accordingly, when discussing the results, it must be recognized by both the researcher and readers that any theoretical implications apply only to this sample.

Table 1: Subject Demographics

| SEX | AGE | RACE | YRS. MARRIED | # & AGE CHILD | EDUC | EMPLOY | DATE OF SPOUSES' DIAGNOSIS | DIAGNOSIS | SPOUSES' HEALTH STATUS |
|---|---|---|---|---|---|---|---|---|---|
| F | 52 | C | 29 | 1 son 19 | HS | Full | 9/00 | Biliary tree | Remission |
| F | 51 | C | 30 | 3 sons 22,19,16 | BA | Home | 11/00 | Lymphoma | Remission |
| F | 50 | C | 26 | 1 dtr 23 | BS+ | Retired | 11/00 | Lung | Remission |
| M | 49 | C | 27 | 1 son 20 | BA+ | Full | 7/00 | Breast | Remission |
| M | 63 | C | 33 | 1 dtr 25 | MA | Full | 1994 | Breast | Remission |

*Sample Size*

The issue of sample size in qualitative inquiry seems to be ambiguous. Patton (1990) states, "There are no rules for sample size in qualitative inquiry" (p. 184). Lincoln and Guba (1985) recommend sample selection to the point of redundancy (p. 202). Glaser and Strauss (1999) consider theoretical saturation to be the criterion for judging when to stop sampling. Theoretical saturation occurs "when no additional data are being found whereby the researcher can develop properties of the category" (p. 61). McCracken (1988) suggests eight participants in a homogeneous group.

This research sample consisted of the first five cancer survivor spouses who met the criteria. As will be discussed in the data analysis section, all readers agreed that theoretical saturation had been reached. One of the guiding principles comes from Patton's (1990) statement "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size" (p. 185).

*Setting*

The participants determined the setting for interviews. Ideally, I hoped to interview them in their home environment to get a more informed, rich contextual background. Observing participants in their own surroundings could provide data I would be unable to access otherwise. Two participants chose to be interviewed in their homes, one at the place of employment, and two in my office. Primarily, they chose settings that were most convenient.

*Interviewing*

The interview technique for this study was semistructured interviews. Morse and Field (1995) propose that this type of interviewing be used when "the researcher knows most of the questions to ask but cannot predict the answers" (p. 95). With this technique, the researcher can obtain data as well as allow participants to respond freely. Patton (1990) discusses this approach as one of four interview types. The advantage of using an interview guide is increased data comprehensiveness in a fairly systematic manner. The interview guide acts as just a guide, allowing participants the freedom to explain a situation or describe their responses. It provides a

framework within which the researcher can develop questions, sequence the questions, and make decisions about which information to pursue in greater depth. Meanings, understandings, and interpretations cannot be standardized. Consequently, each question can be altered to fit the individual. This method also challenges the interviewer to be an excellent listener in order to identify terms, topics, and responses that need to be pursuëd.

The questions used in the interview guide were created to accomplish the goal of providing the interviewees an opportunity to freely convey their experiences. Particular attention was paid to designing open-ended descriptive and interpretive questions (see Appendixes C and D for complete questionnaires).

The interview process took place face-to-face and was audio taped. The interview began with the researcher providing personal background and interest to help establish credibility and rapport. The informed consent form was reviewed and signed by participants (see Appendix A). Subsequently, I asked for basic demographic information, and then proceeded into the semistructured interview. Each interview lasted between one and one-half hour. After signing a confidentiality statement (see

Appendix B), another counseling psychology student transcribed the audiotapes. Transcripts were coded and identifying information was eliminated by the researcher. Notes were taken during the interview process to provide contextual and nonverbal information.

*Data Analysis*

The process of data analysis in grounded theory begins with theoretical sampling. Glaser and Strauss (1999) define theoretical sampling (a term more or less synonymous with purposeful sampling, Lincoln & Guba, 1985), as "the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next, in order to develop his theory as it emerges" (p. 45). With this process as a background, they then describe four stages of the constant comparative method of qualitative analysis. This method is very similar to inductive data analysis, but has some distinctive differences. The principle distinction is that the constant comparative method is a means for deriving theory, not just a means for processing data (Lincoln & Guba, 1985). Glaser and Strauss (1985) further elucidate the differentiation:

No attempt is made by the constant comparative method

> to ascertain either the universality or the proof of suggested causes or other properties. Since no proof is involved, the constant comparative method in contrast to analytic induction requires only saturation of data - not consideration of all available data, nor are the data restricted to one kind of clearly defined case. The constant comparative method, unlike analytic induction, is more likely to be applied to the same study to any kind of qualitative information, including observations, interviews, documents, articles, books, and so forth. As a consequence, the constant comparisons required by both methods differ in breadth of purpose, extent of comparing, and what data and ideas are compared (p, 104).

Maxwell (1996, p.78-79) writes about data analysis strategies with a focus on context. In particular, he discusses categorizing strategies and contextualizing strategies. The difference between the strategies seems to be that categorizing strategies are prone to context stripping, in which the data is separated from the context. Contextualizing strategies attempt to understand the data in context. This distinction is an important factor when analyzing data in terms of the specific research question.

Maxwell implies that the constant comparative method could be subject to context stripping. The earlier discussion on context in this study supplies the information needed to provide a coherent analysis.

The researcher, one other counseling psychology graduate student, and a licensed psychologist conducted the data analysis in the present research. After signing the confidentiality statement (see Appendix B), each reader studied the full transcripts and independently reviewed, coded, and analyzed the data. When the three separate analyses were completed, the researcher and readers met together to compare findings. The researcher also met with each reader at least two more times individually to clarify findings. Based on the results of these discussions, our mutually agreed outcome generated grounded theory. Any themes not agreed upon were included in deviant case analysis as a part of discrepant evidence. Other than the researcher, participants' nonverbal behavior and tonal qualities could not be directly observed. Thus, the readers were dependent on the researcher's observations, recall and retention. Using notes written during the interview, the researcher attempted to give an accurate report of the interview experience. Nevertheless, it is

acknowledged that this could have some influence on the reader's analysis.

*Constant Comparative Method of Data Analysis*

The constant comparative method has become a standard form of qualitative data analysis. Even so, I believe it is worthwhile to review. The constant comparative method consists of four stages: 1) comparing incidents applicable to each category; 2) integrating categories and their properties; 3) delimiting theory; and 4) writing theory (Glaser & Strauss, 1999). The following is an explanation of each stage and how these stages were applied to the current research.

*Comparing Incidents Applicable to Each Category*

Each incident or data bit is coded by the researcher into as many categories of analysis as possible, as categories emerge or as data emerge that fit into an existing category. The researcher decides which data to include and how the data is then categorized. Remembering that qualitative data analysis is not a linear exercise, but rather a process involving continual adjustment, makes this phase multifaceted. The researcher's background, criteria, and research questions are but a few of the factors influencing coding and categories. Categories need

to have two aspects: internal, or meaningful in relation to the data; and external, meaningful in relation to other categories (Dey, 1993). I found Glaser and Strauss (1999) to be somewhat vague in how categories are determined. However, Lincoln and Guba (1985) suggest that the investigator draw on "his or her tacit knowledge in making these judgments; errors made as a result of using such knowledge are correctable on successive review" (p. 340-341). McCracken (1988) offers a five stage process for developing categories and Morse and Field (1995) delineate specific coding levels. In Qualitative Data Analysis, Dey (1993) presents the most comprehensive examination of creating categories. His writing on creating, assigning, and splitting and splicing data guided the category development in this research.

The first rule is "while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (Glaser & Strauss, 1999, p. 106). As a result of this process, the investigator discovers two kinds of categories, those that the investigator has constructed (sensitizing concepts) and those that have emerged through the respondents (indigenous concepts). Identifying these

concepts facilitates both the analysis and validity procedure by refining the data.

