

A PRELIMINARY ANALYSIS OF PSYCHOSOCIAL ADJUSTMENT  
IN YOUNG BREAST CANCER SURVIVORS

by

KELLIE MARTENS

B.A., University of Michigan, 2007

A thesis submitted to the  
Faculty of the Graduate School of the  
University of Colorado in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Clinical Health Psychology

2014

This thesis for the Master of Arts degree by

Kellie Martens

has been approved for the

Clinical Health Psychology Program

by

Kristin Kilbourn, Chair

Evelinn Borrayo

Krista Ranby

February 3, 2014

Kellie Martens (Ph.D., Clinical Health Psychology)

A Preliminary Analysis of Psychosocial Adjustment in Young Breast Cancer Survivors

Thesis directed by Assistant Professor Kristin Kilbourn

### **ABSTRACT**

Although breast cancer is typically considered a disease that affects women at an older age, younger women are also impacted by breast cancer. Additionally, current literature suggests that women who are diagnosed at a younger age face greater challenges adjusting to breast cancer survivorship. Young survivors are often in the midst of starting their career, beginning a family, and planning for their future. Thus, a cancer diagnosis drastically interrupts these plans. This study examined the relationship between different variables that are commonly studied in young breast cancer survivorship. Women were eligible if they were diagnosed between the ages of 19-45 years, were post-treatment at the time of the study, and first-time survivors of breast cancer. Participants were recruited from social media websites, online support and advocacy group, and cancer centers across the United States. Participants completed an online survey. This study examines the structure of the hypothesized latent variables included in a proposed structural model of psychosocial adjustment to breast cancer survivorship. Two of the four hypothesized latent factors were supported by the data, and a revised structural model of psychosocial adjustment to young breast cancer survivorship is provided. Follow-up research should examine the structural model and determine the most important factors in predicting young breast cancer survivors' quality of life and life satisfaction.

The form and content of this abstract are approved. I recommend its publication.

Approved: Kristin Kilbourn

## **DEDICATION**

I dedicate this work to my husband and my daughters. Thank you for your support and encouragement every step of the way.

## **ACKNOWLEDGMENTS**

I would like to thank my mentor, Kristin Kilbourn, for all of her guidance throughout this project. I thank Krista Ranby and Evelinn Borrayo for their support and input as my committee members. I thank Megan Grigsby, Stephanie Hooker, and Ryan Asherin for their support and help; they are not only my colleagues, but they are also my friends. I would like to acknowledge Piera Triolo for her efforts in this study. Finally, I would like to acknowledge all of the many individuals and organizations who helped me reach eligible participants: my mother, Bethany Aronrow, Rocky Mountain Cancer Centers, Laurri Jones, Dr. Rachel Rabinovitch, Dr. Virginia Borges, StupidCancer, Komen, Young Women's Breast Cancer Program at Siteman Cancer Center, Young Survivors Network Inc., The Young Breast Cancer Survivorship Program at UCLA, Ashley at 3 Little Birds 4 Life, Young Breast Cancer Survivors of SW Michigan/Kalamazoo area, Young Survivors United Against Breast Cancer, Beyond the Pink Moon, Jo Vogeli, Lacey Clement, Samantha Saxton, The Leukemia and Lymphoma Society, University of Colorado Hospital Cancer Center, Kelly Adams, Dr. Robert Fisher, and more. Due to the large outpouring of support I received, it is likely that I forgot someone; your efforts are appreciated more than you know.

## TABLE OF CONTENTS

### CHAPTER

I. INTRODUCTION .....	1
Quality of Life and Life Satisfaction .....	2
Psychosocial Adjustment to Survivorship.....	3
Distressing Reactions to Survivorship.....	3
Adaptive Reactions to Survivorship .....	4
Theory .....	4
Biological.....	5
Social/Practical.....	6
Psychological .....	7
II. STUDY AIMS AND HYPOTHESIS .....	8
III. METHOD .....	11
Procedure .....	11
Sample.....	11
Instruments.....	14
Quality of Life.....	14
Satisfaction with Life .....	15
Benefit Finding. ....	15
Hope.....	16
Positive Impact of Children.....	16
Distress.....	16

Fear of Recurrence.....	17
Anxiety and Depression.....	17
Decision Regret.....	18
Psychological Diagnosis.....	18
Financial Concerns.....	18
Social Support.....	19
Parenting Concerns.....	19
Age.....	19
Fertility Concerns.....	19
Treatment Decisions.....	20
Comorbidities.....	20
Survey Feedback.....	21
Data Analysis.....	21
Descriptive Statistics.....	21
Reliability Analysis.....	21
Confirmatory Factor Analysis.....	22
Correlations .....	22
IV. RESULTS.....	22
Initial Observations of Variables.....	23
Reliability of the Psychosocial Scales .....	24
Analysis of Latent Variables .....	26
Correlations .....	29

