INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®

Transforming Personal Reality:

A Descriptive Study of the Experiences of Women Diagnosed Initially with Advanced Stage Breast Cancer

Viva Jane Tapper

A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington

2000

Program Authorized to Offer Degree: School of Nursing

UMI Number: 9976068

Bell & Howell Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

In presenting this thesis in partial fulfillment of the requirements for the Doctoral degree At the University of Washington, I agree that the Library shall make its copies freely available for inspection. I further agree that extensive copying of the dissertation is allowable only for scholarly purposes, consistent with "fair use" as prescribed in the U.S. Copyright Law. Requests for copying or reproduction of this dissertation may be referred to University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106-1346, or to the author, P.O. Box 873, Port Townsend, Wa 98368; FAX 360-379-9029; vtapper@u.washington.edu.

Signature____________________

Date 5/16/00

University of Washington
Graduate School

This is to certify that I have examined this copy of a doctoral dissertation by

Viva Jane Tapper

And have found that it is complete and satisfactory in all respects,
and that any and all revisions required by the final
examining committee have been made.

Chair of Supervisory Committee:

Frances M Lewis 5-16-00
Frances Marcus Lewis May 16, 2000

Reading Committee:

Kristen M Swanson 5/16/2000
Kristen M. Swanson May 16, 2000

Marie Annette Brown 5/16/2000
Marie-Annette Brown May 16, 2000

University of Washington

Abstract

Transforming Personal Reality:

A Descriptive Study of the Experiences of Women Diagnosed Initially with Advanced Stage Breast Cancer

Viva Jane Tapper

Chairperson of the Supervisory Committee:
Professor Frances Marcus Lewis
School of Nursing

The purpose of this study was to discover and elaborate the illness-related experiences and processes reported by a homogenous sample of women whom were initially diagnosed with advanced stage breast cancer and to generate an explanatory model of these processes and experiences.

Flowing from a pragmatic paradigm, within a symbolic interactionist perspective, grounded theory methodology was utilized. Eight women were interviewed on three occasions each over time to capture the course and nature of the processes in which these women were engaged.

The core category that explained the process the women endured was Transforming Personal Reality. Within the context of the traditional medical trajectory women experienced four psychodynamic processes: Realizing, Processing, Battling, and

Being. Following a circular pattern of the dawning of awareness, connecting with providers, following up on their instincts, and perceiving urgency, the diagnosis of advanced stage breast cancer horribly imploded the woman's world. Their breast cancer diagnosis signaled an end to the reality they had perceived before, and they entered a process of reconstructing a reality that fit their experiences. The women gathered evidence of the significance of the diagnosis. They gathered energy for the battle to be waged for survival. Blasted by chemicals and radiation, and carved by surgeon's knives, the women in this study endured significant side effects, physical pain, and bore emotional and psychological scars. They also experienced a psychological and spiritual process that required reflection on personal meaning and purpose, deciding how they were going to deal with their existence and a reawakening to their life in the present. The hallmark of living with advanced stage breast cancer was the transformative process that each woman experienced in which her life was changed forever.

The discussion chapter includes interpretation of results, comparisons with existing literature, methodological recommendations, clinical implications, and future directions.

TABLE OF CONTENTS

Page
List of Figures........vi

List of Tables........vii

Chapter I: Background and Significance........1
Introduction........1
Estimated Cases and Death........1
Demographics........1
Age........1
Race........1
Incidence and Mortality Trends........2
Survival Rates........3
Age at Diagnosis........3
Stage at Diagnosis........3
Statement of the Problem........3
The Cancer Trajectory Framework........4
Psychosocial Adjustment in Early Stage........5
Advanced Breast Cancer as Recurrence........5
Research on a Heterogeneous Breast Cancer Population........6
Attribution of Findings from Studies on Other Cancer Types........7
Purpose of the Study........7
Significance to Nursing........8

Chapter II: Review of Literature........10
Introduction........10
Definitions of Fundamental Concepts........10
Disease Trajectory........10
Psychosocial Adjustment to Cancer........11
Quality of Life........12
Demands of Illness........13
Theoretical Perspectives on Psychosocial Adjustment........13
Attribution Theory........13
Cognitive Adaptation to Life-Threatening Events........13
Assumptive World Theory........14
Theoretical Models of Adjustment to Cancer........14
The Coping Framework of Adjustment........15
Prognostic Indicators........15
Fear........16
Importance of Homogeneity in Studying Coping Skills........16
Group Support and Longevity........17
Emotional Control and Psychosocial Adjustment........18
Advanced Stage Breast Cancer Research in Great Britain........18

Cognitive Response and Coping Styles....19
Psychiatric Diagnoses....20
    Diagnosis at Advanced Stage as a Traumatic Event....20
    Differentiation of Adjustment Disorder....21
    Prolonged Duress Stress Disorder....21
    The Effects of Prolonged Psychological Disturbance....22
    Suicide....22
The Relational Model of Adjustment....23
    Social Support....24
    Effects of Social Support on Demands of Illness....25
    Effects of Social Support on Immune Function....25
    Swanson's Caring Theory....26
An Existential Model of Adjustment....27
    Recognizing Mortality....27
    Personal Meaning....28
    Personal Control....28
    Meaninglessness....29
    Existential Phases....29
    Existential Psychotherapy....30
    Psychotherapy in a Theological Model....31
        Spirituality....31
        Faith....32
        Self-Transcendence....32
Interventions....33
Summary....33

Chapter III: Methodology....36
Section I: Methodological Perspective....36
    Epistemology....37
    Ontology....37
    Symbolic Interactionism....38
    Grounded Theory....41
        Grounded Theory Data Analysis Methods....42
            Coding Paradigm....43
            Constant Comparative Analysis....43
                Open Coding....43
                Axial Coding....44
                Selective Coding....45
                Core Construct....45
                Memoing....46
Section II: Study Design....47
    Participants....48
        Sampling Strategy....48
        Criteria for Selection....48
        Recruitment....48
            Protection of Human Subjects....49

Participant Safety......................................49
Confidentiality..50
Collection of Data......................................50
Section III: Analysis of Qualitative Data..............51
First Steps and Open Coding..........................52
Axial Coding...52
Selective Coding and Choosing the Core Construct..............53
Evaluation of Core Construct and Explanatory Theory.............53
Summary...55

Chapter IV: Results..56
Part I: Sample Description..................................56
Part II: The Core Explanatory Construct..................59
Domain I: Realizing...63
Category IA: Dawning of Awareness.......................64
Having a Hint Something was Different....................66
Knowing Something was Wrong............................66
Attributing it to Something Else..............................67
Interactions Related to Dawning of Awareness...............70
Category IB: Connecting with a Provider....................70
Having Breast Symptoms......................................71
Presenting with a Broken Hip................................71
Having a Suspicious Spot on a Mammogram...............71
Category IC: Following Up on My Instincts....................72
Ignoring it for a Long Time....................................72
Letting the Provider Know its Still There....................73
Being Convinced by the Provider to Come In..............74
Category D: Perceiving Urgency...............................74
Domain II: Processing...76
Category IIA: Deciphering Messages..........................78
Coming to Know Things were Serious........................78
Being Ripped Apart...79
Category IIB: Facing the Possibility of Death...................81
Gathering Evidence...82
Forgetting the Percentiles......................................83
Wondering What His Words Really Meant....................84
Treating Me as if I'll be Cured................................84
Putting a Time Frame on It....................................85
Never Facing the Possibility of Death........................85
Category IIC: Shattered Existing Reality.......................86
Category IID: Trusting: A Leap of Faith........................87
Experiencing a Sense of True Caring..........................87
Believing...89
Category IIE: Paying the Consequences for Others' Mistakes..............................90
Domain III: Battling...92

Category IIIA: Battling to Stay Alive..........................93
Getting Through the Devastating Cure..........................93
Encountering Pain..........................95
Concentrating on Healing..........................96
Category IIIB: Being Dictated by the Disease..........................97
Making Major Adjustments in our Lives..........................97
Letting Go of Former Responsibilities..........................100
Thinking of it as a Process..........................100
Category IIIC: Fighting the Battle Inwardly..........................100
Zeroing In..........................101
Focusing on the Positive
and Sweeping Aside the Negative..........................102
Category IIID: Faith Carrying Me Through..........................104
Domain IV: Being..........................106
Category IVA: Reflecting on purpose and meaning..........................107
Prioritizing..........................108
Knowing its in God's Hands..........................109
Category IVB: Deciding How to Deal with My Existence..110
Not Being any Answers..........................111
Realizing Life's Fragility..........................111
Accepting What's Happened to Me..........................112
Being Ready to Go to the Next Stage..........................114
Category IVC: Reawakening..........................114
Living for the Present..........................115
Realizing how very Little Control We Have..........................115
Centering around the Realization of Reality..........................115
Patient/Provider Interactions..........................117
Summary..........................118

Chapter V: Discussion of Results..........................119
Section 1: Interpretation of Results..........................119
Discussion of Core Construct:
Transforming Personal Reality..........................119
Relationship of Model to Original Theoretical
Underpinnings of This Study..........................130
Attribution Theory..........................130
Cognitive Adaptation to Life-Threatening Events..........................131
Assumptive World Theory..........................131
Relational Theory..........................131
Caring..........................132
Existential..........................132
Spiritual Needs..........................133
Pragmatic Needs..........................133
Divergence and Convergence
with Prior Literature and Research.......................... 133
Limitations of the Study..........................137

Determining Theoretical Saturation.....137
Formal Member Checks.....137
Single Method Only.....138
Methodological Recommendations.....138
Mixed Methods.....138
The Process of Inquiry.....139
Data Gathering by Telephone vs. Face.....139
Birthing the Model.....141
Clinical Implications.....141
Future Directions.....143
List of References.....146
Appendix A: Cancer Disease Trajectory.....165
Appendix B: Summary of Psychosocial Studies R/T Women with Advanced BrCa.....166
Appendix C: Recruitment Sites for the Puget Sound Region.....170
Appendix D: Criteria for Eligibility Sheet Given to Individual Sites.....171
Appendix E: Script for Initial Contact from Site Intermediary.....172
Appendix F: Script for Investigator's First Telephone Contact.....173
Appendix G: Participant Interview Schedule with Associated Phase of Treatment.....175
Appendix H: University of Washington Consent Form.....176
Appendix I: Structured Interview Schedule.....178
Appendix J: Demographic Characteristics of Individual Women in Advanced Br Ca Study.....179
Appendix K: Data Audit Trail.....181
Appendix L: Women's Report of Subjective and Objective 'Clues' From Providers for Determining Seriousness of Diagnoses.....184
Appendix M: Providers' Caring Behaviors as Reported by Participants.....186
Curriculum Vita.....188

LIST OF TABLES

Number Page

1. Demographic Characteristics of the Study Participants..........57

2. Women's Stage and Treatment Type During Course of Treatment..........58

3. Transforming Personal Reality: Domains, Categories, and Properties..........61

4. Domain I: Realizing..........64

5. Patient Length of Delay Associated with Initial Symptoms..........65

6. Patient vs. Provider Initiated Process..........66

7. Sources of Patient Reported Delay..........69

8. Direct Provider Communication of Non-Urgency..........75

9. Domain II: Processing..........78

10. Domain III: Battling..........92

11. Domain IV: Being..........107

LIST OF FIGURES

Number Page

1. Flow from Philosophical Principles Through SI to Grounded Theory....................37

2. Heuristic Model of Transforming Personal Reality
Superimposed on the Traditional Medical Trajectory....................................60

ACKNOWLEDGEMENTS

Many have helped to point the way for me through my years of study.

My warmest gratitude is extended to my dissertation committee for the invaluable guidance and nurturance in this process. I feel privileged that I have had the good fortune to interact with this group of intelligent, insightful, and perceptive human beings. Their exceptional wisdom and talent has significantly assisted this work as well as my own personal transformation process. I am very grateful to you for being willing and able to participate in this work together.

I wish to express my most sincere appreciation, respect, and thankfulness to Dr. Frances Marcus Lewis for the endless number of hours she has spent guiding, teaching, and grooming me for the scholarly world. Her exquisite mentorship has provided the key ingredient for my personal and academic development. This work is a reflection of her deep professional commitment and consistent, loving encouragement. As long, as I live, I'll never be able to thank her enough for the inspiration of her work and her way of being.

Dr. Kris Swanson will forever be my mentor in caring theory, and interpretive methods. She is gratefully appreciated for demonstrating caring-in-action by opening her heart, her life, and teaching her perspectives to me. Her scholarly feedback on this dissertation was invaluable. I am very thankful for Dr Swanson's kindness and grace.

I am forever grateful to Dr. Marie-Annette Brown for her role in teaching me how and why we think and talk about various aspects of dying, and for encouraging me to go forward with this work. Her understanding of the needs of people with life-threatening illness has been priceless.

I am exceptionally appreciative of Dr. Katherine Graham's provision of scholarly advice, and personal and spiritual encouragement that has helped to point the way. Dr. Graham's understanding of quality of life has contributed immensely to this study.

My warm appreciation is extended to Dr. Scott Ramsey for participating as the GSR in this process.

Special acknowledgement is due Dr. Linda Lewis for the creative and technical talent she contributed to the preparation of the power point presentation for this study, and Dr. Marcia Killien for recommending her.

Acknowledgment is also gratefully extended to the funding sources that provided financial support for this study:

- Women's Health Research Fellowship-National Institute of Nursing Research Grant No-T32 NRO7039
- Oncology Nursing Society-Rhone Poulence Rorer New Investigator Award 1999
- Washington Health Scholarship

DEDICATION

First, to the women who participated in this study: I am forever touched by the wisdom and grace of these women who acted courageously in sharing their journey with me so that their stories might be heard by the scientific world. I pray that I have honored their words by presenting them in the spirit with which they were intended, and that their spirit may endure by helping to point the way for other women to come.

I also wish to dedicate this dissertation to my dear husband and best friend, Dr. Bruce J. Tapper for every good reason. He has provided enduring, and loving support through many years of education and absence. Thank you for helping me to know that I am always loved, and that even though we are apart, our commitment to one another is the center of our world.

For almost thirty years I have been dedicated to my son Robert, his well-being, and his sense of personal value in this world. When I started school ten years ago, I dedicated myself to transforming my life in a way that might be most helpful to him by becoming the best I could be. I wanted to demonstrate for Robert that powerful transformation can occur, with the help of the Lord, when one is dedicated to serving Higher Ideals. I especially dedicate this work to my dear son, and his precious wife, Dana, and their two dear children Trevor and Morgan: Thank you for being the very special and enduring Reasons that I was able to endure in the most difficult of times through this process. The meaning that I attribute to you and your experience on this Earth, propelled me forward even through the darkest hour.

To my sister, Mariann Leone, who taught me what it means to be a woman and a friend. To KoLynn Powell, Penny Brewer, Nancy McKindsey, Kathy Anderson, and Julie Thompson, my sisters and colleagues who lovingly encouraged me through this scholarly process.

Finally, to Drs. Margaret and Jack Provonsha, whom have been like dear parents to me. They lived a life that initially inspired me to consider the possibility of personal transformation. Their unconditional love and unfailing support sustained me through the early years of this academic process. I will be forever grateful for Dr. Margaret's weekly letters of encouragement when I first left home to go away to school. She mentored to me in every way a loving, incredibly intelligent and outspoken Christian woman possibly could. I feel very fortunate to have known her, and to have been the recipient of her very special friendship. Till we meet in Heaven. Rest in peace, dear Dr. Margaret.

CHAPTER I: BACKGROUND AND SIGNIFICANCE

Introduction

Estimated Cases and Deaths

Breast cancer is the most common malignancy among women in the United States accounting for one out of three cancer diagnoses. At least one woman out of eight in the United States will be diagnosed with breast cancer over their lifetime. The American Cancer Society (ACS, 2000) estimates 184,200 new cases of breast cancer will be diagnosed in 2000 in the United States. Approximately, 40,800 women are expected to die in the year 2000 from this disease (ACS, 2000). The overall pattern of breast cancer mortality reveals high rates for Western, industrialized nations, particularly those of northern Europe and North America (ACS, 2000). The US breast cancer rates rank tenth in the global community (ACS, 2000).

Demographics

Age

The incidence and mortality of breast cancer increases with age. Nearly 77% of women with new diagnoses of breast cancer are over the age of 50. The rates of probability for developing invasive breast cancer leap from 1 in 235 for women in the birth to age 39 range, to 1 in 25 for ages 40-59, and 1 in 15 for ages 60-79 (ACS, 2000). While lung and bronchial cancer are the leading causes of death in women aged 60-80, breast cancer is the leading cause of death between the ages of 20 and 60 (ACS, 2000).

Race

White women are more likely to develop breast cancer than African-American women (113.2 vs. 99.3 cases per 100,000). However, African-American women are more likely to be diagnosed at an advanced stage (13.8 % vs. 8.9%) and die of the disease (31.4 vs. 25.7 per 100,000) (ACS, 2000). Additionally, Asian and Hispanic women endure high incidence rates (72.6 and 69.4 respectively), but have much lower mortality rates (11.4 and 15.3 respectively). Native Americans experience the lowest incidence rates at 33.9 per 100,000 yet still have higher mortality than Asian at 12.3 vs. 11.4 (ACS, 2000).

Incidence and Mortality Trends

Following a steady, annual rate of increase between the years 1940 to 1987 of between 1 to 4%, the incidence of developing breast cancer appears to have stabilized (ACS, 2000). However, between the years 1980 to 1990 an 18% increase in mortality among African-Americans was witnessed. Since 1990, a general trend towards decline in mortality is seen while mortality for black women remained relatively constant.

The use of mammography for screening is credited for the stabilization of incidence rates. Increased incidence of early stage breast cancer (in situ and ductal carcinoma in situ) rates ten years ago have been offset by lower (9 to 10%) incidence rates for advanced cancer in that same time period. As diagnosis at earlier stages increases, we are finding mortality rates declining. Again, increased use of mammography, as well as improved treatment (i.e. chemotherapy), directly impact mortality rates.

Mortality by race differences is hypothesized to be related to aggressiveness of tumor type, and possible limitations in access to medical care and socioeconomic and cultural factors. However, few studies have directly ascertained factors related to poverty, education, delay in seeking and accessing care, and few still have addressed factors related to social support and coping (ACS, 2000).

Researchers (Facione & Giancarlo, 1998; Burgess, Ramirez, Richards, & Love, 1998) have pinpointed as influences on the delayed presentation of Anglo, Latina, and African-American women presenting with advanced breast cancer:

> Incorrect symptom attribution, reluctance to consider the threat posed by the symptom, failure to tell another person about the symptom, and expectations of abandonment by male partners, deportation, prejudice, and refusal of treatment due to poverty. (p. 430)

Survival Rates

Relative survival rates are determined by comparing survival rates of the general population who are similar with respect to age, gender, and race to a group of cancer patients. Relative survival rates for women diagnosed with breast cancer, in all stages combined, are approximately 84% at five years after diagnosis, 67% after 10 years, and 56% after 15 years (ACS, 2000).

Age at Diagnosis. Women who develop breast cancer when they are younger than age 45 have a lower survival rate (79%) than women aged 45-64 (84%), or women 65 or over (87%). Researchers hypothesize that younger women's lower survival rates are related to more aggressive tumors and lower response rates to hormonal therapies (ACS, 1998).

Stage at Diagnosis. While the prognosis for early stage disease is optimistic more than 80% of women with early stage (I & II) will be cured (ACS, 2000; Swanson, 1992), the prognosis for advanced stage (III or IV) disease is harsh. Generally, survival has an inverse relationship to the stage of cancer at detection. The five-year survival rate is 78% when cancer is diagnosed at a regional stage (where cancer has spread to surrounding tissue; 31% of breast cancers are diagnosed at this stage), and 22% when cancer is diagnosed at a distant site (where cancer has metastasized; 6% of cancers are diagnosed at this stage) (ACS, 1998, 2000).

Statement of the Problem

The Cancer Trajectory Framework

The human response to cancer is a multidimensional biological, psychosocial, and spiritual process within a trajectory framework subjectively experienced by the diagnosed person and the family (Corbin & Strauss, 1991; Dorsett, 1991; Lewis, 1997; Weiner & Dodd, 1993). Stemming originally from the seminal work of Glaser and Strauss (1965, 1968), the concept of an illness trajectory was formulated from research on the chronically ill. "Illness trajectory" refers to the total organization of the work experienced in the course of an illness as well as to the impact on, not only the women, but also their families and health professionals. The kinds of work referred to are illness-related (e.g., crisis prevention, symptom management, diagnostic-related); every-day life work (e.g., activities of daily living, housekeeping, occupational and marital work, and childrearing); and biographical work (e.g., interactions with spouse or significant other, children, and health professionals, expressions of concern, caring, or anger). It relates also to the relationship among these people that then further affects both the management of the course of illness, as well as the fate of the woman who is ill (Weiner & Dodd, 1993).

However, inconsistency in examining the importance of the illness trajectory has produced many studies that view cancer patients as a heterogeneous population. Persons do vary both along the disease trajectory, and on the cancer-related issues with which they are having difficulty (Lewis, 1997). Failing to consider differences in the clinical experience at each stage of the disease trajectory negates any potential for a true picture of the individual's psychosocial needs (Appendix A).

Psychosocial Adjustment in Early Stage

Many studies depict the psychological adjustment to the diagnosis of early stage breast cancer as marked by shock and disbelief, followed by a combination of hope, resolve, and concern for existential issues regarding the individual's mortality (Cella, Mahon, & Donovan, 1990; Weisman & Worden, 1976). Predictive variables for emotional distress in early stage breast cancer include: minimal social support, regrets about the past, pessimism, marital problems, and psychiatric distress at the time of diagnosis (O'Connor, Wicker, & Germino, 1990; Weisman & Worden, 1976; Worden, 1989), among others.

Advanced Breast Cancer as Recurrence

Women with breast cancer recurrence face uncertainty, grief, feelings of injustice, fear, and anger (Chekryn, 1983). While past experience and current setting may predict the severity of stress response (Schmale et al. 1976), the extent to which the woman is surprised by the recurrence may be among the most important influence on adjustment. Women with recurrence in advanced stage may be more prone to the characteristic stress responses of depression, anxiety, intrusive dreams, heightened arousal, vulnerability, and social withdrawal (Cella et al. 1990; Jenkins, May, & Hughes, 1991; Lewis & Deal, 1995; Northouse, 1996; Weisman, 1979; Weisman & Worden, 1985/1986).

Further, recurrence occurs at local, regional, or distant sites with clear correlations to prognosis. We know that recurrence at the local site is known to affect extreme measures of anxiety and depression in 45% of women with breast cancer (Jenkins et al. 1991). Therefore, it may be hypothesized that women initially diagnosed with advanced stage breast cancer may experience even higher levels of personal distress. However, the specific concerns of this population are yet to be described in the research literature (Lewis, 1997). Even when research has been conducted on this population of women, there has been an unbalanced emphasis on objective, time-bound measures that may not represent an informed model of the lived reality of women presenting with advanced stage breast cancer. Understanding the distinct, subjective views, issues, and illness-related processes of these women whose initial diagnosis is in advanced stage will provide a credible, descriptive basis for a program of research benefiting this specific population (Lewis, 1997).

Research on a Heterogeneous Breast Cancer Population

Advanced stage breast cancer may be diagnosed as either a recurrence of a Stage I or II disease, or as an initial diagnosis. In the last twenty-five years, considerable research on women with breast cancer has focused primarily on initial diagnosis in the early stage or recurrence of breast cancer disease. However, existing studies on recurrence have not always distinguished advanced breast cancer disease as initial diagnosis (Cella et al, 1990; Chekryn, 1984; Lewis & Deal, 1995; Mahon, Cella, & Donovan, 1990; Weisman & Worden 1985/1986). This distinction is both clinically and scientifically important. In some instances, either no staging of the disease process is reported, or data from a heterogeneous population are reported. In addition, studies on women with advanced stage breast cancer (Coward, 1990, 1991; Spiegel, Bloom, Kraemer, & Gottheil, 1989; Spiegel, Bloom & Yalom, 1981) have not differentiated initial diagnoses from recurrence. Given the state of the research to date, both clinicians and scientists are unable to derive implications related specifically to an initial diagnosis of advanced stage breast cancer.

Attribution of Findings from Studies on Other Cancer Types

Studies examining psychosocial implications of advanced stage cancer combine heterogeneous samples of various types of cancers and attempt to attribute findings to homogenous breast cancer samples (Fawzy, Cousins, Kennedy, Elashoff, & Morton, 1990; Fawzy, Kemeny, Fawzy et al. 1990; Ganz, Hirji, Sims et al 1993; Greer, Moorey, Baruch, 1991; Linn, Linn, & Harris, 1982; O'Connor et al 1990; Taylor 1983). It is known that the needs of women with breast cancer and the meanings attributed to the experience are inherently unique (Colyer, 1996; Lewis, 1995). Consequently, it is hypothesized that meanings attributed to other types of advanced cancer may not be attributable to advanced breast cancer.

Purpose of the Study

Considerable research exists on the psychosocial adjustment in early stage and recurrence of this life-threatening disease. However, little is known about the experience of women diagnosed initially with Stage III or IV breast cancer. The purpose of this study was to discover and elaborate the illness-related experiences and processes reported by a homogenous sample of women whom were initially diagnosed with advanced stage breast cancer and to generate an explanatory model of these processes and experiences. With a substantive focus on existential themes, the systematic documentation of the range and quality of these womens' responses and adaptational processes initiated in this particular stage of the disease trajectory will enhance understanding of the function these processes performed. Finally, understanding the psychosocial demands at the advanced stage of the breast cancer disease trajectory will augment our understanding of how to best serve the needs of women experiencing advanced breast cancer through development of clinical guidelines, and more clearly point to directions for future research.

Therefore, in this grounded theory investigation of women's responses to initial diagnoses of advanced stage breast cancer, the research questions asked were:

1) What is it like to experience an initial diagnosis of advanced stage breast cancer?
2) What processes and interactions are initiated within the woman, between herself and her family, health care professionals, and society at large by this life-threatening diagnosis?
3) What is helpful and unhelpful to women experiencing advanced stage breast cancer?
4) What are the areas of convergence and divergence with the existing literature focusing on this specific population?
5) What are the appropriate methodological considerations when studying this population?
6) What clinical implications can be determined from the findings of this study?
7) What recommendations for the direction of future research emerge from this study?

Significance to Nursing

Nurses are vital members of the treatment teams that provide professional care to individuals with advanced breast cancer. This study is relevant to nursing by seeking to conceptually and empirically elaborate the personal and social meanings and illness-related processes associated with advanced stage breast cancer. Such a study will contribute to nursing knowledge and will guide theory development and clinical practice in psycho-oncology and advanced practice nursing roles.

CHAPTER II: REVIEW OF LITERATURE

Introduction

This review of the literature provides a summary of what is currently known about issues of women living with breast cancer. Particular emphasis was placed on their psychosocial adjustment to advanced stage disease. There are three main theoretical perspectives in the published literature: coping, relational, and existential (Lewis, 1997). These theoretical domains have overlapping characteristics, but for the purposes of this review the literature will be summarized in a way that is most comprehensive and illustrative of the current thinking in this field. First, a table of all the currently existing literature focusing specifically on advanced stage breast cancer is provided (Appendix B). Next, the fundamental concepts referred to in the current study are defined. Finally, the theoretical perspectives of psychosocial adjustment are presented followed by a comprehensive review of literature specific to this study.

Definitions of Fundamental Concepts

These terms are widely used in the literature focusing on women's psychosocial adjustment to breast cancer and are particularly pertinent to the current study: disease trajectory; psychosocial adjustment to cancer; quality of life; and demands of illness:

Disease Trajectory

A disease trajectory is a heuristic that summarizes key junctures over time on the course of an illness. This illness course can be shaped and controlled through proper management both assisted by and complicated by technology. Derived from research by Benoliel (1975), and Glaser and Strauss (1965, 1968), the trajectory heuristic conceptualizes the phases through which patients pass, as well as the differences in problems and management associated with each phase (Appendix A). Others have applied the concept to cancer research as a means to describe phenomena relevant to various stages (Bloch & Kissane, 1995; Dorsett, 1991; Holland, 1998; Lewis, 1997; Wiener & Dodd, 1993). This heuristic assists the clinician to determine the appropriate timing of clinical interventions, and identifies, from the received view, the biological, and psychological phases through which a patient is expected to go. To date, however, the literature has been dominated by empirical studies on women with breast cancer who are drawn from different stages of the illness trajectory, but whose results are aggregated in the study results. Women with advanced breast cancer, diagnosed initially or as recurrent, may likely experience varying responses and needs compared to women diagnosed in early stage breast cancer. A determined attempt by researchers to differentiate the phase/stage of the cancer trajectory being studied will lead to a less confounded understanding of the relationship of women's responses to their stage of breast cancer (Lewis, 1997).

Psychosocial Adjustment to Cancer

Psychosocial adjustment is a multicomponent process that can be depicted within a biomedical disease trajectory as well as by psychosocial transitions subjectively experienced by the diagnosed person and family (Lewis, 1997). Factors determining psychological adjustment are society-derived, patient-derived, and cancer-derived (Holland, 1998). In an attempt to standardize referral and care, the term "distress" has been chosen for use in the National Comprehensive Cancer Network Guidelines (NCCN) because it is less stigmatizing, sounds "normal", and can be measured by self-report (Holland, 2000).

Quality of Life

Quality of life is a subjective concept that embraces a multidimensional construct (physical, psychological, spiritual, social, vocational, sexual). As cancer treatments become more successful in extending life, the demand for evaluation of quality of this extended survival has increased. Quality of life measurement has provided a 'gold standard' for current outcome assessment in many clinical trials. However, the definition and methodologic approaches to measurement of this concept in psychosocial adjustment to breast cancer research continues to be debated (Lewis, 1997). Some researchers prefer to see the concept integrated into a model of adjustment rather than used as an endpoint (Graham, 1992; Lewis, 1997). Lack of a consensus definition has interfered with the ability to develop a widely accepted tool (King et al. 1997). Recently, a quality of life tool was inductively validated in a qualitative study that included 687 mail-back surveys from people with cancer (Dow, Ferrell, Haberman, & Eaton, 1999). Main themes included: struggle between independence-dependence, balance, wholeness, life purpose, reclaiming life, multiple losses, having control, altered meaning of health, and a family perspective of surviving cancer. There is no data yet on how this will be appropriate to women with advanced breast cancer. Previous research has indicated the need for quality of life scales specific to women with breast cancer (Fawzy, Fawzy, Arndt, & Pasnau, 1995; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998) while other authorities question the over-reliance on objective measures of quality of life in cancer patients (Lewis, 1997). A growing consensus within the healthcare community indicates that the therapeutic effectiveness of clinical trials must be assessed with regard to the quality of patients' experiences.

Demands of Illness

The demands of illness are a means of conceptualizing the illness experience (Packard, Haberman, Woods, & Yates, 1991). The tasks generally defined for the person with a life-threatening illness include:

- Responding to the physical fact of disease
- Taking steps to cope with the reality of disease
- Preserving self-concept and relationships with others in the face of disease
- Dealing with affective, existential, and spiritual issues created by the disease

Theoretical Perspectives on Psychosocial Adjustment

Various theories can be utilized in framing this study: Attribution Theory, Cognitive Adaptation to Life-Threatening Events, and Assumptive World Theory,

Attribution Theory

This theory maintains that following a threatening or dramatic event, people will make attributions for the purpose of understanding, predicting, and controlling their environment. By understanding the cause of an event, one may also begin to understand the significance of the event and what it symbolizes about one's life (Weiner & Dodd, 1993).

Cognitive Adaptation to Life-Threatening Events

This theory centers around three themes: 1) a search for meaning in the experience; 2) an attempt to regain mastery over the event in particular and over one's life more generally; and 3) an effort to restore self-esteem through self-enhancing evaluation. Successful adjustment depends on the ability to sustain and modify illusions that buffer not only against present threats, but also against possible future setbacks (Taylor, 1983).

Assumptive World Theory

This theory postulates that a person generally views the world as benevolent and meaningful, and the self as worthy. Trauma abruptly disrupts and disintegrates one's inner world in which the victim then sees herself as helpless and weak in a malevolent, meaningless world. Victims no longer see their world as safe (Janoff-Bulman & Frieze, 1983). It is hypothesized that women who are suddenly faced with an initial diagnosis of advanced breast cancer are thrust into a traumatic situation not unlike other types of victimization.

Three assumptions that change as a result of the trauma are: 1) the belief in personal invulnerability; 2) the perception of the world as meaningful; and 3) the view of the self as positive. The coping task includes coming to terms with shattered assumptions. Women will need to work on constructing a new assumptive worldview. Reestablishing a view of the world as meaningful will involve regaining a positive self-image, including improved self-perceptions of worth, strength, and autonomy. A new assumptive view of meaning will need to be examined, altered, and reexamined until one's sense of victimization and conceptual systems are congruent. This task is based on the interdependence of emotion and cognition (Amick-McMullan, Kilpatrick, Veronen, & Smith, 1989).

Theoretical Models of Adjustment to Cancer

The breast cancer literature may be organized into three theoretical perspectives that guide research: coping, relational, and existentialism (Lewis, 1997). Each perspective postulates that an advanced stage diagnosis poses a significant threat. However, core differences exist in the method utilized to reduce the threat and to implement adjustment to the illness (Lewis, 1997).

The Coping Framework of Adjustment

The assumption of this model is based on enhancing coping mechanisms in the patient. Derived from Lazarus and Folkman's (1984) theoretical model, coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping is a process-oriented mobilization of efforts to manage. Coping refers to the attempt to ward off, reduce, or to assimilate an existing or expected stressor either by means of cognition or action. A good psychosocial history is essential (Erickson, 1963). A normal stress response may be characterized by shock, numbness, and denial. Even despair and hopelessness may follow a cancer diagnosis. Later, anger, disruptive anxiety, and debilitating depressive symptoms may be seen. The more advanced an individual's psychosocial development, and the more successfully that person has integrated previous conflict, the more capable they will be in meeting present crises and coping with adaptational demands (Feldman, 1973).

Prognostic Indicators

The underlying principle of this approach is that coping varies with the diverse requirements and illness demands over the course of the trajectory. While some report no difference from controls on measures of well being (Schmale et al. 1983), several studies (Payne, Sullivan, & Massie, 1996; Pettingale, Burgess & Greer, 1988; Taylor, Lichtman, & Wood, 1984; Trief & Donohue-Smith, 1996; Wainstock, 1991) have noted that advanced stage disease is the number one predictor of level of psychological adjustment. Other prognostic indicators for psychological distress in breast cancer include younger age, (Ganz et al, 1993; Trief & Donohue-Smith, 1996), elevated depressive symptoms (Pasacreta, 1997), functional status (Ganz et al. 1993; Pasacreta, 1997), phase of treatment (Wainstock, 1991), recurrence (Jenkins et al, 1991), previous psychiatric diagnosis (Jenkins et al 1991; Maunsell, Brisson, Deschenes, 1995; Pinder et al. 1993), nature of the marital relationship (Lewis & Deal, 1995; Schmale et al. 1983; Sinsheimer & Holland, 1987), and preoperative mood (Ramirez, Richards, Jarrett, & Fentiman, 1995).