The researcher and two readers mutually agreed upon what data was relevant and which categories were identified. Transcripts were thoroughly scrutinized; researcher notes were discussed; and inclusive criteria were decided. Subcategorizing and category splicing (Dey, 1993) were primarily performed by the researcher. Successive reviews further distinguished the categories and relationships.

*Integrating Categories and Their Properties*

At this point, the analysis process begins to shift "from comparison of incident with incident to comparison of incident with properties of the category that resulted from the initial comparison" (Glaser & Strauss, 1999, p. 107). Lincoln and Guba (1985, p.342) further state that "the comparison shifts from a more or less intuitive 'look-alikeness' or 'feel-alikeness' judgment to a judgment of whether a new incident exhibits the category properties that have been tentatively identified." This step enables the researcher to begin category integration as relationships become more obvious and categories more coherent. As a result, theory begins to emerge.

By jointly collecting and analyzing the data, this stage became more of a progression in analysis rather than a specific change in approach. Again, the researcher and readers continued to refine categories. By integrating categories and their relationships, we were able to begin seeing theory emerge.

*Delimiting the Theory*

Theory is now beginning to solidify and fewer modifications are required as the data is processed. The list of categories may be reduced as they become saturated; that is, when "no additional data are being found whereby the researcher can develop properties of the category" (Glaser & Strauss, 1999, p. 61). This primary goal, theoretical saturation, delimits the categories by reducing their number as well as reducing the number of modifications. This process, in turn, achieves the goal of solidifying theory. Guba and Lincoln (1981) suggest using a test they describe for category completion. Although they acknowledge that no infallible procedure exists for developing categories, they do offer an approach of extension, bridging, and surfacing. These steps are similar to Glaser's approach and will be considered in data analysis at this stage. The use of other professional

literature also was incorporated during this stage.

An issue needing to be addressed is more commonly dealt with in content analysis. Tabulating incidents within categories is often used in content analysis to increase reliability or establish provisional proof in theory development (Glaser & Strauss, 1999, and Morse and Field, 1995). However, constant comparative method analysis does not typically involve this procedure. In Social Theory and Social Structure, Merton (1957) encourages the use of tabulation for validity and in instances when the research is focused on developing theory. The present research will look over the number of incidents within each case to explain differences between cases as the data is categorized.

*Writing Theory*

This step is the unifying stage in which all the information gathered and analyzed is brought together to generate the grounded theory. Notes, interviews, discussion, and relevant literature all contribute to the final stage of writing theory.

The researcher was solely responsible for this step, using the data analysis carried out in the previous steps. The result is a substantive, mid-range theory that will

contribute to research on the meaning of QOL to spouses of cancer survivors.

*Validity*

Qualitative research methods produce different validity issues than quantitative methods because of their differing philosophical and fundamental approaches to research. According to Maxwell (1996) the types of validity involved in qualitative research are description, interpretation, and theory. In addition, two specific threats of researcher bias and participant reactivity also need to be considered.

The main threat to description validity is inaccuracy or incompleteness of data (Maxwell, 1996). This issue was addressed by audio taping interviews, transcribing them verbatim, and recording all notes and observations. "Rich" data was included to further assure validity. Maxwell defines rich data as "data that are detailed and complete enough that they provide a full and revealing picture of what is going on" (p. 95).

The main threat to interpretation validity is "imposing one's own framework or meaning, rather than understanding the perspective of the people studied and the meanings they attach to their own words" (Maxwell, 1996, p.

90-91). The use of two independent readers in the data analysis addressed this threat by providing autonomous analyses that are then mutually agreed upon. The major threat to theoretical validity is not considering alternative theories or paying attention to discrepant data. Both of these threats were dealt with through methods described by Patton (1990), Lincoln & Guba (1985), Denzin (1989), and Maxwell (1996).

Triangulation was my primary form of validity testing. Triangulation involves collecting information from a variety of sources and using a variety of methods. For theory triangulation, theoretical frameworks derived from previous studies that have approached my topic from different viewpoints were used. Furthermore, I thoroughly examined my data for discrepant evidence to assess if any of my conclusions should be modified (Maxwell, 1996). Based on the results of the discussion with the other readers, our mutually agreed outcome was incorporated into the generated grounded theory. Any themes not agreed upon were included in deviant case analysis as part of discrepant evidence. Therefore, some suppositions were modified. Since the emphasis of this study was to generate substantive theory and not to verify formal theory, I

believe this reasoning satisfied qualitative validity criteria.

Evaluator effect was previously addressed as a concern in validity. Recognizing and attending to the issues of researcher bias and participant reactivity also increased the validity of this study. Guba and Lincoln (1981) best express the importance of the skills, competence, and rigor of the researcher:

> The naturalistic inquirer is himself the instrument, changes resulting from fatigue, shifts in knowledge, and cooptation, as well as variations resulting from differences in training, skill, and experience among different "instruments" easily occur. But this loss in rigor is more than offset by the flexibility, insight, and ability to build on tacit knowledge that is the peculiar province of the human instrument (p. 113).

# Chapter 4

## Stories About Quality of Life - Findings

### "It's like Your Whole World Gets Rocked"

> ...You know, it's quite a little bit...a real high roller coaster. And then when you start seeing and thinking things are going to level off, they don't.

Analysis showed that participants' responses fit into five major categories and eight subcategories. The five categories are personal issues, spousal issues, social aspects, motivation, and financial burden. Responses were arranged according to common concerns and issues. Subcategories were then developed to expand and clarify each category. (see Figure 2)

### *Personal Issues*

This category was developed to understand the spouses' experience and what impact cancer has had on their life and QOL. Their partner's cancer diagnosis has had a profound impact on how they live their lives, as well as how they approach the present and future. Four subcategories: life satisfaction (Being happy with what you have), self-concept (I am not defined by the fact that he has cancer), feelings (You're always afraid the cancer's going to come back), and philosophy/existential impact (These other things are not