Revising the Structural Model .....	31
V. DISCUSSION AND CONCLUSIONS.....	33
REFERENCES .....	41
APPENDICES	
A: FUNCTIONAL ASSESSMENT OF CANCER THERAPY-BREAST .....	46
B: SATISFACTION WITH LIFE SCALE.....	53
C: BENEFIT FINDING MEASURE.....	55
D: HOPE SCALE. ....	56
E: IMPACT OF EVENTS SCALE-REVISED. ....	57
F: CONCERNS ABOUT RECURRENCE SCALE. ....	58
G: HOSPITAL ANXIETY AND DEPRESSION SCALE.....	61
H: DECISION REGRET SCALE.....	66
I: FINANCIAL PROBLEMS SUBSCALE OF THE QLACS.....	67
J: REPRODUCTIVE CONCERNS SCALE. ....	68
K: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT .....	70
L: CHARLESON COMORBIDITY INDEX.....	72

## LIST OF TABLES

### Table

1 Demographic and Diagnostic Characteristics of Participants.....	13
2 Psychometric Properties of Psychosocial Scales.....	24
3 Exploratory Factor Analysis of the PICS.....	25
4 Correlations between Latent and Measured Variables .....	29
5 Correlations between Modeled Variables and Outcomes of Quality of Life and Life Satisfaction.....	30

## LIST OF FIGURES

### Figure

1 Hypothesized Model of Adjustment to Survivorship in young breast cancer survivors....	10
2 Measurement Model of Adaptive Reactions.....	26
3 Measurement Model of Distressing Reactions.....	26
4 Revised Structural Model .....	31

# CHAPTER I

## INTRODUCTION

In the United States, an estimated one in eight women will be diagnosed with breast cancer at some point in their lives (National Cancer Institute [NCI], 2011). With the exception of basal and squamous cell skin cancers, breast cancer is the most common type of cancer in all women (American Cancer Society [ACS], 2012). Although women over the age of 50 represent the largest group of breast cancer survivors, young women are also affected by cancer of the breast. Breast cancer incidence rates in women under 50 have remained stable since 1985, whereas mortality rates of young survivors are decreasing (ACS, 2012). In other words, young survivors of breast cancer represent a growing population in the United States (NCI, 2011).

Young survivors of breast cancer have been defined differently throughout the literature, with some researchers defining “young” as under age 40 and others defining “young” as under age fifty-five (Knobf, 2006; Howard-Anderson, Ganz, Bower, & Stanton, 2012). For the purposes of this study, young survivors of breast cancer are defined as women ages 19-45 at the time of diagnosis. The lower limit of this age range was chosen to distinguish young adult survivors from adolescents. The upper limit was chosen to represent a synthesis of prior researchers’ definitions of young survivors, and to include women younger than age 50, which is the average age of onset for menopause in the United States (National Institute of Health [NIH], 2012). Despite the varying definition of young survivors, studies comparing younger survivors to older survivors suggest that young survivors share unique concerns and challenges associated with cancer survivorship.

## **Quality of Life and Life Satisfaction**

Many of the studies reporting quality of life of young survivors of breast cancer compare them to older survivors of breast cancer. In comparison to older survivors, young survivors report lower health-related and global quality of life (Avis, Crawford, & Manuel, 2005; Wenzel et al., 1999). Although one study (Cimprich, Ronis, and Martinez-Ramos, 2002) found that younger survivors report better physical quality of life but poor social quality of life, Kroenke et al. (2004) found that young survivors have poorer quality of life (QoL) across all health and social domains including physical functioning. Furthermore, a systematic review by Howard-Anderson, Ganz, Bower, & Stanton (2012) found that young breast cancer survivors' quality of life is significantly lower than older survivors as well as age-matched controls without a cancer history, and that this finding applied to multiple domains of quality of life.

In addition to quality of life, this study includes a more broad measure of life satisfaction. To date, no other studies have specifically examined young breast cancer survivors' satisfaction with life. Satisfaction with life is a subjective evaluation of one's life, based only on one's own standards of what is important (Diener, Emmons, Larsen, & Griffin, 1985). Whereas many quality of life measures examine specific constructs such as health, social life, and finances, life satisfaction does not relate to any specific constructs. Thus, although it should be expected that quality of life and life satisfaction are related to one another, satisfaction with life may provide a more general sense of how happy an individual is with their life.

## **Psychosocial Adjustment to Survivorship**

Brennan (2001) defines adjustment in the context of chronic illness as “the psychological processes that occur over time as the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment” (p. 2). By this definition, adjustment is an on-going process and may consist of both negative and positive reactions to survivorship. Therefore, this study will examine factors influencing the distressing and the adaptive reactions to survivorship, as well as the influence that these reactions have on quality of life and life satisfaction. Specifically, this study will examine the following distressing reactions to survivorship: 1. Depression, 2. Anxiety, 3. Fear of Recurrence, 4. Distress, and 5. Decision Regret. It will also investigate the adaptive reactions of: 1. Benefit Finding and 2. Hope.