Fear

Gotay (1984) found that women with advanced cancer experienced fear related to their diagnosis. The progression of disease, restrictions on activities, and side effects of treatment caused equal difficulty for them. The most prevalent coping strategy to combat worry about their family's future involved taking actions that would help others cope after they died, such as fostering independence in children. The women in her study utilized strategies such as talking to oneself, praying, having faith and hope, talking to others, living for today, and finding something meaningful about the situation (Wainstock, 1991).

Importance of Homogeneity in Studying Coping Skills

Adapting to fear and uncertainty at the time of diagnosis is different from another stage of the illness. Heim, Valach, and Schaffner (1997) emphasized the importance of studying a homogenous group of patients as they looked at age, time elapsed since diagnosis, and time as a distance from death in their longitudinal intervention. Their research identified psychosocial adaptation, including feelings of well being, as clearly dependent on the distinct stages of illness with differing demands and stressors. Specific features of coping were observed exclusively in specific illness stages.

Heim et al's (1997) research identified poor coping as a pattern of resignation, or fatalism, combined with a passive avoiding attitude or blaming self and environment. Good coping included seeking and perceiving social and emotional support and an attitude of stoical acceptance of the cancer illness, combined with an effort to maintain self-control over the illness. The goal of psychological intervention was to enhance the quality of life by strengthening social support, and by modifying coping behavior.

Group Support and Longevity

Spiegel, Bloom and Yalom's (1981) much cited research on group support for metastatic patients reported patients in their treatment were less anxious, confused, fatigued, and fearful after meeting weekly for one year. A subsequent analysis by Bloom and Spiegel, (1984) found emotive-expressiveness helped maintain individual mood over time, and decreased pain experience. Emotional support was thought to influence psychological well-being primarily by its relationship to one's outlook on life. Being able to freely discuss intimate thoughts and feelings was linked to increased meaning and fulfillment. Furthermore, Spiegel et al (1989) observed that their treatment group survived 36 months vs. 18 months for controls. Eventually, a retrospective study on the medical records of subjects in the group revealed that differences in the disease course appeared to be independent of differences in medical treatment (Kogon, Biwas, Pearl, Carlson, & Spiegel, 1997). The researchers hypothesized that the support groups' increased longevity was a result of improving mood and overall coping in women through group cohesion. However, their objective criteria lacked measurement of group cohesion, therefore, it is difficult to know exactly what mediating variables were operating in the original study. The longevity statistics have been oft quoted in the literature. A replication of the Spiegel's work is currently underway in a Canadian multicenter randomized controlled trial (Leszcz & Goodwin, 1998).

Emotional Control and Psychosocial Adjustment

Following Spiegel et al's lead, Classen, Koopman, Angell, & Spiegel (1996) studied the relationship between emotional control and psychological adjustment to having advanced breast cancer. They demonstrated that emotional adjustment was positively associated with expressing emotion and adopting a fighting spirit and negatively associated with denial and fatalism. Without a universal standard for psychosocial adjustment, and only 17% of the variance in this study explained, it is difficult to determine the generalizability of these findings.

The initial results on these cross-sectional studies suggest a certain level of coping strategies are conducive to increased adjustment. This may not be true over time, however. For example, although "fighting spirit" may be high at one point, over time the patient may wear out, or wear out their social support, and result in the quelling of fighting spirit, or a decrease in emotional control.

Advanced Stage Breast Cancer Research in Great Britain

At the same time, Watson et al (1991) in Great Britain were formulating their own research program that dovetailed in conceptual development with Spiegel et al (1989). Interested in prognostic indicators of women at all stages of breast cancer, as well as other types of cancer, they studied the relationships between emotional control (inhibition

\

to express emotions), adjustment to cancer, and depression and anxiety. Findings included: emotional control, fatalism, helplessness and psychological morbidity were positively linked. While only 10% of this research team's sample in a 1991 study had metastasis disease, patients receiving adjuvant psychological therapy showed significantly greater improvement than control patients on psychological outcome measures of anxiety, depression, helplessness, fatalism, and anxious preoccupation with the disease (Greer et al. 1997). Throughout the 80's and 90's this group continued to develop these concepts and associated scales, used primarily in Great Britain, with large cancer patient samples (Greer & Watson, 1987; Greer, Moore, & Watson, 1989; Morris, Greer, Pettingale, & Watson, 1981; Watson & Greer, 1983; Watson et al. 1988).

Cognitive Response and Coping Styles

Researchers have analyzed cognitive responses and other psychological variables that form definitions of coping styles (Burgess, Morris, & Pettingale, 1988). In an early study, a 2-year longitudinal follow-up of 160 consecutive admissions for breast biopsy demonstrated that elevated lability and depression scores pre-surgically predicted poorer post-surgical adjustment two year later (Morris, Greer, & White, 1977). Since then, research on effects of psychosocial stress on cancer prognosis has produced varying reports (Barraclough, Pinder, Cruddas, Osmond & Taylor, 1992). A metanalytical review of 58 studies after 1980 (focusing on psychological sequelae related to a cancer diagnosis) reported that cancer patients seem to be significantly more depressed than the normal population (Spijker, Trijsburg, & Duivenvoorden, 1997).

Psychiatric Diagnoses

The prevalence of the specific diagnoses of Anxiety or Depression versus Adjustment Disorder varies highly in the literature (Hopwood, Howell, & Maguire, 1991; Jenkins et al, 1991; Pasacreta, 1997). Rates of depression have been defined in a variety of ways. Rates up to 47% have been attributed to psychological morbidity (Jenkins, May & Hughes, 1991). However, at closer inspection, 13% met the DSM-IV criteria for anxiety and/or depression. A full 68% of persons with psychological morbidity following the breast cancer diagnosis were deemed Adjustment Disorder (Derogatis, 1983). More recent literature indicates a range of 25%-41% for psychopathology depending on phase of treatment process (Ramirez et al. 1995). A review of the literature revealed that a variety of measures have been used to diagnose psychological morbidity, and there has been minimal use of the DSM-IV as a standardized guide.

Diagnosis at Advanced Stage as a Traumatic Event. While an emphasis has been placed on recurrence (at any stage) as traumatic (Cella et al, 1990; Chekryn, 1984; Weisman & Worden, 1985/1986) initial diagnosis of advanced stage breast cancer has been conceptualized as a traumatic event (Strain, 1998). Others (Green et al. 1998; Passik & Grummon, 1998) have more recently claimed that the Diagnostics and Statistics Manual (DSM-IV) (APA, 1994) diagnosis of Post-Traumatic Stress Disorder (PTSD) is suitable for persons diagnosed initially with advanced breast cancer. Little is known, however, about the PTSD symptoms in women with advanced stage breast cancer. Relatively low rates of PTSD are being found in general cancer patients. A study of nonmetastatic breast cancer found 5-10% of women met the DSM-IV criteria for PTSD (Green et al. 1998). Higher levels of PTSD in women with breast cancer have also been associated with less social support, greater pre-cancer trauma history, less time since treatment completion, and more advanced stage (Andrykowski & Cordova, 1998).

Classen et al. (1993) observed that trauma constitutes an abrupt physical disruption in ordinary daily experience that renders a person helpless as the world suddenly becomes unpredictable, threatening, and assaultive. Symptoms experienced during trauma include: dissociation (feeling detached, dazed, in a state of shock, feeling as though things around them are unreal, sense of numbness), and amnesia for the event (being told the diagnosis); anxiety, manifested by hyperarousal, difficulty concentrating, exaggerated startle response, muscle tension, restlessness, palpitations, fatigue, and insomnia; rage, despair, hopelessness, guilt feelings.

<u>Differentiation of Adjustment Disorder.</u> Because Adjustment Disorder is so frequently diagnosed it is important to understand some of the criteria that differentiates it from Acute Stress Disorder, Depression, or Anxiety. Consideration of onset and duration of symptoms is one of the primary factors in the differential. If symptoms last between two days and one month they may then meet the criteria of Acute Stress Disorder (APA, 1994). Symptoms not meeting the DSM-IV criteria for Depression, Anxiety, or Acute Stress Disorder may be considered Adjustment Disorder if symptoms occur within three months of the onset of the cancer diagnosis. Certainly, Adjustment Disorder may coexist with an anxiety or depressive component.

<u>Prolonged Duress Stress Disorder.</u> On the other hand, Dr. Donald Meichenbaum (personal communication, March 26, 1999), a internationally recognized authority on the PTSD diagnosis, declines to confer the diagnosis of PTSD on women in advanced stage breast cancer. He does not perceive advanced stage breast cancer as an isolated exposure

to a traumatic event (as is the intent of the DSM-IV PTSD diagnosis). Due to the cumulative effects of an unremitting stressor, such as advanced stage breast cancer, Dr. Meichenbaum suggested that "prolonged duress stress disorder," would be a more appropriate diagnosis. However, because the symptomatology is much the same as PTSD, cognitive-behavioral treatment as structured for persons with PTSD is highly effective (D. Meichenbaum, personal communication, March 26, 1999).

The Effects of Prolonged Psychological Disturbance. The effects of continued psychological disturbance has been debated in the literature. However, we do know that in addition to many persons experiencing depressive and/or anxious symptoms they may also experience impaired function (Pasacreta, 1997), and psychoneuroimmunological mechanisms (Bovbjerg, & Vladimarsdottir, 1998; Kiecolt-Glaser & Glaser, 1992; C. Landis, personal communication, April 23, 1999; Pettingale, 1985), as well as psychoneuroendocrinology (Musselman, McDaniel, Porter, & Nemeroff, 1998) mechanisms may also be seriously affected.

Suicide. Suicidal ideation, or a request to hasten death, often occurs while suffering with unrecognized and untreated psychiatric disturbances, and poorly controlled physical symptoms. Nevertheless, cancer patients commit suicide most frequently in the advanced stages of disease (Breitbart & Krivo, 1998). Eighty-six percent of suicides occurring among medically ill patients do occur in the preterminal or terminal stages of illness (Farberow, Ganzler, & Cutter & Reynolds, 1971). In a Finnish study, Hietanen, Lonnqvist, Henriksson, & Jallonoja (1994) found that 100% of patients with cancer who committed suicide stated cancer was the fundamental reason for doing so. Patients at highest risk have a preexisting psychopathology, currently suffer with depression and hopelessness, delirium, pain, exhaustion, loss of control, and helplessness (Breitbart & Krivo, 1998).

The Relational Model of Adjustment

The relational model of behavioral adjustment focuses on the primary relationships of the woman with advanced breast cancer (Lewis, 1997). Consideration of the people with whom the woman with breast cancer lives, and significantly relates to, is a more recent focus of research. The focus is on the system, not just the woman with breast cancer because "they directly affect, mediate, or moderate the patient's behavioral adjustment and quality of life; they are also directly and negatively impacted by the cancer" (Lewis, 1997, p. S24). Lewis' (1989, 1993; Lewis & Deal, 1995) and others' (Northouse, Laten, & Reddy, 1987) descriptive studies have documented spousal and childrens' levels of distress that highly correlated with the disruption experienced by the diagnosed patient. Lewis' (1989, 1993) model-testing studies have specified the processes through which the family members adjust to breast cancer (Lewis, 1986, 1993, 1997; Lewis & Hammond, 1992). The process described was framed in terms of a problem or challenge that the family worked through, not as a psychopathological process. The adjustment over time of families with children to the mother's breast cancer changed. Changes included fewer illness-related demands on the family and improvements in the marriage. However, with the passage of time there were no changes in the mother's level of depressed mood, the family's coping behavior, and the total household level of psychosocial functioning. Dr. Lewis' program of study focusing on the family has served to increase empirical understanding of the mother's mood, and its effect on the family (Lewis, Hammond, & Woods, 1993).

Depression in women with breast cancer is the single most important factor that needs to be modified to enhance the family's well being (Lewis, 1998). While extensive work has occurred in women with recurrent cancer (Lewis & Deal 1995), and single women (Lewis, Dahlias, Shands, Sinsheimer, & Hammond, 1996) the woman with advanced stage breast cancer and her family have as yet to be explicated.

Lewis and Deal's (1995) work examining the effect of recurrence of breast cancer on the married couple interestingly concluded that while the couples' behavioral function was minimally impacted, their individual mood and marital quality suffered. Researchers called for attention to the spouses of women with breast cancer (Northouse, 1996; Northouse, Dorris, & Charron-Moore, 1995), and concluded that partners have a mutual influence on one another and that consideration of the couple is required when planning care for the women with breast cancer.

Social Support

By conceptualizing social support as assistance in psychosocial adjustment (Thoits, 1986), research has shown that social support may, in fact, directly affect not only accommodation to stress (Bloom, 1982), and quality of life (Ferrell et al. 1998), but also longevity (Kogon et al. 1997; Maunsell et al. 1995; Spiegel et al. 1981; Speigel, Bloom, Kraemer et al, 1989). Without support, the demands of illness may be accentuated and have the potential of causing great harm to individuals and the family system (Loveys & Klaich, 1991). Reduced ability to meet the demands of the illness (Woods, Yates, & Primomo, 1989) such as decreased social activity, loss of strength, and fears about the effects of the disease and mortality issues will vary among individuals and by stage of disease (Zabora, Blanchard, Smith, Roberts, Glajchen, Sharp, BrintzenhofeSzoc, Locher, Carr, est-Castner, Smith, Dozier-Hall, Pointsky, & Hedlund, 1997). Examining the association of demands of illness to stage of disease may increase potential for effective social support.

Social support has been thought of as a buffering effect. Providing the woman with social identity feedback, and emotional support, and assuring the woman that she is loved and valued as a person may actually buffer the intrusiveness of disease and positively affect quality of life and psychosocial adjustment (Bloom, 1982; Bloom, Stewart, Johnston, & Banks, 1998).

Effects of Social Support on Demands of Illness

The demands of illness reported by women with breast cancer included the direct effects of the disease, the personal disruption that occurs as a consequence of the illness (changes in self-perception, preoccupation with both personal meaning of the illness and attributions about the illness), and the environmental transactions (such as interactions with health care providers) necessitated by the illness (Woods & Lewis, 1995). Social support is an important source of recovery for persons diagnosed with cancer, and may reduce the demands women associate with their illness.

Effects of Social Support of Immune Function

For some time, social support has been thought to promote biologic or behavioral adaptation in the face of stress. This, in turn, may lead to positive effects on immune function, and limit the effects of stress-related endocrine changes possibly associated with tumor proliferation (Fawzy et al. 1993; Maunsell et al. 1995). In a study by Levy et al (199) higher natural killer cell activity was predicted by the perception of high quality emotional support from a spouse or intimate other, perceived social support from the patient's physician, and actively seeking social support as a primary coping strategy. More work is needed to understand the role of social support in modulating natural killer cell activity.

Swanson's Caring Theory

Another way to conceptualize social support is through the concept of caring, a "nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility" (Swanson, 1991, p. 162). Through her research with women who miscarried, Swanson empirically derived a theory of caring that consists of five basic processes or ways of relating to others. These include: Maintaining Belief, Knowing, Being With, Doing For, and Enabling. Swanson (1993) depicts caring as:

> 1) Grounded in the maintenance of a basic belief in persons and their capacity to make it through events and transitions and face a future with meaning; 2) anchored by knowing the other's reality, knowing translates the idealism of belief maintenance into the realism of the human condition; 3) conveyed through being emotionally present to the other, and that their experiences matter to the health provider; 4) enacted through doing for by simply doing for the other what they would do for themselves if it were at all possible; and 5) enabling through coaching, informing, and explaining to the other, supporting the other, assisting the other to focus in on important issues, helping her to generate alternatives, guiding, offering feedback, and validating the other's reality. (p. 357)

Swanson claims that when practitioners are informed about disease trajectories their caring therapeutics will promote the well-being of those they encounter.

This theory has yet to be applied purposely to women with advanced stage breast cancer. More evidence is required to understand in what ways women with breast cancer will benefit from caring behaviors by providers and significant others so that women with advanced stage breast cancer may experience fundamental well-being.

An Existential Model of Adjustment

The term existential in philosophy refers to the point of view that holds that there is no essence of human consciousness separate from existence. The vulnerable, transitory nature of existence is not a problem, but rather inherent in the beauty and meaning of life. The more people face fragility, the more they live authentically. Thus, dealing with death is not only a necessity, it is an opportunity to sort out the important things in life (Spiegel & Classen, 2000).

The existential paradigm carries with it a most intensely personal nature of highly charged aspects of the cancer diagnosis: existential plight (Gotay, 1984; Halldorsdottir & Hamrin, 1996; Weisman & Worden, 1976, 1985); the threat to one's assumptive world (Janoff-Bulman & Frieze, 1983); themes of uncertainty, (Chekryn, 1985; Mast, 1998; Mishel, 1990); the personal significance of the cancer diagnosis (O'Connor et al); meaning reconstruction (Chekryn, 1984; Frankl, 1963, 1984; Lewis, 1989; O'Connor, Wicker, & Germino, 1990; Taylor, 1993; Yalom, 1980); self-transcendence (Coward, 1990, 1991; Reed, 1992); and spirituality (Burkhardt, 1994; Dein & Stygall, 1997; Hawks, Hull, Thalman, & Richins, 1995; Rozario, 1997); Existential issues are "firmly planted in ontological bedrock, the deepest structures of human existence (Yalom, 1980, p. 355)."

Recognizing Mortality

Ernest Becker (1973) concedes that humans have the mind to recognize their own mortality. For some, a paradox exists in the belief that part of us can never die, yet we can also acknowledge and understand our own mortality (Yalom, 1980). When a woman is forced into an encounter with a life-threatening illness, the urgency creates an "existential plight" (Weisman, 1980). Symptoms are interpreted within the context of who one is, and what one does. Thus, the first touch of illness can create an issue of meaning: What can this symptom mean for me?

Personal Meaning

The development and utilization of the concept of "meaning-making" may describe a very important aspect of women's adjustment to advanced stage breast cancer (Antovosky, 1980, Frankl, 1984; Lewis, 1989; Yalom, 1980). The importance of derived meaning and purpose in relation to the psychosocial adjustment of patients with late-stage cancer has a beginning literature. The meaning that women with breast cancer assign to their disease may well have an impact on the effectiveness of their coping strategies (Lazarus & Folkman, 1984; Lewis, 1989; Luker, Beaver, Leinster & Owens, 1996; Taylor, 1983).

Personal Control

The concept of personal control in adults with late-stage cancer was explicated in Lewis' (1982, 1987) work examining the association of experienced personal control and quality of life. The fact that subjects did not experience greater anxiety or lowered self-esteem when they experienced lower levels of control over their health opened some interesting questions regarding personal control as it relates to quality of life in late-stage. Later work (Lewis, 1989) on these same concepts revealed that the extent to which the patients attributed meaning to their situation was a significant predictor of both higher self-esteem and lower anxiety pointing the way for a focus on meaning making in late-stage cancer. Content analysis on 57 patients characterized the patients' experience with cancer: monitoring progress, waiting it out, refocusing control, and turning it over. What was new about this data was the realization that end-stage patients still actively attempted to bring routine, order, and control to their daily lives despite their disease. These ideas contributed generously to the conception of patients as "active meaning makers." (Lewis, 1989, p. 40)

Yalom's (1980) discussion of the repression of death anxiety further illuminates the relationship between personal control and existential anxiety:

> It is a matter of no small importance that one be able to explain and order the events in our lives into some coherent and predictable pattern. To name something, to locate its place in a causal sequence, is to begin to experience it as under our control. No longer, then, is our internal experience or behavior frightening, alien or out of control; instead, we behave (or have a particular inner experience) because it is something we can name or identify. The 'because'offers one mastery (or a sense of mastery). I believe that the sense of potency that flows from understanding occurs even in the matter of our basic existential situation: each of us feels less futile, less helpless, and less alone, even when, ironically, what we come to understand is the fact that each of us is basically helpless and alone in the face of cosmic indifference. (p. 189)

Meaninglessness

A human being can only construct a new life meaning by facing the very vortex of meaninglessness and arrive at a posture of heroic nihilism; living with dignity in the face of absurdity (Yalom, 1980). A human being must invent her own meaning and then commit herself fully to fulfilling that meaning. We cannot catch hold of meaning on intellectual grounds, but on existential grounds, out of our whole being, through faith (Tillich, 1952).

Existential Phases

In the diagnostic phase of advanced breast cancer, the woman is confronted with the confirmation of her fears. This encounter with life-threatening illness forces a review of both one's sense of past, as well as one's future. Previously unresolved issues such as the way one copes with illness, and of the expectations one can have for support are seriously considered.

Existential Psychotherapy

The woman experiencing an intial diagnosis of advanced stage BrCa is facing a time of urgent experience in which the crisis is apt to elicit a myriad of psychodynamic defenses. An analogy of anxiety, related to loss of control, can be made to nascent oxygen in which the nanosecond it is removed from the subconscious and consciously recognized it is transformed into another state (i.e. Phobia or panic attack, etc.) (Yalom, 1980).

Existential psychotherapy is the work dedicated to exploring themes of being, choice, freedom, death, isolation, and absurdity. Yalom writes that within existential psychotherapy a person is regarded as "a consciousness who participates in the construction of reality." (1980, p. 23)

Yalom (1980) said, "Psychopathology is, by definition, an effective defensive mode." (p. 41) The terror of death is ubiquitous. Most encounters with concept of death are rarely in its stark form due to conventional defenses such as repression, displacement, or rationalization. Most develop adaptive coping modes that consist of denial-based strategies such as supression, repression, displacement, belief in personal omnipotence, acceptance of socially sanctioned religious beliefs that "detoxify" death or personal efforts to overcome death through a wide variety of strategies that aim at achieving symbolic immortality (Yalom, 1980).

Yalom (1980) refers to existential psychodynamics as a conflict that flows from the individual's confrontation with the origins of existence that is catalyzed by urgent experiences such as confrontation with death leading to the collapse of some fundamental meaning-providing schema. The four ultimate concerns in existential psychotherapy are: death, freedom, existential isolation, and meaninglessness.

If there is suffering, or pain, the woman may raise questions regarding the usefulness of life. Is living worth the price of suffering? Thus, there may be a renewed appreciation of personal strengths or a renewed sense of faith. As a woman begins to face the reality of her death, consideration of what might be considered an acceptable death occurs. A woman may consider, "What business is necessary, what reconciliation is required (Steeves & Kahn, 1987)?"

Psychotherapy in a Theological Model. A theological model of transformation actually contains many of the same themes of change that appear in psychological models. Theological models emphasize change in two areas: First, by looking at ourselves differently we gain a renewed perspective on what we can be. We cease to define ourselves in terms of our own limited goals, and struggle to define ourselves according to the will of God. Second, by seeking a desert of solitude we can reflect on what God expects of us, and what we really say to ourselves when we are afraid or confused (Propst, 1988).

Spirituality. Paradoxically, humans have the ability to recognize both their transcendence and their mortality. Hope of a union with a higher being may bring comfort. Some will experience strengthening and be reaffirmed. Others may be unable to find meaning, and instead feel only a sense of despair. Human beings can be extraordinarily comforted by the belief that there is some supraordinate, coherent pattern to life and that each individual has some particular role to play in that design (Yalom, 1980).

We know that concerns exist, for people with a life–threatening illness, about a relationship with a Divine Being. Approximately 85% of people with life-threatening illness use prayer. However, about 20-25% of physicians profess faith. Might this indicate that there are spiritual needs going unmet (Jimmie Holland, personal communication, April 27, 2000)?

Faith. Faith in the ultimate meaning is preceded by trust in an ultimate being. Tillich (1952) taught that the courage to be is based on a personal encounter with God. The courage to be is an expression of faith.

Faith is the overarching, integrating and grounding trust in a center of value and power sufficiently worthy to give our lives unity and meaning. A woman faced with an advanced diagnosis of breast cancer contemplates the meaning of her life, and may find no immediate answer.

Self-transcendence. Niebuhr (1953) contends that it is only in confrontation with a greater transcendent being, that feelings of self-transcendence and freedom are verified. Because experiences that bring us face-to-face with death point to something outside of the natural, we want an ultimate key to understanding the world that comes from beyond even our own limited capacity to understand or transcend. He says that, "the source of meaning and confrontation must always lie outside of things, because something inside the flux is not adequate to explain everything." (Propst, 1988, p. 82). Self-knowledge and transformation occur for the individual when they know they are confronted by God.

Interventions

The advanced cancer patient's confrontation with death, isolation, and meaninglessness offers researchers a challenge for the determination of appropriate interventions. Little is known about ways or methods of enhancing the patient's abilities or skills to manage the existential concerns about cancer (Lewis, 1997). However, Taylor (1993) does suggest strategies for promoting a clear sense of meaning: encouraging patients to tell their life story, help patients to create legacies, facilitate social support, and explore cognitive strategies.

Some researchers (Ashby, Kissing, Beadle, & Rodger, 1996) think that the constructs of coping skills and cognitive behavior therapies may be more applicable to women with early stage disease, while supportive psychotherapies, which encourage the sharing of feelings about existential concerns, could be more suited to patients with advanced breast cancer (Tapper, 1999).

Women with advanced breast cancer are challenged by multiple losses-their health, breast, sense of femininity, confidence, dreams and belief in the future. The facilitation of adaptive grieving is a primary goal. Clarification of fears can promote a sense of realism-based mastery.

Summary

The multidimensional process of psychosocial adjustment of women with advanced stage breast cancer is clearly associated with the traditional medical illness trajectory. Advanced staged breast cancer can be considered a significant insult to, not only the physical, emotional and spiritual integrity of the woman, but also those same domains as they relate to her family and other significant relationships in which she is engaged.

What is known about the breast cancer literature can be organized into three theoretical perspectives that guide research: coping, relational, and existential. The coping framework focuses on enhancing women's coping mechanisms. We know that advanced stage disease is the number one predictor of level of psychological adjustment. Other prognostic indicators include: age of the woman, stage of the disease, time since diagnosis, and premorbid psychological state. Group support has long been cited for reducing anxiety, confusion fatigue and increasing longevity. Emotional control has been positively linked with psychological morbidity. Various DSM-IV diagnoses are currently attributed to the effects of living with advanced stage breast cancer. Approximately 30% of women with breast cancer are experiencing psychological morbidity, however, only 3% are being treated.

The relational model of behavioral adjustment focuses on the primary relationships of the woman with advanced breast cancer. Effects of depression in the women on their families need to be modified. Attention to the partners and children of women with breast cancer is a current focus in research, but is generally not currently implemented in practice. More evidence is required to understand in what ways women with advanced stage breast cancer will benefit from caring behaviors by providers and significant others.

The existential nature of the experience precipitates a focus on the contingency of life and its fragility. Facing this fragility leads to living life more authentically. Prioritizing important things in life enhances a sense of personal meaning and control.

Faith, and a sense of reliance on something larger have been helpful in transiting this process. How women come to terms with the impact that such a sudden threat has on their life influences her outcome.

What is not known is how women successfully integrate the diagnosis and its meaning into their consciousness, what psychological predispositions are helpful for success in adapting to the threat, and how one is best assisted through this process by health care professionals. The factors inherent in past research focusing on group process that influence longevity are not known. Various interventions influencing better outcomes for women with advanced stage breast cancer continue to be debated in the literature.

What needs to be known is how can we best identify the 30% that are at risk for psychological morbidity, and quickly refer them for assistance? What interventions will be most effective, both in terms of decreasing distress, not only to the woman with advanced stage breast cancer, but also to her family, and her health care providers, but also increasing QOL? How can we best address the spiritual needs of women with advanced stage breast cancer? How can national standards, and institutional standards be implemented for the psycho-oncology care of the woman with advanced stage breast cancer?

CHAPTER III: METHODOLOGY

This chapter describes the methodology used for the current study. Included is the design of the study, sampling strategy, and questions addressed by this research, data collection and recording procedures, and data analysis techniques. Also addressed are the trustworthiness of the research and limitations of the study.

This chapter consists of three sections. The first section focuses on a comprehensive discussion of the methodological perspective driving this study. The second section centers on a detailed description of the study design and protocol. Finally, the heart of the third section is a step-by-step report of the analysis engaged in by the principal investigator for this dissertation research.

Section I: Methodological Perspective

Methodology refers to the diverse principles, philosophical frameworks, procedures, and practices that govern research. Understanding the rationale and assumptions for methodological practices as well as the practices themselves are critically important to understanding methods of analysis. Acceptance or rejection of ways of knowing is guided by assumptions concerning the nature of knowledge, the nature of reality, and the phenomenon into which we inquire. Therefore, since questions of methodology are secondary to questions of paradigm (Guba & Lincoln, 1994), briefly examining the epistemological, ontological, and methodological orientation of the Pragmatic paradigm that informed Symbolic Interactionism may be a helpful prelude to appreciating the methods that were utilized in the current study.

Paradigm	Pragmatism
Epistemology	Both objective and subjective points of view
Ontology	Accept external reality
Methods	Quantitative + Qualitative
Logic	Deductive + Inductive

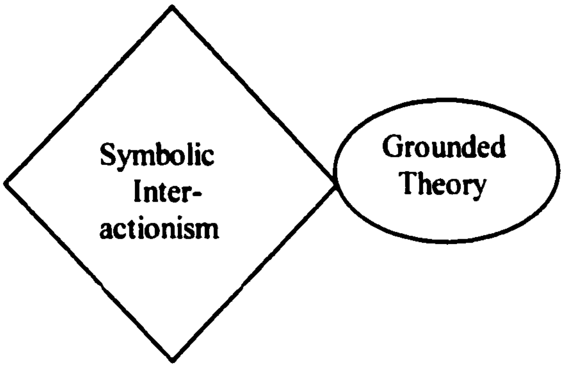


Figure 1: Flow from Philosophical Principles of Pragmatism through Symbolic Interactionism to Grounded Theory Methodology (Tashakkori & Teddlie, 1998).

Epistemology

Each paradigm assumes a particular epistemology based on the question, "What is the nature of the relationship between the knower, or would-be knower, and what can be known?

In response to the black and white contrast of the incompatibility thesis that "either a dualism or singularity, or an objective or subjective point of view as witnessed in the war between postpositivists and constructivists" pragmatists challenged that research may be both objective and subjective in epistemological orientation (Kathleen Knafl, personal communication, Feb 28, 1999. So, rather than two poles, pragmatists perceive a subjective-objective continuum throughout a study (Tashakkori & Teddlie, 1998).

Ontology

Within each paradigm is situated a corresponding ontology based on the question, "What is the form and nature of reality, and what can be known about it?"

By the early 1990's, some researchers were displeased with the dichotomization between postpositivism and constructivism. The conflict moved toward resolution via a paradigm shift toward pragmatism (Howe, 1988; Cherryholmes, 1992; Murphy, 1989). The roots of pragmatism can be traced to William James and John Dewey. Pragmatists accept an external reality; they view human beings as acting organisms who construct social action.

Pragmatists believe that there may be causal relationships but that we will never by able to completely pin them down (also known as cautiously optimistic pragmatism). They believe the research question is more important than either the method they use or the worldview that underlies the method (Tashakkori & Teddlie, 1998). Howe (1988) explained that for pragmatists "truth" is a normative concept like "good," and "Truth is what works" is best seen not as a theory, or definition, but as something interesting about the nature of truth. American pragmatists, John Dewey (1922), George Herbert Mead (1934), and Herbert Blumer (1969) are credited with the formation of Symbolic Interactionism from which grounded theory methodology flowed. Pragmatism informs the philosophical epistemology of symbolic interactionism.

Symbolic Interactionism

Symbolic Interactionism came into use as a label for a distinctive approach to the study of human life and conduct. Symbolic Interactionism rests on three premises.

The first premise is that human beings act toward things on the basis of the internal or external meaning that the things have for them. Rather than view human behavior as the product of various factors that act upon human beings, and have been referred to as stimuli, attitudes, or conscious or unconscious motives, the symbolic interactionist's position is that the meanings that things have for human beings are central in their own right.

The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellow human beings. This includes the larger socially constructed meanings brought to the interaction. In other traditional views, one seeks to explain the meaning of a thing by isolating the psychological elements that produce the meaning, whereas Symbolic Interactionism sees meaning as arising in the process of interaction between people.

The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person to deal with the things encountered. People point out to themselves the things that have meaning. The formulation of such meaning is an internalized social process in which the person interacts, communicates with oneself, and self-designates meaning. The process becomes a manner of managing meaning that has been socially determined. For example, the person selects, checks, suspends, regroups, and transforms the meanings in light of the situation placed. This interpretation is a formative process in which meanings are used and revised as instruments for the guidance and formation of action. It is important to this thought that meanings are developed through a process of self-interaction of socially determined knowledge (Blumer, 1969; B. Bowers, personal communication, May 5, 1999).

The position of Symbolic Interactionism is that the "worlds" that exist for human beings and for their groups are composed of "objects" and that these objects are the product of Symbolic Interactionism. Categories of objects include: 1) physical objects such chairs, or trees; 2) social objects such as doctor, husband, or friend; and 3) abstract objects such as philosophical doctrine or compassion. The nature of the object of reflection consists of the meaning that it has for the person for whom it is an object. The meaning sets the way in which the object is perceived, the way in which the person is ready to talk about it, and most importantly, the actions taken toward it. Each object may have a different meaning for different people, and arises fundamentally out of the way they are defined to the person by others with whom interaction occurs. For example, meanings are patterned in relation to social group participation. Meanings are also contextually situated and vary for any given person across contexts (Berger & Luckman, 1966).

If human beings are, indeed, organisms with 'multiple selves,' and if their action is, indeed, an outcome of a process of interaction and self-designation, methods that use SI will explain social action and respect and accommodate these features (B. Bowers, personal communication, May, 5, 1999). The researcher would want to see the operating situation as the participant sees it, perceive objects as the participant perceives them, and to ascertain their meaning in terms of the meaning they have for the participant. The researcher wants to take the role of the participant and see the world from the participant's standpoint.

Symbolic interactionists begin the data analysis with a 'sensitizing image' of the interactional process built around such concepts as self, language, and social setting among others. The researcher then moves from sensitizing concepts to the immediate world of social experience and permits that world to shape and modify his conceptual framework, moving continually between the realms of the more general social theory to the worlds of the participants. Symbolic interactionists seek explanatory theories that are interpretive, grounded, and that derive from the data. These tenets have contributed directly to the methodology, grounded theory.

Grounded Theory

The methodology commonly known as grounded theory was originally developed by two sociologists, Barney Glaser and Anselm Strauss (1967). Strauss was strongly influenced by pragmatist writings and inspired by Symbolic Interactionists, Dewey (1922), Mead (1934), Hughes (1971), and Blumer (1969). Glaser, with a quantitative background, saw the need for making comparisons between data and to identify and relate concepts. Together, Glaser and Strauss, in collaboration with a nurse researcher, Dr. Jeanne Quint Benoliel, conducted a grounded theory investigation of the dying process. The outcomes of their endeavors were two books: Awareness of Dying (1965) and Time for Dying (1968). Later, Julie Corbin, another nurse researcher, influenced the explication of grounded theory in her work with Strauss (Corbin & Strauss, 1998).

Grounded theorists believe that there is a socially constructed reality, and that truth is enacted. Grounded theory means theory that was derived from data, systematically gathered and analyzed through a rigorous research process guided by symbolic interaction. In this method, data collection, analysis, and emergent theory are closely related. A researcher does not begin a project with a preconceived theory in mind, unless the purpose is to elaborate upon, and extend existing theory. Rather, the researcher begins with an area of study and allows the theory to emerge from the data. Preoccupation with prior theory can stand in the way of the researcher's attempts to hear and listen to the voices being studied. Grounded theories, because they are drawn from data, are likely to offer insight into the human interaction processes, enhance conceptual understanding, and provide a meaningful guide to action (Corbin & Strauss, 1998).