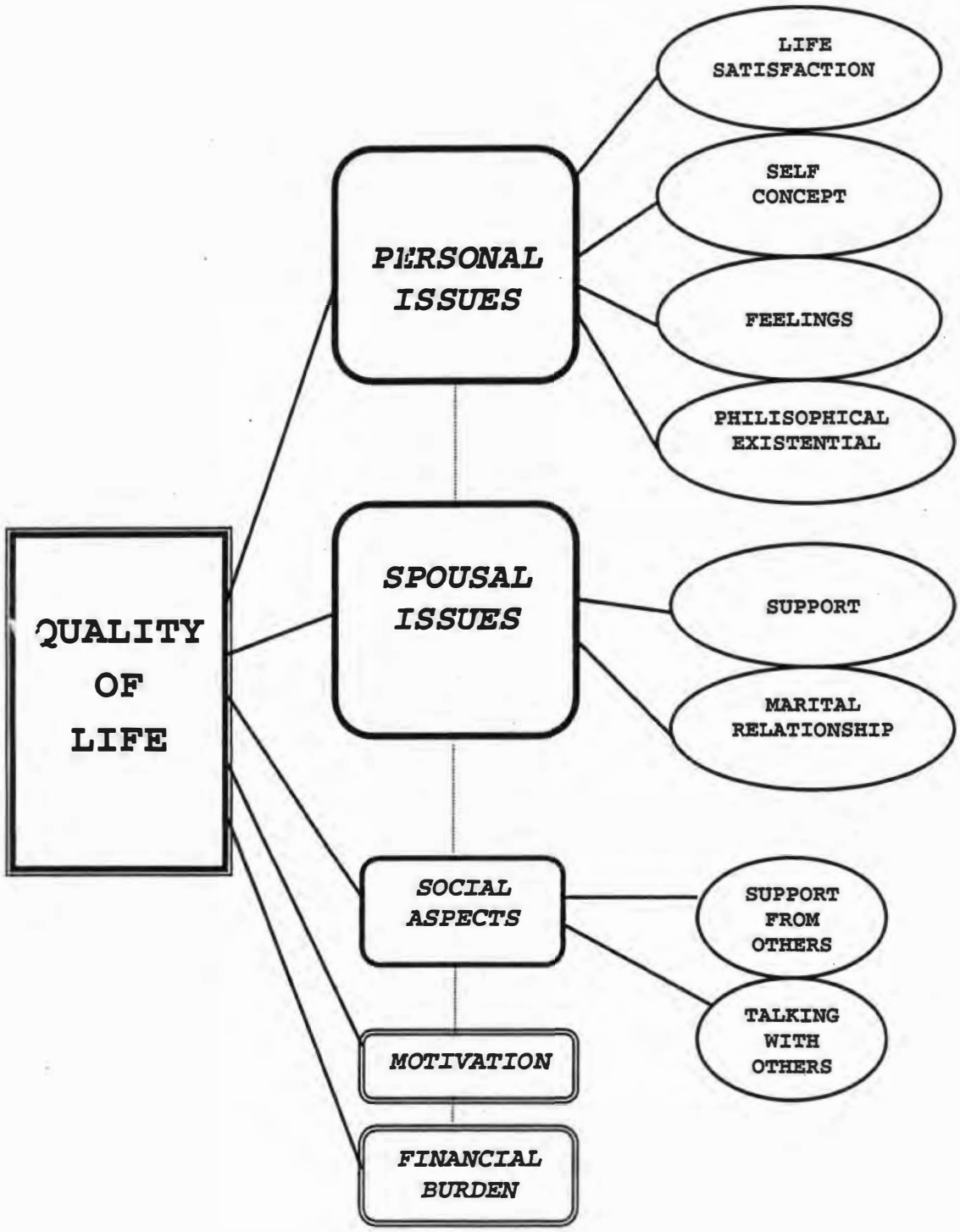



Figure 2. Quality of Life Domains

as important) make up this category. Each of these subcategories reflects a different aspect of the individual.

*Life Satisfaction*

"Being Happy With What You Have"

As mentioned in previous chapters, defining QOL is a complex and often confusing task. The participants in this study had similar difficulties. In fact, QOL frequently was discussed in terms of what had changed, rather than what it was.

Life satisfaction centers on being able to have material comforts, financial security, and satisfactory relationships with others.

..... Being happy with what you have. Not stressing over what you don't… Well, I'm gonna go with that, that what is good QOL to me. And I guess that's what I would…getting along with people that are close with you…. Being happy, not worrying about what's going to be. Just being satisfied.

..... Seeing those around me happy (LAUGH). People trying to work together. Not putting up obstacles…I don't whatever kinds…kinda saying okay how can we make this work.

..... Well, I would like to have just the generalized comforts of being able to have family members around me, have enough to eat, and enough money to pay my bills, to be able to just do some things that we like to do, have God in our family in the center and live from there on.

.....is for us to be able to have…to be able to share things together, to be able to enjoy our life together, to be able, you know, to have uh, some things that we want.

..... where I could provide for my family and uh, so that if she wanted to work, she could if she didn't want to she wouldn't have to. Yeah, and we could have a comfortable home with a view of the mountains which we have on top of the hill. And, you know, have friends, and you know, get involved in the community, church and all that sort of thing.

However, the cancer diagnosis appears to have changed the spouses' life satisfaction; for some it is improved, for some it is mixed, and for some it is worse.

..... So...the good thing that happened I guess was that she had an opportunity to retire from work.

..... our QOL is better because he's home… So our QOL since he has been home, since he has been diagnosed is better except that I find within me there's this little underlying sadness that lives in me right in here that wasn't there before. And that… I don't know that that affects our QOL, but that does affect me. . So having him home is good. (Pause). I guess that's my answer. I described it, how, you know, yes our QOL…no it hasn't been changed because of his cancer but it has certainly changed me.

..... So that's where, I guess um, we were finally just moving along there pretty good and then BOOM she gets breast cancer.

.....well our life is definitely changed. But I don't know so much that the quality of our life is really changed. I think we really…I think we've adapted to this new situation. And it was tough...

.....So, in those ways, that has affected quality. I mean that it's there, you know. It doesn't affect us getting up every day, doing what we have to do, but that's changed.

..... Well, even though it seems that we've been very fortunate, and we have in many many ways, uh, her illness in particular has changed our QOL. Uh, it's still good but there are some areas where it's different uh, than it was before... so I would say just in general about the QOL I think it's still good, in fact we're very fortunate.

*Self Concept*

"I Am Not Defined By The Fact That He Has Cancer"

Spouses spoke about having to surrender obligations and activities that brought meaning to their lives. A spouse with cancer involves significant reorganization of their schedules. Even though spouses continued to work or resume some pre-cancer activities, maintaining outside interests seems difficult and at times, impossible.

.....I think that I've given up most of the things I like to do with the exception of reading (pause) because I don't have time.

..... Because before the illness you have other outside interests and other obligations. So when a person gets sick you start to feel like you are slacking off on other duties so you try to keep some of your other duties and also take on the responsibilities of what your partner was doing and in my case it was kind of the breadwinner.

..... I'm very involved in (survivor) and very involved in (Son) and uh, since his illness I've just given up all my volunteer work.

For many, personal needs became secondary to their partners. They focus on the survivor rather than themselves. An interesting observation is that all the

cancer survivors were capable of living independently at this time. No one was on treatment, and most were working. Gradually, it became obvious that most of the responses continued to have the implication that survivors were still sick and incapacitated. Although, the diagnosis and treatment occurred years ago, spouses are preoccupied with the survivors' health. In other words, there was no return to normalcy.

..... much of my life is centered around my relationship with (spouse).

..... You know, we were laughing last night and I said 'man I am still waiting just to figure out what I wanna do when I grow up!' You know: what is that one thing that you look forward to doing everyday and going and doing that, you know, what is that? And then I made this statement that what would matter now if I did find it because I couldn't do anything about it. And the leader asked me to clarify that and she said 'could you give me an example of why you said that.' And I said: well, right now there is nothing I can do except I've got to take care of him. That is totally who I am right now. That everything I do is centered around that.

..... But it was just like every decision like that is based on what's happening to him or are there doctor's appointments to go to? Um, is he going to be okay, even to go out to lunch with friends? And he is doing so much better now that I felt that I could do that. And one of my friends said you better go now because he's gonna get worse. We know that, and there will be a time when I won't be able to go. So, I don't know. QOL is pretty much…this is my life for the next few years or however long it is…I have to be able to take care of him…So if I did figure out what I wanted to do I couldn't do it. I can't go take a job or get involved in school, um, because I'd never know when I would have to be here to take care of him. Which is exactly

where I want to be. I wouldn't have it any other way. I'm just thrilled that I am here and that I can take care of him but at the same time it's very confining, I feel confined, I sort of feel trapped, you know? (I: Yeah). Although, it's not something that I would change. I'm so, I guess so involved in the here and now and taking care of him and making sure he's happy.

The result of giving up normal activities and focusing on the survivor leaves the spouse with little time or energy for self care. Priorities revolve around the needs of others before taking care of self.

..... The big difference for me is you function and you get through your daily things, you do the routine things that need to be done to take care of everybody. But when you lay down at night you are so weary and tired that you don't even want to go on the next day but you know you have to. You want to find something that is outside of me...

..... Oh yeah. I think the hardest rule of a caretaker is to take care of yourself because the hours are not fair.

....., 'cause I feel like times are still… just things I could not…and I'm working on it…I'm working on it.

However, some spouses were able to find satisfaction in their lives. Even with life changes that appear to be stressful, they are able to find self affirming activities and maintain positive beliefs.

..... I mean my life is still unbelievably good...

..... And so whenever I can if I can share something that is helpful then that is good. I um, I think it's in my nature to kind of be helpful (laugh), so um, it makes me feel good if I can do something to help someone else.

..... don't know but…I think that I deal with things pretty well.