## **Distressing Reactions to Survivorship**

In addition to the findings that young survivors report lower QoL life than older survivors, young survivors also report more clinical depression, depressive symptoms, anxiety, distress, and fear of recurrence than older survivors (Howard-Anderson, Ganz, Bower, & Stanton, 2011; Liu et al., 2011). Young survivors report fewer positive psychosocial effects (such as benefit finding) after breast cancer treatment (Costanzo, Ryff, & Singer, 2009). Since these factors seem to be particularly salient for young breast cancer survivors, this study seeks to understand their relationship with quality of life and life satisfaction.

## **Adaptive Reactions to Survivorship**

Despite the challenges associated with a breast cancer diagnosis, some women also report positive outcomes after such a life-changing experience. Benefit finding in breast cancer patients has been shown to improve psychosocial adjustment (Lechner, Carver, Antoni, Weaver, & Phillips, 2006; Carver & Antoni, 2004). In addition to relieving distress and depression, benefit finding has been shown to improve physical health across diverse medical populations, including breast cancer patients (Bower, Low, Moskowitz, Sepah, & Epel, 2008).

On the other hand, some studies have shown that benefit finding in general does not relate to well-being, quality of life, or psychological adjustment (Fromm, Andrykowski, & Hunt, 1996; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Lehmen et al., 1993; Tomich & Helgeson, 2004). Benefit finding may correspond with higher levels of distress. For example, Park et al. (1996) found that undergraduate students who reported more benefit finding about the most traumatic event in the past 6 months actually reported more intrusive and avoidant thoughts in regard to the event than did those who reported less benefit finding. In other words, benefit finding may not always be negatively correlated with symptoms of distress. For the purposes of this study, benefit finding and hope are considered adaptive reactions to survivorship, and are hypothesized to positively impact QoL and life satisfaction.

## **Theory**

Why might young women react in such a unique manner to breast cancer survivorship? Rowland (1989) proposed the life-stage perspective, a theoretical model which other researchers have applied to breast cancer survivorship and age differences

within survivors (Cimprich, Ronis, & Martinez-Ramos, 2002). From this perspective, women 45 and under have unique biological, personal, and social goals that a breast cancer diagnosis may disrupt. Cimprich, Ronis, and Martinez-Ramos propose that these unique goals may help explain the distinctive reactions of young women to breast cancer survivorship. For example, since women in this age group may be more likely to set the goals of having a family, they may be more likely to express concerns about fertility in relation to cancer treatment. For the purposes of this study, the unique factors faced by young survivors will be organized in terms of biological, psychological (rather than “personal”), and social factors influencing reactions to survivorship.

In other words, this study will approach adjustment to survivorship from a biopsychosocial framework. When mothers receive a diagnosis of breast cancer, it not only affects their biological health; it also influences their relationships and psychological well-being. Based on the aforementioned literature on quality of life and psychosocial adjustment to survivorship, certain biological, psychological, and social factors may influence young survivors’ adjustment to survivorship.

### **Biological**

Young survivors may experience biological concerns such as infertility, treatment decisions, and comorbid medical diagnoses. Infertility is a primary concern for this population, in women who already have children as well as those without children (Gorman, Usita, Madlensky, & Pierce, 2011; Camp-Sorrell, 2009). Younger women who express more reproductive concerns after treatment also report more depressive symptoms and lower quality of life. These reproductive concerns may influence treatment decisions, which in turn affects quality of life (Andersen, Bowen, Morea, Stein, & Baker,

2009). For example, younger women may be more likely to undergo chemotherapy and/or radiation than older women (Arndt et al., 2004). Comorbid diagnoses and later stage at diagnosis have been found to negatively impact psychosocial and survival outcomes in early stage breast cancer patients (Land, Dalton, Jensen, & Ewertz, 2010). Additionally, younger women who undergo chemotherapy also report lower QoL than those who do not (Hopwood, Haviland, Mills, Sumo, & Bliss, 2008). Along with concerns about fertility, treatment decision, and comorbidities, age will be considered as a biological factor in this study; even within this sample, age of diagnosis may impact quality of life and life satisfaction.

### **Social/Practical**

Additionally, unique social and practical concerns, such as dependent children, financial concerns, and social support may impact young survivors' reactions to survivorship. For example, young women are more likely to have dependent children. Because more women are having children into their forties than in previous decades, (Matthews & Hamilton, 2009) the upper limit of the age range for this study reflects survivors who are more likely to be mothers than older survivors. Mothers diagnosed with early stage breast cancer may express concerns in regard to feelings of guilt, their children's ability to cope, role confusion, a perceived lack of social support from healthcare professionals, and struggles maintaining a household with dependent children (Semple & McCance, 2010). Not surprisingly, some women also express concerns about genetic factors which may put their daughters at risk for breast cancer (Barnes et al., 2000).

On the other hand, some qualitative research suggests that motherhood in breast cancer patients may influence a sense of increased social support and making meaning in life (Billhult & Sergesten, 2003; Semple & McMcance, 2010). Additionally, social support has been found to significantly positively correlate with QoL (Sammarco, 2001). This study proposes that having dependent children and social support will be associated with a more adaptive reaction to survivorship, but that financial concerns will be negatively associated with benefit finding and hope and positively associated with more distressing reactions to survivorship.