Grounded Theory Data Analysis Methods

Grounded theory data analysis methods, distinct from a discussion of methodologic perspectives, deserve specific attention. This section includes details of grounded theory data analysis. Analysis is the interplay between researchers and the data that includes a number of distinct features and guidelines such as the making of constant comparisons, and the use of a coding paradigm to ensure conceptual development and density (Strauss, 1987).

The major difference between grounded theory and other methods is its emphasis on theory development (Lowenberg, 1993). The built-in style of extensive interrelated data collection and theoretical analysis is the foundation for verification of its resulting hypotheses throughout the course of the research. Conceptual density refers to the richness of concept development and relationships, which rest on great familiarity with, and repeated checking of associated data (Strauss, 1987).

Grounded theories must be traceable to the data that gave rise to it. Grounded theorists follow closely with the pragmatist position in that their theories are not the formulation of some discovered aspect of a preexisting reality "out there." To think otherwise is to have a positivistic position. Theories are interpretations made from given perspectives as researched. Faithfulness to the substantive data means that grounded theory must correspond closely to the data it is to be applied to in daily situations.

Important characteristics of a grounded theorist include ability to critically analyze and to recognize the tendency toward personal bias. The grounded theorist must also be able to think abstractly, be flexible, be sensitive to words and actions, and maintain a sense of absorption and devotion.

Coding Paradigm. Coding helps the researcher to identify, categorize, and conceptualize the phenomena (Strauss & Corbin, 1998). The researcher, moving back and forth from one type of coding to another, becomes more intimate with the data. The purpose of coding is to build theory; the codes are analytic tools and the building blocks of theory. In order to appropriately code, the researcher must be able to consider alternative meanings and be systematic and creative. The analyst must not enter the project with preconceived concepts, framework, or design, maintaining a balance between objectivity and sensitivity.

Constant Comparative Analysis. Comparative analysis is a staple feature of grounded theory methodology (Strauss & Corbin, 1998). Within each level of analysis, the researcher compares incident to incident, but also each incident is compared to other properties or dimensions of that code, category and domain. Also, by asking theoretical questions about each case, and by thinking comparatively along properties and dimensions of categories, the researcher's mind is opened to the range of possibilities for other cases. The actual properties emerge from the data, but maintaining an open mind to recognize properties and dimensions allows richer, and more specific theoretical explanations (Strauss & Corbin, 1998).

There are three types of coding: 1) open; 2) axial; and 3) selective.

Open Coding. First, open coding is the researcher's first attempt to open up, or 'fracture' the data. This is a provisional, unrestricted type of coding that involves the process of breaking down, examining, comparing, conceptualizing and categorizing data.

The researcher will look for 'in vivo' codes (terms used by the participants), give a provisional name to each code, ask specific questions about words or phrases used in the analysis, move quickly to relevant dimensions, look for comparative cases, and utilize constant comparison (Strauss, 1987).

Open coding is a dynamic and fluid process through which concepts are identified and their properties and dimensions are discovered in the data. The code may be taken from the words of the participants (emics), or can be placed by the analyst (etics) because of the imagery or meaning the data evoke when examined comparatively and in context (Strauss & Corbin, 1998).

The grouping of concepts into categories reduces the number of units to work with. Categories increase analytic power because they have the potential to explain and predict. There are two sources for categories: the data (including in vivo) and the literature (Strauss, 1987).

During open coding, characteristics of categories, properties and dimensions are developed. A property defines and gives meaning to a category. A dimension is the range along which general properties of a category vary, and give specification to categories and variation to theory.

There are various ways to do open coding: line-by-line, sentence-by-sentence, or paragraph-by-paragraph. The researcher asks, "What is the major idea in this sentence, or paragraph, and/or what makes the document different from previous ones I've examined?"

Axial Coding. Next, axial coding builds on the first step. It is a set of procedures whereby data are put back together in new ways after open coding by making connections between categories. In addition, categories are related to subcategories through their properties and dimensions. This is accomplished by utilizing conditions (why, where, how come, and when), context, action/interactional strategies (people's organized, purposeful, or deliberate action taken to resolve a problem) and consequences (from the action or condition) (Strauss & Corbin, 1990, 1998). During axial coding, the researcher questions and explores the properties of the categories and begins to build up a dense texture of relationships around the 'axis' of the category being focused on (Strauss, 1987). The researcher asks, "What seems to be going on here?" Coding for process, the researcher purposefully examines action/interaction and notes movement, sequence, and change as well as how it evolves in responses to changes in context or conditions (Strauss & Corbin, 1998).

Selective Coding. Finally, during selective coding the researcher works with the systematic linking of the categories to the core construct or phenomena, and to each other. This involves the process of integration. Saturation should be evident at this point. No new properties, dimensions, or relationships emerge. If not, the researcher must ideally continue data collection. There should be sufficient data to also verify or validate the relationships as well as the categories. An analytic gestalt depends on who the analyst is and also the evolution of thinking that occurs through immersion in the data and the cumulative memos and diagrams. The range of variability is established through the concepts that vary dimensionally along properties. (Strauss, 1987; Strauss and Corbin, 1998).

Core Construct. The core construct evolves from the research and is an abstraction. It consists of all the products of analysis condensed into a few words that seem to explain the explanatory social process. The criteria for choosing a core construct includes:

1. The core construct must be central. All other categories can be related to it.
2. Must appear frequently in the data-within all, or almost all cases.
3. Explanation is logical and consistent-no forcing of data.
4. Name or phrase sufficiently abstract that it can be used to do research in other substantive areas.
5. As the construct is refined analytically through integration with other concepts the theory grows in depth and explanatory power
6. The construct is able to explain variation as well as the main point. When conditions vary, the explanation holds although may look different. One should also be able to explain cases of disconfirmation in terms of the central idea (Strauss & Corbin, 1998).

Memoing. Throughout the analytic process, maintaining a systematic memoing structure is essential. The memos actually contain the clues to integration and become the trail for other researchers to audit. As research proceeds it becomes more abstract. These reflections of analytic thought help the analyst gain distance from the material by forcing her to move from working with the data to conceptualizing the data. Memos are also important for documenting the existence of dimensions related to an abstract core construct.

There are three kinds of memos:

1. Code memos-memos containing the actual products of the three types of coding (open, axial, and selective).

2. Theoretical memos: sensitizing and summarizing memos that contain an analyst's thoughts and ideas about theoretical sampling and other issues.
3. Operational memos: memos containing procedural directions and reminders.

It is important to date and reference memos. Also, they should contain headings denoting the concepts or categories to which they pertain. They may include short phrases of data, and should be cross-referenced to data.

Now that the groundwork has been laid for the methodological perspective we will proceed with what was actually done in the current study.

Section II: Study Design

The purpose of this study was to identify and describe the process of psychosocial adjustment to advanced stage breast cancer by women who were experiencing advanced breast cancer as their initial cancer diagnosis. Of primary importance were the patterns that emerged as women entered this initial segment of the advanced stage disease trajectory. Of particular importance to this researcher were the words that the women used to describe their process of interaction with themselves and others and how they came to ascribe meaning to that process. It was also essential to hear how they described the intricate details of their feelings, thoughts, and behaviors. Since it was the earnest desire of this researcher to understand the world of the participant as they saw it, and made meaning of it, and since the primary purpose of grounded theory is to generate explanatory theories of human behavior (Denzin & Lincoln, 1994), grounded theory was the preferred methodology of choice within a symbolic interactionist perspective.

The major emphasis was placed on soliciting emic viewpoints (participant's literal words) through intensive face-to-face interviews that assisted in determining the meanings and purposes that the women ascribed to their actions, as well as contributed to "grounded theory" (Glaser & Strauss, 1967; Strauss & Corbin, 1998).

Participants

Sampling Strategy

Convenience sampling was utilized; every woman who met study criteria and volunteered to participate was accepted. According to the tenets of grounded theory, data analysis began from the first interview. Theoretical sampling did not occur because so few women were available for recruitment within the study period time.

Criteria for Selection

Eligibility for participation included:

1) Having a physician's initial diagnosis of identified Stage III or IV breast cancer within the previous eight months.
2) Having no previous diagnosis of cancer or psychotic disorder.
3) Being available for interview in person at least once during the three interview opportunities.
4) Being willing to engage in subsequent interviews within approximately 1 month, or within a subsequent phase of the treatment process, so that a range of experiences could be captured.
5) Being able to speak and read in English.

Recruitment

Recruitment occurred through oncology clinics throughout the Puget Sound region (Appendix C). Site intermediaries were in place at each site and invited eligible women to receive a phone call from the principal investigator with a full description of the study. The site intermediary sought out the women meeting the eligibility criteria and verified staging of disease eligibility with the site oncologist (Appendix D). Only the site intermediary had access to medical information prior to the subjects' signed consent. The site intermediary verified that the oncologist had informed the patient of their disease status before the woman was invited to join the study. A script for initial contact was given to the site intermediary for invitation purposes (Appendix E).

After the participant authorized the site intermediary to disclose her name and number, the principal investigator telephoned the potential subject utilizing the specific protocol (Appendix F). Eligibility was reviewed again, and the study was described to the potential subject. Afterwards, an invitation to participate was extended, and an appointment set to visit the participant's home, or participant-recommended site.

Protection of Human Subjects. Procedures for recruiting participants were approved by the University of Washington Human Subjects Review Committee prior to approaching the study participants. The voluntary nature of this study was fully elaborated at the time of recruitment and consent. Participants were told that they could withdraw from the study, decline to answer any objectionable questions, or terminate an interview at any time. Any of these actions could occur without penalty or loss of treatment benefits to which the participant was otherwise entitled. One woman, whose husband was also diagnosed with advanced cancer of another type, declined to answer one question regarding the nature of their relationship.

Participant Safety. The principal investigator is a nationally certified, and state licensed psychiatric nurse practitioner in the State of Washington with the clinical ability to assess for emotional duress. A referral system was in place for women determined to be 'unsafe.' Two mental health providers, experienced in existential issues, had agreed to be available for referral for such purpose. The consent form also clearly informed the subject that these options were available, and could occur without jeopardy to her treatment process. While the participants did, at times, experience profound sadness, none of the women were deemed unsafe at any time by the principal investigator, nor referred to a mental health provider for any reason.

Confidentiality. Confidentiality of all written and recorded materials was assured by assignment of code number to written materials, destruction of taped records after transcription, and storage of transcribed and analyzed data in a locked filing cabinet in the prinicipal investigator's office.

Collection of Data

The first interview occurred as soon after the diagnosis as possible, but no longer than 8 months since diagnosis. A total of 24 interviews with eight study participants were conducted. Interviews were conducted in the home three times per participant. A total of 18 interviews occurred in the participants' homes. Telephone interviews occurred 5 times, and 1 interview occurred in the principal investigator's professional office (Appendix G). Not all interviews were possible face-to-face. Four were required to be by telephone due to participant distance at that time. One participant asked for her third interview to be by phone because she wasn't feeling well.

All women were initially interviewed face-to-face except for one because she lived several hundred miles away. The second meeting with that person did occur face-to-face because she was in Seattle on business. See Appendix G for schedule of interviews, location of interview, and associated phase of treatment. The principal investigator personally conducted all the interviews.

At the initial meeting, the researcher reviewed the study procedures, answered questions, and obtained consent from the participant before beginning the interview. All interviews lasted approximately 1 hour. See Appendix H for Consent Form. A Structured Interview Schedule was initially in place to assure that certain questions were asked (Appendix I). However, the schedule was used as a guide only to ensure that all participants answer a consistent set of research questions. Proceeding with an open-ended question, participants were given every freedom to converse as they wished. The researcher made every attempt to ask all questions on the Interview Schedule but within the natural flow of the participant's dialog.

Section III: Analysis of Qualitative Data

In a multiphased process the transcripts were analyzed by the researcher according to the tenets of grounded theory as thoroughly described in the previous section.

The qualitative data analysis occurred simultaneously with data collection. All interviews were tape-recorded with the participant's permission, and the data was transcribed verbatim. These transcripts were checked by the researcher for 100% accuracy. Throughout this process, the researcher attempted to maintain an objective stance, that is, maintain openness, a willingness to listen and to 'give voice' to the participants, and represent them as accurately as possible. The primary concern in the inductive data analysis was for accuracy of representation of domains, categories, and concepts and how they vary dimensionally.

First Steps and Open Coding

Following the transcription of each of all 24 interviews, data were verified by listening to all of the tape-recorded interviews and editing the transcriptions for 100% accuracy. The transcribed interviews were then read in full three times focusing on the general gestalt of the women's experiences before the data were broken into units of analysis. Units of analysis, or open coding of complete ideas, were then established in the transcribed data. These steps, outlined in Strauss and Corbin's (1990) text defined open coding process as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p. 61).

Following open coding, analysis proceeded to aggregate emics into categories. Emics were chosen based on the explicative power for the broadest base in the data. Considerable effort to exclude all extreme cases was maintained. The purpose was to represent the general experience of the largest group of women. Categories were then grouped according to a common characteristic that was shared by each emic. Constant comparative analysis, the process of inspecting data and redesigning a developing theory in a circular and continuously growing process, occurred throughout the research process from initial data collection through coding to final analysis and writing (Barbara Bowers, personal communications, April, 1999). All final codes, properties, categories, domains, and core construct derive from emic data.

Axial Coding

Axial coding occurred via relating categories to subcateogries along the lines of their properties and dimensions. The emics had been sorted into categories prompted by the question of the data, "What is going on here?" To determine relationships and associations, the coding paradigm involved conditions, context, action/interactional strategies and consequences. Asking how, where, when, why, and with what results of the data yielded the relationships among categories. Categories were defined as broad conceptual areas. Properties were defined as dimensions of the categories (Lewis, Haberman, & Wallhagen, 1986). Combining process and structure revealed some of the complexity of the data. During the entire course, the continuation of constant comparative analysis was performed (Appendix J).

Selective Coding and Choosing the Core Construct

In axial coding, categories were systematically developed and linked with subcategories. In selective coding, the process of integrating and refining categories proceeded (Strauss & Corbin, 1998). Recognizing relationships among categories required a great amount of time, interpretation, and selectivity.

Identification of the core construct was a necessary prerequisite for integrating the data. The core construct was the central phenomenon around which all the other categories became systematically linked (Strauss, 1987). The original categories were then reorganized around the explanatory construct. The reconstruction stage involved a review and critique of the explanatory theory and further refinement of the theory. When ultimate parsimony was reached in the final version, the theory of Transforming Personal Reality was born.

Evaluation of Core Construct and Explanatory Theory

The empirical grounding of this study can be judged by the range, density, and systematic relatedness of its theoretical concepts, as well as by the theory's specificity and generality (Strauss & Corbin, 1998). The intent to obtain trustworthiness (credibility, transferability, dependability, and confirmability) in data collection and analysis needs to include monitoring scientific integrity and data quality control (Lincoln & Guba, 1985). Credibility was considered the most important component in establishing the trustworthiness of the results and inferences from this research. Methods for determining trustworthiness include (Lincoln & Guba, 1985):

1. Prolonged engagement: spending an adequate amount of time in the field to learn the 'culture' and test for misinformation. This was accomplished by interviewing each woman three times. This provided the opportunity to build on, or refute data gathered and already analyzed.
2. Peer debriefing: exposing oneself to a peer for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind. Throughout the process the principal investigator met regularly with the dissertation chairperson, Dr. Frances M. Lewis, to verify fit between categories, properties, domains, and core construct and the emic data related to these. The two coders reached a 100% consensus on the coding for all twenty-four interviews.
3. Negative case analysis: Understanding of the patterns and trends is increased by considering the instances and cases that do not fit within the pattern. In depth exploration of negative cases occurred in this study.
4. Member checks: the process of asking members to check the analytic categories, conclusions, and interpretations. This occurred at the conclusion of the study by asking two participants for disconfirmation of any aspects of the study results.
5. Thick description: involves the detailed description of all information. All information will be thoroughly described in the Results chapter.

6. Dependability audit: Information regarding the appropriateness of inquiry decisions and methodologic shifts. This was made available by consistent, and accurate memoing, and journaling of all aspects of the research process (Lincoln & Guba, 1985). Generation of the Data Audit Trail (Appendix J) required a carefully identified trail of raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, and materials relating to intentions and dispositions (Lincoln & Guba, 1985).

Summary

Data were derived from transcribed audiotapes of a three interviews each with eight women for a total of 24 interviews. The open-ended questions asked in the interviews were designed to allow women to identify and describe with elaboration the various aspects of their experience. Data were analyzed utilizing grounded theory inductive analytic techniques to describe the experiences as well as to generate mid-range theory related to the processes in which women with advanced breast cancer were engaged.

CHAPTER IV: RESULTS

The results of the data analysis are presented in two parts. Described in the first section are the demographic characteristics of the participants as well as their pathways through the disease trajectory. Elaborated on in the second section is the exposition of the explanatory theory, Transforming Personal Reality that describes the process of living with an initial diagnosis of advanced stage breast cancer.

Part I: Sample Description

The sample involved women who were single, married, or widowed. Each of the eight women was diagnosed with advanced stage breast cancer (Stage III or IV) within the eight months prior to the first interview. None had prior history of cancer that was consistent with the study eligibility criteria. The research sample included five Caucasian women, two African-American women, and 1 self-described 1/2 Scotch-Irish and 1/2 Native-American" woman. See Appendix J for demographic data for the individual women. Table 1 on the following page includes the range of demographic characteristics of the study participants.

Table 1: Demographic Characteristics of the Study Participants.

Characteristic of Women	Value	Frequency
Age in Years	35 37 39 45 Missing data (~50's) 53 70	1 2 1 1 1 1 1
Ethnicity	Caucasian African-American "½ Native American"	5 2 1
Highest Education Attained	Some High School High School Graduate Some College College Graduate Master Degree	1 1 3 1 2
Mother's Employment	Managerial Teacher Retired All on medical leave during study	6 1 1
Family Income	Missing data 35,000-39,000 40,000-49,000 50,000-59,000 70,000+	1 2 1 1 3
Children Living at Home	Infant grandson 5-8 11-13 14-17 Early 20s	1 5 2 4 5

Study participants ranged in age from 35 to 70. Five of the eight participants are 45 years of age or younger and 50% of the sample were younger than 40. Six of the eight women had at least some college education and seven worked outside the home. Six women worked in managerial positions (one in a health care clinic, one in a law firm, and one owned and operated family business), one was a special-education teacher, and one woman was retired. All of the women claimed they were unable to work for at least the majority of the treatment phase because of the effects of treatment. Family income varied from $35,000 annual income to over $70,000 annually. (One woman who omitted financial information is estimated to have a very modest income). Seven of the eight women had a reported income equal to or greater than $35,000 annually. Five of the women had children still living at home. Several children were between the ages of five to eight years old, and several were adolescents.

This study focused on women with advanced stage breast cancer who were experiencing varying stages of the treatment process during the three interviews. All eight women had various courses of chemotherapy, and either was radiated, or was scheduled for radiation therapy. Two women, both Stage IV, did not undergo mastectomies.

Table 2: Women's Stage and Treatment Type during Course of Treatment.

Woman's Code Name And Number	Stage	Mastectomy	Chemotherapy	Radiation
Sue – 11	IV	X	2 rounds	Scheduled
Jill – 12	III	X	3 rounds	Scheduled
Mary - 13	III	X	2 rounds	X
Edie - 14	IV	O	2 rounds	X
Amy - 15	IV	X	2 rounds	X
Iris - 16	IV	O	1 round	2 rounds
Ann - 17	III	X	1 round	Scheduled
Pam - 18	III	X	1 round	Scheduled

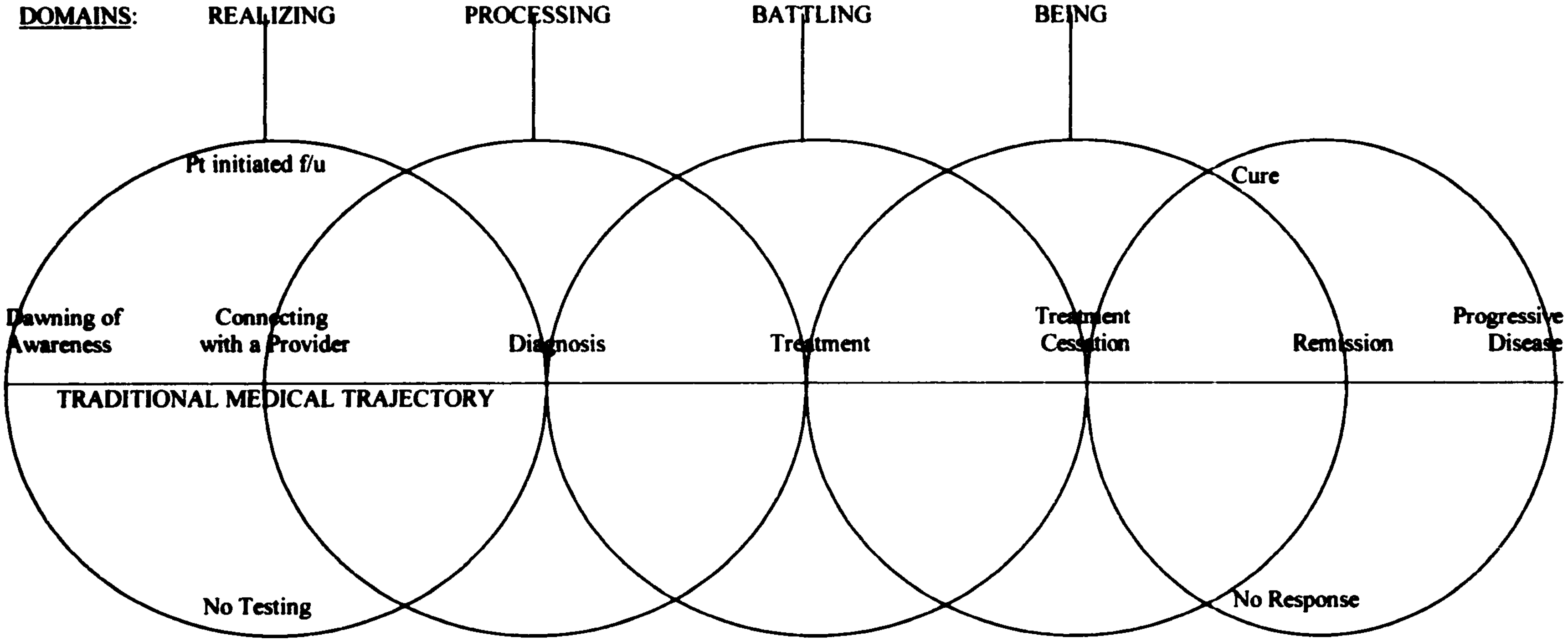
X = Yes; O = No

Part II: The Core Explanatory Construct: Transforming Personal Reality

The analysis of the interview data occurred over several phases. The overall core construct that organized the processes through which the women experienced advanced breast cancer was Transforming Personal Reality. This core construct, and four domains, was derived from over 490 open codes and 250 categories. Through the process of reconstruction, the core explanatory construct and 15 categories emerged. The process of Transforming Personal Reality involved four overlapping domains: Realizing, Processing, Battling, and Being. See Figure 2 for the heuristic model of Transforming Personal Reality.

Within each domain the woman came to know more about herself, her disease, her potential outcomes, her loved ones, and what she perceived as her next step in the process. Initiated either by the disruption of the woman's perception of her existing personal reality through self-discovered or provider-discovered physical changes, a process of transformation of her personal reality began to unfold.

Through the process of engaging and connecting with a provider, undergoing testing, and being diagnosed, women were signaled, some more clearly than others, that indeed they were facing a life-threatening situation. With the dawning of the full meaning of their devastating diagnosis women rallied their personal resources for action and prepared to battle for their life. Evident throughout the process of transformation was the woman's interaction, first and foremost with herself and her beliefs, as well as the interaction between herself and her family, her providers, and her community.



REALIZING	PROCESSING	BATTLING	BEING
Dawning of Awareness Connecting with a Provider Following up on My Instincts Perceiving Urgency	Deciphering the Messages Facing the Possibility of Death Shattering Existing Reality Trusting: A Leap of Faith Paying the Consequences for Others' Mistakes	Battling to Stay Alive Being Dictated by the Disease Fighting the Battle Inwardly Faith Carrying Me Through	Reflecting on Meaning and Purpose Deciding How I'm Going to Deal with My Existence Reawakening

Figure 2: Heuristic Model of Transforming Personal Reality Superimposed on the Traditional Medical Trajectory.

Table 3: Transforming Personal Reality:

Domains, Categories, and Subcategories of the Explanatory Process.

I. REALIZING

- A. Dawning of Awareness
  1. Having a hint something was different
  2. Knowing something was wrong
  3. Attributing it to something else
- B. Connecting with a Healthcare Provider
  1. Having breast symptoms
  2. Presenting with a broken hip
  3. Having a suspicious spot on a mammogram
- C. Following Up on My Instincts
  1. Ignoring it for a long time
  2. Letting the provider know it's still there
  3. Being convinced by the provider to follow-up
- D. Perceiving Urgency

II. PROCESSING

- A. Deciphering the Messages
  1. Coming to know things are serious
  2. Being ripped apart
- B. Facing the Possibility of Death
  1. Gathering evidence
  2. Forgetting the percentiles
  3. Wondering what his words really meant
  4. Treating me as if I'll be cured
  5. Putting a time frame on it
  6. Never facing the possibility of death
- C. Shattering Existing Reality
- D. Trusting: A Leap of Faith
  1. Experiencing a sense of true caring
  2. Believing
- E. Paying the Consequences for Others' Mistakes

III. BATTLING

- A. Battling to Stay Alive
    1. Getting through the 'devastating cure'
    2. Encountering pain
    3. Concentrating on healing
- B. Being Dictated by the Disease
    1. Making major adjustments in our lives
    2. Letting go of former responsibilities
    3. Thinking of it as a process: An everyday thing
- C. Fighting the Battle Inwardly
    1. Zeroing in
    2. Focusing on the positive and sweeping aside the negative
- D. Faith Carrying me Through

IV. BEING

- A. Reflecting on Meaning and Purpose
    1. Prioritizing
    2. Knowing it's in God's hands
- B. Deciding How I'm Going to Deal with my Existence
    1. Not having any answers: A wonder of life
    2. Realizing life's fragility
    3. Accepting what has happened to me
    4. Being ready to go to the next stage
- C. Reawakening
    1. Living for the present
    2. Realizing how very little control we have
    3. Centering around the realization of reality

Domain I: Realizing

Realizing was the first phase of the women's transformation process. The process of Realizing encompassed the dawning of the initial awareness that a change had occurred. This process involved the period of time on the traditional medical trajectory in which the woman connected with a healthcare provider through to the moment she was given the diagnosis. Data from the women suggested that this pre-diagnostic stage, a period of time prior to the actual time of being told the diagnosis, was a time in which significant and vitally important personal experiences were occurring in the lives of these women.

At the initial stages of Realizing, women reported they were aware of symptoms and concerns. For most of the women, the earliest intrapsychic perception of aberrant DNA replication is most often easily disregarded. However, the very few who are conscious of experiencing it referred to it as an "intuition," or a "sense." Five women, Jill, Mary, Edie, Iris, & Pam were not aware that cellular changes had occurred until they could physically feel a lump in their breast. Three women were even less aware of physical changes that were eventually discovered by their provider.

Within the domain of Realizing all eight women developed awareness of a change in their health, utilized a provider, perceived urgency, and followed up on their instincts. At varying rates they became increasingly conscious that a physical change was occurring and chose to utilize a health care provider. Diverse pathways of patient/provider interaction were initiated by the participants or providers for a variety of reasons. Their perception of urgency was associated in most cases with the amount of time to follow up. The necessity for some women to follow up on their instincts and get themselves to a provider for further evaluation will also be discussed. All citations from the women's data will be listed after each quote by participant number (ten was added to each number-i.e. #1 became #11), occasion letter (a = 1st interview, b = 2nd interview, c = 3rd interview), and line number in parentheses as a clarifier for the reader. Fictitious names have been provided to protect the anonymity of the participants. Roman numerals are used to indicate the 4 domains, capital letters outline the categories within the domains, and sub-categories are numbered 1, 2, and 3, etc.

Table 4. Domain I: Realizing - with Associated Categories and Subcategories.

I. REALIZING

- A. Dawning of Awareness
    - 1. Having a hint something was different
    - 2. Knowing something was wrong
    - 3. Attributing it to something else
- B. Connecting with a Healthcare Provider
    - 1. Having breast symptoms
    - 2. Presenting with a broken leg
    - 3. Having a suspicious spot on a mammogram
- C. Following Up on My Instincts
    - 1. Ignoring it for a long time
    - 2. Letting the provider know it's still there
    - 3. Being convinced by the provider to follow-up
- D. Perceiving Urgency

Category IA: Dawning of Awareness

Six women, Jill, Mary, Edie, Iris, Ann, & Pam either had a symptom, an intuition, or a combination of the two that preceded being evaluated by a provider. The quality and character of the initial symptoms varied widely. However, the most common initial symptom was discovery of a lump in their breast by Jill, Mary, Edie, Iris, & Pam. Follow up by a health care provider ranged from a few days to 2 years. Ann knew she had physical changes, redness and swelling, but attributed them to recurring mastitis. Amy and Sue's tumors were discovered during either a provider initiated evaluation or a routine mammogram screening.

Table 5 . Patient Length of Delay Associated with Initial Symptom.

Participant	**Symptom**	**Length of Delay to TX**
Sue	Suspicious mammogram	> 1 year
Jill	Lump	~ 3 months
Mary	Lump	~ 4 months
Edie	Lump	~ 2 years
Amy	Broken leg 3 days after 1st "seeing breast changes"	4 days
Iris	Lump	1 week
Ann	Redness & swelling	~ 6 months
Pam	Lump	Few days

In previous literature (Lewis, 1997), the traditional medical trajectory has been considered primarily a linear process. The data from this study indicated that, at any point along that traditional trajectory, and especially before becoming fully engaged with the system, women had many opportunities to choose to fall away, or be pointed away because of their provider's decisions about seriousness of the symptoms. Just because women initiated contact with a provider did not automatically set them on track in the trajectory for medical management. Two women's cases, Jill's and Mary's, were delayed between 3 and 4 months by providers while the women either *"knew something was wrong, or had a hint something was different (Table 6)."*

Table 6. Patient vs. Provider Initiated Evaluation Process.

Patient initiated				**Provider initiated**	
Emics	Having a hint something was different	Knowing something was wrong	Attributing it to something else	Having a broken leg	Having no clue
Participant	Mary & Iris	Jill & Pam	Edie & Ann	Amy	Sue

Women who experienced symptoms entered the health care system for one of three reasons: 1) having a hint something was different; 2) knowing something was wrong; and 3) experiencing a symptom, but attributing it to something else.

IA1. Having a hint something was different. Two of the women, Mary and Iris intuited, or "had a hint that something was different" and required follow-up.

> *I had got in the shower one day and realized that there was a lump. And, questioned my husband... if that's where he can feel the same thing I was feeling. ...I had planned on making an appointment for a physical anyway, so I figured while I was in there I'll just have them check and see what this lump might be. (13a14-16)*

IA2. Knowing something was wrong. Two of the women, Jill and Pam, felt they "knew something was wrong," and saw their physician who allayed their fears by asserting it was nothing.

> *I felt that there was something wrong. It wasn't just all in my mind. I... I knew there was something wrong... (12c448-449)*

Pam was so convinced that something was wrong she went right away to the surgeon before her mammograms came back even though her primary care provider also told her "it was nothing."

IA3. Attributing it to something else. Edie, whose signs and symptoms hinted there was a difference, reported clearly *"thinking it was something else."* She admitted knowing of a lump in her breast for two years, but hadn't sought medical assistance earlier because she attributed it to *"just another fibroid tumor like many large-breasted women in our family frequently have (14)."*

Also contributing to delay were attributions of these symptoms to other conditions. For example, Ann said,

> *"I had a large red mark on my one breast. It was hot, inflammatory, and it...ached, and my breast became very enlarged. A year before this, I'd had a red mark on that breast, had gone to the doctor and he thought it was just a skin problem and gave me some topical treatment for that and it took me even within 6 months...it had faded slightly. So when it started to get red again, I thought it was something of the same order (17a33-43).*

She chose to not follow-up because she thought she was experiencing a recurrence of mastitis that she had taken antibiotics for the previous year. Their attribution of symptoms to some other cause lead at least these two women to delay acting on those symptoms.

Even though the dawning of awareness for two women's breast cancer, Amy and Sue, were provider initiated, Amy was able to discuss, only in retrospect at our third meeting, *"thinking there's a knowing that we have (15c263)."* She had reported in our first two meetings that her initial awareness occurred when the doctor told her that the broken leg was metastasized breast cancer. In our last conversation by phone from another state, Amy was describing how she annually traveled to this same location for her company's meetings (where she was at the time of that interview and where the awareness initially dawned for her).

> *... it's this time last year when I was here, at this meeting that I remember that first night doing... self exams in the shower, and thinking how lumpy my right breast was, and I thought, you know, "You've got your physical when you get home, you've got your children coming, and for the first time, to have a nice break and a vacation and just let go of this, you know, cause it'll be okay." You're just going to get yourself all worked up over nothing. But when I walked out of the shower in the mirror, I remember I could see that... I mean I... even saying it gives me chills, cause I just got cold chills, but when I looked in the mirror I could see the difference between my right breast and my left (15c195-210).*

Within four days of returning home Amy broke her leg. Her housekeeper, present at the time, later reported that Amy had exclaimed, *"I'm afraid I have cancer,"* as she lay on the bed in excruciating pain waiting for the ambulance. She *"does not remember saying that, or thinking that (15)."*

Like Amy, Sue reported a series of several factors, both participant and provider initiated, that directly contributed to delay of her diagnosis. 1) She was away on a trip when she *"had a mammogram with a suspicious spot on it, and decided to wait until she returned home to follow up,"* 2) When she did go home and got her second mammogram she "was told to come back in six months." 3) In six months she returned for a third mammogram, and "received a letter from the hospital saying it was normal" 4) Months later, she received a call from the gynecologist's office asking, *"Have you seen the surgeon?"* when she *"didn't know she was supposed to."* 5) Next, she had difficulty getting an appointment with the surgeon. After setting a time a few months in the future, the office called her to come in early, but she *"couldn't get away from the office."* When her scheduled appointment time did arrive, the doctor's office cancelled it, and rescheduled for three months later. 6) Finally getting in to see the surgeon, he said, *"I don't understand why you are here,"* and sent for yet a fourth mammogram. At that same visit she told the surgeon she had *"enlarged lymph nodes along my collar bone."*

He told her *"it was nothing,"* and they would check on it in a few months. 7) In the meantime, the mammogram did show that *"whatever I had had grown,"* so she was sent for a needle biopsy. She specifically waited for the results in the pathologist's office, and was told, *"There were no cancer cells present."* 8) Finally, some time later she was *"called back in by the surgeon"* who said that there were cancer cells present, and that more tests needed to be done. This woman's diagnostic and treatment phases were significantly delayed by a lengthy series of miscommunications and misunderstandings by the woman, the provider, and the health care system.