..... one thing that makes me feel really good, I feel like every day that whatever I'm doing now is preparing me for what I'm gonna do, it's gonna add to that. And just to keep going forward, whatever it is. And that's what I feel like at the present time.

Others experience frustration and loneliness.

.....I think the thing that I find frustrating is that I sometimes feel in a quandary, that this is more than I can deal with. But there's a part of me that wants to keep everything just as normal as possible.

..... since these changes have taken place, spending more time by myself, even more I am comfortable as a loner sort of, there are times when I desire the company of other people. The problem is I desire the company of female people much more than male people and most of the time that's been platonic, not always. So that is perhaps a more sinister change in the lifestyle. And I'm not saying that the cancer brought this on but it didn't happen before the cancer.

*Feelings*

"You're always afraid the cancer's going to come back"

Even years after the diagnosis has been made and couples are encouraged to get on with their lives, doubts linger. Fear is the predominant emotion that everyone shared.

.....I think there's been a lot of fear.

.....Yeah, I get upset. I mean I've never had this kind of fear before.

.....Yeah, more frightening. Yeah, I'm afraid...

.....I think my biggest thing is right now, is fear. .....The fear now that we're past the five year threshold is that she'll develop a new cancer.

.....Uh, well. Of course there's always the background fear that it will recur, that she'll get the cancer…that it will show up again. Every time she coughs I wonder if it's something with her lungs like her mother had. The first cancer that came back was lung cancer for her mother. But I don't think it's a huge issue with fear.

Participants' nonverbal communication suggested an underlying pervasive sadness. At some point in the interview process, all had tears, long pauses, and sighs. They seemed to be putting on a brave front, an attempt to be strong. Many interviews were interspersed with moments of humor, but the general tone remained cautious and sad.

.....I'm depressed, very depressed.

.....I was so mad, and sometimes I am angry at him.

.....So I have that anger sometimes of why didn't he quit smoking years and years ago. That pops in for me too, you know. I have anger that we're in this financial situation we're in. I'm very angry about that. Sadness just watching him die is so sad. It is so sad. It's very sad. And lonely. I feel very alone.

..... So the QOL issue is…I felt, I guess you could say I've had a range of emotions to all this answer. From feeling guilty myself, like maybe I helped bring it on to I really feel upset for her having to go through such a traumatic kind of a thing.

*Philosophical and Existential Beliefs*

"These Other Things Are Not As Important"

Beliefs about the future center on hope, faith and

acceptance. No longer do spouses take for granted a carefree, happy future, much less a future together. However, all expressed hope - hope that the worst was behind them and the potential for happiness was possible. Their cautious optimism seemed grounded in their need to hold on to the knowledge that they had successfully beaten cancer once and could do it again.

Mundane disappointments and aggravations once complained about are now viewed as inconsequential. Appreciating life, relationships, health have become the focus of getting through life.

..... And that's how I look at the future, that we will grow old together and that he will be well enough for us to live…to eventually retire and for us to work for my son, live with him and make his life miserable for 20 years.

..... And you do hope, you want to beat the odds. But in a way I feel that… I mean I do believe that you pull from the universe what you ask for in ways and get back what you put out. (DEEP SIGH). See I'm a real prepared, too. I believed if you were prepared (LAUGH) you won't need it, you know. And, what I feel like…I don't know, like you know, can't pretend it might not happen. You can hope for that

.....It's been a miracle. I mean a real miracle.

.....I try desperately to hold on to my faith for the future. To know that God is in control that everything that has happened to us so far. Because he should never have done as well as he did. Most people are sick with chemo, he was not. And doctors are amazed at how well he's doing and I'll just take it as a sign that God is…has had his hand upon the whole thing and that he is in control so. We

live our life that way. I have great hopes for the future.

..... these other things are not as important…in the whole scheme of things they are just not a big a deal. That's all there is to it. I mean in an ideal world you wouldn't have to deal with stuff like this but you know we don't live in an ideal world and we have to take whatever's kind of dealt out to you, I guess. So that's kind of the way I look at it now. You know I feel that given the weight…I'm just trying to accept these things.

..... this cancer thing is like there's a lot of uncertainty, you know. And you tend to you know; have to kind of deal with things on a day-to-day basis. You never know for sure if something is gonna like, come back or…I think it just kinda puts your life in a little bit more perspective with the way you want to live and so forth because just don't take so many things as for granted that we do. Because I feel like, you know, uh, we are trying to make the best of our lives.

.....And like a friend said, there's a fine line between false hope and denial.

*Spousal Issues*

The predominant subject in all interviews was the spouse with cancer. Even when participants began to talk about themselves or others, the discussion always came back to the survivor. QOL for cancer survivor spouses is therefore heavily influenced by their beliefs about being able to effectively support the survivor. In addition, their marital relationship became an area of complex changes in roles and needs. Trying to help the survivor as well as get their own needs met within the relationship created a stressful condition.

"I'm Going to Support That Person As Much as I Can"

Support has many different forms, from physical care to whatever it takes to make life happy. Daily life revolves around anticipating needs and vigilantly assessing the survivor's mood. Once again, many responses imply that the survivor is unable to adequately maintain their usual lifestyle. Furthermore, some responses dealt with the past, during diagnosis and treatment, rather than the present. Seemingly, the events occupy present thoughts and actions.

..... But I really…yeah, what I feel like is I want to make his life as good and happy and stress free and carefree as I can.

..... so I'm gonna support that person as much as I can. I'm going to be there and you know, whatever I can do to make that person's life better.

.....So it's not my place to be critical or anything like that at all. It's my place to be…to try to support her. So that's what I've been trying to do.

..... whatever it takes, we'll get through this...

..... Most definitely…. I want him to enjoy what he wants to…..'I wanna go to the flea market, you wanna go?' I was in the middle of mopping the floor, I dumped the water and left. That's…that will always be there but my time I spend with him may not be there tomorrow.

..... I'm just up and down, up and down. It's just all you do, you focus on that. And you know, when he was so sick I had to make sure…I took care of everything that went

in his mouth and everything that came out. I mean just…I monitored every thing.

.....And so I try to be there for her with whatever it was. If it was hooking those tubes that she has on her side that had to drain for weeks, taking her to doctor's appointments and I think I went to all of them with her. And through all the chemo and stuff and the radiation. Fixing her food and waiting on her and whatever I could do.

..... So I had some books and some research and I went on the Internet and I pulled out my cancer books that were old but gave me data. So I did a lot of research about the types of things he had and his options.

.....And if something was wrong, he'd call me and I'd have to go running to the hospital and I was trying to work, trying to take care of a house, and animals, make sure my son was in college, in school, and that things were getting done there, and so it really has been terrible.

..... I made the decisions. I had the power of attorney, we had the living will done, we had all the correct paperwork done. You have to become educated so quickly. And I've never been a person that shies away from making a decision. Um, I can make decisions, that was never a problem for me. But yeah, more mutual and not so uh, life depending kind of decisions, you know. So it's just, yeah, decisions it's just one right after another.

*Marital Relationship*

"You Know I'm Sick, You Could Be A lot Nicer"

Companionship appears to be the major alteration in marital relationships. Spouses believe they can no longer depend on their partner for the comfort and support they once had. For some, physical comfort seemed to be gone. For others, the need to protect their partner from stress prevented them from sharing daily frustrations and fears.

..... He said to me once, he said 'you know I am sick, you could be a lot nicer' (LAUGH). And I said, 'you are gonna have to be a lot sicker for me to be nicer' (LAUGH).

..... (PAUSE) Mmm, you don't realize how much you care about somebody until you think you're gonna lose them (DEEP BREATH)...