### **Psychological**

Previous psychological diagnoses, including anxiety and depression, have been found to decrease breast cancer survivors' quality of life (Reich, Lesur, & Perdrizet-Chevallier, 2008). Although a previous diagnosis alone does not mean that a patient will exhibit problematic psychological symptoms during treatment and survivorship, it does suggest an increased risk for negative affect including depressive thoughts, fear of recurrence, or overall psychological distress. This study hypothesizes that self-report of at least one previous psychological diagnosis will be associated with more distressing reactions and less adaptive reactions.

## **CHAPTER II**

### **STUDY AIMS AND HYPOTHESIS**

The study aims were as follows:

1. To describe young breast cancer survivors' adjustment to survivorship, based on the current literature.
2. To examine the utility of the included scales in a sample of young breast cancer survivors who completed the scales in a web-based survey.
3. To test the measurement model (i.e., the latent variables) of a hypothesized structural model using confirmatory factor analysis.
4. To broadly discuss the relationship between constructs in the hypothesized model.

Figure 1 illustrates the proposed theory-driven structural model and the hypothesized relationships between variables. Circles indicate latent variables, whereas rectangles indicate measured variables. The absence of a connecting line between two variables implies that there is no direct effect hypothesized between those two variables. For the purpose of this study, the structural model was not tested; only the measurement model was examined. These analyses are considered preliminary in that they will inform a future analysis of the structural paths (i.e., the relationship between latent variables, measured exogenous variables, and outcomes).

The model in Figure 1 hypothesizes that adaptive and distressing reactions to survivorship will predict quality of life and life satisfaction, and that adaptive and distressing reactions are predicted by social and practical concerns, biological concerns,

and psychological diagnoses. Specific to the latent structure tested in this study, Adaptive Reaction is a latent variable consisting of three indicators: hope, the positive impact of children during cancer, and benefit finding. Distressing Reaction is a latent variable consisting of five indicators: decision regret, depression, anxiety, distress, and fear of recurrence. Social/practical Concerns represents a latent variable consisting of three indicators: parenting concerns, social support, and financial concerns. Biological Concerns is a latent variable consisting of five indicators: age, stage, infertility, treatment decision, and physical/cognitive symptoms. Because structural equation modeling is a complex analysis that requires reliable measures and latent variables that fit the data well, the structure of these latent variables was tested before proceeding with more data collection and a structural analysis of the entire model.