Diagnosis was reportedly delayed in a total of seven cases - Sue, Jill, Mary, Edie, Amy, Iris, and Ann by participant, provider, institutions, or combinations of these players. In five cases, the diagnosis of advanced stage breast cancer was delayed by non-action of the participant (Sue, Edie, Amy, Iris, and Ann). In addition to the diagnosis being delayed by participant action, providers contributed to the delayed diagnosis for three women (Sue, Jill & Mary). In fact, Sue reported both a false negative report and a delayed notification by a medical institution. Table 7 illustrates which patient or provider participated in delay as reported by each of the women.

Table 7. Sources of Patient Reported Delay.

Participant	Patient	Provider	Institution
Sue-IV	X	X	X
Jill-III	O	X	X
Mary-III	O	X	
Edie-IV	X	O	
Amy-IV	X	O	
Iris-IV	X	O	
Ann-III	X	O	
Pam-III	O	O	

KEY: Pt Delay / Prv Delay
Pt No Delay / Prv Delay
Pt Delay / No Prv Delay
Pt No Delay / No Prv Delay

Interactions Related to the Dawning of Awareness

At this point in the trajectory, before the woman had seen a provider, the primary interaction is with the self. Only Pam referred to being scared when she first felt her lump. The other women with symptoms focused on rationally determining what was occurring. Even though, Mary did ask for feedback from her husband about the physical finding of a lump:

> *I questioned my husband...if that's where he can feel the same thing I was feeling (13a15-16).*

No other women reported discussing interactions with their family, friends, or co-workers regarding this stage of development.

Amy remembered, in retrospect, experiencing a *"cold chill"* when she first saw the differences in her breasts reflecting in the mirror a year earlier:

> *I'm wondering if there was an inner knowing, a sensing something is wrong (15c5-6). I look back on this and I think how completely out of touch I had to be with my body, to have it metastasize into a tumor that would break my hip, and not realize 15c191.*

Category IB: Connecting with a Healthcare Provider

Eventually all women connected with a provider when she followed up on either breast symptoms (Jill, Mary, and Edie, Iris and Pam), a broken leg (Amy), or routine mammogram (Sue). Initial contact with a provider was a pivotal point for these women. Following patient initiation of contact, providers then had the professional duty of appropriately following up. Each woman's path can be traced through the system, details of which are provided in Figure 2.

IB1. Having breast symptoms. Two women with breast symptoms, Jill and Mary, were challenged in their attempts to connect with a provider for a satisfactory resolution of their concerns. They initiated contact with the provider, but were told, *"I am sure it was nothing (12a15),"* or *"give it a couple of months" (13a23).* Jill was referred for a mammogram and sonogram as a result of that first visit, but they returned 'false negative.' Mary was not referred for testing. Both women then had the burden of following up on their instincts in the future.

Jill, who "knew something was wrong," was told by her provider at their first meeting that

> *He was sure it was nothing, but he sent me for a mammogram and a sonogram at the same time. And I had those and they assured me that it was absolutely nothing and that this lump may even grow um, but it would just be fluid and it was nothing to be concerned about (12a12-19).*

Mary's provider was

> *thinking it might been a pulled muscle or maybe a cyst. And just basically said 'keep an eye out on it – see if the swelling may go down' (13a21-23)*

Even though Edie and Ann initially delayed in presenting to the provider because they were attributing symptoms to something else, they received immediate response to their breast symptoms and promptly proceeded down the path toward testing and diagnosis. Connecting with the provider, and the results of that connection were vital in determining whether one proceeded on the path toward treatment or not.

IB2. Presenting with a broken hip. It was shocking for Amy to suddenly be writhing on her bed with hip pain and find it was related to breast cancer!

> *I had to call 911 because...I broke my hip bone, and I remember arguing with them that it couldn't have happened, because I didn't fall or anything and I had strong bones. But when we got to the hospital, what actually happened is that I had a, a tumor that broke the hip (15a10-16).*

IB3. Having a suspicious spot on a mammogram. Sue never had a clue before *"hearing that she had a suspicious spot on her mammogram."* She became initially aware that there might be a problem when a nurse informed her that she required follow-up. Her subsequent providers, however, did not find any abnormalities, and she was allowed to go without follow-up for many months (see p 66 for details of Sue's case).

Category IC: Following up on My Instincts

Iris and Pam followed up immediately on their instincts that something was wrong, and Amy entered the health care system for assistance with a broken leg. All three successfully connected with the system and were followed up. This section focuses on the five women, Sue, Jill, Mary, Edie, and Ann, who did not become engaged by the provider at the first connecting opportunity. For these five women, one of three possibilities occurred. They either 1) did not follow up on their instincts by ignoring it for a long time before they convinced themselves that their changed physical state warranted medical follow up (Edie and Ann); 2) convinced their provider that they needed follow-up by following their own instincts and returning to the provider (Jill and Mary); or 3) being convinced by their provider that they needed to come in for further evaluation (Sue).

IC1. Ignoring it for a long time. Two women, Edie and Ann, delayed presentation to their provider because they believed their lumps were related to non-serious conditions. Edie primarily assumed that her physical changes were related to common occurrences in her family, and also was affected by her previous, negative experience with providers, as well as 'believing that cancer doesn't hurt.' She said:

> *I found out at a really late stage. ...partly out of negligence, but partly out of I think...I don't know if it was denial or just figuring...I've had a lot of negative experiences with doctors when I was growing up in. And so I'm not a person that just runs right to the doctor for everything. Um, but then also I have heard the old, you know clichés...like "breast cancer doesn't hurt" and um, uh "fibrocystic things do." We tend to have larger busted women in my family and so we have a*

> *lot of fibrocystic problems. ...so I just assumed that was what it was...so I just kind of ignored it for a long time. I'm figuring it was probably at least two years (14a10-25).*

In reference to following up on her instinct, Ann shared:

> *I have no history of cancer in the family. ...I've been in excellent health and had no symptoms of any kind until...I thought I was having...mastitis in the breast ...and the antibiotics didn't do any good, and I had a hint that there was something really different about it all...I had a large red mark on my one breast. It was hot, inflammatory,...and it ached and my breast became very enlarged, which originally, you would think of as being mastitis. Then I started to get an inverted nipple. A year before this, I'd had a red mark on that breast, had gone to the doctor and he thought it was just a skin problem and gave me some topical treatment for that and it took me even within 6 months... it had faded slightly. So when it started to get red again, I thought it was something of the same order. But the very fact it was coming back, and then adding these added symptoms made me realize that it was something different going on here (17a33-43).*

IC2. Letting the provider know it's still there. This section is devoted to Jill and Mary, two women who were either not referred for testing, or were 'falsely' told their results were negative. In both cases the women initiated follow-up based on their own instincts that something was indeed wrong. It was their job to convince the provider to work it up even though they did not perceive any urgency from their providers that they required follow up. Jill's ability to follow up on her instincts clearly encouraged the diagnostic process.

> *I went back to my doctor right before Christmas and said, "OK, this is really growing and it's...pulling in my nipple with it." And he's "Oh it's just filled with fluid, let's take some of that out." Well, he couldn't get any fluid off of the lump, and then sent me to get...a needle biopsy...(12a21-25).*

Mary shared her experience in finding the lump and eventually convincing her doctor that follow-up was necessary:

> *And I went after a couple months; the lump's still there. I followed back up about middle/end of February, letting her know it was still there. And from there we decided that we should have a mammogram. And I had never had a mammogram before. There's...no history of any type of cancer or anything (13125-29).*

At the second interview Mary shared in retrospect:

> *It hurt, it hurt a lot to know that (she is starting to cry here) I could be dead today if I wouldn't have followed up on my instincts. 13b157-159*

IC3. Being convinced by the provider to come in for further evaluation. As described before, Sue experienced a lengthy series of miscommunications with her providers and institutions; however, there was an initial plea from a health care provider to follow up:

> *I had a mammogram in, in 1997 that had a suspicious spot on it and I had this mammogram in South Dakota 'cause I went and saw a doctor there and she had me go for the mammogram and then we were leaving and I got a call from the nurse from the radiation center who said, "You know, I really think you need to come back in and have another mammogram" and I said "I'll do it when I get back to Juneau" - "What does this mean?" and she said "Well, it could mean anything" but she said "Our doctors are very good here and I think that you really need to do this. If this was me, I would do this"(11a21-33).*

After a series of subsequent communications, and her second and third mammograms she was convinced by a health provider to go for further evaluation:

> *...in about October, I got a call from the gynecologist's office saying, "Have you gone and seen the surgeon and have you done anything else about this mammogram?" And I said, "Well, I didn't know I was supposed to. I got a letter saying it was okay." And she said "No, no, no" and she said, "I've been trying to get your file off my desk and you were supposed to go and see the surgeon." And for the life of me, I don't ever recall being told that.*

Category ID: Perceiving Urgency

The fourth category of Perceiving Urgency was experienced by each woman. Some women perceived urgency from their provider before diagnosis. These women's perceptions of urgency were generally associated with the provider's reactions upon initial inspection. This process was therefore defined as existing within the overlap between connecting with the provider and the beginning of testing and can extend past the point of Getting Hit when the woman was shattered by the diagnosis.

The first signs of perceived urgency were stimulated by the woman's perception that her provider had determined that there might be cause for immediate follow up. Two women, Iris and Pam, perceived urgency when their provider first inspected and palpated their breasts. Pam said:

> *...when I finally got to the surgeon with the lump. ...everybody is smiling and saying, "Well, you know, most lumps aren't malignant, and everything is going to be fine probably," I get to the surgeon, who is laughing and joking, and having a good time, talking to my fiancé, until he feels the lump and...his face shut down and he quit talking and said to the nurse, "Get me a biopsy needle." Dramatic change in his demeanor...he biopsied me immediately...I got really scared again and I was like, "Ooh, no!" I could just tell from his tone of voice and his face.... (18a 54-63).*

Therefore, even though there were not definitive, objective test results available at this point women were able to perceive the urgency of their state.

Three women, Sue, Jill, and Mary, received direct and indirect statements from providers that discouraged any sense of urgency. See Table 8 for examples of direct statements that communicated non-urgency to the women.

<u>Table 8: Direct Provider Communication of Non-Urgency.</u>

"Why are you here?" 11a65
"Probably just enlarged lymph nodes" 11a73
"We'll check on that sometime in January." 11a74
"There were no cancer cells" 11a80
"Not seeing any sign of cancer 11c14
"I am sure it is nothing" 12a15
"It is absolutely nothing" 12a16-17
"This lump may even grow, but it would just be fluid and it was nothing to be concerned about" 12a18-19
"Oh, it's just filled with fluid" 12a23
"It was absolutely nothing" 12b396
"Don't even worry, it'll probably grow on you. 12b398
"Keep an eye out on it" 13a22
"See if the swelling may go down" 13a23
"Give it a couple months or so" 13a23-24

Other ways that providers indirectly communicated non-urgency were by *"not leading me to think that there was anything to be concerned about," (12b410) "canceling appointments and rescheduling months later,"(11a62) "making it difficult to get an appointment,"(11a54)* and by *"playing it down quite a bit like it wasn't that big a deal."(18a35).*

The interconnection of behavior, emotions, and thoughts played a significant role in encouraging women to initially connect with a provider. Women chose whether to utilize a provider, to attribute her symptoms to benign familial problems, or to delay medical follow-up. Providers chose whether to attribute the women's symptoms to something more serious and test, or not, and thereby communicate to the woman that her concerns were valid or invalid. Whereas each woman entered the health care system through various routes, and with various symptoms, each was in reality presenting for the same exact reason. Each woman did have undiagnosed advanced stage BrCa. At this time they were in the pre-diagnostic stage, in the Realizing Phase of Transforming.

Certain sub-processes initiated in the Realizing phase would continue through subsequent phases. For example, the process of Coming to Know carried over to each phase as each woman realized more clearly her current state of health, processed the significance and full meaning of their diagnosis, battled through the treatment, and began to balance as they established transformation.

Domain II: Processing

Perceiving urgency was now rapidly transforming into the women's action of deciphering the messages that entered their consciousness from themselves, providers, and family members. Information was flowing fast. As women came to know the seriousness of their current state, they worked to gather evidence of the full meaning of their provider's words, or the absence of words. Participants struggled to understand the meaning of their provider's behaviors even as they were thrust into a frenzy of medical appointments. The result: *"The reality of it all hitting you (17c12)"* and *"getting ripped apart (17c910)"* not only by the message, but also the manner of delivery, and "*not knowing what to do (17c891)*, and feeling like life was *"zooming out of control (15a212)*." With this *"horribly shocking and terrifying (15a153; 15c190)"* news, some women suddenly began *"wondering about their chances of living (18b207),"* and started *"facing the possibility of death (12a389)."* Coming to know that the reality that had been their bedrock was *"completely shattered (17c970)"* was frightening, and swift decisions were necessary. Women reported that transformation from the old, shattered reality to a another enduring, acceptable reality was assisted by determining that they were cared for by providers and significant others, allowing them to "*take a leap of faith to trust (14b324),"* and by resting in their beliefs about the meaning of all this.

As the women moved forward with processing toward the domain of Battling, and throughout the rest of the process, a sense of being very angry for *"having to pay the consequences for others mistakes(12)"* was present.

The domain of Processing includes five categories: 1) Deciphering Messages; 2) Facing the Possibility of Death; 3) Shattering Existing Reality; 4) Trusting: A Leap of Faith; 5) Paying the Consequences for Others' Mistakes

Table 9: Domain II: Processing – with Associated Categories and Subcategories.

II. PROCESSING

- A. Deciphering the Messages
  - 1. Coming to know things are serious
  - 2. Being ripped apart
- B. Facing the Possibility of Death
  - 1. Gathering evidence
  - 2. Forgetting the percentiles
  - 3. Wondering what his words really meant
  - 4. Treating me as if I'll be cured
  - 5. Putting a time frame on it
  - 6. Never facing the possibility of death
- C. Shattering Existing Reality
- D. Trusting: A Leap of Faith
  - 1. Experiencing a sense of true caring
  - 2. Believing
- E. Paying the Consequences for Others' Mistakes

Category IIA: Deciphering the Messages

Women continued to attempt to decipher objective and subjective messages they received from self, providers, family, and their community throughout the whole trajectory. However, they were most actively engaged in deciphering subjective, objective, direct, and indirect messages in this particular domain.

IIA1. Coming to know things were serious. Once recognized by their physician as needing follow-up, they received messages such as "*seeing big, big, buttons that said, Urgent! Urgent! Urgent! (18c485).*" One woman reported "*an instant knowing that this was a serious thing (14a62)*" based on her physician's facial response during initial examination. Edie reported, "*knowing that the doctor felt confident that it was cancerous and very advanced even before the biopsy (14a44).*" Sue said she "*had the impression* *from the Dr. that it was very, very serious, and that it had spread (11a292).*" Some of the subjective and objective clues communicated to the women by the provider from which she came to know things were serious are listed in Appendix L. The consequences of witnessing, observing, and hearing these clues made it more graphically real in the process of accepting the fact that their diagnosis was something serious.

IIA2. Being Ripped Apart. Most women could recite the date, time, and location of the very moment when their existence was "*ripped apart (17c906)*" when hearing their diagnosis. Particularly, at this point, those women who had little reason to suspect the seriousness, Sue, Jill, Mary, Amy, and Ann responded by being very shocked, angry, and frightened. Amy remembered, "*Being terribly shocked about the fact I had cancer (15c190),*" and "*feeling like a force trying to destroy me at first (15a171-173),*" and wondering "*how much more can I take? (15)*"

Iris remembers only that the medical and nursing staff appeared very concerned for her and the welfare of her children. However, she reported feeling "*rather numb,*" and didn't really experience any emotion about it for a few weeks afterward (Iris, personal communication, March 13, 2000). Edie said "*it is almost like being there, but you're not there, and you're hearing everything and seeing all this happening, and looking at it at you body and knowing how it's misshapen and changed (14a34).*"

This is the first time in the whole process of transformation where women admitted, "*feeling like their life is zooming out of control (18a212).*" Ann talked about "*going through the falling apart (17c969),*" and "*being out of control emotionally (17c930).*" Edie shared a fascinating experience of being hit with the sudden realization of how vulnerable she was.

> *...it was more at the beginning and it (waking up in the middle of the night with hard dreams) had to do with being or realizing how out of control we are of things, even though we think we are in control of our lives, and it just was such a frightening thing to me to realize how little control we really, truly do have in our lives. That we can control how we handle 'em and what we do with 'em,...just the whole concept all of a sudden of realizing...how little control we have was just very, very frightening to me (14b142-161)*

Most women admitted the experienced times of being terrified. Sue, living in a rural area in another state, decided immediately to fly to the Seattle area for a second opinion. She arrived on Friday, and "waited in the clinic from 10 in the morning until 5 in the afternoon to see the oncologist." He basically told her she *"had stage IV breast cancer, and there was nothing he could do for her that day, but that she should go home and prepare to stay for some time when she returned."* She went home, *"got her business in order,"* and returned for four months to have chemotherapy and surgery.

Some women reported *"receiving the news in a very unexpected way (17)."* For example, four physicians and one nurse told Sue, Jill, Amy, Ann, and Pam their diagnosis over the telephone. Ann reported:

> *I received the news in a very...unexpected way.... Dr. ____ was out of the office, and was going to be out for 2-3 days when the biopsy came back and it was positive, and she (the nurse) knew that this type of cancer needed to be dealt with immediately instead of waiting for another week. So she called me and had to give me the news via the telephone, instead of having me come in. ...I must admit it just literally took my breath away. ....I couldn't believe it. It took me quite a while for it to really sink in, but she'd already lined up appointments for me and what to do and where to to; so it was just a matter of my biting the bullet and doing it (17a13-17a20).*
>
> *...she was communicating urgency, and it just blew me..., and I ran out, and I said, "(spouse), you won't believe this telephone conversation I just had," and it just...ripped me apart (17c906-910).*

Pam reported the manner in which she received the news:

> *"The doctor told me 72 hours turn around time for the lab. Within 24 hours he was calling me at home at 5 o'clock at night and saying, "Honey, it was*

> *cancerous." While apologizing profusely for telling me on the phone, he also directed me to come to his office, and the hospital right away to get the papers arranged, so surgery could occur in the morning (18a84-93)."*

Sue and Jill discussed the difficulty they experienced in facing a weekend knowing they had at least Stage III breast cancer, and needing to wait until Monday to do further tests to ascertain whether there was metastasis or not. Jill shared:

> *I was diagnosed with cancer on...a Friday. ...And that was a weekend of living hell because I was told at that point that...most likely the cancer had spread elsewhere in my body. Just because the tumor was so large they couldn't imagine it not being anywhere else. And, so I had to wait until Monday to start going through the battery of tests to find out where else the cancer was. The doctors told me "the odds were extremely high that it was somewhere else in my body (12a159-169)."*

Category IIB: Facing the Possibility of Death

At this point in their processing women experienced the consequences of getting hit with the diagnosis. For some it was immediately crushing, and for others it took some time before hitting them. Whether it was immediate, or delayed, the consequence of "*the reality of it all hitting you (17c906)*" was "*facing the possibility of death (12a389)*" and "*wondering about your chances of living (18b207).*" Women remembered thinking "*I didn't know how long I had: Did I have six weeks? six months (12b510; 11a154)?*" Women discussed the effect of providers "*putting a time frame on it.*"
They commented negatively on the provider's ability to pass on information, and the intimidating aspects of setting dates for life expectancy.

Gathering evidence became the women's primary task in this category. Pam was "*needing to know (18b210)*" about the reality of her life expectancy. On the other hand, Jill said "*looking to the future gets difficult, (12b91-92),*" so she didn't "*dwell on the future a whole lot (12b97).*" Fear and frustration were the common phrases used by the women to talk about this time. Ann said, It's *"like being in the dark and you don't know where you're going (17b401)."* Amy admitted it was *"terrifying if you think about it (15a416)."*

Looking to the future became difficult. *"Being confronted with the percentiles (17)"* about their mortality was an unpleasant task. In the meantime, trying to determine what the provider's words really meant was a full-time job, particularly when behavior and words were contradictory.

IIB1. Gathering evidence. Receiving the diagnosis was not the end of data gathering for the women. The confirmation that indeed something serious was happening to them was a catalyst. Women and providers needed to know how far her breast cancer had progressed and what type of metastasis, if any, was involved so that a treatment protocol could be designed. Edie asutely commented, *"You're trying to pick up what they're...trying to say in a kind way...yet knowing the underlying message is very serious (14b354-356)."* She also said that directly *"asking him, or the other doctors"* was her best defense for her anxiety about the possible consequences.

Women varied on type, amount, and depth of information they needed or sought. Most women were content to listen to what their providers said. Edie said:

> *It was my understanding that there was hope, but there was very minimal hope that I would make it through this (14b339-340)."*

Every method of data gathering was utilized by the women. Women continued to become astute observers of their providers. Subjective as well as objective data continued to be processed. Many behaviors and attitudes that a provider exhibited became data: Being positive, having a positive attitude, and being treated in a caring manner were clues that the women took to mean a positive outcome was expected.

IIB2. Forgetting the percentiles. Part of gathering the evidence from the providers was figuring out how bad was the cancer. "*Trying to figure out what you're going to go through,*" and "*what it's going to be like*" became a challenge and a quest. Amy "*wanted to know everything (15).*" She said "*they're not feeling that I'm going to drop over. I'm being told I have a pretty good chance.*" Ann was told by her doctor that "*it depends upon whether you go into remission or not, and whether any symptoms reappear (17).*" She was frustrated with not knowing what that meant, and not getting any answers.

"*Being constantly confronted in the writings with categories and percentiles reinforced the possibility that there wasn't a 100% chance you were going to live (18),*" said Pam. Ann found it necessary to "*discard and throw the percentiles out of your thinking.* "*They have nothing to do with you. You are a person alone-not a statistic (17).*"

Pam wanted to know what her chances were. She wanted to be "*as factual about it as she could (18).*" She said, "*Finding out I have a 30% chance that the left breast had it, or would have it (18)*" made it easier to agree with his suggestions for a double mastectomy. She wanted to know "*what her odds were of living or dying (18),*" to help her make decisions. She felt very concerned that "*the doctors weren't being very straighforward (18),*" and that she was not getting "*the full story.*" She said:

> *It seems like they're afraid to tell you something that's going to scare you or hurt you (18b220).*"

She compared her situation to the kids to whom she taught special education. She observed the school principal not "*telling the complete truth*" about whether, or not, the child was developmentally disabled. *"Just like those parents, we need to know. We need to have correct expectations (18)"* of our potential.

<u>IIB3. Wondering what his words really meant?</u> The women were trying to *"figure out how bad the cancer is (18b285)."* Mary reported *"He was talking in doctor words, and I was wondering what her words really meant-what is he saying?"* Both Sue and Pam said, *"I was wondering what her words mean really." Does, you're not going to die mean I have a 100% chance of living?"* At this point, some women wondered if they were being told everything. They were wishing *"the doctors would tell them more (18)."*

<u>IIB4. Treating me as if I'll be cured.</u> Still, equally, if not more telling were the unspoken messages given to women that were perceived as prognostic indicators of their mortality. Always knowing she had the *"option to ask questions (11a348),"* Sue said

> *I don't think I've been given a death sentence...They're treating me as if once I have the surgery, and the second round of chemo I'll be cured (11a380-382)!"*

Later, when asked what she meant by *"treating me"* she said

> *Giving me the feeling that I was going to have a cure by not talking about not being cured, never talking about the bad part of it, and not giving dates (11b133-139).*

<u>IIB5. Putting a time frame on it.</u> Two women, Sue and Iris criticized their clinician for *"not knowing how to pass on information."* Providers that *"put a time frame on it"* were considered negative and were avoided. Sue, who had providers at the large, urban oncology center, and in the rural area was appalled when her provider in the rural area *"put a time frame on it (11)."* She reported that:

> *He told me he thought I had about ten good years left. He talked about other patients thinking they would survive, and this was quite upsetting, and not helpful. I felt angered that he would give me a time frame when nobody has a time frame.*

> *I didn't ask him. It never crossed my mind. Consequently, I wondered, "Am I going to survive this with that kind of an attitude (11b42-11b53)?*

Iris criticized her first doctor for attempting to *"intimidate her by telling her negative things."* She reported that her oncologist told her,

> *"I'd like to give you longer, but you don't have that long to live. Wishing you had longer to be with you kids, buy you don't. You'll maybe last a year, and that's about it (16b238)."*

Iris shared her perspective on his motivation for this behavior:

> *Just because he thinks I'm not listening to him any more, he's telling me things when he wants to scare me. He's wanting me to do this and that, so he'll say things to make it seem like you don't have that long: You better listen to me and do things this and that way. Consequently, I'm wishing I had a more positive-talking doctor-even a Christian doctor. The doctor knows that I don't want to go through radiation therapy again because of how it was last time for me." So, he tells me, "You've got to go through it...if you want...a little bit more time with your kids (16b)."*

Her response was to quit treatment. Within a few weeks she became quite ill and was hospitalized.

IIB6. Never facing the possibility of death. A few women admitted "never talking" with their provider about how long they might live. Mary said, *"I'm taking it one day at a time. I never asked her how may years I would have left (13)."* At the first interview Amy reported that she had not discussed the possibility with her doctor because *"I think that's at the other end (15)."* If it looks worse than what they thought then we'll have to discuss that." Pam admitted "never having to really work through that because she wasn't told her staging by the provider until being asked to participate in this study. Four women, Mary, Iris, Ann, and Pam, reported in their first interview that they never *"discussed how long I might live (13a210; 15a426)."* Pam said, *"I'm thinking I'm not really facing the thought that I might die (18b282)."* Ann said *"I can't afford the* *negative. (17)"* However, in subsequent interviews, all but Mary admitted they had begun the process of facing the possibility of their death.

Category IIC: Shattering Existing Reality

> *...absolutely shattering your existing reality and changing your whole life pattern (17c952; 961).*

By this time, the women were coming to know that where they were at was shattered, and life would never be the same again. The reality of the significance of the diagnosis fractured their perception of what was real, whole, and stable about life. Women responded primarily by *feeling scared of the unknown (11a152; 18a202; 13b584; 17b348); frightened (15b201); powerless (18a599);* and *anxious (18a1177).* They were *depressed from being scared (16c47);* felt really sorry for themselves *(12a837);* and felt *vulnerable (14b165)* and *out of control (14b146; 13c160; 17c961).*

Dealing with the reality of the diagnosis was frustrating. Ann said she *"didn't want to take time out for this."* She had *"too many other things she wanted to be involved in, including family things."* Her husband had recently been diagnosed with advanced prostate cancer and was undergoing treatment. Just before getting her own diagnosis she was in the process of closing down their summer home where they had been staying. The phone and power had been disconnected. Back home on the East Coast, she had been responsible for helping care for a schizophrenic daughter-in-law and her son. While on the West Coast, she was responsible for caring for her 100 year-old in-laws. She was lamenting the fact that she was unable to help her ailing parents, or her grandson anymore:

> *Hoping it doesn't catch up with us before it catches up with them (17b484).*

Category IID: Trusting: A Leap of Faith

> *It was just an inner feeling that I got from him and this sense of caring, of true caring, that he had, and understanding, and his straight-forwardness, but very kind and gentle nature...just his whole demeanor...then it was just a leap of faith on my part to trust him (14b313-324).*

One important way these women reconstructed a meaningful existence was through learning to trust: themselves, family, providers, and God. Taking the leap of faith to trust required reinforcement of caring relationships with partners, families, and providers and 'having the peace' that comes with believing.

IID1. Experiencing a sense of true caring. Edie and Amy spoke clearly about the caring capacities of their oncologist and what that meant to them. "*Experiencing compassion being expressed through his manner, his touch, and his sensitivity to you*" made me feel cared for. He is "*concerned about how I'm doing.*" I know he is caring because he

> *spends just as much time with you as you need. He maintains the belief that I will make it through; he knows how I am because he listens with a real ear and not with a passive, oh...yeah...yeah," type of ear. You can sense that he's very aware of the other person and their feelings (14b313-325).*

Some other ways that their doctors expressed a sense of true caring included, "*listening to me (12c107); letting me know what to expect (13c194); answering all the questions (15a512); being real open with me (14c111); explaining the diagnosis and stage really thoroughly (16a266); expressing a positive attitude (11b101),* and *taking everything that I say seriously (14c112).*" Consequently, women were "*better able to respond accurately to the provider (11).*" They were comfortable in telling him how they were feeling, and comforted in knowing they could trust him. Edie felt very grateful, and blessed, knowing he was "the one," and *"didn't mind sitting and waiting my turn to see him (14)."*

Ways that were specifically listed as helpful by nurses included *"looking at me like an individual that they loved and cared for just like anybody else. Not looking at me like, 'Wow I feel sorry for her.' I needed that so (16a278-280)."* The people characterized as caring nurses always *"called you by name (14b398); always friendly (16a275); willing to answer any question I had (14b386); complimenting me on how well I did when they gave me a treatment (16a290); behaving in a very attentive way,"* and exhibited a *"caring manner (14b389)."* Refer to Appendix M for a comprehensive list of caring behaviors by health care professionals as reported by these participants.

On the other hand, Amy experienced a serious breach of trust by having her confidentiality blatantly violated. Amy said:

> *When having to entrust you life with doctors and nurses...need to know they have the highest ethics possible. Provider told my competitor who kept asking him and bugging him that I have cancer. I never dreamed he would discuss any information about a patient. Not being able to trust somebody is devastating. ...resulting in feeling a lot of stress has been added because I'm right in the middle of a business merger. These behaviors impacted my admiration for the doctor.*

Feeling cared for by partners and family was essential. Ways that women found family helpful were *checking on me all the time (14a239); just being present (14a238); helping me put things in place for when I was having surgery (18a473); and staying with me (18a 480).* However, if that kind of support was unavailable the woman tended to withdraw temporarily. She found she did not have the energy to take care of others in the way she might have in the past, and provide the kind of self-nurturance she intuited she needed. Three women, Mary, Iris, and Pam, particularly experienced a conscious choice to change they way they related to family. Pam said,

> *I think its me that's changed, and not them (18a783).*
> *Dealing with everyone else's emotions and fear on top of your own can keep me from dealing with some of my emotional issues (18a373).*

Iris decided not to tell her family for a few months after diagnosis because she needed time to adjust. She said everybody would think the diagnosis would mean it was the end (16a81).

Women with children were particularly struck with how difficult it would be on the family for them to not survive (12a434). Pam lamented not talking more with her kids about their feelings related to the potential loss of their Mom.

> *I didn't make a conscious choice not to talk to them. I just wasn't thinking about needing to do that...I guess I was getting so sick that I just wasn't aware. There's nothing talked about it in the literature they give you (18a896-902).*

IID2. Believing. Faith became an integral part, if not the primary source, of the support system for nearly every woman in this study. Each expressed their belief in God and credited their relationship with their Creator as a source of personal peace and comfort, and a knowledge that their family would be provided for.

> *My faith was carrying me through all of this (12a50). Believing that I have something waiting for me at the end of all this. I'm going to a beautiful place (12c228). I couldn't imagine going through this without having the peace. ...go to bed at night and I felt like... Jesus was wrapping his arms around me, and just holding me, and telling me that everything was OK. And even as I face whatever my possibilities are now, I mean somebody asked me am I afraid to die? And I said, "I'm not. I'm going to a much better place." I said, "I will miss my family, and I'll miss my kids and my friends" I said, " But I'm not afraid to die. That's not a fear that I have, because I have this. It's an inner peace...and people who... aren't a Christian ...have a really hard time fathoming it. It's just a peace that you cannot describe to anybody. ... I have this peace that I can go to bed at night and I don't have the nightmares. And I don't have the worries and the concerns that you know, so many people have that keep them awake at night so they can't sleep. ...I can go to bed at night, and I know that even if I don't wake up the next*

> *morning, my family's going to be taken care of. I'm going to a better place (12a278-307). Not being able to imagine going through this without having the peace, and without knowing the Lord (12a332).*

Jill, Mary, Amy, and Iris talked about the transition that occurred in their lives as they turned to spiritual support following the turmoil that arose *"when the reality of it all hit you (12b216; 13b348;14b33; 15a228; 16a11)."* Jill talked about the process of coming closer to the Lord through her crisis. She said she

> *It was after I became diagnosed with cancer that I realized I wasn't that strong in my faith. I wasn't willing to go out and talk like this about my faith to total strangers in the oncologist's office. Then, I realized that I have something waiting for me at the end of all this. And, I really feel sorry for those that don't. You can sense those people that don't. You can sense a loss, the lack of peace...not being able to come to terms with what's going on. So, I have become a witness, and it has just really strengthened my faith (12b242-261).*

Category IIE. Paying the Consequences for Others' Mistakes

Sue, Jill, and Mary felt they were *"paying the consequence for others' mistakes (12c)."* They were angry and hurt about knowing that their BrCa likely could have been found earlier if their provider was "not trying to get the appointment over with so quickly (13).

Mary was hurt:

> *I've put my trust into this doctor, not only as a patient, but...I worked there as an employee with her and there's a lot of trust there and the fact...it happened and it took so long for her to say OK, well let's do this, I just feel hurt...all that she was really thinking of is just getting that visit done...I just felt like she should have sent me straight to a place to follow-up on it. I can't even think of the words of I'm feeling outside of hurt...it bothered me and it still does (13b184-195)*

Jill talked about feeling angry at first *"because I had this cancer when it was much smaller (12a28).* She felt her original primary care doctor ignored her once she was referred to the oncologist by never following up to see how she was doing:

> *And that's what made me angry, it was that he was so insensitive, the only reason he was really calling me I think was to...cover himself, and say you know, " I don't think this would have changed if I would've diagnosed it...then." You know. God forbid his malpractice insurance...be hit or something like that. And that made me angry, and it's also made me angry that this is a doctor that I went to for...probably two and a half years, and my entire family went to him. He knew us quite well, and not once has he called me, or even written me a letter since the diagnosis. ...it wouldn't have been hard for him to drop a line and say...just wanted to let you know that I think about you...." Anything. You know? And I never heard from him, and it's so pitiful (12b426-433).*

In a subsequent interview, Jill shared her experience of having those original films re-read by another provider:

> *I just recently had my x-rays, my mammogram and my sonogram, re-read...these were the mammograms and the sonogram that they told me, 'Oh, nothing's there. It's just a fluid filled mass.' And I had them re-read and the doctor said, 'Oh-ho. Yeah, this is cancer, I can see it plain as day right here.' And... and that made it wash all over me again...all of a sudden, 'What if...' would've I been Stage III if they would have found it right then and there... would've I had to go through as much as I did this past year, if they would've diagnosed it properly? But again, I didn't have anger...and it's funny, because the friend that I was with..was so angry and so mad at...the radiologist and at my primary doctor and...and I just didn't have that. I don't have the anger. I'm disappointed, yes, have the what ifs, yes...but I don't want the...same mistakes to happen to someone else...but I don't have...an anger towards the individuals that did it. I mean, mistakes were made and, unfortunately they were mistakes that... that I have to pay the consequences for (12c392-413).*

Mary continued to feel angry throughout the process that the provider took "so long to follow up (13)."