..... And then you feel guilty because you instituted some kind of roughhouse play fun. And you can't do that anymore, you know..... but you're afraid to do that either..... He's trying to continue on but...that's changed a whole lot for us..... doctors saying 'oh you can have sex, you can have sex.' But that's a joke. There is just no ambition to stay up long enough to watch TV for him let alone for any other activities. That, I've adjusted to well. It's okay with me..... It's always been a very good understanding relationship. But yeah I still miss not being able to be held and snuggled and just the comfort of him holding on to me and knowing...I always had that when I was sick you know. Even though the sex couldn't be there, we always had the intimacy and the cuddling and the holding and that kind of thing we always get by with that but it's not there now. We can't do that. But I do miss being held and being snuggled

..... I don't have the support from him that I had from him before he was sick where I would go to him for a problem because now he's not able to handle the everyday problems that we generate. I can't snuggle him because he's cut on one side and the ports on the other side and it's like 'be careful, don't come in here, watch this....' So I've lost that.

..... our lives became more a more individual proposition than it had before...

..... our relationship, my wife and I, it may not sound like it but it's still good, it's still strong. There's still a lot of love there. Um, it may be that I'm trying to say that there is more frustration there than there used to be but there's still a strong relationship.

..... Yes, it has impacted upon the companionship component of our marriage. Um, I won't say that the sexual relationship has changed all that much because of the cancer, and that's what we're talking about here. Uh, but

being together, at least the time of togetherness has diminished. But yes companionship would be one word that has impacted uh; maybe a little bit of communication has been impacted too because of that. Uh, maybe a little bit of intimacy has been changed a little bit.

.....He was never a big talker. Beforehand he would just kinda clam up but he's shared more with me since the diagnosis of cancer.

Although spouses made varied attempts to support their partner, not all efforts were helpful. In particular, trying to ease their partner's stress was frequently met with resistance. Often, communication became a source of frustration.

.....The most disturbing one was that frustration, um, when I would try to uh, relieve her stress and then she would come back at me 'well that's causing more stress' and I'd say 'oh my let's just forget it.' So that again has limitation on our communication.

.....Then I set about trying to reduce some of the stress but she was resistant to changing her lifestyle in whatever little ways that I suggested. Uh, it may have been simple little things like going to bed earlier or not doing this or doing that. It was nothing major but just, I had empathy for her and I just said 'well why don't you do this? Why don't you do that? Well, when she would not respond favorably in my opinion then I would get frustrated and lose my patience and then she would say, well you're causing more stress than the other thing that you are arguing against. So then after several of those little occasions, I started saying, okay. So that had it's own little divisive effect. I…I know I didn't approach it exactly right by losing patience but I felt like it was pushing me away and she wasn't letting me in to do something helpful.

.....And it's like, I can't say the right thing (giggle), and then she pushes my buttons and I push her

buttons and we get…it's like. And I'm thinking, you know, I'm trying my best not to, you know, lose it here. I realize that she can't really help herself and just what's happening.

..... So I've gotten used to this different looking person...

..... (I) Other people have said to me that it's like being on a roller-coaster emotionally, you go up and down and…um, never quite know what's around the corner, and…
(P): No, (PAUSE). It's true, you just can't. I guess whereas before when…again definitely you don't know what's around the corner. Uh, what tomorrow brings. But like I said it's kind of a (???). Not that I feel guilty because I've always thought, you know, at time when you bicker over things that were so unimportant, I always go away thinking, I wish we'd left it. But now you know, you know what a waste it is.

One respondent saw the cancer diagnosis as a positive influence on his marital relationship.

..... but we've really grown closer together. I mean I think there are actually some good things that have come out of this. Seems too weird to say that but…I mean she's actually said…she said that this cancer has been a good thing to happen.

*Social Support*

Social support includes any person other than the spouses who provide comfort through actions and communication. As will be seen in chapter five, social support has been studied extensively in regards to relieving distress for survivors. A few studies have also examined the impact of social support on spouses. If social support does have an effect on distress levels, than

it can impact QOL. Therefore, identifying support or lack of, could be valuable.

An interesting finding in this study is that social support can be both beneficial and detrimental for spouses. When asked about individuals who supported them through the cancer experience, spouses were able to quickly identify friends, family and the church. However, along with this, came comments on how other people had actually been hurtful. Individuals wanting to encourage spouses frequently offered advice or opinions that caused spouses to withdraw.

*Helpful Support*

"A Group of Angels"

.....Well, um, you know, actually (survivor) is a very supportive person.

.....My daughter has been a very positive force. My female friends have been very good.

.....But my daughter is wonderful. She is my rock. And my two friends I was telling you about earlier.

.....We have some good friends and we have some family and the Wellness Community.

..... My church family probably. They were always right there. You know coming to the hospital with me, making phone calls, sending him cards. And I think the other thing was my family was very supportive…..

So I don't know, I think the most important things for us has been my church family and my family. You know, they've been right there all the time. A group of angels

every once in a while will pop into your life without you even realizing they are there and they are people that you don't even think about, can make a difference.

..... It's like the people I work with.. you know she's kind of standoffish, she's got some problems too. One time she came up and just put her arm around me and said 'you know, we're in this for the long haul and I'll help you wherever I can.' And that meant a lot to me because I knew she was feeling some of my hurt and I could vent more to her. To vent to people and to have them not be afraid to come back and hear you again is important.

..... I talked with a few friends but not just everybody. But there was this woman sitting (GIGGLE) beside me in ... waiting for her daughter to finish and she told me all about her grandson being sick and I told her all about my husband (LAUGH) and we got up and left, you know. And I thought, why did I tell this lady this, you know. It was safe.

.....The ministerial staff of our church and the parish nurse. And the chaplains at UT are wonderful.

*Damaging Support*

"And People Put All These Little'Oh'"

..... 'oh, toughen up, you've got faith, you know, you're doing great, I know you'll be able to hold on.' But the truth is I'm not holding on, I'm not doing great, and I would like people be more saying 'you know, I know I'm really sorry you are going through this and I hope we can help you, we will, and we know it's tough and …' instead of 'oh, you are doing such a great job and you are tough, and you'll get through this.'

..... It seems as though if people go through the cancer and during remission, when he's in it, they are supportive and calling and "Oh, you're doing such a great job and, you'll make it, you'll make it.' The truth is I don't think I'm gonna make it, I'm pretty sure I'm not gonna make it. I'll get through it, but I won't make it.

..... people always say, 'oh, find something for yourself' I don't have the energy for myself…

..... And the biggest thing that I resent the most is everybody telling me to toughen up and they I know I can do this.

..... Uh, we went to a meeting of people with just lung cancer at UT just the other day and there was a lady in there saying 'I am so tired of…feel sorry with everyone with cancer, but if you've got lung cancer I don't feel sorry for you. Well you deserve it. You smoked, you shouldn't have smoked.' You know. And I had one of (spouse's) cousins who would never do anything to hurt me or him …when I called and I told her about his cancer, she said 'Oh, I'm not surprised.' Would you imagine saying that about anyone with prostate cancer? Liver cancer? I'm not surprised. But with lung cancer, they feel they have the right to say that.

..... And sometimes we didn't wanna talk about what we heard. Sometimes we couldn't even talk until hours had passed.

.....I've gotten where I don't tell people as much 'cause they say 'well don't obsess over things.' Well, you're not obsessing, you're absorbing, you're formulating, you're working it through.

..... I don't talk to people, (PAUSE) uh, about our daily life, no, I mean. Like I said no one here knows. Mostly people ask…there are some people that I just refuse to talk to about it. I just feel like that's our stuff. And people put all these little "oh".

*Financial Burden*

"I'm Further in Debt Than I've Ever Been"

The financial impact of having a spouse with cancer is a subject every participant talked about. The mounting healthcare bills, time off from work, and other related

expenses have had enormous influence on their lives. Although finances are mentioned in a few professional studies in discussing QOL, for these participants money was a major source of anxiety. Their savings were depleted, plans for the future shattered, and current economic choices limited.

.....We were fortunate to have money to live on…But, we don't have any now. It's gone.