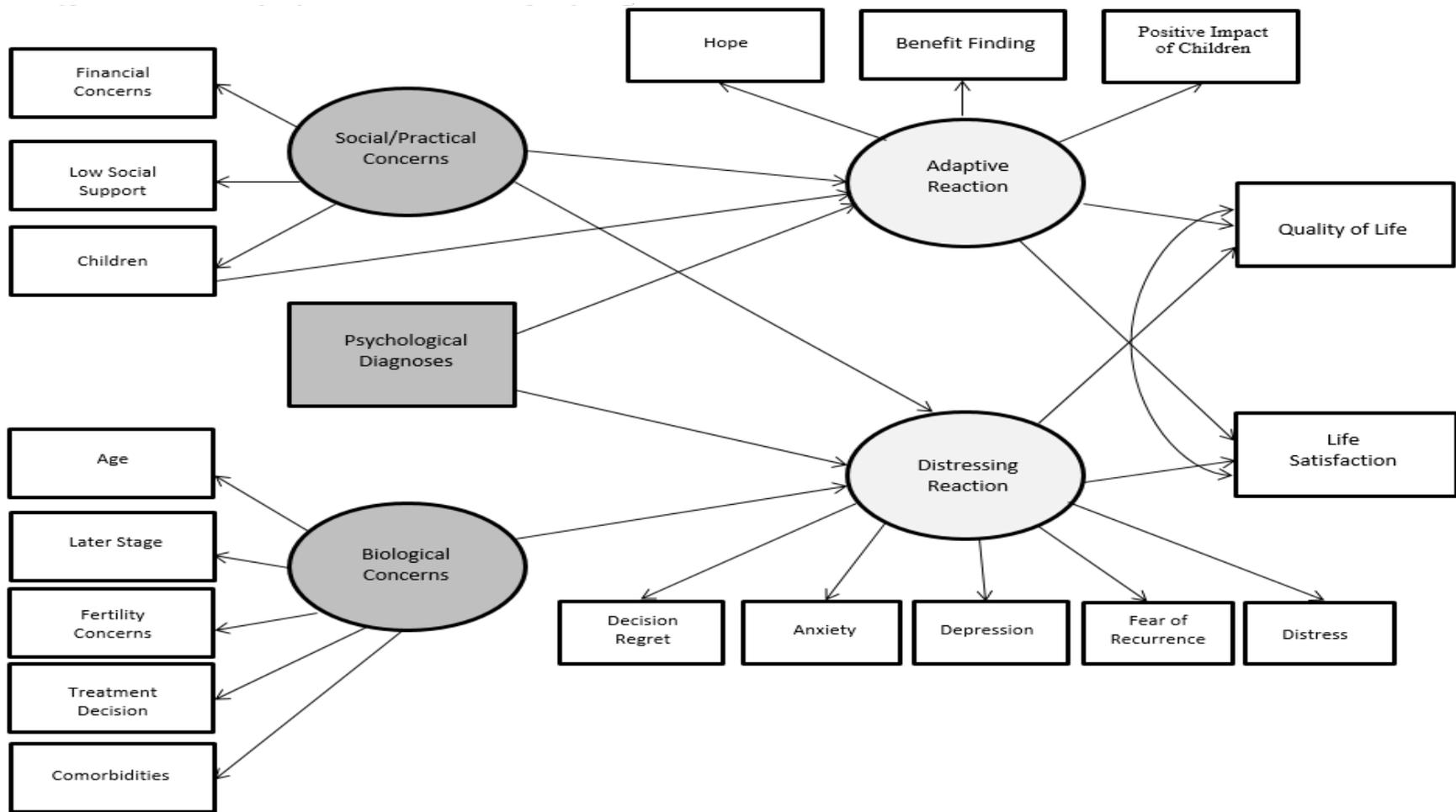


Figure 1

*Hypothesized model of adjustment to survivorship in young breast cancer survivors.*

## **CHAPTER III**

### **METHOD**

#### **Procedures**

The appropriate permissions were obtained from institutional and hospital review boards prior to beginning recruitment. The sample was recruited from local cancer centers as well as online support groups, email blasts, listservs, message boards and social media sites. All participants, regardless of the recruitment source, were administered a web-based survey from Qualtrics. Participants who learned of the survey in-person (e.g., a flyer at a cancer center) entered the survey link into their web-browser and were taken to the study consent page. Participants who learned of the survey online clicked on a link to the same page.

Participants were informed of the potential risks for this study, including possible emotional upset or distress after answering some questions. These potential risks were considered minimal, unlikely, and most likely temporary. Even so, participants were provided with contact information for local and national cancer support resources, as well as contact information for a licensed clinical psychologist with specialized training in psychosocial oncology. Further, the consent page was preceded by three comprehension questions that assessed participants' understanding of the study and potential risks.

#### **Sample**

According to Kazdin (2003), this study utilized a cross-sectional case-control design. In a cross-sectional design, "participants are selected and assessed in relation to current characteristics" (p. 2). Specific to this study, participants must meet the following inclusion criteria:

- a. Female first-time survivors of any stage (0, I, II, III, IV) of breast cancer
- b. Age 19-45 at the time of diagnosis
- c. Post-treatment (with the exceptions of hormone therapy and antibody therapy)
- d. English speaking
- e. Access to the internet to complete the web-based survey

Adequate sample size is an important factor when performing a structural equation model (SEM) analysis (Tabachnick & Fidell, 2012). MacCallum, Browne, and Sugawara (1996) provide guidelines for the minimum sample size necessary for different levels of power and to ensure goodness-of-fit, and allude to a sample size of at least 300 for a full structural equation model analysis. However, a smaller sample size may be appropriate for testing the measurement model, and the goal of this study was a minimal of 150 participants. Others have completed a structural analysis with as few as 60 participants (Tabachnick & Fidell, 2012).

Because the majority of the participants were recruited online, it was possible to monitor the number of times the consent page was viewed as well as the completed surveys. Two hundred forty two people total viewed the consent page, 50 of them dropped out before clicking “I agree.” Of the 192 who clicked “I agree” on the consent page, four were pregnant and 15 were not first-time survivors of breast cancer; they were thus ineligible to continue with the measures. Of the 173 remaining, 20 more dropped out of the survey before they had completed the demographic questions and at least one of the scales. Thus, the final sample size of  $n = 153$  is reflected in Table 1, which presents the demographic and diagnostic characteristics of the participants.

Table 1

*Demographic and Diagnostic Characteristics of Participants (N = 153)*

Variable	Total	Variable	Total
Race/Ethnicity	N (%)	Time since diagnosis	N (%)
Caucasian	143 (93.5)	≤ 1 year	23 (15.6)
Hispanic	4 (2.6)	1 – 2 years	49 (33.4)
Other	6 (3.9)	3 years	13 (8.5)
Age	Mean (SD)	4 years	12 (7.8)
Time of survey	41.39 (6.76)	5 years	9 (5.9)
Time of diagnosis	36.94 (5.22)	≥ 6 years	41 (26.8)
Marital Status	N (%)	Years since diagnosis	Mean (SD)
Partnered	112 (73.2)	Years	4.44 (4.61)
Single	41 (26.8)	Current treatment	N (%)
Education	N (%)	Antibody therapy	2 (1.3)
College degree	119 (77.8)	Hormone therapy	2 (1.3)
No college degree	34 (22.2)	Antibody/Hormone	1 (.65)
Employment status	N (%)	None	148 (96.75)
Employed full-time	101 (66)	Past Treatment	N (%)
Unemployed	32 (20.9)	Mastectomy	119 (77.8)
Employed part-time	20 (13.1)	Chemotherapy	121 (79.1)
Stage	N (%)	Lumpectomy	53 (34.6)
O	10 (6.5)	Radiation	88 (57.5)
I	30 (19.6)	Antibody therapy	25 (16.3)
II	80 (52.3)	Hormone therapy	59 (38.6)
III	24 (15.7)	Reconstruction	102 (66.7)
IV	5 (3.3)	BRCA	N (%)
Unsure	4 (2.6)	BRCA 1 mutation	10 (6.5)
Comorbidities	N (%)	BRCA 2 mutation	12 (7.8)
None	106 (69.3)	No mutation	90 (58.8)
1 or more	27 (17.6)	Unsure	28 (18.3)