> *She should've sent me straight to have an ultasound or mammogram, or whatever needed to be done. I just felt that she should've sent me to a breast center, and not take so long for her to say OK, well let's do this. Currently wondering if I want to file a lawsuit against my doctor. Feeling bothered and on edge thinking I wouldn't be here today if I didn't follow up on what I needed to. Feeling "upset because maybe it's something that they could've caught on earlier where it wouldn't have got this aggressive (13)."*

Jill said the consequence for her was *"trusting my own instincts above what a doctor is going to say. Now when I have something wrong, I say, 'prove to me that it's nothing serious (12c448-453)."* She will not let a provider again treat her that way.

Domain III: Battling

Not marshalling your best today means there might not be a tomorrow (17a537-538).

Along the trajectory between being ripped apart by the diagnosis and beginning treatment, the process of Battling emerged as an integral aspect of the womens' process of transforming personal reality. All women were beginning to confront and coexist with the physical, cognitive/emotional, and spiritual components of fighting the battle to stay alive.

Included in the domain of Battling are four major categories: 1) Battling to Stay Alive; 2) Being Dictated by the Disease; 3) Fighting the Battle Inwardly; and 4) Faith Carrying me Through.

Table 10: Domain III: Battling – with Associated Categories and Subcategories.

III. BATTLING
A. Battling to Stay Alive 1. 'Getting thru the devastating cure' 2. Encountering pain 3. Concentrating on healing B. Being Dictated by the Disease 1. Making major adjustments in our life 2. Letting go of former responsibilities 3. Thinking of it as a process: An everyday thing C. Fighting the Battle Inwardly 1. Zeroing in 2. Focusing on the positive and sweeping aside the negative D. Faith Carrying me Through

Category IIIA: Battling to Stay Alive

Battling to stay alive focuses on the psychosocial aspects of the transformation process at the treatment phase of the trajectory. The battle to stay alive is comprised of three subcategories: 1) Getting through the 'devastating cure;' 3) Encountering pain, and 4) Concentrating on healing.

IIIA1. Getting through the 'devastating cure.' The physical effects of treatment for advanced stage cancer have been well documented elsewhere (Crivellari et al. 2000; Lippman, 2000). Generally, the medical treatment includes chemotherapy, or radiation before surgery, then surgery likely followed by more chemotherapy and/or radiation. Finally, many women with estrogen-positive tumors are recommended to take Tamoxifen.

This phase of the transformation process was experienced by women as the *"most physically consuming and exhausting."* Each woman expressed a desire of *"just getting through the treatment."* Mary described the battle as *"a battle against the chemicals (13):"*

> *"It's a battle...some people get hospitalized because they don't react to it very well. Some people react well, and there's not a problem at all. The battle is taking in all the stuff they're pumping into your system just to make sure you stay alive for however long you can (13)."*

The side effects of medical treatment were quite negative and made life miserable for at least part of the process. The primary complaints were lack of energy, nausea, and hair loss. However, at the first interview, many women were just beginning treatment and were pleased to announce that their side effects were limited. Then, by the second interview women more often complained about the nausea, vomiting, exhaustion, and hair loss. Getting through the devastating cure focused mainly on side effects related to treatment for advanced stage BrCa.

Jill experienced panic attacks related to a high dose chemotherapy she had earlier decided would be a good extra step.

> *...all of a sudden, you know, I'm doing...these panics, like, "Oh my," you know, "Here I am going in for this high dose of chemotherapy, that's what's going to kill me. It's going to ruin my heart," I talked my concerns over with the doctor-I'd hate to have heart failure over the cancer (12c93-100).*

An example of transformation of personal identity occurred for Sue when she was getting through the devsatating cure. At first, she expressed gratitude by saying that she *"felt fortunate because the did not look like the others she saw in the waiting room who had lost their hair(11a)."* By the second interview she was balding, and she described herself as *"just dealing with it as it happens - letting it go its own way(11b)."* At first, she did not want to be one of them-the others marked by baldness, and now, being one of them was perfectly acceptable, normal, and natural.

Each woman had a story about how she adapted to the change in her appearance wrought by the battle with the chemicals. Three women, Sue, Jill, and Mary, said that losing their hair was one of the hardest parts. Jill said *"it was a huge deal to me"* because she was working hard at *"not wanting to bring attention to herself or her family."* She didn't want take her daughter to school and have her little friends asking her *"what's wrong with your Mommy?"*

Without doubt, the primary benefit to treatment was cure or remission, Edie was ecstatic when announcing, *"I've gone into remission (14)!"* Iris admitted that the radiation helped with her pain. Edie was pleased to note that the chemotherapy reduced her tumor and lymph node size.

Iris, growing weary of battling the chemicals, described treatment as *"drastic,"* and chose to discontinue it:

> *...now that the treatments have stopped...I'm kind of...feeling in pain again, and feeling very fatigued again and just a lot of the symptoms that I thought that I had gotten rid of are...have come back.... He knows I really don't want to go through the chemotherapy again and he was thinking about radiation therapy, and I've went through that before and that was really drastic...for me, because...I was getting in a lot of pain...It just burned up my skin a lot and it peeled and it got raw, and I just went through a lot of healing...now I'm at the point where I just don't really want to go through any of that anymore...I've gotten a lot of natural things at the health food store...that has really healed a lot of people with cancer...I just don't want anymore chemicals...going through my body to pull me down like that anymore, because it just takes a big wear and tear on my body and I just...went through it, and it was just so drastic for me that I just don't want to go that route again...(16b15-65).*

IIIA2. Encountering pain. Varying degrees of pain were described by the women in this sample. Two women in this sample, Amy and Iris, encountered *"a lot of harsh pain through having breast cancer."* Iris described it as so much severe pain she was not able to drive. She required pain medication throughout the day every three to four hours. At one point, the pain started getting worse and worse, and then went *"out of control. They put me in the hospital to give me morphine IV...(16a466)"*

Iris described the return of pain after a period of relief:

> *Really last time, it was very much so in my lower back. That has not come back ...because that was one of the areas that the cancer had spread to, and it also has spread in my leg bone area and... my thigh area, too...it's come back in... my thighs, my knees, and my legs...this time around....*

Women learned to live with intolerable levels of pain. Amy had experienced excruciating hip pain initially, but following the *"insertion of pins,"* and a lengthy rehabilitation she was quite mobile. Then, the leg pain returned, and she was *"so worried that it was related to metastasis"* that she tried to manage it without medical intervention. This recurrence of leg pain was also during the holidays when her business was at its busiest. Because family interaction was so important to her she had planned a trip back East at this time to be with her daughter and her family. While on her trip she developed pneumonia and was hospitalized. All the while the leg hurt, but she was attributing the discomfort to *"being so ill with the pneumonia."* Upon return, though, her leg pain required that she *"come off the airplane in a wheelchair. I knew it needed to be addressed when I couldn't get to my front door without screaming in pain (personal communication, #15)."*

IIIA3. Concentrating on healing. For all women, the time of dealing with the devastating cure coincided with the time to concentrate on healing. Edie said, *"Being able to take the time off from work has been a blessing. Being able to sleep when I need sleep has been necessary (14c617)."* Most women were completely fatigued with the chemotherapy and required many hours per day in bed. For women with young children this was a huge challenge. Jill described how her employers made a credit card available to her for ordering meals and subscribed her to a babysitting service. Most women admitted that during treatment they were not able to focus on anything other than healing.

Iris talked about some of the inner processing that occurred for her as she concentrated on healing

> *When I get scared, I just really have to shake it off, because then I know from me being scared, I can go into a depression, or...can cause high blood pressure...and different things to rare up that don't need to, so I just have to learn to shake things off and go on and...I've gotten so strong about that...for now it's not a problem for me to do it (16c46-53).*

Many women had stories of how they *"psyched themselves up for the battle."* Ann told the story about how 10 days after she was diagnosed she saw a program on television describing a particular woman's experience with BrCa. After a lengthy report about a courageous battle Ann thought the woman would be victorious. However, the reporter said that she had died the night before.

> *And I kind of.... I didn't need to know that. I didn't need to know that. That was hard because I'd already...psyched myself up to battle it, and with that little phrase at the end of this piece, it kind of said, "Hey, back to reality." That was kind of a hard one...it put everything in reality. It made you look at where it was and where you were going and the kind of a fight you had and you really never do know what's going to come down the pipeline, except you're going to try your hardest, is all I can say. No matter what, you've got to try your hardest. No matter what stories you hear, what negatives you hear (17a44-257).*

Category IIIB: Being Dictated by the Disease

This was a pivotal time for many women as they began to reframe their reality. The women were making major adjustments in their lives, letting go of former responsibilities, and starting to think of the illness as an ongoing process. Ann said,

> *Oh, I'm angry about it, cause I don't understand why me. ...Yes, I'm angry. You can't help but be angry when you...basically are a healthy person, and I really don't have the time for this kind of...I don't want to give that time... I don't want to give the selfishness of having...I feel extremely selfish that my whole life is being dictated by this crazy disease. Every morning, every day, I'm completely dictated by what the drugs have been doing to me, where to go get the drugs... I mean, it's just, everything that's been going on since October 22nd has been dictated by this crazy disease, and we wouldn't even be here right now. I'd be in North Carolina with my family, or I'd be in California with the rest of my family. We would not be here. Our whole life has been changed around because of this (17).*

IIIB1. Making major adjustments in our lives. As in other phases of the process of transforming personal reality women interacted with themselves and others regarding the full reality of their prognosis. During the treatment phase, Sue referred to *"being treated as if I'll be cured."* Based on specific treatment from her providers, Sue assumed her prognosis was highly favorable. She said that her providers were

> *...giving me the feeling that I was going to have a cure by not talking about not being cured, never talking about the bad part of it, and by not giving dates (11a).*

Part of the adjustment process during the treatment phase included changes in relationships. Mary and Iris discussed the difficulty of fading support:

- *Now, it's just me and my Mom-everyone else is kinda fading away (16).*
- *It's bothering me because it's not over yet. Feeling bothered because I'm the one that's sick and I shouldn't have to call everybody to let them know how I'm feeling 13b412*
- *Feeling like I'm out there alone 13b457*

Jill talked about "*not being able to do the little things any longer.*" She was primarily referring to the impact the cancer and treatment had on her interactions with her 2 and 6 year old daughters. Jill was necessarily forced to spend less time with them. She was not able to pick up her two year old for some time after surgery. She was sad about being too weak from treatment to spend the time with her young children that she would have liked to, and was sad for having to wear gloves to change diapers. In addition, having lots of people in their home, as they took turns to help, was difficult on the family's privacy.

Life was definitely dictated by the treatment. For the women, accepting that they needed help, or adjusting to needing to ask for help was a major transition. Pam described herself as not being a person who asks people for help, and how difficult it was to allow that transformation in herself to occur:

> *So, they knew about the nausea and the throwing up, but a lot of these side effects aren't listed on the brochure I was given and weren't discussed at first with me... my fingers... "My fingers hurt...I broke down and I told her that, too. "My fingernails are coming off. My fingers hurt. I can't open anything," you know. I had to call my dad 4 weeks ago after I fell apart, I got so sick. I had to call my dad and ask him to come fix me lunch. I'm not a person who asks people for help. I'm an extremely self-sufficient person and that's an emotional problem and I don't know how to describe it.... "Nobody will ever have the power to control me again." And the way to make that happen is to be totally self-sufficient. Then, nobody else has the power to control you. So, ...asking for help is not something I do...and...I got up to try to fix something to eat for lunch and I threw up... and I got up again and tried to fix something for lunch and I threw up, and I knew I had*

> *to eat and I knew I could eat if I could stay down, so I had to call him and ask him to come fix me lunch, and so then when that happened, the kids and Jessie were asking me questions and I said, "Well, I need you guys to leave something in fridge, you know. You're eating all the leftovers. Leave them in the fridge, so I can just get up, grab them and sit down and eat (crying)(18)."*

Pam referred to the delicate balance of needing to ask for help and not wanting to prick the consciousness of heretofore naïve children, she commented that she had to learn to ask them for help, *"even though that meant they may now be feeling things that they hadn't had to feel before...(18)."*

On the other hand, a unique, and very valuable transformation ocurred for Jill who said:

> *...as hard as it is for me to accept the help, I've realized how much other people needed to help me, that it makes them feel like they were a part of what was going on around me, and...I've actually gotten to where I ask for help now when I need it...I call on people to help watch my youngest daughter for me, so that I can go to the doctor's appointment; and before, I would have never done that...I think that's been really growing, really growing point for me, just to realize that... sometimes people feel so special ...and so useful when you're letting them help you (12c343-350).*

At the same time, Iris clarified how the transaction of accepting help and communicating the need for help occurred for her:

> *...usually people ask me. I always say, "No, I'm doing fine." I'm the type of person that, you know, I'm not a person to go ask anybody for help, and then I'm not one that, if they ask me...would say I need help. The people that kind of know me, my mom and my sister, the ones that have been helping, have just been coming doing, because they know that I need, and they know how I am, that I won't admit that I need help, because I'm just not used to it. That's a hard thing for me to ask for, because...I've always been able to just do for myself...My friend just...started doing because she learned that, okay, Kim is going to keep saying no, and she's just going to keep pushing herself and pushing herself...(16)*

Iris later reflected, *"everything just kind of fell in place. I just kind of accepted it."*

IIIB2. Letting go of former responsibilities. Ann, in her second interview, discussed the pitfalls of struggling to give up former roles. She offered, "*Women need to be flexible. Women have to not be concerned about things changing.*"

> *We have one family member who is married to...a bipolar, who's had a very, very rough go of it and a very small child, and...I've been the one that's had to help care for the baby...Now, she's been hospitalized... and I can't be there for them... it's rough; but I've got a job. I've got to get myself better so I can be with them. You let go of them (responsibilities), but then you go round them, and you say, 'I'm going to get myself back to them.' ...You recognize you still can get back to them, but for now, you've got another job to do, so you can get back to them.*

IIIB3. Thinking of it as a process. Mary shared:

> *It is a process...it is a process because twelve weeks I was battling it, and after the twelve weeks, I've had surgery and to me, I'm still battling it because I'm still going through treatment-so it's not done...it's a battle...there is a battle and the battle is taking in all the stuff they're pumping into your system, just to make sure that you stay alive for however long you can...it's just an everyday thing (13b317-345).*

She said, *I pray every night that it's all gone and I can live another day (13b349). Realizing you still have to fight it, and probably always will is a good strategy (13c).*

Ann said it took a long time to face that "*my whole life pattern was changing (17).*" Conflict occurred when the woman was not ready to accept that change. Pam was adamant about "*not wanting her life to change,*" and distraught and "*angry*" about finding that it was changing. She began to suspect that those changes would be enduring:

> *This is a bad thing that's happened to me, and no matter how much I fight it's changed my life. I am not able to fix the changes the breast cancer has caused. It makes me mad. I was planning to just get it over with and get on with things-thinking everything's going to be the same as soon as the bad thing is gone. Now, I'm thinking that's not what happens (18).*"

Category IIIC: Fighting the Battle Inwardly

> *You turn to fight your battle inwardly...(17a366). ...maybe how you deal with it is going to be the one way of getting over the hump. And the way you marshall*

> *your inner strengths and your body chemistry and whatever's going on, might be...just the thing that'll take you up and away (17a460-463).*

Ann painted vivid word pictures of turning to fight your battle inwardly. She was joined by every other woman in the study in describing the personal process where they were able to mentally prepare themselves for the battle by "*marshalling your inner strengths and your body chemistry (17a462).*" She recommended, "*visualizing the battle and visualizing what's going on.*" Ann reported thinking of the cancer as "*the beast,*" and "*chase the beast out of town.*"

IIIC1. <u>Zeroing in</u>. Ann described a type of focusing she practiced:

> *...you've got to zero in on what you want to do and then find how you can navigate yourself down the road and...you can't exclude things from life because things are going to go on no matter what...and you are going to feel the pressure. You can't just zero in on yourself because you are part of the world. You can't erase from it, but you have to decide how it's going to effect you, if it's going to effect you in a positive or negative way. See, just like I said, an awful lot is going on in my family right now. Now, I could let it affect me negatively and keep me from fighting, but instead, I've got to zero in and say I am going to fight, and fight over it, so I can help my family (17).*

Mary specifically had recurrence on her mind when she shared how she refused to focus on the negative and its consequences:

> *...Not dwelling on it. Just keeping your mind occupied and busy so that you don't dwell on it. Not dealing with the thought of recurrence yet. Trying to put it on the back burner cause I can't deal with that now. Having to deal with the present right now cause actually I just don't want to think about it. If you're dwelling on that, instead of working on today, you're going to take your chance away for today (13).*

Part of fighting the battle inwardly resembled Iris' description of training herself to stay in the same mood. She said

> *I tell myself to be uplifted all the time. I put positive things in my head and keep it there and not let it leave. When I feel like it's leaving I just read something positive to put it back in my mind (16a490-494).*

IIIC2. Focusing on the positive and sweeping aside the negative. Every woman contributed insight on navigating herself down the road toward the positive and away from the negative. For some it was a matter of life or death:

> *Staying positive means you live longer (13c151).*

Ann's battle perspective was quite literal. She thought that it was imperative to

> *Sweep the negatives aside...each time you get a negative like that, you have to sweep it aside or it can bring you down. It can make one of your soldiers weak and that might be where the arrow gets in (17a209-210). You can't erase from it, but you have to decide how it's going to effect you, if it's going to effect you in a positive or negative way (17a486.)*

Iris, shared the inner dialogue she experienced that helped her navigate between positive and negative after she learned that the cancer had metastasized to her brain:

> *...get myself back together, get myself thinking on positive things, and...shake off the negative thinking, and...just get some positive thinking in my head and... the negative thinking was... 'Is this going to affect my thinking?'...or going to cause some confusion...in my thinking...and then the positive thinking was... 'No, it's not going to, it's just caused some swelling'...and they had to give me some medicine to reduce...the swelling of my brain...I just started thinking, 'No, ...I'm not going to change...everything will still be the same'... I just had to get positive thoughts in my head like that (16c46).*

Women assessed their providers for positive vs. negative behaviors. Sue had examples of positive provider behaviors that directly contributed to her constructed reality of the doctors looking for a cure:

> *...from what I had gathered from the doctors...they were looking for a cure. No, (they didn't use that word), but they were very positive... And he said, "Everything...looks really good." And that was... a more positive...attitude I guess. They never talk about the...bad part of it...they're always so positive...I think that's what I was picking up on, was the positive attitude...it's kinda hard to put a finger on, but they don't give dates, they don't...talk about not being cured...I think it's the attitude...it's just in how they treat you...always with an up, up feeling. I think that's why...I felt...good about it...but I can't think of the words...that...gave me the feeling that I was going to have a*

> *cure...I think it's their behavior...Their attitude said this is a curve in the road... and we're working to straighten it out...(11b91-160).*

Family had the capacity to contribute positive or negative support to the woman. Several participants experienced waning family support during treatment and were very bothered by it.

> *...it kinda bothers me because they don't call like they used to or come by... I think they think it's all over and it's really not. There's more treatment that I have to go through to make sure that it's all gone (crying) and the only way to do those treatments is through the chemo and the radiation. It really kinda hurts (hard crying) to know that they're not calling as often as they used to (13b396-425).*

Also, family often provided the stimulus for being positive. Mary said:

> *In order for me to be here, I need to be positive, and think positive that everything is going to be okay and think positive that everything is going to be okay, and I'm going to be fine, and that I will be here to take care of my family and my kids (13c334-337).*

Ann assessed for family contribution to the positive vs. negative scale and found that she used support to fight her inner battle:

> *Fighting the battle by turning to those that are giving me the positive vibes I need to make my inner self fight it (17a367-369). Worrying about it can keep me from fighting the fight (17a472-473). Knowing I could let it affect me negatively and keep me from fighting (17a489).*

Iris was a good example of someone whose behavior was directly affected by what she considered 'provider negativity.' Iris felt that her provider was negative by telling her that she didn't have that long to live and wouldn't "*be around long enough to even try to do for my kids (16b220).*" She reported, "*Not liking to hear him talk like that because it's just too negative and I'm kind of a positive person (16b230).*" She said that her provider said she "*might last a year without treatments,*" and she really did not like the "*negative spirit about him. Too negative talking for me (16a315-316).*" She decided that she really wanted to try someone else, eventually did so, and was pleased with the connection with her new provider.

Iris' behavior was also affected by the negativity she perceived existed in a group setting. She visited a support group once, but chose not to continue because they did "*not have anything positive to say (16a599).*" She complained that they were "*going on*" about the pain and the hot flashes they were going through (16a596). She thought they did not "*look very healthy or uplifting (16a600-601)*"

Iris noticed the consequences of being negative:

- *Having worse health (16a618)*
- *Experiencing worse pain (16a619)*
- *Everything was just turning for the worst (16a620)*

Sue was willing to talk about how her perspective had changed over time since she was diagnosed with advanced stage BrCa.

> *...just in the fact that...I accept what's happened to me and...will just deal with...the day to day things. You can do it in a negative way or you can do it in a positive way and the positive way is much better than the negative way, and so I think...once you realize that...life goes on whether you are positive or negative I feel like I've transitioned from a pessimist to an optimist...I regress every so often, but...I don't have that... that pessimistic quality that...was there as much (11c326-331).*

Category IIID: Faith Carrying Me Through

My faith is carrying me through all of this (12a58)

Each woman recognized how her faith had carried her through the experience. Every woman turned to her own perception of God for spiritual assistance and found comfort and peace in doing so.

There also appeared to be an association with *"being positive"* and *"spiritual blessings."* Jill said

> *I have a list that is probably five pages long of all the positive, good, wonderful things that have happened and a very few lines that say, "Diagnosed with cancer (12a60-64)." The offers of help and blessings that I have received have far outweighed any of the negative yet. 12a70-71*

Jill explained that, for her, the battle is keeping up her faith.

> *Fighting the battle is keeping up my faith. Knowing that faith keeps me going, and gives me peace. Actually I am fighting and winning the battle. I think that it's mentally more than physical. I have mentally fought the battle, and I've won. Cuz', my faith in Jesus, I mean, I've won that battle. Physically, maybe the cancer will win in the end. I don't know. It doesn't matter to me. Because mentally I've prepared myself for, and I know I can handle whatever comes down the road. So, fighting the battle is just keeping up my faith (12b486-495)*

Something waiting for me at the end of all this (12b249)

> *I didn't really have the 'what ifs' ...I would accept it and just go on...*
> *It (Acceptance) just means that everything is in God's hands, and that He is in control, and that if I just accept it and give it Him, just leave it in His hands, and... let him take care of it, then it takes the worry off of me (16c89-98).*

Some women expressed purpose and meaning in their lives by *"trying to get as much accomplished as possible (15a193)."* They not only focused on getting business affairs in order, by also 'missions' that they wanted to finish. Amy described her personal satisfaction in accomplishing business mergers to free up some of her assets for her children. She also expressed pleasure in knowing that a scholarship fund was being developed at a local college, and she was especially fulfilled by contributing to the organization of a support group for women with breast cancer.

Both Iris and Jill stated that they would not have made it through if it were not for having God in their lives.

> ***Believing that doing it on my own would have resulted in a nervous breakdown (16b74). ...Not being able to imagine going through this without knowing the Lord (12a332).***

Ann felt that *"God had given her the gift of life"* and her task was to *"choose to use her brain and heart to the best of her ability (17a415-426)."* Women referred to the power of prayer in their lives. Edie believed that *"her recovery"* (remission) was a miracle (14c379). In fact, she was having a hard time sharing her health status with others because she *"did not want it to seem like I deserved it more (14c399)."*

Faith in God also provided confidence that families would be cared for. Jill said that she knew that *"God would be walking with her family and carrying them through each day."* She was able to rest knowing that her husband's faith was strong which meant that her children would be brought up in the same faith. Knowing that her family would *"manage just fine"* supplied her with a peace that she wanted to share with others. She found meaning and purpose in *"transpiring a peace to others (12a374)."*

Domain IV: Being

Living for the present: 'Yesterday is passed and tomorrow's yet to come, and today is a present from God.' And that's what I call it, a present, present time (12b112-115).

The domain of Being occurs from the beginning of the 'devastating cure' through the end of treatment. Throughout this process women experienced a myriad of emotions, behaviors, and thoughts about how they were going to deal with their existence. They reflected on the meaning and purpose of their lives and experienced reawakening. At the center of this domain, treatment ceased which symbolized an end to its side effects and the time of their returning to work. There was also a transition to reduced interaction with their provider and the health care system. During this time, women continued to focus on the positive, attempted to stabilize their lives after many adjustments, and focused more on their faith and getting back into their lives. In this final phase women were realizing life's fragility, learning to live for the present, and coming to terms with the impact this traumatic process had, and would likely continue to have on their lives.

Table 11: Domain IV: Being and Associated Categories and Subcategories.

IV. BEING
A. Reflecting on Meaning and Purpose 1. Prioritizing 2. Knowing it's in God's hands B. Deciding How I'm Going to Deal with My Existence 1. Not being any answers: A wonder of life 2. Realizing life's fragility 3. Accepting what has happened to me 4. Being ready to go to the next stage C. Reawakening 1. Living for the present 2. Realizing how very little control we have 3. Centering around the realization of reality

Category IVA: Reflecting on meaning and Purpose

The women reported that at this time they were meditating on what they had survived and hoped to continue to survive. There was also a sense of gratitude for being alive, being in relationship to others, and honoring the impact their diagnosis had on everyone in their network.

In our final interview, Amy was able to reflect on what this experience had been like for her:

> *...thinking what this year has been for me, and the growth, and the...gratitude I have for the treatment team I have and for the friends who have been there for me, and... and the closeness of the family and it's been real hard for my son,*

> *and...at least finally.... you know, he's finally been able to break down and... and...we've come to grips more with it (15c227-230)*

IVA1. Prioritizing. Sue contemplated the importance of prioritizing the meaningful things in life in terms of helping others:

> *...if I feel like I'm helping them...it makes me feel pretty good, or if I feel that I can be somebody that they can listen to...or that I can listen to them, or they can ask questions, I feel...real good about that. I think that there is something out there for me to do, but I don't know what it is yet and we'll just have to wait and see. I think it's pretty important (to prioritize the meaningful things in life). I feel like I've got to give something back. Well, I've had a really nice support system and I just think that...I need to share that with other people...that need it...because I think that's part of what helped me through (11c198-213)*

Edie contributed her sense that *everything is meaningful (14b643).*

> *...we all have our place, you know, which I believed that anyway, but...that no place is too little to have an impact and that hopefully I'll remember that more in dealing with myself and with other people...if I keep this other aspect, that maybe I won't miss so much in things that I can pick up and learn from other people, too (14b628-638).*

Ann shared that setting goals was one way that she prioritized meaningful things in her life, and that this mechanism was how she made it through the process. She said that, "*Being concerned about where you are trying to go (17b199)*" served as an impetus to helping you "*keep a positive look forward down the road (17b133).*" She offered that, "*Deciding what is most important (17b148),*" while avoiding "*crying because you stubbed your toe (17b149)*" had been most helpful to her. The process of evaluating all the little things for importance helps you to focus on "*getting down the road (17b148).*"

Goal-setting was important. Four of the women spoke of making goals and continuing to utilize focusing skills developed earlier. In this fourth domain, while continuing to implement the skill of focusing on the positive and sweeping the negative aside, Mary was able to begin to move forward with goals that she had originated before the traumatic diagnosis. She described some of how she thought:

> *Mainly just keep my head up and staying strong...it's something that may happen and, something that I have to go through and I just keep a positive attitude and I try not to have any negativity around me. I try and keep that away. My husband definitely tries to keep that away. We don't want any negative attitude around. We just want to hear something positive. So I kinda basically ignore, like set goals...one of my goals before I found out was I wanted to plan on getting a house and before I could even start looking, that's when I found out that I had the breast cancer so that kinda put everything on the back burner. ...now my goal is to work for the house, for my kids to have their own room and once I know I've accomplished that I'll feel a lot better and I know a lot of other things'll have been taken care of, but my main goal right now is to have a home where my kids can play in the backyard and have kids over to play and have that swing set (13b360-376)*

Jill could identify what the priority of her everyday was:

> She wasn't quite two when I was diagnosed with cancer...the first 4-5 months I didn't have the energy to spend the time doing something as simple as making chocolate chip cookies...tears dwell up in my eyes thinking that I've missed out on five months of her life cuz' I was not feeling well, so I have to make the most of each day...just create those memories for the kids now in case I'm not around in the future (12b123-136).

Another type of prioritizing was expressed in Jill's lament about what she would miss most about her life if she doesn't "*beat it if it comes back again (17).*"

> *...who's gonna put the hair ribbons in their hair? ...as they get older...who's gonna make sure that they have panty-hose to go with their dress...? And are they wearing a slip under that?" ...it's the little things that mothers do, and I stop and I think about those. And uh, future, and I want to be there, I want to be there for them to...help them through the heart breaks when they lose their first boyfriend, and those things make me real sad when I start to...think about the future. And, and then I have to stop, and I have to refocus, and I have to give God my blessings for all the things I have, and all the things I've been able to have, and all the memories that I've had through the years, and the time that I've had with them.*

IVA2. Knowing it's in God's hands. Iris was confident in her belief that she could "give everything to God – leave it in His hands, and let Him take care of it (16c94-

97). Consequently, she experienced more positive feelings, and said, "It takes the worry off of me, I can stop my thoughts about it, I can accept it and go on (16c91-118)."

> *.... (my faith) plays a big role in helping me go on. ...having faith and believing that everything is alright, ...It plays a big part in my life (16c576-580).*

Amy had experienced "*Feeling like a force trying to destroy me at first (15a171-173).*" She wondered "*Gee, how much more can I take (15a173)?*" She had lost her husband suddenly two years earlier, and now could barely get around. She admitted thinking, "*I'm not in control of this. I don't believe in a God that tries to, to do that.*" *15a173-176* She explained in an untaped conversation that she "*didn't believe that God would make her responsible for her own healing,*" and that "*she would not be a failure if her attitude didn't create perfect health for her.*" She said she was tired from trying to muster every positive thought, will, and personal strength imaginable. She "*couldn't do that any more.*"

Category IVB: Deciding How I'm Going to Deal with my Existence

> *Deciding how to deal with your existence is one of the hardest things (15c43).*

One of the unique aspects of the domain, Being, can be compared a long strenuous hike to the top of a hill where one is able to look forward to where the path will take them in the future, and also look back to honor where they have been. Seven of the eight women were able to appreciate the personal changes that they were experiencing and felt that their perspective on life was enhanced.

Women had experienced an implosion of the reality they had come to rely on. This caused for many a deconstruction of their existing reality. Now, they were forced to enter the process of reconstructing a reality with purpose and meaning for them that supported continued functioning in this world while battling a life-threatening illness.

Earlier they called it a Battle for Survival, now it was vital that they experience being fully present in their current reality.

IVB1. Not being any answers: A wonder of life. There appeared to be an association between making attributions and being ready to go to the next stage.

> *I felt like there...ultimately weren't any answers...there's not an answer as to why I got the cancer...I didn't feel picked on or singled out or anything like that and so...it's just OK, there's not really an answer as to why to some things. They just happen 'cause we're in this world and, and there could be a whole lot of things contributing to it or nothing. Who knows? And I think about that stuff and contemplate it, but I don't get usually all wigged out about it. It's just kind of a wonder of life (18).*

Amy was attributing the cause of her cancer to the trauma of suddenly losing her husband two years earlier in a tragic automobile accident while he was in midlife.

> *I think it was from the grief that I was going through, and...I think that trauma brought it on, ...and that was just kind of the crowning glory (15c71-72).*

IVB2. Realizing life's fragility. Jill had a unique way of perceiving her expected timeline:

> *Because of this disease, and because of the likelihood of it coming back somebody's given me this...death sentence...they've said... this could most likely be the way that you die is through this cancer. ...so it's kinda like a guy on death row...you've got six days...and then...your time is up. And so you've gotta make the best of those six days (12b177-186)*

Edie experienced a profound change in her perception of reality. Consequently, she enjoyed more in depth, meaningful connection with her sons:

> *...maybe it was just was the realization of the...fragility of life, that we never really know...dealing with things as they come and trying not to make big deals out of it, trying to just cope with whatever it is, and deal with whatever is going on...but I think that it brought a real awareness, like I said, of the fragility of life and...taking for granted...closeness...(14c259).*

Jill explained that by determining her advanced stage was associated with a delayed diagnosis, and not her own misconceptions of her body's signals she learned to assert herself in a more self-helpful way with providers and put this behind her.

> *...it finally allowed me to put it to an end, because now I know. Okay, yes. I did have the cancer in October of 1998 when I went to my doctor... and I felt that there was something wrong. It wasn't just all in my mind. ...I knew there was something wrong...and now I know that I have to trust my own instincts...above what a doctor is going to say...Now, I'm saying "prove it to me that it's not cancer." Not being willing to take the risks anymore of believing exactly what you're saying. Now... when I have something wrong, prove to me that it's nothing serious. Don't just tell me that it's nothing (12c445-451).*

IVB3. Accepting what has happened to me. Nearly every woman talked about the need to accept what had happened to her. The consequences of acceptance were, for Sue and Jill, *feeling a sense of relief (11c31; 12a39)*, or others, *desiring to spend quality time with my friends and my children (15a156)*. Sue shared what it was like for her as she approached her provider following the end of treatment and subsequent bone scans:

> *I was ready to go on to whatever the next stage was...I was ready to accept whatever he told me. I guess I realize now that cancer isn't something that you die from immediately and...that I had more time...so it just seemed like I was ready...and I don't know what brings you to that point other than the fact that you have to accept your disease and...and once you do that then you're ready to move on. I just think that it's...something that's within. ...I knew that I wasn't to go...without fighting...I feel comfortable with...myself and...the cancer, and I can't tell you why, other than the fact that I know that I have good medical help...and I guess I had the faith that Dr. ___ wouldn't let me go easily...and maybe it was because I was feeling better and that gives you hope (11c32-46).*

While most remembered *experiencing a horrible shock (15a149)* initially, they were learning that they *had to deal with it (12b80-81)*. Most eventually came to the point of feeling accepting of the cancer and its impact on their lives. However, some thought they would *not accept how long it took to take care of (13b237-241)* originally. Jill, for example, had her ultrasound reread, after completing treatment, to determine if the original provider had misdiagnosed her. Jill shared that this knowledge was helpful in her acceptance of the experience.