.....Long illnesses can wipe a family out. We're pretty deep into our home equity loan just to get through. We ended up having to take a home equity loan just to live. We're deep into debt now.

.....Well, we've been married for 29 years and I'm further in debt than I've ever been and have a mortgage on the house…debt-wise we were really deep into debt with all the cancer and him being out of work.

.....We may end up having to sell the house.

.....financially I'm gonna be in a very bad situation, but what am I gonna do?

.....I try not to worry him about the money. I take care of all the bills, I pay all the bills, I take care of all that. Um, He has no idea really our financial situation probably.

..... But our financial situation is very much up in the air.

.....(I) Sounds like the financial aspects have had a big effect on your QOL.

(P) Oh, big, very big. But I can handle the money part.

*Motivation*

This last category is included to provide the context in which the participants chose to be involved with the study. Spouses expressed appreciation for the opportunity to speak out and share their stories. They want society to know that they, too, are experiencing the fears and angst more commonly associated with the survivor. The following quotes are the few available on the taped interview. However, all participants expressed enthusiasm and gratitude for the chance to talk about their experience.

> ..... I appreciate the fact that you're doing this. That's one reason why you know, I was happy to do this because it's great that you are devoting your energy and time into a dissertation that deals with this because I think that it's real important.

> ..... Well, I think that the biggest thing is that I'm glad you're doing this because I think that we the caretakers and the people who are left after the people die have needs of support afterwards. And I would also like to have people look at the caretaker as the one who suffers as much as the person who suffered that. and more so the children.

> ..... I hope that your study will show the people of doctors and institutions that the caregivers are in as much pain as the person going through it if not more.

# Chapter 5

## Implications

The findings in this study confirm the perception that QOL is a personal, multidimensional concept. For spouses of cancer survivors, QOL has similar domains as those of other individuals, but notable differences exist.

Some areas discussed by the participants have received a lot of attention in the professional literature. In particular, research involved with spouse adjustment and coping, social support, family dynamics, and gender differences has grown over the last twenty years. Unfortunately, as mentioned by Haddad, Pitcheathly, and Maguire (1996) and Sales (1992) the literature suffers from a lack of methodological rigor, small samples, different measurements, and various disease factors. Consequently, drawing conclusions about existing research must be done cautiously. Nevertheless, current studies can provide additional perspectives as well as background.

The few studies focusing on spousal issues center on concepts such as adjustment, spousal distress, and strain. Most of the research involves couples who are coping with advanced or palliative stage cancer. Caring for a loved one who requires care or preparing for a loved one's death is a

different experience than adjusting to life with someone who has had cancer. Furthermore, QOL entails more than merely adjusting or decreasing distress.

One particular study by Wilson (1991) has documented some of the same personal issues as revealed in this research. She interviewed husbands whose wives were undergoing chemotherapy for breast cancer. Using unstructured interviews, she was able to record and explore her subjects' experiences in depth. Wilson developed a three stage model based on her informants' experiences. The second stage, "becoming a veteran", is the approximate time period in which cancer treatment is over and no recurrence has occurred. Her respondents described feelings of fear, anger, and sadness. Husbands attempted to disguise their negative feelings in an effort to protect their wives. This stage included a "making it through" phase of guarded optimism. Although grateful treatments were over, spouses were afraid to be too optimistic about the future. While struggling to return to a sense of normalcy, husbands continued to be vigilant, protective, and focused on their spouses. They learned how to live day-to-day.

In another study on husbands of breast cancer survivors by Zahlis and Shands (1991), seven conceptual

domains were identified that describe the demands cancer made on husbands. Similar to Wilson's (1991) results, these domains include: reacting to the wife's illness; negotiating the illness experience; adapting his lifestyle to meet the demands of the illness; being sensitive to her needs; thinking about the future; attempting to minimize the effects of the illness; and feeling the impact on their relationship. Spouses in the current study describe similar experiences and feelings, in spite of gender differences or other variables.

Haddad, Pitceathly, and Maguire (1996) identify nine possible psychosocial hurdles facing spouses. In their chapter on psychological morbidity in cancer patient partners, they describe these hurdles, talk about the extent and impact of psychological morbidity, as well as distinguish risk factors for affective disorders. The psychosocial hurdles consist of uncertainty, helplessness, search for meaning, sense of failure, stigma, isolation, lack of support, practical problems, and treatment side effects. Each of these was mentioned by the spouses in this study. As a component of quality of life, these individual hurdles and domains merge to form the psychological foundation for building a life with a spouse who has had

cancer. Individuals came to grips with this new existence in different ways. All continued to grapple with what had happened and simultaneously move forward with their lives.

The effects of cancer on marital relationships have been investigated for the survivor, spouse, and couple. Studies by Gritz, Wellisch, Siau and Wang (1990), Keller, Henrich, Sellschopp and Beutel (1996), and Skerret (1998) document that a partner with cancer alters marital communication despite differences in the type of cancer or prognosis. Gritz et al. (1990) studied testicular cancer patients and their spouses, reporting some decrease in communication but consistently high quality. The majority of couples felt closer since the diagnosis, with 5.9% reporting feeling farther apart. Studying a similar population as the present study, Keller et al. (1996) describe 22% of their couples having less open communication. Their data showed that 75% of spouses felt their marital relationship was unchanged, with 1% stating it was worse. Skerrett's (1998) study with twenty couples described marital communication as becoming selective. That is, cancer was a part of life but not a dominant force on a daily basis. All these articles reported varying amount of spousal distress, sometimes associated with

gender. Nevertheless, most of the spouses seemed to be able to effectively deal with their partner's cancer experience without substantial negative changes.

As a separate entity, communication changes were not a central concern for the current study's participants. Other components such as sexual issues, role changes, and physical comfort were mentioned as well, but not as a principal areas of distress in their relationships. Responses indicate that all of these factors influence quality of life, but as a part of a more global category such as companionship.

Participants in this research appear to experience more distance within the marital relationship than has been reported in previous studies. Even though spouses are more focused on the survivor than before the diagnosis, the quality of their interactions has changed. Literature reviews by Haber (1994), O'Mahoney and Carroll (1997), and Sales (1992) stress the fact that the impact of cancer on survivor spouses is an ongoing process throughout the relationship. Variables such as gender, caregiving demands, stage of illness, family dynamics, and type of cancer contribute to what the individual is currently experiencing. This study has a very small, homogeneous

sample, which may contribute to the similarities they experience within their marriages.

Earlier studies on couples document the complexities of spousal support. Spousal attempts at providing support for the patient have been met with mixed results. Although spouses attempted to reduce the stresses experienced by the survivors, not all efforts are successful. As Hannum, Giese-Davis, Harding, and Hatfield (1991) state, "The husbands of breast cancer patients do not simply provide "social support"; they are involved in an intricate web of coping processes that affect both parties." (p.14) Studies by Baider et al. (1996), Wilson and Morse (1991), Wilson (1991), Zahlis and Shands (1991) describe the struggles spouses experience when trying to encourage their partner. Wilson and Morse (1991) identify this as "buffering", a process by which husbands of breast cancer survivors try to reduce daily stresses and protect their wives. "It required a delicate balance of patience, persistence, understanding and compassion within a caring relationship." (p. 80) This process of buffering is similarly described in the previously mentioned studies. Baider et al. (1996) state that spouses are as distressed as the patients, but deprive themselves of support for fear of burdening the patient.

Spousal support consumed a large part of this sample's time, energy, thoughts, and feelings. As identified by Wilson and Morse (1991), participants were involved in actively doing whatever was needed to meet the survivor's physical needs and also take on the role of protector and advocate. These two components of buffering were referred to continually during the interviews. The importance of this finding is that the survivor spouses have not returned to their premorbid behaviors even though the survivors were now capable of living independently. The spouses remained vigilant, trying to anticipate any possible sign of impending difficulties. Watchfulness has become a common, routine experience.