## **Instruments**

Each scale was scored using methodology from the authors of the scales and/or using the most common method in previously published measures. Thus, some scales' total scores are reflections of the sum of the items whereas others are the mean of the items. Individual participants were only assigned a total score for a scale if they answered at least 75% of items on that scale. Although there was some variability in the number of valid responses for each of the individual scales, the majority of the participants were given total scores on all of the scales. Notably, the PCQ measure of Parenting Concerns and the PICS measure of the Positive Impact of Children were only seen by participants who answered that they had dependent children.

## **Quality of Life**

The Functional Assessment of Cancer Therapy for breast cancer (FACT-B) consists of 37 items assessed on a 5-point likert scale: *0 = Not at all, 1 = A little bit, 2 = Somewhat, 3 = Quite a bit, 4 = Very much*. There are five subscales, which taken together create a global measure of health-related quality of life (see Appendix A). These subscales measure more discrete parts of quality of life, including physical well-being, social/family well-being, functional well-being, and additional concerns. Participants are asked how much a statement applies to them over the past seven days. The FACT-B was designed specifically for use with breast cancer patients, and has high internal consistency; Cronbach's Alpha ( $\alpha$ ) = .90 for the total FACT-B measure and the subscales' have internal consistencies ranging from  $\alpha = .63-.86$  (Brady et al., 1997).

## **Satisfaction with Life**

The Satisfaction With Life Scale (SWLS) is a five item measure assessing overall perceived life satisfaction (see Appendix B). It is a positively framed measure, and participants answer on a seven point likert scale which gives scores ranging from “low satisfaction” to “high satisfaction.” The scale has a reported  $\alpha = .87$  and has been found to correlate highly with other measures of subjective well-being (Diener, Emmons, Larsen, & Griffin, 1985).

## **Benefit Finding**

Tomich and Helgeson (2004) refer to positive changes that result from the trauma of being diagnosed with cancer as benefit finding. They designed a 17-item measure (see Appendix C) specifically to capture benefit finding after having breast cancer. More recently, 15 items of the original measure have been used to maximize reliability. The items focus on diverse potential benefits ranging from family and social relationships, life priorities, sense of spirituality, career goals, self-control, and the ability to accept circumstances. Response options are, “I disagree a lot” (0), “I disagree a little” (1), “I agree a little” (2), and “I agree a lot” (3). The scale was adopted from Behr’s Positive Contributions Scale, which was used with parents of disabled children. It has been used with breast cancer survivors, including young survivors of early stage cancer of the breast (Lechner et al., 2003). Previous studies have demonstrated that the scale has an internal consistency of  $\alpha = .91$ . The items appear to be face valid for the construct of finding benefit after having breast cancer.

## **Hope**

Snyder et al. (1991) designed a measure of the construct of hope (See Appendix D). The measure consists of 11 items total; seven items actually assessing hope and four filler items. It has been found to have convergent validity with other measures of related constructs, as well as high internal consistency ( $\alpha = .80$ ). It has previously been used with survivors of breast cancer (Stanton, Danoff-Burg, & Huggins, 2002).

## **Positive Impact of Children**

The Positive Impact of Children Scale (PICS) was developed by the primary investigator specifically for this study. It was designed to measure the positive effects that may be reported by women who have dependent children during a chronic illness such as cancer, and was based off of qualitative literature. The PICS contains five items such as “my children gave me a reason to fight the cancer” and “having children helped me focus on the positive.” Items are scored on a 5-point likert scale ranging from *not at all* to *almost always*. The psychometrics properties of the PICS in this sample are discussed in the Results section.

## **Distress**

The Impact of Events Scale- Revised (IES-R) will be used as a measure of distress (see Appendix E). It consists of 22 items, each assessed on a four point likert scale: *0 = Not at all*, *1 = A little bit*, *2 = Moderately*, *3 = Quite a bit*, *4 = Extremely*. The IES-R, although often used to assess PTSD symptomology, has also been used as a measure of general stress/distress with breast cancer patients in randomized controlled trials (Stanton et al., 2005). It consists of three subscales which assess Intrusion, Avoidance, and Hyperarousal. The Intrusion subscale assesses intrusive thoughts,

nightmares, intrusive feelings and imagery, and dissociative-like re-experiencing. The Avoidance scale focuses on numbing of responsiveness, avoidance of feelings, situations, and ideas. The Hyperarousal subscale assesses anger, irritability, hypervigilance, difficulty concentrating, and a heightened startle response (Christianson & Marren, 2008). The IES-R has an internal consistency of  $\alpha = .96$  and has demonstrated convergent validity with the PTSD checklist and the PTSD Coping Inventory (Creamer et al., 2003).