> *...and the doctor said, "Oh-ho. Yeah, this is cancer, I can see it plain as day right here." ...and that made it wash all over me again, ...I had this...all of the sudden, "What if..." What would have...would've I been stage III at the time they found it, if they would have found it right then and there... would've I had to go through as much as I did this past year, if they would've diagnosed it properly? ... but again, I didn't have anger... and it's funny, because the friend that I was with...was so angry and so mad at...the radiologist and at my primary doctor and..I just didn't have that. I don't have the anger. I'm disappointed, yes, have the what ifs, yes....but you know, ...I don't want the same mistakes to happen to someone else..but I don't have...an anger towards the individuals that did it (12).*

Other examples from the participants of expressed acceptance included:

> *I'm facing the fact. Yes, that's true, I have cancer...*
> *I'm accepting it and just hoping 13b212*
> *Coming to accept the prognosis and pathology report 13b213*
> *Accepting the fact what has happened 15b345*
> *Learning to let go and accept 15b387*

Iris expressed acceptance as a consequence of *being more positive (16c89):*

> *Accepting it and just going on... (16c89-92)*

For Amy, other consequences of acceptance included:

> *Changing my lifestyle entirely 15c241*
> *Selling one of my businesses 15c242*
> *Changing my diet completely 15c241*
> *Sleeping a lot more than I ever did before 15c244*
> *Working on de-stressing my life 15c245*
> *Doing what you can do 15a150*
> *Being as happy as I can be 15a153*
> *Not being down all the time 15a154*

On the other hand, Pam was lamenting the impact that cancer had on, not only her life, but the lives of her loved ones, and the kids she taught in school:

> *... you kind of have to accept defeat... with cancer. It makes me feel frustrated. I don't like accepting defeat. So I've won a little bit here, because I'm going to live, but...the effects it's had on my life are going to be pretty traumatic. Cause I don't see it as very positive changes yet...it's going to have long term effects on some innocent people because...by my working with them changed their lives and affected their lives very positively (18c789-809).*

IVB4. Being ready to go to the next stage. All the women were pleased to be getting on past the treatment portion of the whole process (11-18). Some said they thought they were *"done with the battle (12; 13c368-369),"* but most thought it "would always be with them (11,14-18)."

Mary talked about how she chose to think about where she was:

> *You have to stay positive. ...you haven't beat it all the way, but you've done all that the doctors have told you to do, and right now you feel like you have beat it. I won't know anything...for another month...for sure, once I go through some more tests to make sure its all gone, but I want to feel right now that it is cured and there's no more in my system (13c148-150).*

Sue very clearly described the precipice she was on:

> *It was such a relief to hear that there was no sign of cancer...and if I hadn't heard those words and heard something else, I was ready for that, too, and ready to go on to whatever the next stage was...I was ready to accept whatever he told me...I realize now that cancer isn't something that you die from immediately... (11c26-41).*

This summary represented a majority of the experiences at this point in the process. However, there was some incongruence as represented in Iris' evaluation of where she was by our third meeting. She described having to "*stop and put things on hold... because you can't do like you used to and you don't have the energy (16c613-515).* Next sentence she was describing that what she learned was to *just keep going (16c541),* and *not put my life on hold because of what I'm going through (16c550).* She was *looking into a career change and looking into school (16c553).* While her providers were candid about a limited survival, perhaps 4-6 months at best, she had an attitude of *trying to go on with my life, and accomplish as much as I can (16c555).*

Category IVC: Reawakening

> *Reawakening, not necessarily a change, but kind of a reawakening of it (14c234-235). Being a real treat to experience it (14c275-284). Feeling better about*

> *things-coping better with them-the better both mentally, physically, spiritually we do (14c289-292).*

In the process of reawakening, women experienced a sense of being freed from the former worries of the world, and able to perceive the world in a new light. One of the aspects of this new perception included living for the present.

IVC1. Living for the present. Amy was very ill, but still attempting to function in every way that she could. During the time that we interacted she expressed a wide range of emotions, but centered on fear and anxiety related to her experience. Now, for the first time a calm and peace were present in her being.

> *...what I want is to be able to be in the present and enjoy the time we do have. I'm not able to tell you (family) how long we have (15c234-235)*
> *Deciding even if this is all I have, I might as well have it be as happy as it can be, and not be down all the time. 15a153*
> *Trying to think in terms of just present 15c44*
> *Thinking beyond the present can be extremely frightening 15c46*
> *Being in the present tense 15c157*
> *Knowing, even without the illness, none of us have the past, and not knowing what's in the future 15c161*
> *Wanting to be able to be in the present and enjoy the time we do have 15c236*

IVC2. Realizing how very little control we have. Edie had a profound, and humbling experience centering on the issue of control:

> *...centering around...just the realization of the reality that we're not as big as we think we are and as independent as we think we are and that a lot of times, what we need to realize is that we can accomplish greatness in, in our smallness. ...and that it's OK for us not to be the Vikings of the world that we think that we are...or the gods of the world that we think we are because great things happen from us...even as limited as we are...when we hold on to the thinking that we are so totally in control of everything in our life...Needing to have a better understanding of what "being in control of ourselves and our lives" is...Being in control can just get way out of hand sometimes (14b563-583).*

IVC3. Centering around the realization of reality. Amy expressed that this experience had "*transformed her life completely (15c280).*" She thought that "*Having a* *terminal illness makes you so much more aware (15c163),* and felt that she had "*experienced a growth process (15c258).*"

> Making it through this process has "*the possibility of transforming women's lives (15c172).*"

Part of the reality for most was knowing that this was not the end of the process. Breast cancer would remain a part of them. It had changed them forever. There lives would never again be the same. Jill thought:

> *Wishing I could say it's not going to continue. It's done. It's over. No, it's going to go on for a while 12a918-920*

Amy knew that her reality was changed forevermore. She said I'm:

> *Wondering where will the cancer go 15c47*
> *Wondering what kind of surgery will you have to have 15c48*
> *Wondering how will you be diminished as a person 15c46-49*
> *Wondering if you will have the courage or strength to stand the pain 15c50*
> *Those things always being with you 15c51*

Women described how they interacted with themselves (the expression of their own thoughts and emotions within), and interacted with their providers, family, and community. Some examples for self and provider ranged from experiencing a sense of true caring from their provider to violation of confidentiality. When the woman and her community interacted experiences ranged from social support at church to various forms of discrimination including how one's ability to perform in their usual employment situation is evaluated. In addition, women's interaction with family members were often the most intense and stressful. Women talked at length about the need to take care of their family members who were "having a difficult time with this," but not having the energy to emotionally nurture themselves and family members.

Patient/Provider Interactions

> *No one asks me these questions, and sometimes I need to talk. It makes me think, it brings out a lot in me...it's helpful for me (16c709-712).*

Women looked back during this process and reflected on their relationship with their provider. They evaluated what had worked and what do not work for them. Knowledgeable caring was the number one criteria for feeling good about their provider.

> *...it was just an inner feeling that I got from him and this sense of caring, of true caring that he had, and understanding and his straight-forwardness, but very kind and gentle nature. ...he even shaves his head, too, so that his chemo patients can feel more at ease with him when they go bald. Just his whole demeanor, ...and his knowledge, his...ability to bring out the knowledge that he had, and...to share all the different options and be real honest with me about all the different side effects and all the different possibilities of things that could happen. And,...just a leap of faith on my part to trust him. I felt it was a real good choice.*

Things that women would like to change about themselves when interacting with providers include:

> *Not being direct enough with providers 18a679*
> *Not knowing why because they didn't tell me the information I wanted (18a683)*
> *Not seeking out any other information 11b210*
> *Not being able to them as many question because I don't see them often enough 18b87*
> *Not remembering questions 18b138*
> *Being hard to ask questions especially if you're sick-like with the Adriamycin (18b140)*

Iris summarized how she viewed her interactions with others:

> *I really talk to people that are kind of on the same level as me...that aren't feeling sorry for me...talking down or negative. I just kind of keep people on a positive roll...those that talk positive...to me.... I kind of hear about how they talk...like, "She's not doing so good," or "She doesn't have that long," or different statements like that. That's fine. I know, everybody's not going to have the faith and believe like I do. ...I just let them do their talking and kind of go on.*
> *I do kind of (avoid them) because people that talk like that to me are just no good for me to be around because...I just don't want to be around people that are feeling sorry for me...(16)*

Summary

We know that women whose initial diagnosis of breast cancer is in advanced stage experience a certain medical trajectory. In addition to this linear progression exists a psychosocial adaptation process that can be described in four overlapping domains. This data exhibits clear evidence for the effect of their interactions with self, provider, family, and community on this adaptive process. Assisting women in their interactive process with all these dimensions can surely promote the highest state of total health for each.

Without the full knowledge of the current meaning of their diagnosis women were necessarily forced into a confrontation with the demolition of previous existing reality in which they were healthy and invulnerable. Suddenly forced to reconstruct a new reality focusing on facing the possibility of death these women gathered enormous courage in the battle to stay alive, and eventually the courage to deal with their existence (courage to be).

The hallmark of living with advanced stage breast cancer is the transformative process that each woman experienced. Each woman's life was changed forevermore after the diagnosis of advanced stage breast cancer.

CHAPTER V: DISCUSSION

The purpose of this study was to discover and elaborate the illness-related experiences and processes reported by a homogenous sample of women whom were initially diagnosed with advanced stage breast cancer, and to generate an explanatory model of those processes and experiences. Five sections will be discussed in this chapter:

1) Interpretation of Results
2) Limitations of the Study
3) Methodological Recommendations
4) Clinical Implications
5) Future Directions

Section 1: Interpretation of Results

In this first section, the discussion will focus on the researcher's interpretations of the results from this current study beginning with an elaboration on the discussion of the core construct, how related to the original theoretical underpinnings of this study, and those implications. In addition, the areas of divergence and convergence with the existing literature are addressed.

Discussion of Core Construct: Transforming Personal Reality

Within each domain the woman came to know more about herself, her disease, her potential outcomes, her loved ones, and what she perceived as her next step in the process. Initiated either by the disruption of the woman's perception of her existing personal reality through self-discovered or provider-discovered physical changes, a process of transformation of her personal reality began to unfold.

Through the process of engaging and connecting with a provider, undergoing testing, and being diagnosed, women were signaled, some more clearly than others, that indeed they were facing a life-threatening situation. With the dawning of the full meaning of their devastating diagnosis women rallied their personal resources for action and prepared to battle for their lives. Evident throughout the process of transformation was the woman's interaction, first and foremost with herself and her beliefs, as well as the interaction between herself and her family, her providers, and her community.

The core construct, Transforming Personal Reality was originally an emic, Transforming Reality. According to Webster's Dictionary (1991), 'transforming' is a verb 1) to change in form, appearance, or structure; metamorphose. 2) to change in condition, nature, or character; convert. Lessons learned from this study support the quality of transforming. Not only were the very structures of the women's physical bodies altered because of the presence of cancer, but also their intellectual and emotional selves were distorted. They had difficulty with memory and reported and exhibited labile emotions. Primarily, the perception of self as a woman, wife, and sexual partner was altered. Also, different was the woman's perception of self as competent mother, friend, sister, and worker. The form and structure of their lives were truly changed.

The all-embracing heart of the data from the women in this study was the effect their sudden, dramatic crisis, and its consequences, had on their personal character, nature, and perception. How these eight women had perceived the world before would be forever altered. Like a lost innocence, their perception of the world, their perceived vulnerability in the world, and their reaction to the realization of the significance of the diagnosis, provoked an existential crisis for each woman. Existential crisis was a natural consequence to the sudden knowledge that the mere fact of their existence was threatened, and prompted a cascade of anxiety when the women realized that their being might, in fact, be mortally wounded. For some, the very ground they walked on became like quicksand because they could not get a firm grasp on reality as they had known it.

According to Webster, (1991) 'personal' is defined as 1) pertaining to, or concerning a particular person; individual. 2) Pertaining to, or characteristic of a person, or conscious being. The particular word, 'personal' was added to clarify the meaning that each, and everyone had the unique ability to perceive the world in her own individual light. That there is not one reality, but many is supported by current philosophical tenets.

'Reality,' defined by Webster (1991) is: 1) The state or quality of being real which is described as: true and actual; existent, as opposed to nonexistent; actual, as opposed to possible or potential; independent of experience. 2) resemblance to what is real. 3) a real thing or fact. 4) something that exists independently of ideas concerning it. 5) something that exists independently of all other things, and from which all other things derive.

Considered simultaneously, the construct, Transforming Personal Reality, means to experience a profound impact in the very nature and character of the womens' personal perception of what it meant to exist, or what was true and actual about their existence. It was as if they saw what was real, actual and true about the nature of their existence for the very first time and were extremely frightened.

Each woman experienced an overwhelming terror when they were faced with the sudden realization that their very existence was seriously threatened. The dread terror that existed prior to and outside of language and image was ubiquitous. It was as if a rent was torn in the curtain of their defenses as Yalom (1980) put it, and raw death anxiety was allowed to erupt into consciousness. Rapidly, however, the unconscious ego repaired the tear and concealed the nature of the anxiety. The brief flash of death anxiety was quickly sublimated into lesser concerns (e.g. fear of losing son's love, or fear of losing job to someone more able to work) (Yalom, 1980).

With an existential center, abundant and consistent data revealed the crisis that these eight women experienced. What was worse, each woman traversed this road of death terror alone. Without coaching or guidance, every woman faced the singularity of their existence and the resultant consequences of that anxiety unaccompanied. With a range of personal difficulties such as the addition of their spouse's terminal illness, trying to raise 5 school aged children, or running two large corporations, these women faced unnecessary, prolonged duress unaided.

The very lack of psychological support to these women could be considered by some abusive and oppressive. To be well-managed biomedically and neglected psychosocially is a betrayal of our health care system. Some women in this study, were not only betrayed psychologically, but also improperly managed by their primary care providers on whom they exclusively depended. Biomedical betrayal is a travesty and unforgivable blunder. It is no wonder then that, in addition to the psychological processing each woman endured, some were preempted from the natural emotional healing process by the anger and sense of betrayal that became a stumbling block for their potential emotional development.

The data clearly distributed amongst four major foci: Realizing, Processing, Battling, and Being. The interconnection of thoughts, emotions, and behavior played a significant role in supporting womens' ability to connect with a provider during the process of Realizing. Women, who could cognitively attribute their symptoms to something other, and less threatening, were more apt to delay (e.g., Edie and Ann) connecting with a provider. Women who "surely knew something was wrong" (Jill and Mary) were certain to be seen and evaluated. In addition, providers own cognitive, behavioral response was associated with appropriate or inappropriate delivery of services. Women felt a huge sense of betrayal learning they had advanced stage breast cancer after their providers were unwilling to follow-up on their concerns about finding a lump. Therefore, patient response, provider response, or a combination of the two in response to the women's signs and symptoms could be associated with reduced delay to diagnosis and treatment.

During the treatment phase women were "Battling to Stay Alive." She focused her intuitive drive entirely on her response to treatment. Often, not feeling well, and having clouded cognition, she "took a leap of faith to put her trust in the doctor." Most women reported being "treated as if they would be cured." Their providers' behavior was the primary signal that cure might be imminent. Their focus of "positive vs. negative" was considered the "engine" to "get them over the hump."

As in the work of Glaser & Strauss' (1967) concept of status passage, and further explicated in work by Olshansky (1987) and, more recently, Brown and Stetz (1999), the process of moving from the self concept of being fully alive, fully expecting to achieve all one's goals, to suddenly be required to face the likelihood that the transition to death was likely, was followed by a period of massive deconstruction. The concept of reality that they had created by their wishes, their dreams, and their desires suddenly vanished.

The women were faced with the horrific reality that they were forced off the path of their creation and onto a possible dead-end. They were running into a brick wall. They were trapped, scared, and wondered what was behind the wall? What was on the other side?

Through the interaction of patient and provider the women struggled with desiring to know, and not wanting to know the full meaning of their diagnosis and its implications. With their desire to know more ebbing and flowing like the tide, the women worked to process the information infiltrating their existence. As these women gained an awareness of the meaning of their life-threatening illness their perceptions of themselves and the world around them was affected. Former ways of perceiving no longer were adequate.

The women were fully engaged in an existential experience facing their existence and the meaning of it. A conflicting tension existed where it must have been difficult for providers to know how to respond to them. Clearly, the women wanted to know more, but at the same time feared knowing more.

Each of these four domains can be thought of as operating in an overlapping, consecutive progression, but in actuality, most women experienced variations of the process in more than one domain. For example, concerns for Deciphering the Message existed all along the trajectory. In addition, women could have a new realization, or dawning of awareness at any point in their journey. The battle continued past treatment, although, the personal strength generally developed while engaging in battle during treatment, for these eight women, transformed into variations of acceptance. Although the broad-spectrum was consecutive movement through the domains, their process was truly dynamic. Many of these actions could be occurring simultaneously, and not necessarily consecutively.

Initially the women suffered, but through time, through faith, through caring, a new reality formed for them. For some, their faith in an existence beyond this Earthly reality sublimely comforted and quieted their fears of separation and nonexistence. Nurtured by the possibility of reunion with their loved ones again, these women appeared to be responding to the physical threat distinctively unlike others who did not profess to have the same perspective. When priorities were placed on things spiritual rather than a material emphasis, women reported less anxiety and fear even though they still experienced a strong sense of the preciousness of life.

The effect of living one's life in a more authentic fashion is primarily the strongest effect of the transformation process. To, in fact, have reduced anxiety as a result of facing the ultimate anxiety is the irony of transformed personal reality. There was a sense of power and strength that proceeded from one's comprehension of their existential crisis. Women felt less futile, less alone, even when, ironically, what they had come to know is that they were alone.

The perspective on every aspect of life was instantly changed. The collapse of previous meaning-providing schema required that women participated in a construction of new reality. What was once meaningful may not have been any longer. What might have been less meaningful perhaps took on a new importance. To view life anew, from a fresh perspective, from a place that was once totally incomprehensible, changed the meaning of everything. To know that what they had always known as real in their daily existence was but a fraction of the total reality was overwhelming. Knowing that there existed a larger reality alongside the one they had always known completely changed their perspective on the meaning of the former reality. Now, they could place the former reality in a larger schema that altered how they thought, felt, and behaved toward the "usual things of life."

The processing of this transformation required abundant alone time. This usually meant less time spent with others, and that often directly affected relationships. After a while, the need to be more authentic in relationships altered the needs and expectations women placed on their relationships. All the while, life was dramatically changing for the loved ones, too.

For several reasons, loved ones may have felt threatened, fearful, or isolated from the one that was ill, and had little understanding of those feelings. Several issues occurred for loved ones. They were threatened by the imagined loss of their valued family member (Mother, Wife, Daughter, Sister), and at the same time usually desired to support her by "pretending that everything was okay." In an effort to protect one another, the woman was often not given the opportunity to discuss her fears. Loved ones may think that their own fears may be burdensome on her, and not disclose their feelings. This delicate dance between needing to express emotions related to the experience, and not wanting to burden loved ones, lose support from them, or be perceived by others that they were "not fighting" resulted in inauthentic existence for many. Because society tells us we must have "fighting spirit" women were excluded from expressing their natural fears, and not allowed themselves to face the fathomless existential anxiety that was actually the way out of it.

Because our society does not easily think or talk about death we are not socialized to know how to feel, think, and behave when the "unmentionable happens." Often, our response is to separate ourselves from the one at risk, so that we may also separate ourselves from our own death anxiety. The women experiencing advanced breast cancer in this study frequently reported that it was easier for them to seclude, and separate, also. A common experience for many women was to feel burdened and overwhelmed by the needs of others. It was seen as a self-protective measure to limit interaction to those who were able to interact in an authentic, and genuine manner, while at the same time, not focusing on the negative possibilities.

One of the fundamental difficulties of this experience for these women was that they did not know what their future would be. Before this sudden threat, the women were attending to their daily lives with perceptions that there was an assurance of tomorrow, and another tomorrow. Now, they suddenly stared at the stark reality, that we all ultimately face, that our lives on this Earth do not go on ad infinitum, that we do have an ending to our experience here.

Suddenly, this was the everyday reality for these women. There were no certainties of how many tomorrows there would be. Their consciousness waxed and waned between coveting each precious moment to deluding themselves that how they thought about something made it real. But, what was real existed regardless of whether they chose to acknowledge it or not. Each woman was fighting the battle for control of one's life. The last stand existed in their personal choice of how they perceived reality.

Once realizing that things were not as they seemed, the woman required professional assistance in confirming the diagnosis. The full reality of the diagnosis ripped the woman apart, shattered her sense of what was once considered real. Only through having a sense of being truly cared for, and believing that she was going to make it did she believe survival was possible. Some women were quite angry and hurt that they had to pay the consequences for others' mistakes by being the one whose diagnosis was missed.

Their battle to stay alive was intuitive and compelling. Having the treatment to focus on was, for some, a diversion from "the other reality." Every woman eventually felt very ill and exhausted from the chemotherapy and radiation. They were required to take 'time out from the normal activities of life' because of those effects. Now, family members and friends could be most helpful. Logistics, particularly for the women with children were especially challenging. Every little thing was a huge chore. Most women had no choice but to "give in" to the debilitating effects and get through the 'devastating cure.'

This phase was a huge insult to any personal control. They required assistance for nearly everything. Letting go of former responsibilities was not something they were used to, and with little coaching on normal thoughts, feelings, and behavior related to this particular phase, women's self-esteem could be negatively impacted. The inner life of the woman at this time was her last domain. She had to give up work and family; what she had left was courage, will, and determination. Focusing on the positive, and sweeping aside the negative became her mantra. It was almost as if the stronger she focused on 'getting down the road,' the more defenses against 'the beast' she could build.

In the end, the last stronghold was the woman's faith. Each woman believed that her faith carried her through. This was the most congruous area of agreement in the data for all the women in the study. At some point, generally toward the end of treatment, women were able to begin to experience some relaxing of their fears, and had more confidence they 'weren't going to go immediately.' They could put up a fight and hold on for a while. Knowing that they were cared for by their Creator enabled them to experience emotional and psychic reprieve.

The mother-child relationship was particularly vulnerable to feelings of abandonment for both parties-especially if the children were adolescent or older and able to process some of what was occurring. In addition, reduced sexual desire strained marital relations. The woman's interest generally decreased especially during treatment. For couples to be able to rely on one another in a new way had the potential for enriching bonds. But bonds were not easy to enhance for some. Ann, for example, had a difficult time because she did not have the energy to deal with her husband's terminal cancer and take care of herself. It was particularly difficult because her husband was not able to act in a reciprocal manner. Instead, Ann sought support from her daughter.

Most women had great difficulty asking for help. It appeared that the women desired to maintain as close to normal a pattern as possible. There also was little evidence of reinforcement for asking for assistance. Most women were not very clear about what was unfolding for them.

Taking responsibility for self was manifested in the fourth domain, Being, in which women focused on deciding how they were going to deal with their existence. The big questions in life came up at this time. Realizing life's fragility appeared to be a gateway to accepting 'what had happened to them.' Women described how they interacted with themselves (the expression of their own thoughts and emotions within), and interacted with their providers, family, and community.

For many women, there were extremes in their interactions with their providers. Some experienced true caring while others experienced personal violation. They wanted a caring provider, but some had experienced abandonment during the diagnostic phase and treatment phases. They wanted a provider who would tell them the truth, but were upset when the provider interpreted the truth in ways that violated the woman's hope.

When the woman and her community interacted experiences ranged from social support at church to various forms of discrimination including how one's ability to perform in their usual employment situation is evaluated.

Women's interaction with family members were often the most intense and stressful. Women talked at length about the need to take care of their family members who were "having a difficult time with this," but not having the energy to emotionally nurture themselves and family members. This caused conflict over prioritizing needs of self versus needs of others.

Relationship of Model to Original Theoretical Underpinnings of this Study

Attribution Theory.

The need to attribute blame to providers or institutions for participating in the delay of diagnosis could, by some, be considered related to the need to make attributions. Other examples of attribution as a means for understanding the events, for example, may be the basis for Ann's need to believe that hormones had caused her cancer. However, relatively few other examples of attribution could be located in this study data. While Edie reported thinking that her lumps were related to the high incidence of fibrocystic changes in many women in her family's breasts, none of the women considered themselves at "high risk" for breast cancer.

Cognitive Adaptation to Life-Threatening Events. Evidence of Taylor's Cognitive Adaptation to Life-Threatening Events occurred in the form of nearly every woman's search for meaning in the experience. Most women also attempted to regain mastery over these events by "focusing on the positive," focusing on the "battle to stay alive," and "reprioritizing," to name a few. The restoration of self-esteem was not as clearly evident.

Assumptive World Theory. Clear indications of the tenets of the Assumptive World Theory burned brightly in the data. Women's descriptions of the extreme violation, or shattering, of their previously existing assumptions of the world as a safe and meaningful place directly describe what Janoff-Bulman & Frieze intended in their theory. The fact that each woman described their work as a form of reconstructing a new worldview agrees with the tenets of the Assumptive World Theory. Some ways that women regained a sense of self as positive, strong and autonomous included their being able to point to the ways they had suppressed "the negative." Assumptions about their pre-existing world are directly impacted, reorganized, and reevaluated.

Relational Theory. Certainly, the focus is on the family as the center of the systems in which the women are engaged. There are also other systems in which the women participate. There were many contributions in this data to enlist further support and understanding of the women's tenuous role in the workplace. Their employer's perception of women's ability to participate on the work team, and the provider's assessment of their ability to return to work and function in a contributing manner were each described as areas of difficulty experienced by these women.

Biological families, as well, could be sources of extreme emotional expression for the women. For example, the relationship of the women to their parents was pregnant with intensity for all involved. The range of effect varied from causing great amounts of stress for her to Mom being the sole source of support for the woman with breast cancer. In all cases, the premorbid relationship was generally intensified.

Caring. Examining the women's experience through the concept of caring, this data indicated that women with advanced stage breast cancer definitely benefited from caring behaviors, and were harmed by uncaring attitudes and behaviors. These eight women shared a pervasive need for caring as described by Swanson (1993). Women were able to point to specific caring behaviors that contributed to an increased sense of self-esteem and well-being. Those women whom were able to point to an experience of caring reported an improved sense of well-being in contrast to women who did not experience being cared for. For example, all women who experienced delay, in association with their provider's behavior, expressed a deep sense of neglect and being uncared for.

Existential. It is the researcher's clinical assessment that each woman experienced an existential crisis. Women were forced to experience this alone because they were unsupported by a person knowledgeable about existential aspects. An ethical imperative exists to provide specialized psychotherapeutic support to women forced suddenly into an encounter with a life-threatening event such as advanced stage beast cancer.

Spiritual Needs. These eight women shared recognition that their spirituality was a fundamental component of transforming personal reality. Perhaps a need to rely on something unchanging, ultimately forgiving, and unconditionally loving, existed to assist them through emotionally surviving this process. Their ability to acknowledge and celebrate the coherence of the overall process tended to be associated with closure on their part, or a movement towards acceptance of their reality.

Pragmatic Needs. Women required assistance with coping, relational aspects, and existential attributes, as supported by existing literature. Women also discussed needs not addressed by the literature such as employment and finances. Further analysis of the data for pragmatic factors such as what specific areas of assistance are required by women related to employment, finances, and support in other pre-morbid roles such as childcare and household maintenance is required.

Divergence and Convergence with Prior Literature and Research

This study's results identified and explicated four major domains: Realizing, Processing, Battling, and Being. Many aspects and properties of the Realizing domain have been documented in the literature. However, what is not currently addressed are certain properties of the category, "Following up on My Instincts," and subcategory, "Letting the Provider Know its Still There."

There is recent interest in the concept of delay and the association with women's thinking related to ignoring signs and symptoms. Yet, only three studies (from the U. K.) related to diagnostic delay in breast cancer could be located on PubMed (Burgess, Ramiriez, Richards, & Love, 1998; Grunfeld, Mant, Vessey, & Yudkin, 1995; Nosarti, et al. 2000). Increasing emphasis on presenting with all signs and symptoms is necessary especially since we know that women who do not think their symptoms are serious are at higher risk for delaying presentation. Providers may gain priceless insight into the woman's world when she presents with uncharacteristic signs and symptoms and requests clarification by attending to her in a caring and concerned manner.

In both cases where the providers were accused of delaying diagnosis, Jill and Mary felt primarily "hurt and uncared for." They present evidence that is devoid of their providers' and families' caring actions. They are convinced that the missed diagnosis is related to lack of ability to care. When applying the principles of Swanson's Caring Theory to Jill and Mary's providers' actions there is further support for the women's charges. Swanson's Theory of Caring includes five domains of behavior: Maintaining Belief, Knowing, Being With, Doing For, and Enabling (Swanson, 1993). Not one of the five domains of the caring theory was met in Jill or Mary's cases.

The entire domain of Processing, the second domain of the woman's experience with advanced breast cancer, is essentially unexplored in the literature. How women came to know things were serious by deciphering messages, and responded to providers 'putting a time frame on it' are essential constructs for providers in the health care system to better understand when considering instituting programs for screening and treatment of breast cancer. These women were observing closely for any data to support, or disconfirm, their continued longevity.

The domain of Battling is among the most thoroughly described domains in the literature. The data from the current study adds to our understanding of this battle in a new area: the effects on family, and how they may be assisted through the process, and their imperative to isolate and 'turn inwards."

The particular aspects of fighting the battle inwardly by zeroing in, focusing on the positive and sweeping aside the negative need to be further explored. Still unknown from the current study is: How do women do it? What is it they do? What is the meaning of 'focusing on the positive?' How does one 'sweep aside the negative?' What psychoneuroimmunological functions are occurring, or not occurring, when a woman responds in this way?

Understanding the role of faith in assisting women in their journeys may be fundamental to establishing a true and meaningful relationship with them. The importance of spiritual support expressed by study participants highlights the possible value of a spiritual counselor in helping women process their distress. A professional trained for this kind of support might work closely with the woman to gain understanding from her particular spiritual framework.

We know from this study that initiating and maintaining a caring relationship requires time to allow both provider and woman to come to trust and respect one another. Currently, this is very difficult given the strict constraints on time in the clinic setting. Taking a serious look at how our health care system is set up to provide true caring, and implementing changes by the way we individually approach our own patients may currently be the most effective way of bringing lasting change.

Examining how our society perceives life-threatening illness may give clues that explain why social support is difficult for many to receive. Overall, advanced stage breast cancer tends to be an isolating experience where women may be cared for by only a few in their family. Perhaps it is the existential anxiety that potential support members face that inhibit their ability to participate in a more meaningful way

While some work occurred in the 1970s and 1980s ala Weisman & Worden (1976) regarding the role of existential theory and advanced stage cancer in general, examining the interpretive data of women with advanced stage breast cancer for existential processes has rarely occurred. Understanding more clearly how women can transition from a place of fear, anxiety, and depression to reawakening with a new reality may enlighten health care providers as to how they can positively affect women with advanced stage breast cancer, and also their families. All who come into contact with woman engaged in this process may likely be enhanced. If employers and co-workers had opportunity to better understand the process the woman was enduring they may not only understand her experience better, but also be in position to be of better support to her in the workplace, for example.

Specific differences existed in this data from studies reported in the literature on women with earlier stages of breast cancer. Even though women in early stage report experiencing existential crises, evidence exists in this study that the stark reality of metastasis, for example, may create a more acute crisis. If a woman was diagnosed with early stage cancer, she could cling to the statistics that 97% survive five years. A woman with advanced stage breast cancer wanted to avoid confronting that only 12% would survive five years. Women with advanced cancer may tend to feel physically worse than women with earlier staged cancer because the treatment is often more intense and prolonged. One other unusual characteristic of this sample not as prevalent in women with early stage is the high percentage of younger women presenting with advanced tumors.

This homogenous sample exhibited less confounding factors than previous heterogeneous samples tend to exhibit such as variations in existential experience related to a more or less direct threat to existence when early and late stage are studied together. Finally, women with recurrence may experience less of a sudden crisis because they have experienced this before, and may even have support systems in place.

Limitations of the Study

There are at least four limitations to the current study: determining theoretical saturation, single method only, and incongruent interview type.

Determining Theoretical Saturation

Potential for difficulty in determining theoretical saturation existed because the sample size was small. Only eight women were recruited for this study who fit the criteria of being within eight months of an initial diagnosis of advanced breast cancer without previous cancer history, and being willing to participate. A larger sample may have yielded both a variety of reported experiences, and further confirmation. However, saturation of the data was achieved with these eight women.

Formal Member Checks

The constraints imposed by the responsibilities of the Ph.D. program and necessary progression to graduation affected the time line of this study. A preferable time line for this study would allow time to include more member checks. It would be ideal to follow these women through their medical and psychosocial trajectory past the point of this study to determine what their experience is after they leave treatment and move into the subsequent phase of their transformation process.

Single Method Only

To achieve a more complete understanding of the range of womens' responses to an initial diagnosis of advanced stage breast cancer utilization of mixed methods might have occurred. Further descriptive ability may have been enhanced by the inclusion of a mixed methodology where standardized scales could be compared to the interpretive responses.

Methodological Recommendations

Mixed Methods

The principle purpose for using mixed methods would be to achieve a more complete understanding of the range of womens' responses to an initial diagnosis of advanced stage breast cancer. Utilization of data from questionnaires may serve to complete, or add dimension to the conceptual map emerging from the qualitative data. Through the utilization of mixed methods it is possible that paradoxes, contradictions, or fresh perspectives may be discovered, and the added breadth and scope to the inquiry will expand what is learned. In addition, the quantitative data will be assessed for areas of convergence with the qualitative data.

Two purposes for mixed method data analysis could be:

1. Completion of the emerging theory
2. Analysis of the extent to which the questionnaires converge with the qualitative data

Completeness is accomplished through varying dimensions and contextual elements of a phenomenon. When utilizing grounded theory for the purposes of theory building, the directional choices for further data collection are grounded in the conceptual framework that is emerging. Multiple methods and data sources can reveal the varied dimensions. By varying the data sources, explanations and compelling arguments could be made more clear. Convergence of data might assist in analyzing the extent to which the questionnaires, which are currently highly utilized by breast cancer researchers, are appropriate to women with an initial diagnosis of advanced stage breast cancer.

The Process of Inquiry

Specific recommendations related to the process of inquiry can be made following the experience with this study. Due to psychotherapeutic training, a therapist is accustomed to asking questions in a particular manner. While the intent is to personally relate deeply and authentically to another, the therapist may actually encourage attainment of specific insight by the individual in their question-asking. The purpose is much different in the research model. All attempts are made to free oneself of therapeutic assessments and direction, so that the most accurate representation possible of the person's experience may ensue from the encounter. Then, instead of trying to feed one statement to the woman for the purpose of producing a particular outcome, the researcher is in a more passive role allowing oneself to the woman's student of what her experience has been. The therapist/researcher must be increasingly diligent of the placement of self in the research interview.

Data Gathering by Telephone vs. Face-to-Face

Other methodological reflections centering on gathering data included determining what the benefits or detriments to interviewing the women by telephone vs. face-to-face were. Rigorous methodological standards issue the importance of consistent data gathering. This study was approached with that in mind. However, it was found that for some women, especially once rapport was developed, allowing distance encouraged a certain candor that might not have occurred face-to-face. Of course, one can only speculate about the differences. However, consider Amy's response, for example. She made and cancelled several appointments for various reasons with this researcher during the course of this study. She also wasn't home for one scheduled visit that required a four-hour round-trip drive. In all fairness, she was unavailable for one interview due to hospitalization, and urgent medical needs related to her recurrent leg pain. Indeed, there was serious doubt that the last interview would even occur. In the meantime though, whenever Amy was contacted by telephone to schedule or reschedule she would solicit moderate to deep engagement. Toward the very end of the study, it became apparent that the only time we could arrange to meet would be by telephone when she was out of state. Permission was granted to tape-record and during that interview she chose to reveal issues that may have been too difficult to confide in person. She told of the discovery of her breast changes at this same location exactly one year before, and her previously unrecognized, unconscious desire to avoid the meaning of those signs and symptoms and subsequent leg pain. It is hypothesized that, not only the distance offered by telephone increased disclosure, but also the existing rapport that had developed over the telephone conversations previous to this interview may have enhanced her willingness to share thoughts she may not have allowed herself to think before. While it is difficult to determine if there was a difference in the type of data that was collected between the two methods, there may well be a place for the telephone in studies whose methods require recurring interviews.