Social support or support from others has been documented by numerous researchers as having an effect on both the survivor and spouse's emotional adjustment. Hoskins et al. (1996) demonstrated an association between social support and health problems and well-being. Those spouses that received more social support experienced less physical symptoms and increased well-being. In a study by Schumacher, Dodd, and Paul (1993) caregivers of persons receiving chemotherapy also experienced decreased depression with perceived adequacy of social support.

Wilson (1991) also confirms this connection in her study of husbands with wives having breast cancer. Informants were able to describe the benefits of talking with others and being able to express feelings about their situation.

Ptacek, Pierce, Dodge and Ptacek (1997) report that an abundance of evidence exists that suggests social support plays an important role in couples' adjustment to cancer. Once again, however, research has been primarily focused on the patient, not the spouse. Ptacek et al.'s study (1997) concentrated on the multiple aspects of social support for spouses. Using a variety of instruments, they studied ninety-five spouses of either breast or prostate survivors. Support was assessed from four different aspects; perceived, received, support seeking, and satisfaction with received. No difference was found in support availability or in support seeking, but wives did report receiving more support and being more satisfied with the support they received. Considering that wives received more support without seeking it, gender differences exist in how spouses are supported by others. This was not a finding in the current study, although this issue was not focused on during the interviews.

Clearly, social support has an impact on the general well-being of individuals, especially in circumstances surrounding cancer. The impact of disapproving or judgmental interactions as reported in this study, has received very little attention. Spouses report feeling defensive, isolated, and misunderstood. Some withdrew from social situations or minimized their interpersonal experiences. As participants talked about these phenomena, they became quiet, sometimes teary. Increased research in this area could provide needed information and suggestions for helping supportive people be more effective.

*Summary*

This study's data indicate that for spouses of cancer survivors, QOL pivots around an intricate core of feelings and adjustment. The focal point is their spouse's health and well-being. QOL is not a static or stable experience. As one interviewee stated "It's like being on a rollercoaster, I'm just up and down, up and down. It's just all you do, you focus on that." Using the qualitative constant comparative method has allowed this study to capture the complex nature of the respondents' experiences. Applying a qualitative approach has generated contextually

rich data and offered the opportunity to understand QOL in greater depth.

What does quality of life mean to spouses of cancer survivors? The major findings emerging from this study imply that QOL is indeed a multidimensional, subjective, personal experience that is influenced by a number of factors. Respondents talked about being happy with what they had, to be able to share with others, and provide for their family. This fairly simplistic sounding outlook is far more complex than it appears. QOL involves the interaction between the individual and the world. The results of these interactions affect all areas of their lives. For this group, the predominant aspect that influences QOL seems to be their ability to adapt to their circumstances, make the best of what they have, and shift their focus in life. Learning to appreciate what you have and make meaning out of what has happened becomes a careful balancing act. QOL is an ongoing process of negotiation, adaptation, and satisfaction. This characterization seems consistent with the previously discussed QOL theories presented in professional literature. (Haas, 1999a, Parmenter, 1994, Ziller, 1974) The data reflects the important dimensions of QOL, but can not be used to imply

value such as a good or bad quality of life. After reading the responses, it could be assumed that the participants' lives were of poorer quality than before the diagnosis. However, no evidence arose to support this assumption. Spouses reported a range of reactions. Life is different - not better, not worse.

How has the experience of cancer impacted their lives? Even though participants appeared to have some difficulty defining QOL, they were all able to express the impact and changes that the cancer had on their lives. Alterations in QOL were expressed on a number of levels. Changes occurred in coping, behavior, feelings, actions, attitudes and hope. Overall, a common theme emerged of relinquishing independence, dreams of the future, and financial security. In the midst of supporting their partners as well as others, they experience fear, sadness, and depression. Throughout all the interviews, participants focused on the past and their spouses. They strive to have hope for the future, but seem stuck in the past. This conflicting experience can create feelings of inadequacy, insecurity, and loneliness. The world does not appear to be a safe place where plans can be made and roles are defined.

Instead, spouses seem to be vigilantly waiting for the next piece of bad news.

Are there specific QOL domains that are most strongly affected in spouses of cancer survivors? Based on the frequency of the responses, spousal issues such as support and the marital relationship are the most strongly impacted. When analyzing the data, it became obvious that some categories contained much more information than others. Although each category was developed by comparing incidents, spousal support and marital relationship contained the largest number of responses. Individual differences resulted in the creation of subcategories. For example, the husbands spoke more about the impact of cancer on their marital relationship. Wives tended to concentrate on being able to support their partner.

The spouses' perceived ability to adequately support the survivor influences all aspects of their lives. When they have a sense of being helpful and relieving stress for the survivor, then spouses feel good. When they are not successful, they talk about feelings of inadequacy and frustration. Self-esteem and psychological well-being are intimately related to taking care of the survivor.

A natural consequence of this behavior is the change in their marital relationship. The present study highlights the powerful effects that cancer has on a couple's relationship. Overall, marital relationships continue to be a positive, loving experience. Relationships remain "strong". For most, however, adjusting to a spouse with cancer has created some distancing between them. The common theme expressed in this category is loss. Shifts in intimacy, communication, physical companionship, and roles contribute to a sense of distance within the relationship. Generally, the spouses were reluctant to ask for what they needed or wanted. Instead, they attempt to solve problems and find comfort by themselves or through others. The need to protect their partner has resulted in emotional isolation within the relationship. Even now, as the survivor is re-entering the world of work and family demands, their spouses continue to carry an emotional burden. A clear example in this study is financial concerns. Previous literature has not addressed this issue and yet, economic problems have caused great anxiety and worry for these participants. Treatment cost and decreased income have forced couples into debt. In their dedication to protecting their partner, spouses are hiding their fears

about their financial situation. Some couples were able to absorb the mounting costs, but have had to modify their current lifestyles. One spouse reported no significant financial impact, but the survivor was not the primary source of income.

As treatments improve and healthcare costs rise, the financial aspects of QOL may potentially develop into an even larger problem. At the time of diagnosis and initial treatment, theses couples were able to receive the best care available, without added worry about bills. Now, as life goes on, they are encumbered with difficult choices they had not anticipated. This added stress, compounded by their wish to shelter their partners, further contributes to emotional distancing.

The results have also validated the importance of social interactions in QOL. As stated earlier, this domain has received some attention in past professional literature, especially concerning patients. Social support has been shown to effect well-being, coping and even physical symptoms. For these spouses, positive support gave them the chance to talk about their lives as well as provide people they could depend on. Their sense of confidence in these relationships gave them something to

hold on to at times of feeling overwhelmed.

Potentially, a noteworthy discovery is how harmful some social "support" can be. In many instances, individuals obviously felt misunderstood, criticized and frustrated. They resented being told to be tough or strong. The result of these types of interactions was social withdrawal. Therefore, either they chose not to share what was happening to them or they monitored what they said. At the same time, they are experiencing some distance within their marital relationship. Since all the participants attend support groups, these groups may offer a safe, nonjudgmental place to talk about themselves. Every person mentioned how beneficial their group was and plans to continue attending. This particular area of social support requires more investigation to better understand both the pervasiveness and consequences of damaging social interactions.

How do cancer survivor spouses make meaning of their experiences? Even with the reported difficulties and changes, spouses were able to use their experience as an opportunity to grow and refocus their lives. For some, cancer meant having their spouse home more. For others, cancer meant an increased appreciation for each day. When

describing their current lives, they use words such as fortunate, unbelievably good, miracle, hope. They saw cancer as a wakeup call. They have learned to appreciate their spouse rather than just take them for granted. The little differences or disagreements within their relationship are no longer important as they once were. One individual said that cancer had been a good thing, they had grown closer together. As one spouse said

> I think it just kind of puts your life in a little bit more perspective with the way you want to live and so forth, because you just don't take so many things for as for granted that we do. Because I feel like, you know, uh, we are trying to make the best of our lives.