### **Fear of Recurrence**

The Concerns About Recurrence Scale (CARS) has 30 items total (see Appendix F). The first four items are an overall fear of recurrence subscale assessing frequency, potential for upset, consistency, and intensity of fears. The overall fear of recurrence subscale has an internal consistency of  $\alpha = .86$  and also correlates with the Intrusive Thoughts ( $r = .64, p < .001$ ) and Avoidance ( $r = .50, p < .001$ ) subscales of the Impact of Events Scale and the Distress ( $r = .54, p < .001$ ) and Well-Being ( $r = -.44, p < .001$ ) subscales of the Mental Health Index (Vickburg, 2003). The overall fear of recurrence scale also correlates with the subscales included in the following 26 items; Death,  $r = .64$ ; Health,  $r = .64$ ; Roles,  $r = .50$ ; and Womanhood,  $r = .53$  (all correlations  $p < .001$ ).

### **Anxiety and Depression**

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report questionnaire consisting of an anxiety subscale and a depression subscale (see Appendix G). Each subscale has an equal number of items, and is designed to assess symptomology over the past week using a four point likert scale. The HADS is appropriate for medical populations because the fatigue and insomnia criteria have been omitted due to the potential confounds of treatment or disease symptoms. The anxiety has demonstrated an

internal consistency of  $\alpha = .80-.93$ ., while the depression scale has  $\alpha = .81-.90$  (Herrmann, 1996). Additionally, when using a cut-off score of 10, both scales show convergent validity with the anxiety and depression portions of the Structured Clinical Interview for the Diagnostic and Statistical Manual of mental disorders (Alexander, Palmer, & Stone, 2010). Each item is scored on a scale of 0-3.

### **Decision Regret**

The five item Decision Regret Scale in Appendix H was designed by Annette O'Connor (2003) to assess patients' regret about health care decisions. It uses a five-point likert scale, shows internal consistency ( $\alpha = .81-.92$ ), and has been shown to have appropriate convergent and divergent validity with other measures of decisional conflict and decision satisfaction.

### **Psychological Diagnoses**

Participants answered the question: "Have you ever been diagnosed with the following: a. Major depression, b. Generalized Anxiety Disorder, c. Anorexia, d. Bulimia, e. Dysthymic Disorder, f. Schizophrenia, g. Panic Disorder, h. Obsessive-Compulsive Disorder, g. Other." Those who answered "other" specified what other diagnoses they had in their history. All "yes" responses were added together to calculate a total of the psychological diagnoses.

### **Financial Concerns**

Financial concerns were measured with the Financial Problems subscale of the Quality of Life in Adult Cancer Survivors (QLACS) instrument (see Appendix I). The subscale consists of four items assessed on a seven-point likert scale, that measure financial concerns specific to the cancer diagnosis and/or treatment. The subscale shows

convergent validity with a measure of economic strain and has good internal consistency, with  $\alpha = .82$  (Avis et al., 2005).

### **Social Support**

The Multidimensional Scale of Perceived Social Support (see Appendix J) consists of 12 items scored on a seven-point likert scale, assessing three domains of perceived social support; it breaks into the subscales of friends, family, and significant other (Zimet, Dahlem, Zimet & Farley, 1988). Unlike the social subscale of the FACT-B which relates more directly to having breast cancer, this measure is a more general measure of social support. The overall scale has good internal consistency, with  $\alpha$  ranging from .84 to .92.

### **Parenting Concerns**

Participants who reported that they had dependent children at the time of their cancer diagnosis were shown the Parenting Concerns Questionnaire (PCQ). The PCQ is a 15-item measure of distress specifically related to parenting during cancer. It was developed for and tested with outpatient oncology patients with children under the age of 18 years and demonstrated a  $\alpha = .83$  (Muriel et al., 2012).

### **Age**

Participants reported their age in years. Age at diagnosis was also assessed.

### **Fertility Concerns**

The Reproductive Concerns Scale (RCS) is a 14-item measure designed specifically for use with young cancer survivors (see Appendix K) and it has been used with young breast cancer survivors in other studies (Gorman, Malcarne, Roesch, Madlensky, & Pierce, 2009). It asks questions about how the cancer diagnosis affects the

ability to have children, the importance of having children, and loss of control of one's reproductive future. It has good internal consistency, with  $\alpha$  ranging from .81 in controls to .91 in young female cancer patients (Wenzel et al., 2005). Unlike the PCQ and PICS, the RCS is designed for use in women without children as well as mothers.

### **Treatment Decision**

Patients with breast cancer face different treatment decisions. The assessment of treatment decisions was based off of the National Cancer Institute's list of treatments for breast cancer (2012). Participants answered the question, "Which of the following breast cancer treatments did you undergo? Please select all that apply." Participants were allowed to select any combination of responses from the following choices: chemotherapy, radiation, lumpectomy, total mastectomy, hormone therapy, antibody therapy, and reconstruction. Participants also answered which, if any, treatments they were currently undergoing.