Birthing the Model

Focusing on another feature of interpretive methodology, the process of developing a model and subsequent theory can be analogized to birthing a baby. First, one has certain responsibilities in the conception of the idea and the motivation to carry it forward. Also, one must nurture, and nourish the embryonic ideas during the incubation period. Allowing a certain time and space specifically for this endeavor is essential. One must commit oneself to the unborn for at least nine months. While coexisting, the fetal expression develops and matures. Then, when birth is about to occur, significant birthing pangs are experienced. At first, these are under control, yet swiftly move beyond, and develop a life of its own. Primarily, it is the idea of allowing time, committing oneself to the endeavor, and understanding that while the research is essential for the process to occur, it is by no means a total product of the researcher. This is the product of honoring women who have experienced an initial diagnosis of advanced breast cancer.

Clinical Implications

First, and foremost, it is ethically imperative to know where to draw the line when asking this population sensitive questions. Having some psychotherapeutic clinical background is necessary to correctly serve these women.

We must not ignore the expressed psychosocial needs of women with advanced breast cancer. Our health care system has developed highly effective chemotherapies and radioactive substances that can eradicate or relieve the symptoms of advanced cancer. However, this same health care system, in some ways, may be irresponsibly, and uncaringly neglecting the psychosocial needs of these women. These women deserve to be cared for, not just biologically, but also in a multidimensional manner for the purpose of nurturing and enhancing their intellectual, emotional, and spiritual well-being.

Consider if you will, a program where individuals from various disciplines, psychiatric nurse practitioners, psychiatrists, psychologists, and social workers come together on a multidiscipline team to specifically address the needs of this population. Because women have historically, and in this study as well, complained of "feeling deserted by the health care system" at various junctures in the road, it would be ideal to assign each woman, and her family with at least one consistent clinician to follow throughout the breast cancer trajectory. A comprehensive understanding of the potential for adding interventions based on true caring to medical and nursing training is necessary.

The purpose of the psycho-oncologist would be to assess and intervene throughout the process, not only for the woman, but the family as well. Women in this study reported that family members' needs weighed heavy on them. Assisting the woman to meet her family's needs would reduce much stress on the system. Women reported feeling emotionally isolated when spouses had difficult expressing their feeling. Support to relationships may increase the opportunity for the womens' need to be met. Therefore, not only offering supportive therapy, on an individual basis, but also coming together as a group with immediate family, or extended families, can greatly assist in the normalization process. This support coach would be available approximately 12 hours per day by page for questions related to the woman's case. Assistance could occur on such matters as negotiating the system, helping family members process their own feelings, and learning how to talk with husbands about various issues, among many others.

While, nursing has successfully contributed excellent, clinically skilled oncology nurses that function in an extremely important role for the woman with breast cancer the demands of the health care system, as it exists, does not allow for the kind of psychosocial support that women need, and are asking for. Evidence exists of the need for development of a psycho-oncology field within nursing. Therefore, it is strongly recommended that cancer centers throughout the world begin implementing a psycho-oncology department to address the expressed needs of women with breast cancer.

Future Directions

Successive work should focus on several areas: First, in addition to continued analysis, the writing of several papers from this data is warranted because of the unique contributions of the data to the literature. As well, continued descriptive work of this population by implementing standardized questionnaires to this same population for the purpose of completing the conceptual map. Various comparisons of qualitative analysis from this study to administered questionnaires would assist in determining if convergence exists between the instruments in common use for this populations to the current study's interpretive data. Further describing the population in this way may add dimension by revealing paradoxes, contradictions, or fresh perspectives. In addition, this purpose would assist in completion of the theory emerging from this study.

Next, a feasibility study for a subsequent intervention study specific to this population would be in order focusing on the benefit of a caring, supportive consistent member of the team. Allowing more time for interviewing providers, as well as performing adequate member checks will enhance the accuracy of the picture achieved.

In addition, further investigation of the psychosocial factors related to increased incidence, delay, and mortality are in order. Regarding the pre-diagnostic area labeled 'limbo,' more understanding is needed about what it is like for women who are in this limbo-land. What is it like to instinctually know that something is wrong, and be required to delay follow-up due to their provider's erroneous decision-making. What does that do to women's psyches? Is this yet another type of oppression? Focus on an even more homogenous sample, (e.g., African-Americans) may yet yield important data related to cultural conditioning.

While we don't know enough about how the battle between positive and negative thinking affect our longevity, we have evidence that there may be an influence. Coming to know how the neuroimmunological system is impacted at the very moment of "being ripped apart" by confirmation of the diagnosis, and following the progression and influences on changes could directly impact how we perceive women's needs as they enter this stage of their lives.

It is not possible to leave death to the dying. The biological life-death boundary is relatively precise: but, psychologically, life and death merge into one another. Death is a fact of life.

> Mantaigne, in his penetrating essay on death, asked, "Why do you fear your last day? It contributes not more to your death than each of the others. Many great thinkers have concluded that death is inextricably a part of life, and that lifelong consideration of death enriches rather than impoverishes life. Although the physicality of death destroys man, the idea of death saves him (Yalom, 1980, p. 33).

The awareness of our personal death acts as a spur to shift us from one mode of existence to a higher one. Heidegger (1962) believed that there were two fundamental modes of existing in the world: 1) a state of forgetfulness of being, of 2) a state of mindfulness of being. When one lives in a state of forgetfulness of being, one lives in the world of things and immerses oneself in the everyday diversions of life. One is absorbed in “idle chatter,” lost in the “they.” One surrenders oneself to the everyday world in a concern about the *way* things are.

In the other state, the state of mindfulness of being, one marvels not about the way things are, but *that* they are. Being continually aware of being-referred to as the “ontological mode.” By remaining mindful of being, one not only is mindful of the fragility of being but mindful, too of one’s responsibility for one’s own being. Only in this ontological mode is one in touch enough with one’s power to change oneself.

Death is the condition that makes it possible for us to live life in an authentic fashion. Life without death would be much less intense. The integration of the idea of death saves us rather than sentences us to existences of terror or pessimism.

In our work with women who are experiencing advanced stage breast cancer let us honor them by encouraging their experience of their own mindfulness of being by expressing that in our behavior as we interact with them. Let us find our own ontological mode, be mindful of our own being, by not being lost in the daily press of ‘not enough time’ and exhibit to our patients how much their lives mean to us, so they in turn, can reach out to their loved ones.

List of References

American Cancer Society. (1998). Cancer statistics 1998, 48, 10-42.

American Cancer Society. (2000). CA: A cancer journal for clinicians, 50, 12-13.

American Psychiatric Association. (1994). The Diagnostic Statistical Manual-IV. Washington, DC: American Psychiatric Association.

Amick-McMullan, A., Kilpatrick, D. G. Veronen, L. J., & Smith, S. (1989). Family survivors of homicide victims: Theoretical perspectives and an exploratory study. Journal of Traumatic Stress, 2 (1), 21-35.

Andrykowski, M. A., & Cordova, M. J. (1998). Factors associated with PTSD symptoms following treatment for breast cancer: Test of the Andersen model. Journal of Trauma & Stress, 11, 189-203.

Antovosky, A. (1980). Health, stress and coping. San Francisco: Josey-Bass.

Ashby, M. A., Kissane, D. W., Beadle, G. F., & Rodger, A. (1996). Psychosocial support, treatment of metastatic disease and palliative care. Medical Journal of Australia, 164, 759-760.

Barraclough, J., Pinder, P., Cruddas, M., Osmond, C., & Taylor, I. (1992). Life events and breast cancer prognosis. British Medical Journal, 304, 1078-1081.

Becker, E. (1973). The denial of death. New York: MacMillan.

Benoliel, J. Q. (1975). Research related to death and the dying patient. In P. J. Verhonick (Ed.), Nursing Research (pp. 189-227). Boston: Little, Brown.

Berger P. L., & Luckman, T. (1966). The social construction of reality. New York: Anchor Books.

Bloch, S., & Kissane, D. W. (1995). Psychosocial care and breast cancer. Lancet, 346, 1114.

Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. Social Science & Medicine, 16, 1329-1338.

Bloom, J. R., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Social Science & Medicine, 19, 831-837.

Bloom, J. R., Stewart, S. L., Johnston, M., & Banks, P. (1998). Intrusiveness of illness and quality of life in young women with breast cancer. Psycho-oncology, 7, 89-100.

Blumer, H. (1969). Symbolic interactionism: perspective and method. Berkeley: University of California Press.

Bovbjerg, D. H., & Valdimarsdottir, H. B. (1998). Psychoneuroimmunology: Implications for psycho-oncology. In J. C. Holland (Ed.), Psycho-oncology. New York: Oxford University Press.

Breitbart, W., & Krivo, S. (1998). Suicide. In J. C. Holland (Ed.), Psycho-oncology. New York: Oxford University Press.

Brown, M. A., & Powell-Cope, G. Themes of loss and dying in caring for a family member with AIDS. Research in Nursing and Health, 16, 179-191.

Brown, M. A., & Stetz, K. (1999). The labor of caregiving: A theoretical model of caregiving during potentially fatal illness. Qualitative Health Research, 9, 182-197.

Burgess, C., Morris, T., & Pettingale, K. W. (1988). Psychological response to cancer diagnosis-II. Evidence for coping styles. Journal of Psychosomatic Research, 32, 263-272.

Burgess, C. C., Ramirez, A. J., Richards, M. A., & Love, S. B. (1998). Who and what influences delayed presentation in breast cancer? British Journal of Cancer, 77, 1343-1348.

Burkhardt, M. A. (1994). Becoming and connecting: Elements of spirituality for women. Holistic Nursing Practice, 8 (4), 12-21.

Cella, D. F., Mahon, S. M., & Donovan, M. I. (1990). Cancer recurrence as a traumatic event. Behavioral Medicine, 12, 15-20.

Chekryn, J. (1984). Cancer recurrence: Personal meaning, communication, and marital adjustment. Cancer Nursing, 7, 491-498.

Cherryholmes, C. C. (1992). Notes on pragmatism and scientific realism. Educational Researcher, 21, 13-17.

Classen, C., Koopman, C., Angell, K, & Spiegel, D. (1996). Coping styles associated with psychological adjustment to advanced breast cancer. Health Psychology, 15, 434-437.

Colyer, H. (1996). Women's experience of living with cancer. Journal of Advanced Nursing, 23, 496-501.

Corbin, J. M., & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. Scholarly Inquiry for Nursing Practice: An International Journal, 5, 155-174.

Corbin, J., & Strauss, A. (1998). Basics of Qualitative Research (2nd ed.). Thousand Oaks: Sage Publications.

Coward, D (1990). The lived experience of self-transcendence in women with advanced breast cancer. Nursing Science Quarterly, 3, 162-169.

Coward, D. (1991). Self-transcendence and emotional well-being in women with advanced breast cancer. Oncology Nursing Forum, 18, 857-863.

Crivellari, D., Bonetti, M., Castiglione-Gertsch, M., Gelber, R. D., Rudenstam, C. M., Thurlimann, B., Price, K. N., Coates, A. S., Humy, C., Bernhard, J., Lindtner, J., Collings, J., Senn, J. J., Cavalli, F., Forbes, J. Gudgeon, A., Simoncini, E., Cortes,Funes, H., Veronesi, A., Fey, M., Goldhirsch, A. (2000). Burdens and benefits of adjuvant cyclophosphamide, methotrexate, and fluorouracil and tamoxifen for elderly patients with breast cancer: The International Breast Cancer Study Group Trial VII. Journal of Clinical Oncology, 18, 1069-1076.

Dein, S., & Stygall, J. (1997). Does being religious help or hinder coping with chronic illness? A critical literature review. Palliative Medicine, 11, 291-298.

Denzin N. K., & Lincoln, Y. S. (1994). Introduction: Entering the field of qualitative data. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research. London: Sage.

Derogatis, L. R. (1983). Misuse of the symptom checklist 90. Archives in General Psychiatry, 40, 1152-1153.

Derogatis, L. R. (1986). The psychosocial adjustment to illness scale (PAIS). Journal of Psychosomatic Research, 30, 77-91.

Dewey, J. (1922). The influence of Darwin of philosophy and other essays. Amherst, NY: Holt & Co.

Dorsett, D. S. (1991). The trajectory of cancer recovery. Scholarly Inquiry for Nursing Practice: An International Journal, 5, 175-184.

Dow, K. H., Ferrell, B. R., Haberman, M. R., & Eaton, L. (1999). The meaning of quality of life in cancer survivorship Oncology Nursing Forum, 26, 519-527.

Erickson, E. H. (1963). From Childhood and Society (2nd ed.). New York: W. W. Norton & Co., Inc.

Facione, N. C., & Giancarlo, C. A. (1998). Narratives of breast symptom discovery and cancer diagnosis: Psychologic risk for advanced cancer at diagnosis. Cancer Nursing, 21, 430-440.

Farberow, N. L., Ganzler, S., Cutter, F., & Reynolds, D. (1971). An eight-year survey of hospital suicides. Suicide and Life-Threatening Behavior, 1, 184-201.

Fawzy, F. I., Cousins, N., Fawzy, N. W., Kemeny, M. E., Elashoff, R., & Morton, D. (1990). A structured psychiatric intervention for cancer patients, I: Changes over timer in methods of coping and affective disturbance. Archives of General Psychiatry, 47, 720-725.

Fawzy, F. I., Fawzy, N. W., Arndt, L. A., & Pasnau, R. O. (1995). Critical review of psychosocial interventions in cancer care. Archives of General Psychiatry, 52, 100-13.

Fawzy, F. I., Fawzy, N. W., Hyun, C. S., Elashoff, R., Guthrie, D., Fahey, J. L., & Morton, D. L. (1993). Malignant melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival. Archives of General Psychiatry, 38, 527-533.

Fawzy, F. I., Kemeny, M. E., Fawzy, N., Elashoff, R., Morton, D., Cousins, N., & Fahey, J. L. (1990). A structured psychiatric intervention for cancer patients, II: Changes over time in immunological measures. Archives of General Psychiatry, 47, 729-735.

Feldman, D. J. (1973). Chronic disabling illness: A holistic View. Journal of Chronic Disabilities, 27, 287-291.

Ferrell, B. R., Grant, M. M., Funk, B. M., Otis-Green, S. A., Garcia, N. J. (1998). Quality of life in breast cancer survivors: Implications for developing support services. Oncology Nursing Forum, 25, 887-895.

Frankl, V. (1963). Man's search for meaning: An introduction to logotherapy. New York: Pocket Books.

Frankl, V. E. (1984). Man's search for meaning. New York: Washington Square Press.

Ganz, P. A., Hirji, K., Sim, M., Schag, C. A. C., Fred, C., & Polinsky, M. L. (1993). Predicting psychosocial risk in patients with breast cancer. Medical Care, 31, 419-431.

Glaser, B. G., & Strauss, A. (1965). Awareness of dying. Chicago: Aldine.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Glaser, B. G., & Strauss, A. (1968). Time for dying. Chicago: Aldine.

Gotay, C. C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science & Medicine, 18, 605-613.

Graham, K. J., (1992). Development of a scale to measure global well-being. Community Nursing Research, 25, 363.

Green, B. L., Rowland, J. H., Krupnick, J. L., Epstein, S. A., Stockton, P., Stern, N. M., Spertus, I. L., & Steakley, C. (1998). Prevalence of posttraumatic stress disorder in women with breast cancer. Psychosomatics, 39, 102-111.

Greer, S. & Watson, M. (1987). Mental adjustment to cancer: its measurement and prognostic importance. Cancer Surveys, 6, 439-453.

Greer, S., Moorey, S., & Watson, M. (1989). Patients adjustment to cancer: The mental adjustment to cancer scale (MAC) vs clinical ratings. Journal of Psychosomatic Research, 33, 373-377.

Grunfeld, E., Mant, D., Vessey, M. P., & Yudkin, P. (1995). Evaluating primary care follow-up of breast cancer: Methods and preliminary results of three studies. Annals of Oncology, 6 S2, 47-52.

Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.). Handbook of qualitative research. Thousand Oaks: Sage.

Halldorsdottir, S., & Hamrin, E. (1996). Experiencing existential changes: The lived experience of having cancer. Cancer Nursing, 19 (1), 29-36.

Hawks, S. R., Hull, M. L., Thalman, R. L., & Richins, P. M. (1995). Review of spiritual health: Definition, role, and intervention strategies in health promotion. American Journal of Health Promotion, 9, 371-378.

Heidegger, M. (1962). Being and time. New York: Harper & Row.

Heim, E., Valach, L., & Schaffner, L. (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. Psychosomatic Medicine, 59, 408-418.

Hietanen, P. Lonnqvist, J., Henriksson, M., & Jallonoja, P. Do cancer suicides differ from others? Psycho-oncology, 3, 189-195.

Holland, J. C. (1998). Societal views of cancer and the emergence of psycho-oncology. In J. C. Holland (Ed.). Psycho-oncology (pp. 3-15). New York: Oxford University Press.

Holland, J. C. (2000, April). Implementing the Distress Scale. Paper presented at the meeting of the American Society of Psychosocial and Behavioral Oncology/AIDS on Psychosocial Oncology 2000 and Beyond: Past Lessons, Future Directions, Vancouver, BC, Canada.

Hopwood, P. Howell, A., Maguire, P. (1991). Screening for psychiatric morbidity in patients with advanced breast cancer: Validation of two self-report questionnaires. British Journal of Cancer, 64, 353-356.

Howe, K. R. (1988). Against the quantitative-qualitative incompatibility thesis or dogmas die hard. Educational Researcher, 17, 10-16.

Hughes, E. C. (1971). The sociological eye: Selected papers. Chicago: Aldine.

Jacob, S. R., & Scandrett-Hibdon, S. (1994). Mothers grieving the death of a child. Nurse Practitioner, 19, 60-65.

Janoff-Bulman, R., & Frieze, I. H. (1983). A theoretical perspective for understanding reactions to victimization. Society for the Psychological Study of Social Issues, 39 (2), 1-17.

Jenkins, P. L., May, V. E., Hughes, L. E. (1991). The psychological morbidity associated with local recurrence of breast cancer. International Journal of Psychiatry Medicine, 21, 149-155.

Kant, I. (1965). Critique of pure reason. (N. K. Smith, trans). New York: St. Martin's Press. (original work published 1781).

Kiecolt-Glasser, J. K. & Glaser, R. (1992). Psychoneuroimmunology: Can psychological interventions modulate immunity? Journal of Consulting and Clinical Psychology, 60, 569-575.

King, C. K., Haberman, M., Berry, D., Bush, N., Butler, L., Dow, K. H., Ferrell, B. Grant, M., Gue, D., Hinds, P., Kreuer, Padilla, G., & Underwood, S. (1997). Quality of life and the cancer experience. Oncology Nursing Foundation, 24, 27-41.

Kogon, M. M., Biwas, A., Pearl, D., Carlson, R. W., & Spiegel, D. (1997). Effects of medical and psychotherapeutic treatment on the survival of women with metastatic breast carcinoma. American Cancer Society, 80, 225-230.

Lazarus, R. S & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer Publishing Company.

Leszcz, M. & Goodwin, P. J. (1998). The rationale and foundations of group psychotherapy for women with metastatic breast cancer. International Journal of Group Psychotherapy, 48, 245-273.

Levy, S. M., Herberman, R. B., Whiteside, T., Sanzo, K., Lee, J. & Kirkwood, J. (1990). Perceived social support and tumor estrogen/progesterone receptor status as predictors of natural killer cell activity in breast cancer patients. Psychosomatic Medicine, 52, 73-85.

Lewis, F.. M. (1982). Experienced personal control and quality of life in late-stage cancer patients. Nursing Research, 31, 113-119.

Lewis, F. M. (1986). The impact of cancer on the family: A critical analysis of the research literature. Patient Education and Counseling, 8, 269-289.

Lewis, F. M. (1987). The concept of control: A typology and health-related variables. Advances in Health Education and Promotion, 2, 277-309.

Lewis, F. M. (1989). Attributions of control, experienced meaning, and psychosocial well-being in patients with advanced cancer. Journal of Psychosocial Oncology, 7, 105-118.

Lewis, F. M. (1993). Psychosocial transitions and the family's work in adjusting to cancer. Seminars in Oncology Nursing, 9, 127-129.

Lewis, F. M. (1997). Behavioral research to enhance adjustment and quality of life among adults with cancer. Preventive Medicine, 26, S19-S29.

Lewis, F. M. (1999). Family issues in cancer care. In C. Miakowski & P. Buchel (Eds.), Oncology Nursing: Assessment and Clinical Care. (pp. 319-331). St Louis: Mosby.

Lewis, F. M., & Bloom, J. R. (1978). Psychosocial adjustment to breast cancer: A review of selected literature. International Journal of Psychiatry in Medicine, 9 (1), 1-17.

Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: A study of the married couple's experience with breast cancer recurrence. Oncology Nursing Forum, 22, 943-953.

Lewis, F. M., Haberman, M. R., & Wallhagen, M. I. (1987). How adults with late-stage cancer experience personal control. Journal of Psychosocial Oncology, 4 (4), 27-41.

Lewis, F. M., & Hammond, M. A. (1992). Psychosocial adjustment of the family to breast cancer: A longitudinal analysis. Journal of the American Medical Women's Association, 47, 194-200.

Lewis, F. M., Hammond, M. A., & Woods, N. F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: The development of an explanatory model. Journal of Behavioral Medicine, 16, 351-370.

Lewis, F. M., Woods, N. F., Hough, E. E., & Bensley, L. S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. Social Science and Medicine, 29, 1261-1269.

Lewis, F. M., Zahlis, E. H., Shands, M. E., Sinsheimer, J. A., & Hammond, M. A. (1996). The functioning of single women with breast cancer and their school-aged children. Cancer Practice, 4, 15-23.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills: Sage.

Lincoln, Y. S., & Guba, E. G. (1994). Handbook of qualitative research. Thousand Oaks, CA: Sage.

Linn, M. W. Linn, B. S. & Harris, R. (1992). Effects of counseling for late stage cancer patients. American Cancer Society, 49, 1048-1055.

Lippman, M. E. (2000). High-dose chemotherapy plus autologous bone marrow transplantation for metastatic breast cancer. New England Journal of Medicine, 342, 1119-1120.

Loveys, B. J., & Klaich, K. (1991). Breast cancer: Demands of illness. Oncology Nursing Forum, 18, 75-80.

Lowenberg, J. S. (1993). Interpretive research methodology: Broadening the dialogue. Advances in Nursing Science, 16 (2). 57-69.

Luker, K. A., Beaver, K., Leinster, S. J., Owens, R. G. (1996). Meaning of illness for women with breast cancer. Journal of Advanced Nursing, 23, 1194-1201.

Maguire, P. (1985). Improving the detection of psychiatric problems in cancer patients. Social Science in Medicine, 20, 819-823.

Mahon, S. M, Cella, D. R., & Donovan, M. I. (1990). Psychosocial adjustment to recurrent cancer. Oncology Nursing Forum, 17, 47-52.

Mast, M. E. (1998). Survivors of breast cancer: Illness uncertainty, positive reappraisal and emotional distress. Oncology Nursing Forum, 25, 555-562.

Maunsell, E. Brisson, J., Deschenes, L. (1995). Social support and survival among women with breast cancer. Cancer, 76, 631-637.

Mead, G. (1934). Mind, self, and society. Chicago: University of Chicago Press.

Mishel, M. (1990). Reconceptualization of the uncertainty in illness theory. Image, Journal of Scholarship, 22, 256-261.

Morris, T., Greer, S., Pettingale, K. W., & Watson, M. (1981). Patterns of expression of anger and their psychological correlates in women with breast cancer. Journal of Psychosomatic research, 25, 111-117.

Morris, T., Greer, H. S., & White, P. (1977). Psychological and social adjustment to mastectomy: a two year follow-up study. Cancer, 40, 2381-2387.

Murphy, S. A. (1989). Multiple triangulation: Applications in a program of nursing research. Nursing Research, 38, 294-298.

Musselman, D. L., McDaniel, J. S., Porter, M. R., & Nemeroff, C. B. (1999). Screening for depression. Journal of the Medical Association of Georgia, 88, 47-53.

Niebuhr, R. (1953). The nature and destiny of man: A Christian interpretation. New York: Charles Schribner's Sons.

Norsarti, C., Crayford, T., Roberts, J. V., Elias, E., McKenzie, K., & David, A. S. (2000). Delay in presentation of symptomatic referrals to a breast clinic: Patient and system. British Journal of Cancer, 82, 742-748.

Northouse, L. (1996). Sharing the cancer experience: Husbands of women with initial and recurrent breast cancer. In L. Baider, C. L. Cooper, & A. K. De-Nour (Eds.). Cancer and the Family. John Wiley & Sons, Ltd.

Northouse, L. L., Dorris, G. & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. Social Science in Medicine, 41, 69-76.

Northouse, L. L., Laten, D. & Reddy, P. (1995). Adjustment of women and their husbands to recurrent breast cancer. Research in Nursing & Health, 18, 515-524.

O'Connor, A. P., Wicker, C. A., & Germino, B. B. (1990). Understanding the cancer patient's search for meaning. Cancer Nursing, 13, 167-175.

Olshansky, E. F. (1987). Identity of the self as infertile: An example of theory-generating research. Advances in Nursing Science, 9 (2), 54-63.

Packard, N. J., Haberman, M. R., Woods, N. R., & Yates, B. C. (1991). Demands of illness among chronically ill women. Western Journal of Nursing research, 13 (4), 434-457.

Pasacreta, J. V. (1997). Depressive phenomena, physical symptom distress, and functional status among women with breast cancer. Nursing Research, 46, 214-221.

Passik, S. D., & Grummon, K. L. (1998). Posttraumatic stress disorder. In J. C. Holland (Ed.). Psycho-oncology. New York: Oxford University Press.

Payne, D. K., Sullivan, M. D., & Massie, M. J. (1996). Women's psychological reactions to breast cancer. Seminars in Oncology, 23 S2, 89-97.

Pettingale, K. W. (1985). Towards a psychobiological model of cancer: Biological considerations. Social Science in Medicine, 8, 779-787.

Pettingale, K. W., Burgess, C., & Greer, S. (1988). Psychological response to cancer diagnosis-I. Correlations with prognostic variables. Journal of Psychosomatic Research, 32, 255-261.

Pinder, K. L., Ramirez, A. J., Black, M. E., Richards, M. A., Gregory, W. M., & Rubens, R. D. (1993). Psychiatric disorder in patients with advanced breast cancer: Prevalence and associated factors. European Journal of Cancer, 29A, 524-527.

Propst, L. R. (1988). Psychotherapy in a religious framework: Spirituality in the emotional healing process. Portland: Human Sciences Press, Inc.

Ramirez, A. J., Richards, M. A., Jarrett, S. R. & Fentiman, I. S. (1995). Can mood disorder in women with breast cancer be identified preoperatively? British Journal of Cancer, 72, 1509-1512.

Random house collegiate dictionary. (1991). New York: Random House.

Reed, P. G. (1992). An emerging paradigm for the investigation of spirituality in nursing. Research in Nursing & Health, 15, 349-357.

Schmale, A. H., Morrow, G. R., Schmitt, M. H., Adler, L. M., Enelow, A., Murawski, B. J., & Gates, C. (1983). Well-being of cancer survivors. Psychosomatic Medicine, 45, 163-169.

Silberfarb, P. M., Maurer, L. H., & Crouthamel, C. S. (1980). Psychosocial aspects of neoplastic disease: I. Functional status of breast cancer patients during different treatment regimens. American Journal of Psychiatry, 137, 450-455.

Sinsheimer, L., M. & Holland, J. C. (1987). Psychological issues in breast cancer. Seminars in Oncology, 14, 75-82.

Spiegel, D., Bloom, J. R., Kraemer, H. C., Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. Lancet, 2, 888-891.

Spiegel, D., Bloom, J., & Yalom, I. (1981). Group support for patients with metastatic cancer. Archives of General Psychiatry, 38, 527-533.

Spiegel, D., & Classen, C. (2000). Group therapy for cancer patients: A research-based handbook of psychosocial care. New York: Basic Books.

Spijker, A. V., Trijsburg, R. W., Duivenvoorder, H. J. (1997). Psychological sequelae of cancer diagnosis: A meta-analytical review of 58 studies after 1980. Psychosomatic Medicine, 59, 280-293.

Steeves, R. H. & Kahn, D. L. (1987). Experience of meaning in suffering. Image: Journal of Nursing Scholarship, 3, 114-115.

Strauss, A. L. (1987). Qualitative analysis for social scientists. San Francisco: Cambridge University Press.

Strain, J. J. (1998). Adjustment disorders. In J. C. Holland (Ed.). Psycho-oncology. New York: Oxford University Press.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage.

Strauss, A., & Corbin, J. (1994). Grounded theory methodology. In N. K. Denizen & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 273-285). Thousand Oaks, CA: Sage Publications.

Strauss, A. & Corbin, J. (1998). Basics of qualitative research. Thousand Oaks: Sage.

Swanson, G. M. (1992). Breast cancer in the 1990s. Journal of Medical Women's Association, 47, 140-148.

Swanson, K. M. (1993). Nursing as informed caring for the well-being of others. Image: Journal of Nursing Scholarship, 25, 352-355.

Tapper, V. J. (1999). Psychotherapeutic trials specific to women with breast cancer: The state of the science. Journal of Psychosocial Oncology, 17 (3/4), 85-99.

Tashakkori, A., & Teddlie, C. (1998). Mixed methodology: Combining qualitative approaches. Thousand Oaks, CA: Sage Publications.

Taylor, E. J. (1993). Factors associated with meaning in life among people with recurrent cancer. Oncology Nursing Forum, 20, 1399-1405.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Compliance with chemotherapy among breast cancer patients. Health Psychology, 3, 553-562.

Telch, C. F. & Telch, M. J. (1985). Psychological approaches for enhancing coping among cancer patients: A review. Clinical Psychology Review, 5, 325-344.

Thoits, P. A. (1986). Social support as coping assistance. Journal of Consulting and Clinical Psychology, 54, 416-423.

Thompson, P. J., Powell, J., Patterson, R. J., & Ellerbee, S. M. (1995). Adolescent parenting: Outcomes and maternal perceptions. JOGNN, 24, 713-78.

Tillich, P. (1952). The courage to be. New Haven: Yale University Press.

Trief, P. M. & Donohue-Smith, M. (1996). Counseling needs of women with breast cancer: What the women tell us. Journal of Psychosocial Nursing, 34 (5), 24-29.

Trijsburg, R. W., van-Knippenbrg, F. C., Rijpma, S. E. (1992). Effects of psychological treatment on cancer patients. A critical review. Psychosomatic Medicine, 54, 489-517.

Wainstock, J. M. (1991). Breast cancer: Psychosocial consequences for the patient. Seminars in Oncology Nursing, 7, 207-215.

Watson, M. & Greer, S. (1983). Development of a questionnaire measure of emotional control. Journal of Psychosomatic Research, 27, 299-305.

Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., & Tunmore, R. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. Psychological Medicine 21, 51-57.

Watson, M., Greer, S., Young, J., Inayat, Q, Burgess, C., & Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer: The MAC scale. Psychological Medicine, 18, 203-209.

Weiner, C. L. & Dodd, M. J. (1993). Coping amid uncertainty: An illness trajectory perspective. Scholarly Inquiry for Nursing Practice: An International Journal, 7 (1), 17-31.

Weisman, A. D. (1979). A model for psychosocial phasing in cancer. General Hospital Psychiatry, 9, 187-194.

Weisman, A. D. (1980). What do elderly, dying patients want, anyway? Journal of Geriatric Psychiatry, 13, 63-67.

Weisman, A. D. (1989). Vulnerability and the psychological disturbances of cancer patients. Psychosomatics, 31, 358.

Weisman, A. D. & Worden, J. W. (1976). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry in Medicine, 7, 1-15.

Weisman, A. D. & Worden, J. W. (1985/1986). The emotional impact of recurrent cancer. Journal of Psychosocial Oncology, 3 (4), 5-16.

Woods, N. F. & Lewis, F. M. (1995). Women with chronic illness: Their views of their families. Healthcare for Women International, 16, 135-148.

Woods, N. F., Yates, B. C., & Primomo, J. (1989). Supporting families during chronic illness. Image: Journal of Nursing Scholarship, 21, 46-50.

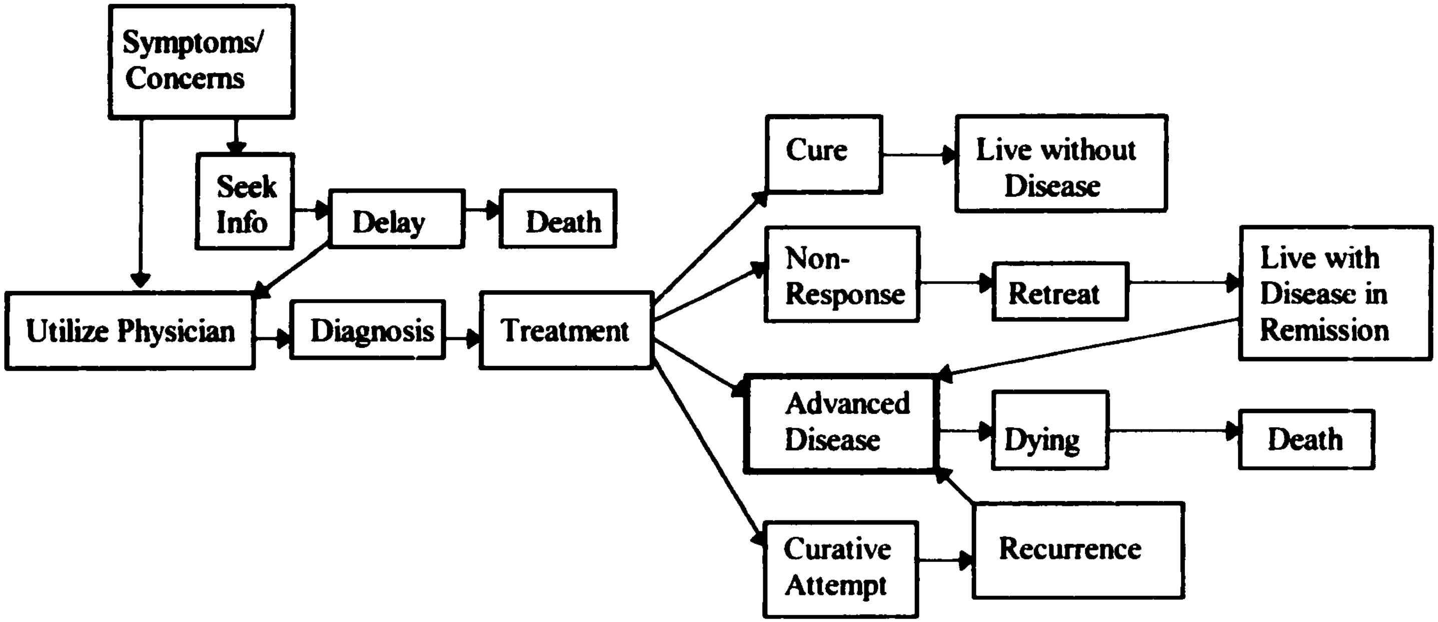
Woods, N. F., Haberman, M., E., & Packard, N. J. (1993). Demands of illness and individual, dyadic, and family adaptation. Western Journal of Nursing Research, 15 (1), 10-25.