Their ability to reframe their experiences gave them the strength to deal with the daily demands of living with a cancer survivor. Whether it was "being prepared", religious faith, or hope, each individual used a personal strategy that helped overcome their fears and doubts.

### *Limitations*

The purpose of this exploratory research was to begin to identify issues that have not been examined previously. As stated earlier, QOL for spouses of cancer survivors has received very little attention in professional literature.

Consequently, studies such as this can provide preliminary information from which future research can develop.

Given the small, homogeneous sample, these results can not be generalized to other spouses. As with many qualitative studies, the data reflects only the experience of the participants and should not be viewed as a representation of all spouses of cancer survivors. Larger, more heterogeneous groups are necessary to support or refute this study's findings. In addition, the fact that all of the participants attended support groups may have influenced the responses. Another limitation inherent with this type of research method is self reported data. In my opinion, the participants were open and honest in discussing their lives. They were forthcoming with potentially uncomfortable information and shared painful feelings and concerns. However, their responses may be influenced by a variety of factors that are not obvious during one interview.

Another limitation is the complex nature of cancer. Types, treatments, side effects, symptoms, prognosis are all different. Because of this, having cancer may result in completely diverse experiences. For example, one participant talked about the effect of her husband's

multiple surgeries on their ability to be physically close. Another spoke about having oxygen in their bedroom. Even though they are all living with someone who has a chronic, potentially fatal illness, the ramifications vary. This study did not evaluate the possible bearing this had on quality of life.

The fact that only one interview was conducted with each individual is another limitation. Longitudinal research is needed to assess what QOL changes, if any, occur throughout the cancer process. Participants have provided a glimpse of life when the survivor is in remission or cured, but even this phase has times of increased stress and worry.

One of the difficulties in studying cancer and quality of life is the ever changing features of both. Although this makes research more complicated, domains can be consistent within specific groups. More studies with spouses are needed to increase our understanding of their experiences. Because of the complexities, collaborative or multidisciplinary research could provide insights that a singular discipline might fail to discover.

## *Conclusions*

This study has contributed to existing research by offering a substantive theory of QOL for cancer survivor spouses. Using data obtained through interviews, analysis reveals a quality of life concept based on personal, spousal, social, and financial issues. Of primary importance to QOL is how the individual interacts with the world. In particular, the individual's relationship with their spouse seems to have a great impact on self esteem and life satisfaction. The participants' ability to make meaning of their experiences gives them the strength to face an uncertain future. They were motivated by the desire to share their stories and inform others of what it is like to love someone with cancer.

More people are living with cancer than ever before. Improved treatments are being developed daily and cancer is no longer a death sentence. However, cancer does not affect just a part of the body - it creates a ripple effect that extends outward to touch all parts of a person's life, including the spouse. We have a responsibility to increase our understanding of life with cancer. Studies such as this are crucial for developing greater insight and providing spouses with a forum to share their lives.

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# Appendixes

Appendix A

**The University of Tennessee**
**Office of Research**
**Research Compliance Services**

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**INFORMED CONSENT STATEMENT**
**Quality of Life for Cancer Survivor Spouses**

**INTRODUCTION**

You are being invited to participate in a research project designed to gain a better understanding of quality of life for cancer survivor spouses. This study is being performed in partial fulfillment of the requirements of the degree of Doctor of Philosophy, University of Tennessee, College of Education, Department of Counseling, Deafness & Human Services.

**INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY**

You are being asked to participate in an audio taped interview with the primary investigator to discuss your experience of living with a spouse who has been diagnosed with cancer. The interview will take place in a setting that will provide confidentiality and that you have chosen. The expected length of time for your interview will be approximately one hour. The only other contact after this would be if the investigator requires clarification of your statements due to poor recording quality.

The audiotape will be transcribed by either the principal investigator or a transcriptionist who has signed a confidentially statement approved by the Office of Research Compliance Services, University of Tennessee. You have the right to read the confidentiality statement before agreeing to be audio taped. Access to the audiotape will be restricted to the investigator and transcriptionist. Audiotapes will be stored at the investigator's office and will be destroyed upon completion of the dissertation. Audiotapes will not be used for any public or classroom use, or future studies. _____ Participant's initials

The audiotapes will be transcribed verbatim, and all identifying information will be deleted from the transcripts. Two copies of the revised transcriptions will be given to two other Ph.D. students for use in data analysis.

**RISKS**

The only possible risks involved in this research is that the investigator will be asking you to share personal experiences, and reactions to your spouse's diagnosis of cancer. If at any time you are experiencing discomfort, you have the right to either stop the interview or ask that the tape recorder be turned off.

**BENEFITS**

The anticipated benefits from this research are to improve the understanding of living with a spouse diagnosed with cancer. The investigator's goal is to provide information that may be helpful to healthcare professionals when working with cancer survivors and families. In addition, copies of the finished dissertation will be available to all participants and the general public.

**CONTACT INFORMATION**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,) you may contact the researcher, Meta H. Gustafson, at the University of Tennessee, Department of Counseling, Deafness & Human Services, phone no. 974-5131. If you have questions about your rights as a participant, contact Research Compliance Services of the Office of Research at (865) 974-3466.

**PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed you data will be returned to you or destroyed. _____ Participant's initials

**CONSENT**

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

Appendix B

**RESEARCH TEAM MEMBER'S PLEDGE OF CONFIDENTIALITY**

**Dissertation of Meta H. Gustafson, MA**

**Quality of life For Cancer Survivor Spouses**

As a member of this dissertation research team, I understand that I will be reading or transcribing confidential interviews. Research participants in this project who agreed in good faith that their interviews would remain strictly confidential have revealed the information in these audiotapes and transcripts. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these audiotapes or transcriptions with anyone except the principal investigator of this project, Meta Gustafson (766-0817) or members of this research team. Any violation of this agreement would constitute a serious breach of ethical standards and I pledge not to do so.

Research Team Member_____

Signature_____Date_____

Research Team Member_____

Signature_____Date_____

Research Team Member_____

Signature_____Date_____

# Appendix C

## Participant Demographic Information

Name_____

Age_____

Gender____

Race_____

Number of Years Married_____

Number and Ages of Children_____

Education Level_____

Employment Status_____

Yearly Income Level_____joint or individual

Date of Spouse's Diagnosis_____

Type of Diagnosis_____

Spouse's current health status; i.e., in treatment

currently, cured, in remission_____

This demographic information represents typical information obtained in similar studies that may be used both in data analysis and theoretical triangulation.

# Appendix D

## Interview Guide

1. I would like to begin by having you tell me a little bit about yourself.
2. What does the concept of quality of life mean to you?
3. Has your quality of life changed since your spouse received a cancer diagnosis?
4. If so, how?
5. What (experiences, feelings, thoughts, and behaviors) can you tell me about to help me better understand your quality of life?
6. What do you (do, think, feel) now that you didn't do before the diagnosis?
7. What has been most helpful for you during this process?
8. Is there anything else you would like to tell me?

Based on previous studies and participant response, I may ask prompting questions concerning:

Specific feelings (such as anger, guilt, grief, spirituality, etc.)
Specific behavior changes (such as sexual activity, social activity, employment, future plans)
Types of support
Influences of healthcare providers

# Vita

Meta Gustafson received her B.A. in Social Work from the University of New Hampshire in 1976. She then worked as a medical social worker until moving to Florida in 1978. In Florida she attended the University of South Florida, receiving a M.A. in Rehabilitation Counseling in 1981. For the next 16 years, she worked at a hospital providing counseling and education to cancer patients and their families. She developed and supervised the only cancer support program in the southeast. During this time she received further education at Sloan Kettering Hospital and Yale University, as well as other facilities. In 1974, she left the hospital and developed a similar program for a group of private practice oncology physicians. She has lectured nationally as well as taught college courses on the psychological aspects of cancer patients and families. Since 1976 she has been pursuing her doctorate in counseling psychology at the University of Tennessee.

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