Worden, J. W. (1989). The experience of recurrent cancer. CA-A Cancer Journal for Clinicians, 39, 305-310.

Yalom, I. D. (1980). Existential Psychotherapy. New York: Basic Books.

Zabora, J. R., Blanchard, C. G., Smith, E. D., Roberts, C. S., Glajchen, M, Sharp, J. W., BrintzenhofeSzoc, K. M., Locher, J. W., Carr, E. W., Best-Castner, S., Smith, P. M., Dozier-Hall, D., Poinsky, M. L., & Hedlund, S. (1997). Prevalence of psychological distress among cancer patients across the disease continuum. Journal of Psychosocial Oncology, 15, 73-86.

APPENDIX A: TRADITIONAL CANCER DISEASE TRAJECTORY (LEWIS, 1997).



APPENDIX B: SUMMARY OF PSYCHOSOCIAL STUDIES R/T WOMEN WITH ADVANCED BRCA

Source	Study Sample	Research Design	Concepts Measured	Research Methods	Comments
Classen, Koopman, Angell, & Spiegel, (1996).	Women (n=101) with advanced BrCa	Cross-sectional	Psychological adjustment, coping styles: fighting spirit, denial/avoidance, fatalism, emotional control	Spearman rank-order correlation, multiple regression. Profile of Moods (POMS), Courtald Emotional Control Scale (CECS), Mental Adj to Cancer (MAC)	Fighting spirit and emotional expressiveness were found to be associated with better adjustment.
Coward, (1990).	Women (n=5) with advanced BrCa.	Interpretive	Self-transcendence	Phenomenology	few subjects, non-transferable data of meaning finding-increased sense of self-worth, purpose in life, and interconnectedness with others.
Coward, (1991).	Women (n=107) with advanced BrCa	Cross-sectional	Associations btwn emotional well-being, illness distress, and self-transcendence (ST).	Correlational, Factor analytic structural equations modeling. Reed's ST Scale, Bradburn's Affect Balance Scale, Cognitive-Well-being Scale, Symptom Distress Scale, Karnofsy Performance Scale.	ST directly affected emotional well-being which had a strong negative effect on illness distress.
Gotay, (1984).	Women with advanced BrCa (n=24), Gynecol Ca (n=7). Total Husbands (n=20).	Cross-sectional, descriptive	Problems, coping mechanisms, and problem resolution.	Semi-structured interview less than I yr (n=4) within 3 yrs (n=17) more than 10 yrs (n=3) Resolution Index-total problems resolved at the highest level of resolution	Fear-most common problem. Men more concerned about women dying. Women more concerned about family's future. Taking firm action, and religious faith most cited coping mechanism.

Source	Study Sample	Research Design	Concepts Measured	Research Methods	Comments
Heim, Valach, & Schaffner, (1997).	Women (n=14) with advanced BrCa of 74 women total BrCa	Cross-sectional descriptive	Coping over time and stage, coping strategies, psychosocial adaptation, illness stages	Discriminate analysis, correlation analysis Bernese Coping Modes, Social Adaptation Scale, Emotional State Scale, ANOVA, observation, interviews	Coping r/t illness stages, and not time. Overall interdependency btwn copng and adaptation. Metastasis- negative emotional impact on family life, yet social support is the primary coping strategy at this stage.
Hopwood, Howell, & Maguire, (1991).	Women (n=271) with advanced BrCa.	Descriptive	Prevalence of affective disorders: anxiety and/or depression	Self-rating questionnaires: Hospital Anxiety and Depression Scale (HADS), Rotterdam Symptom Checklist (RSCL)	One-third of pts' scores suggestive of affective disorders.
Kogon, Biswas, Pearl, Carlson, & Spiegel, (1997).	Women (n=61) with advanced BrCa	Prospective	Differences in disease course r/t differences in medical treatment.	Review of medical records of 86 original women in Spiegel et al, (1981) study.	Women in control received more adrenalectomies and developed more bone and lung mets. Differences in disease course (women in tx survived ~2 X control) appeared to be indpt of diff in medical tx.
Koopman, Hermanson, Diamond, Angell & Spiegel, (1998).	Women (n=102) with advanced BrCa	Cross-sectional, baseline	Relationship btwn distress, reported stressful life events, and perceived social support. Distress: mood disturbance and pain.	Structured Clinical Interview-Depression (SCID) for screening and psych assemt, POMS. Yale Social Support Index, Life Events Scale, multiple regression analysis.	No previous Ca dx (n=4). Social support may shield effects of previous life stress on emot'l adj. Aversive support add'l stress assoc with emot'l distress. Pain grtr with grtr life stress, regardless of social support.

Lewis, (1982).	Women (n=14) with advanced BrCa (of 58 total advanced ca	Exploratory descriptive	Personal control, QOL, purpose in life.	Correlational. Rosenberg's Self-Esteem, The Purpose in Life (PIL) Test, The Anxiety Scale, Health & Locus Con'l	Control over health & life assoc with more perceived PIL, higher self-esteem, and lower self-reported anxiety. Longer hx
Lewis, Haberman, & Wallhagen, (1986).	Women (n=14) with advanced BrCa (of 58 total advanced ca subjects).	Interpretive	Personal control	Content data analysis	Biding Time: monitoring progress, waiting it out, refocusing control, turning it over.
Lewis, (1989).	Women (n=14) with advanced BrCa (of 58 total advanced ca subjects).	Exploratory	Attributions of control, meaning and purpose, psychosocial well-being, purpose in life, anxiety.	ANCOVA, regression analysis, correlation matrices, analytic structural modeling equations.	The extent to which pt attributed meaning to their situation was a significant predictor of both higher self-esteem and lower anxiety. Neither control nor expr with ca predicted anxiety or self-esteem.
Pinder, Ramirez, Black, Richards, Gregory, & Rubens, (1992).	Women (n=139) with advanced BrCa.	Descriptive, correlational	Psychiatric disorder: depression, anxiety	Questionnaires: HADS, chi squared tests, Fisher tests, univariate & multivariate analysis, step-wise logistic regression.	Clinical depr more prevalent among lower SES pts and lower performance status. Clinical anxiety unrelated to SES or perf status. Depression difficult to id b/c physical symptoms similar to ca.

Spiegel, Bloom, Kraemer, & Gottheil, (1989).	Women (n=86) with advanced BrCa.	Retrospective descriptive	Social support, survival, group therapy & interactions.	Cox's proportional hazards model, O'Brien's logit-rank procedure, Kaplan Meier plots, Silcoxon's rank sum, t and X2 tests.	Difference in survival from time of randomization until date of death nearly double for tx (37.6 vs 18.9 mos).
Spiegel, Bloom, & Yalom, (1981).	Women (n=86) with advanced BrCa	Randomized clinical trial	Group support, terminal illness, psychology of dying, affective response, maladaptive coping response, denial, phobias.	Psych support group meeting 1 1/2 hrs weekly X 1 yr data collection Q 4 mos. Health Locus of Control, POMS, Janis-Field Scale, Slopes Analysis, Regression	Groups provided psychological benefit-less anxious, confused, fatigued, and fearful

APPENDIX C: RECRUITMENT SITES IN THE PUGET SOUND REGION

Drs. Acuna and Lawrence - Port Townsend

Harrison Memorial Hospital - Bremerton

Multicare Systems - Tacoma

Drs. Reimer, Murphy and Johnson - Bremerton

Self-Referrals

Francis Senecal, MD - Tacoma

University Hospital Cancer Center - Seattle

APPENDIX D: CRITERIA FOR ELIGIBILITY SHEET GIVEN TO INDIVIDUAL SITES

Living with Advanced Stage Breast Cancer

Purpose of the study:

To describe women's personal accounts of living with advanced stage breast cancer

Participants:

- Women, any age, with no diagnosis of psychosis

Criteria for eligibility:

- Advanced stage breast cancer (stage III or IV)
- Recently diagnosed (within last 6-8 months)
- Lives in Western Washington
- Can speak and read in English

Factors that exclude women from participating:

- Previous history of a cancer diagnosis

What participants do:

- Agree to initial telephone contact with the researcher following brief description and invitation by site intermediary (see script)
- Receive a telephone call from the researcher describing the study
- Consent to taped interviews in their home a total of three times (~1 hour each visit)
- Fill out 5-7 questionnaires each home visit (~30 minutes each visit)

APPENDIX E: SCRIPT FOR INITIAL CONTACT FROM SITE INTERMEDIARY

When you contact a woman to determine her willingness to hear more about this study, please use the following script:

The University of Washington School of Nursing is conducting a research study of women with breast cancer. Viva Tapper is a doctoral student who is very interested in talking to women like yourself. Her long range hope is to develop programs and services for women with breast cancer to decrease the distress they are going through. We believe that you fit the criteria for study participation.

IF IN DOUBT ABOUT ELIGIBILITY, PLEASE CONFIRM USING LIST BELOW:

- Women, any age, with no diagnosis of psychosis.
- Advanced stage breast cancer (stage III or IV)
- Recently diagnosed (within last 6-8 months)
- Lives in Western Washington
- Can speak and read English

Script continues:

"Would you be willing to receive a telephone call from the researcher, a doctoral student in the School of Nursing, who would explain more about the study to you?"

*If **YES**, please obtain both daytime and evening telephone numbers along with the best times to contact her.*

*If **NO**, thank the woman for her time and please wish her a nice day.*

Contact:
Viva J. Tapper, MN, ARNP
University of Washington School of Nursing
vtapper@u.washington.edu
cell/pager (360) 301-2035

APPENDIX F: SCRIPT FOR INVESTIGATOR'S FIRST TELEPHONE CONTACT WITH POTENTIAL PARTICIPANT

To be used for follow-up contact with potential subjects received from site intermediary.

Introduction: Hello. Is this ______(Prospective subject name)____________________? This is Viva Tapper. I'm the doctoral student from the School of Nursing at the University of Washington who is very interested in learning what your experience with breast cancer has been. _____(Site Intermediary at the referring clinic)__________ gave me your name and phone number. Would you like more information about this study?

If ***NO,*** thank the woman for her time and terminate the phone call.

If ***YES,*** *Ask*: Is this a good time to talk?

IF NO, Ask: What time/date would be a better time to tell her more about this study?

Reverify eligibility criteria: What words has your doctor used to tell you about your cancer? When were you diagnosed? Have you ever been diagnosed with cancer before? Do you live in Western Washington?

Study Description: I will come to your home, or place of convenience three times. Each time I will ask you a set of questions just so I can learn what it like for you with your breast cancer. Each time we are together will last about 45 minutes to one hour, depending on how much you want to share with me at that time. You will be able to take as little time as you want or stop whenever you want. You are also free to not answer any question. You are free to omit anything you wish.

With your permission I will ask to tape-record your interview with me. Afterward, I will also ask you to fill out a short set of questionnaires which should take about 30 minutes. Examples of the most sensitive questions I might ask include: "Some women find the diagnosis of breast cancer raises philosophical issues. How has this been for you?" or "How has your family responded to your illness?" Examples of items on the questionnaires include: In the last week 1) how bothered have you been by things that don't usually bother you; and 2) how happy have you have felt.

Are there any questions that I can answer for you at this point?

A written consent form will be provided at our first meeting which will tell you all your rights including things I am telling you now. Included in the consent will be a request to look at your medical records to verify your treatment protocol, medical diagnosis, and all medications.

Your decision to participate, or not participate in this study, will not affect the medical care you receive. Your care will in no way be affected by your decision. Please remember you will be free to withdraw from this study at any time without penalty. Are you still interested in participating?

Setting an Appointment: Thank you for answering my questions. Do you have any (other) questions? May we set up an appointment for our first visit at a time that is convenient for you?

May I have directions to your home? Thank you. We can plan on spending about 1-1.5 hours together. I'm looking forward to meeting you. See you on Day and Time. Should you have any questions about the study, or our appointment, please call me at (360) 301-2035.

***If screened Out:* Thank you for answering my questions. I'm sorry we will not be able to proceed further because ________(stipulate which criteria not met)_____________. I wish you the very best . Thank you again for inquiring about this study.

APPENDIX G: PARTICIPANT/RESEARCHER INTERVIEW SCHEDULE ASSOCIATED WITH PHASE OF TREATMENT

		Occasion A		Occasion B		Occasion C	
#	Date of DX	Taped Interview	Phase of Tx	Taped Interview	Phase of Tx	**Taped Interview**	**Phase of Tx**
11	1/99-IV	4/28/99	1st chemo	7/27/99*	Post sx/ 2^{nd} chemo	11/11/99*	**Tamoxifen**
12	1/99-III	6/10/99*	1^{st} chemo	7/29/99	2^{nd} chemo	**1/4/00***	**Radiation**
13	3/99-III	7/20/99	Post sx/1st chemo	8/25/99	2^{nd} chemo	**1/6/00***	**Tamoxifen**
14	5/99-IV	7/21/99	2^{nd} chemo	8/19/99	Remission!	**9/23/00**	**Tamoxifen**
15	4/99-IV	7/28/99	1^{st} chemo & radiation	2/16/00*	Post sx, 2^{nd} chemo	**3/21/00***	**Pre hip replacement**
16	12/98-IV	8/9/99	Post radiation	10/11/99	2^{nd} chemo	**1/26/00**	**2^{nd} radiation**
17	10/99-III	12/28/99	1^{st} chemo	1/10/00	1^{st} chemo	**2/7/00****	**Pre-sx**
18	7/99-IV	12/16/99	Post sx/1st chemo	1/18/00	1^{st} chemo	**2/8/00**	**Pre-radiation**

* Telephone interview
** PI's office

APPENDIX H: UNIVERSITY OF WASHINGTON CONSENT FORM

LIVING WITH BREAST CANCER

INVESTIGATOR: VIVA J. TAPPER, MN, ARNP
DOCTORAL STUDENT
FAMILY AND CHILD HEALTH NURSING
(360) 301-2035

Investigators' Statement:

PURPOSE AND BENEFITS

The purpose of this research study is to learn from you what you are currently going through as a result of your breast cancer. The information you give will help health providers understand the serious issues that women in the future might experience. Although you personally might not benefit directly from this study, the long range hope is to develop programs and support services to better assist persons like yourself.

PROCEDURES

There will be a total of three interviews lasting approximately one hour or less each. The time and place of these will be scheduled convenient to you. All of the interviews invite you to share the feelings, thoughts, and behaviors you are experiencing as a result of the breast cancer. Examples of the most sensitive questions follow: 1) "Some women find the diagnosis of breast cancer raises philosophical issues. How has this been for you?" and 2) How has your family responded to your illness? With your permission all three interviews will be tape-recorded. In addition, 5 questionnaires will be given to you at each visit. They will take approximately 30 minute to complete. Examples of items on the questionnaires follow: Please rate on the scale provided, 1) how bothered you are by things that don't usually bother you; and 2) how happy you have felt in the last week. You are free to not answer any questions you do not wish to answer.

RISKS, STRESS, AND DISCOMFORT

There are no physical risks involved in your participation with this study. Most women find that they benefit from discussion of their experience. Should the program cause you any discomfort (perhaps related to talking about your breast cancer), and you should want assistance in dealing with these feelings, we well gladly assist you in getting a referral to an appropriate resource. Your permission must be given before a referral is made because all information you share with me is kept strictly confidential within the limits of the law. Many women find, however, that talking about their experience with a trained health professional is very helpful. You are entitled to terminate this process at any time should you feel unable to continue.

OTHER INFORMATION

All information you share will remain strictly confidential. You will have the right to review your tape and delete any portions you may wish. All audiotapes and questionnaires will be identified only with an assigned code number. After the tapes are typed they will be destroyed. No one but I will be able to link you name with your code number. Your code number will be stored in a locked filing cabinet at the University of Washington, and only I will have access. After the data are analyzed it will be stored indefinitely. Results from this dissertation study will be available to all participants upon request. You may refuse to participate or may withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled.

Signature of Investigator Date

Subject's Statement

The study described above has been explained to me. I voluntarily consent to participate in this activity. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about my rights as a subject will be answered by the investigator listed above.

I understand that Ms. Tapper will store my interview tapes indefinitely so that she can share my words with other health professionals like nurses and physicians. I know, too, that I am free to delete any portion of my interview that I do not want others to hear.

Signature of Subject Date

I give consent to the tape-recording of all three interviews with Viva Tapper.

Signature of Subject Date

I give consent to allow Viva Tapper access to my medical records for the following medical information: 1) current medical diagnosis, 2) current medical treatment plan (i.e. radiation, or chemotherapy), 3) current medications prescribed by my physician.

Signature of Subject Date

cc: Subject & Investigator's File

APPENDIX I: STRUCTURED INTERVIEW SCHEDULE

---

1. Tell me briefly what life was like for you before your illness.
2. Little is known about the process for women of coming to know about their breast cancer. Please describe for me, in a way that I can truly come to know, what it is like for you to be told you have advanced stage breast cancer.
3. What words can you use to describe what it is like to have advanced stage breast disease?
4. Carry me into where you are now. What does this experience mean to you?
5. How has your family responded to your diagnosis/illness?
6. Some women find that the diagnosis of BrCa raises deep philosophical issues. How has this been for you?
7. What has it been like for you to be cared for?
8. Is there anything else you would like us to know about your experience?

APPENDIX J: DEMOGRAPHICS FOR WOMEN IN THE LIVING WITH ADVANCED STAGE BREAST CANCER STUDY

#	Stage	Age	Marital Status	Children	Employment Position	Family's Annual Income	Ethnicity
1	IV	53	Married X 35 yrs	3 daughters 2 sons 1 grandson	Health Program Manager for State of Alaska	$35,000-39,000	Caucasian
2	III	39	Married X 15 yrs	2 daughters 2 YO & 6 YO	On leave from Managing law firm	$70,000+	Caucasian
3	III	35	Married X 15 yrs	6 YO daughter; 11 YO son	Clinic Manager for a physician's office	$35,000-39,000	African-American
4	IV	45	Single-divorced X 5 yrs	3 adult sons in their 20's	Customer Accounts Manager in the aviation industry	$40,000-49,000	"1/2 Scotch-Irish and 1/2 Native-American"

#	Stage	Age	Marital Status	Children	Employment Position	Family's Annual Income	Ethnicity
5	IV	~50s	Widowed X 2 yrs	2 adult daughters; 1 adult son	CEO-two family-owned businesses	not given (~high)	Caucasian
6	IV	37	Single-divorced	2 sons: 5 YO & 14 YO	On leave from Office Coordinator Position	not given (~low)	African-American
7	III	70	Married X 46 yrs	2 adult sons; 1 adult daughter	Retired Teacher	70,000+	Caucasian
8	III	37	Single; live-in fiancé X 3 yrs	13, 14, 16 YO daughters; 5 YO step-daughter, & 8 YO step-son	Special Education Teacher-on leave	50-59,000	Caucasian

APPENDIX K: DATA AUDIT TRAIL

1. Twenty-four interviews with women with advanced stage breast cancer taped. Participant 1 was '#11,' interview 1, 2, and 3 were labeled 'a, b, and c,' and so on.
2. PI had taped interviews professionally transcribed verbatim by three different transcriptionists.
3. PI personally edited and verified verbatim transcriptions.
4. PI loaded the edited and verified verbatim transcripts onto computer in Word 6.0 and 2 copies were also loaded onto diskettes for back-up.
5. Each tape was stored with participant number, and notation of whether interview was in person or by telephone, in a box in the researcher's office.
6. The verified data was printed out in its entirety to be used for analysis. It was stored in large notebooks by participant number and session letter.
7. A summary of each interview was typed and stored for contextual reference.
8. The data was broken into units of analysis and 460 open codes were saved to diskette.
9. Open codes were placed in a working file by participant number first. Open codes for each participant were printed out and stored in separate binder.
10. Then, open codes were assembled into categories (axial coding).

    A working file side-by side with was set up for moving data from participant's open code file to various category files.
11. Approximately 250 category files were established and downloaded onto diskettes for storage. Each category was printed out with associated emics and stored in

alphabetical order in a binder. Several categories with 1 or 2 emics were place in one file labeled "multiple" to save paper. These are excellent cross-references.

12. Simultaneously with coding, theoretical memo files were established both by participant number, and also by date. These were also saved to disk.
13. At the same time, conceptual diagrams were drawn almost daily to catch a "snapshot" of conceptual relationships as they developed.
14. All interviews were again read three times for conditions, actions, and consequences to further dimensionalize.
15. The process of analyzing the data took several months. The data was constantly compared on all dimensions. Breaks were required away from data to "stay fresh." By making connections, and putting the data together in new ways dimensions of categories formed.
16. Selective coding occurred by choosing a core category and verifing that all the categories related to the core, and all sub-categories related to categories. This process went from macro to micro inspection of the data several times, and required several consultations with Dr. Lewis. Transforming Personal Reality emerged as the core category, and addressed all the sub-categories as well.
17. Finally, the coding was exhausted. No new categories, sub-categories, or other possibilities for a core category developed. Printouts of each domain with associated categories and subcategories as supported by all the individual emics were stored in notebooks and on disk. Also, all intercations: self/self; self/family; self/provider; self/community/; self/Creator; family/provider;

family/community, etc were printed, filed, and downloaded to disks. One zip-drive copy was made of every final file.

18. Writing the results chapter, and discussion of findings was supported by including verbatim emics, and contextual information.

APPENDIX L: WOMEN'S REPORT OF SUBJECTIVE AND OBJECTIVE 'CLUES' FROM PROVIDERS FOR DETERMINING SERIOUSNESS OF DIAGNOSES

An instant knowing that this was a serious thing 14a62

Objective clues/signs

Seeing in the pictures of the ultrasound the very definite abnormalities 14a55
Surgeon telling me that there were cancer cells in the lymph nodes 11a83
Biopsy showing cancer cells 11a84
Being told whatever it was that I had had grown 11a76
Seeing that it is really growing and it's its pulling in my nipple with it." 12a21-22
Not being able to get any fluid off of the lump 12a24
Results coming back and said yes, it was advanced cancer 12a27-28
Biopsy proving that it was cancer 13a35
Telling me that getting the results from the biopsy would probably be 2-3 days, and it was 24 hours 18a84

Subjective clues/signs

Knowing they felt confident before they even had done the biopsy that it was cancerous and that it was very advanced 14a44-46
Things happening at that time that made me right away know it was a serious thing 14a48-49
Saying, as soon as she examined me, "let's just go right ahead and do the ultrasound as long as we're here"
Coming back in and saying she wanted me to wait to get dressed because they wanted to make sure all the films had come out clearly 14a57
Saying that the doctor was waiting to talk to me and that he had just gotten off the phone with my doctor. 14a60
Not feeling like that was the normal way of handling 14a64
Being very immediate in their response 14a68
Knowing this type of cancer needed to be dealt with immediately instead of waiting for another week 17a19-20
Telling her I wanted to see the surgeon as soon as possible 18a46
Calling and making a referral 18a47
Seeing the surgeon before I even got my mammogram back 18a46-49
Telling me-"it was not good-it was large-peach-sized" 18a71-72
Fact it was coming back with these added symptoms made me realize that it was something different going on here 17a43

Dr saying "There's a slight chance it could have been a mistake on the test" 18a136
Thinking the reason that the Dr hurried it was because the lump was so large 18a138
Sending me for a mammogram and a sonogram at the same time 12a15-16
Lining up appointments for me 17a24
Telling me what to do and where to go 17a25
Having the impression from the Dr. that it was very, very serious, and that it had spread 11a292-294
Hearing that he had just gotten off the phone with my doctor 14a61
Outlining any changes…they were to be called day or night 14b369
Calling me at home 18a89
Having a space for surgery tomorrow 18a90
Needing you to come to my doctor's office, get the papers and come to the hospital and get signed up, so we can do it tomorrow morning 18a95
Saying he never calls people on the phone and tmells them such a thing 18a97
Apologizing profusely about calling me at home 18a98
CR diagnostic process
Portraying of all that different information let me know it was very serious 14b373-374
Receiving the news in an unexpected manner 17a13
(Calling me at home…X several women)
Not coating the diagnosis. 11a328
Saying she wanted me to wait to get dressed…to make sure all the films had come out clearly 14a58
Hearing that the doctor was waiting to talk to me 14a60
Going right ahead and doing the ultrasound…as long as we're here 14a52
Knowing they felt confident…before they even had done the biopsy that it was cancerous and that it was very advanced 14a44-46
Telling me the severity of everything 14b342
Telling me (these indications) were…very advanced. 14b346-348
Seeing in the pictures of the ultrasound…the very definite abnormalities 14a5

Observing for non-verbal clues/signs that the provider "knows"

Dr was really lit up-talking with my boyfriend, and when he found the lump all that light just went off 18a54-60
Just seeing the look on his face 18a60-62
Telling from his tone of voice and his face, which is really amazing 18a63-64
He didn't tell me, but he knew it was cancerous 18a68

APPENDIX M : PROVIDERS' CARING BEHAVIORS AS REPORTED BY PARTICIPANTS

Letting me know what was going to happen 13c193

- Letting me know what I needed to do 13c194
- Letting me know what to expect 13c194
- Dr being right there for you explaining everything to you 16c722
- Sharing all the different options 14b321
- Doctor answering questions 15a512
- Being real honest with me about all the different side effects and all the different possibilities of things that could happen 14b321-323
- Going over a lot of things 13c192
- Explaining all the treatments 14c147
- Going into a lot of detail in explaining what that particular one chemo does and possible reactions 14c149
- Really good about explaining everything and not ever making me feel like I'm asking it too many times 14c1163
- Being real open with me 14c111
- Explaining the diagnosis and stage really thoroughly 16a266
- Explaining what needs to be done 16a271
- Always explaining the reason why 16a273
- Taking everything that I say...seriously 14c112
- Not making me feel like my questions...are silly 14c109-114
- Never feeling uncomfortable with waiting up to 45 min for an appt b/c they do take the time 11c141
- Feeling like that's really important and I want them to be giving that time to other people, too, cause I know I need it, when I'm in there 14c144
- Explaining all the treatments 14c147
- Really good about explaining everything and not ever making me feel like I'm asking it too many times 14c1163
  - CONSEQ>Having a lot of faith in my oncologist 15a246
  - Thinking he's wonderful 15a247
  - Feeling very comfortable talking to him that's one of the reasons I chose him. 15a513-514
  - Thinking he's like the Bernie Siegal of Tacoma 15a248
    - CONSEQ>Feeling it's important to have a doctor that you're comfortable with 15a250
    - Knowing he's excellent
    - Feeling like he's a very compassionate man 15a513-522
    - CONSEQ>Going in and talking to about any little concern 12c135
    - CONSEQ>Feeling helped 13a158
    - Feeling really touched to know that I have a ...doctor that really cares about me. 13a 158-160
    - Making a difference 16c722

Being helped by the nurses 16a273

Looking at me like an individual that they loved and cared for just like anybody else 16a280
Always being so friendly 16a275
Not looking at me like "Wow I feel sorry for her." 16a278
Needing that so 16a282
Willing to answer any question I had 14b386
Complimenting me on how well I did when they gave me a treatment 1 16a290
Interacting in a good, close manner 14b385
Willing to answer any questions that I had 14b386
Asking questions to spur questions 14b387
Behaving in a very, very attentive and caring manner 14b389
Always calling you by name 14b398
Always knowing who you were the second you called or walked in 14b399
Always remembering without having to go through all their books 14b400
Staying really on top of everything with each person 14b402
Remembering little details from one time to the next 14b405
Asking you about it off the top of their head 14b407
Getting calls on Saturdays and Sundays checking to see how I was doing 14b408
    CONSEQ> Experiencing their attentiveness 14b386
    Experiencing their whole (caring) demeanor 14b397

Viva J. Tapper, PhD, ARNP

Office: 1135 Lawrence Street, P.O. Box 873, Port Townsend, WA, 98368 360.301.2035.
Home: 281 Lane De Chantal, Port Townsend, WA, 98368 (360) 379-8482;
FAX 360.379.9029.

Education

Doctor of Philosophy in Nursing Science, June, 2000.
University of Washington School of Nursing.

University of Washington School of Nursing, June, 1997
Master of Nursing-Psychosocial Nurse Practitioner Program

Walla Walla College School of Nursing, June, 1995
Bachelor of Science in Nursing, cum laude

Certifications/Licenses

Board Certified Clinical Specialist in Adult Psychiatric and Mental Health Nursing, The Board of Certification of Psychiatric and Mental Health Nursing Practice, American Nurses Credentialing Center, No. 298679-01, expires November 30, 2002.

Advanced Registered Nurse Practitioner with prescriptive authority-Washington State Nursing Commission, No. AP30004411, expires June 29, 2001.

DEA Registration-No, MT0313510 Issued 2/17/98; Expires 11/30/00

Registered Nurse-Washington State Nursing Commission, No. RN00120817, expires June 29, 2000.

Scholarships, Training Grants, and Honors Awarded

Oncology Nursing Foundation/Rhone Poulence Rorer New Investigator Research Grant, May 15, 1999-May 15, 2001
Citizen's of the World Scholarship, for development of scholarly collaboration with other nations, June, 1998
University of Washington's Women's Health Center Training Grant, funded through National Institute of Nursing Research No. T32NRO7039 May 1998-May, 2000
Washington Health Scholarship, 1994-2000 training for underserved populations
Walla Walla College Scholarship, 1995

Clinical Experience

Private Practice, February 1, 1998-present) -1135 Lawrence Street, Suite C, Port Townsend, WA 98368 (360) 301-2035. Providing psychotherapeutic and medication evaluation services to individuals and families: assessment, diagnosis, and treatment of psychiatric disabilities, substance abuse, and psychosocial distress related to the chronic or life-threatening illness. Emphasis is placed on a multidimensional approach to health and well-being.

Advanced Practice Nurse-June 23, 1997-December, 1997

Center for Excellence in Substance Abuse Treatment Education Fellowship position at the Seattle VA (6E inpatient addictions treatment unit). Administered admission assessments, psychiatric evaluations, performed psychotherapy, and participated in group work and patient teaching. Administrative nursing, physiological nursing skills, and research skills were also utilized.

Advanced Clinical Practicum-September, 1996-June, 1997

Jefferson Community Counseling Center, Port Townsend, WA. Russ Geoffrey, MD and Rick Strassman, MD-clinical preceptors for psychiatric medication evaluations.

Previous Employment Experience

9/97-6/98	***Research Assistant***, Single Women with Breast Cancer Project, Frances Lewis, PhD, RN, FAAN, Primary Investigator, NIH, NINR funded research
6/97-12/97	***Advanced Practice Nurse***, Veterans Administration Puget Sound Health Care System, 1660 South Columbian Way, Seattle, WA 98108, (206) 764-2123. Psychiatric evaluations, admissions, individual addictions counseling, milieu management, groups, medications. Joseph Reoux, MD, Medical Director; Kay Tanaka, MN, ARNP-nurse manager on 6E, Addictions Treatment, Inpatient Unit
6/93-6/94	***Medication Aide and Personal Caregiver***, Cherry Blossom Cottage, 11177 S.E. Cherry Blossom Drive, Portland, OR 97216, (503) 256-9777. Provided medications and care for 24 residents at this extended care facility. Sylvia Griffin, RN
6/92-6/93	***Private Tutor***, Anatomy and Physiology, Chemistry, Algebra, and Trigonometry
2/82-9/91	***Costume Designer's Assistant*** for several major motion pictures. Responsible for negotiating and maintaining wardrobe budget, hiring and supervising crew, buying costumes, managing the set, organizing costume fittings, and arranging disbursement of costumes to location.

Scholarly Projects

Writing several papers for publication from the dissertation study and preparing lectures to various oncology and academic groups. I have agreed to teach a course on concepts of the family for the year 2000-2001 at UWSON. Continuing private practice.

My dissertation study focused on the process women experienced as they adjusted to an initial diagnosis of advanced stage breast cancer: Transforming Personal Reality. Frances Marcus Lewis, PhD, RN, FAAN served as my committee Chairwoman, mentor, and preceptor of the two-year NINR Women's Health Research Training Grant.

September, 1998-As Citizen of the World Scholar, and on invitation by Beijing Nursing School and the China's Ministry of Health, key-note speaker at the first international conference in psychiatric nursing for nursing instructors in China. Focus on development of a psychiatric textbook and training program for psychiatric nurses. Currently coordinating further collaboration between University of Washington faculty and Beijing Nursing School.

My master's thesis was a secondary analysis of qualitative data collected by Shirley Murphy, PhD, RN, FAAN (UWSON) for an NIH funded study. The purpose was to describe how parents, bereaved suddenly by the violent deaths of their children explored existential issues. Comparing parents exhibiting high suicidal ideation with those who did not revealed that cause of death, as well as spiritual orientation, affected parents' outcomes.

Presentations

Transforming Personal Reality: A Descriptive Study of the Experiences of Women Diagnosed Initially with Advanced Stage Breast Cancer, Scholarship Day, University of Washington, June, 2000.
Transforming Personal Reality: A Descriptive Study of the Experiences of Women Diagnosed Initially with Advanced Stage Breast Cancer, Women's Health Center Training Grant Fellows, May, 2000
Randomized Clinical Trials, Western Institute of Nursing Conference, Spr, 1999.
Psychotherapeutic Trials Specific to Women with Breast Cancer:
Interventions Specific to Women with Breast Cancer: The State of the Science. University of Washington School of Nursing, Spring 1998.
The Psychiatric Nurse Practitioner in Private Practice, University Women's Club, Washington State University, Spring, 1998.
The Future of Nursing Theory, University of Washington School of Nursing, Winter, 1998.

Professional Associations

American Society for Psychosocial and Behavioral Oncology/AIDS
Oncology Nursing Society
Association of Advanced Practice Psychiatric Nurses-Seattle Chapter
American Nurses Association/Washington State Nurses Association, No. 25242.
Sigma Theta Tau International, Honor Society of Nursing, Psi-Chapter-at-Large

Staff Privileges

Consultation privileges at Jefferson General Hospital in Port Townsend, 834 Sheridan Street, Port Townsend, WA.

Publications

Tapper, V. J. (1999). Psychotherapeutic Trials Specific to Women with Breast Cancer: The State of the Science. Journal of Psychosocial Oncology, 17 (3/4), 85-99.

Tapper, V. J. (1999). Parkinson's Disease. In P. P. Bailey, T. M. Buttaro, K. H. Oas, & J. Oas (Eds.), Primary care: A collaborative practice. St Louis: Mosby-Year Book, Inc.

Tapper, V. J. (1997). Pathophysiology, assessment, and treatment of Parkinson's Disease. The Nurse Practitioner Journal, 22, 76-95.

Dissertation Committee:

Chairperson:
Frances Marcus Lewis, PhD, RN, FAAN
UW Family and Child Nursing
Box 357262
Seattle, WA 98195
206.685.0808

Kristen M. Swanson, PhD, RN, FAAN
UW Family and Child Nursing
Box 357262
Seattle, WA 98195
206.543.8228

Marie-Annette Brown, PhD, RN, FAAN
UW Family and Child Nursing
Box 357262
Seattle, WA 98195
206.543.8208

Katherine Graham, PhD, RN, FAAN
UW Family and Child Nursing
Box 357262
Seattle, WA 98195
206.685.0842