### **Comorbidities**

The Charlson Comorbidity Index (CCI) assesses for the presence of 19 pre-existing medical conditions. Typically, the CCI is scored by giving different weights to the conditions based on severity and risk of mortality (see Appendix L). Because very few women endorsed any comorbidities in this sample, the CCI was dichotomized as either no comorbidities or at least one comorbidity. The index has been validated for use with breast cancer patients, and it has been shown that breast cancer patients generally have a low score on the CCI (Charlson, Pompei, Ales, & MacKenzie, 1987).

## **Survey Feedback**

Participants were asked about the ease of transitioning throughout the survey, both in terms of the survey format as well as the time-frames for each different scale. One question also assessed if participants felt that the questions in the survey “adequately capture” their experience as a breast cancer survivors. Finally, all participants were provided a space at the end of the survey to type in any qualitative feedback they had about the survey.

## **Data Analysis**

### **Descriptive Statistics**

Descriptive statistics were analyzed using IBM SPSS version 22 software. Descriptives were examined in order to better understand the data and to revise any errors in data entry from the Qualtrics software to SPSS. Means, standard deviations, ranges, skew, and kurtosis were examined to understand the distribution of the individual scales.

### **Reliability Analysis**

Internal consistency of the scales in the sample was also analyzed using SPSS. With the exception of the PICS measure of the Positive Impact of Children, the remaining psychosocial scales were tested only to confirm adequate internal consistency (Cronbach’s Alpha > .70). Because the PICS was designed for this study and has not been previously evaluated for psychometric soundness, it was analyzed using principal axis factoring and a direct oblimin rotation to examine the item loadings and to determine if a single-factor solution is appropriate for the scale. It was also examined using a reliability analysis to confirm adequate internal consistency. Further, the PICS was compared to Tomich and Helgeson’s Benefit Finding measure and the PCQ measure of

Parenting Concerns for an examination of construct validity using a bivariate correlation analysis.

### **Confirmatory Factor Analysis**

After establishing adequate internal consistency for the individual scales, confirmatory factor analysis was used to test the measurement model of the hypothesized model in Figure 1. Four separate confirmatory factor analyses were performed using Mplus version 7; one analysis was performed for each latent variable and its hypothesized indicators.

### **Correlations**

After the structure of latent variables was tested, supported latent variables were correlated with all other variables in the model and the outcomes of Quality of Life and Life Satisfaction. Despite the fact that this study does not examine the coefficients of each path, the correlations provide a useful understanding of the relationship between constructs in this sample of young breast cancer survivors. These associations also guided the proposed alterations to the structural model (see Figure 5), which will be tested with more participants in a later study.

## CHAPTER IV

### RESULTS

#### **Initial Observations of Variables**

The descriptives for each of the psychosocial scales are presented in Table 2. An analysis of the frequencies of treatment decisions raised concern for future analyses; it became apparent that there was no meaningful way to categorize participants' treatment decision based on the yes/no format of their responses. Participants were able to answer yes to multiple forms of treatment and therefore could fall into numerous groups. It also did not make sense to create a composite of treatments by adding them together because the variability of treatments may not be attributable to the number of different treatments a patient has. The variability that may be attributable to multiple rounds of the same type of treatment (e.g., multiple rounds of chemotherapy) was not captured by the yes/no format of questions. Furthermore, treatment decision, calculated first as a sum of total treatments and then as an ordinal variable, did not correlate with the other indicators of Biological Concerns. Therefore, after analyzing the descriptive statistics for treatment decisions, the variable Treatment Decision was removed from the Biological Concerns latent factor model.

In terms of feedback regarding the survey, 76% of participants said that they felt the questions adequately captured their experience as a breast cancer survivor. Forty five participants typed in qualitative feedback about the survey. These results will be examined further in subsequent research.

## Reliability of the Psychosocial Scales

Each of the psychosocial scales demonstrated adequate internal consistency, each scale demonstrating a Cronbach's alpha value greater than .70. The PICS, which was subjected to additional analyses, also demonstrated adequate internal consistency. These values are presented along with descriptive statistics in Table 2.

The PICS was analyzed for psychometric soundness using an empirical cut-off of eigenvalues greater than 1 at  $p < .05$ . Bartlett's test of sphericity was significant,  $\chi^2(10) = 139.97$ ,  $p < .001$ , and the Kaiser-Meyer Olkin measure of sampling adequacy was .75. Both indices suggest that the sample responses were factorable. The exploratory factor analysis suggested a one-factor solution using all five of the items, which explained 54.94% of the variance in the PICS item scores. The item "my children distracted me from the cancer" had a low factor loading of .36, but all other loadings were above .40, which can be considered adequately high for loadings in an exploratory analysis. The factor loadings are presented in Table 3. Cronbach's alpha of the PICS = .77, suggesting adequate internal consistency of this new scale. The PICS was significantly correlated with Tomich and Helgeson's measure of benefit finding ( $r = .54$ ,  $p < .01$ ). The positive impact of children was not significantly associated with parenting concerns. These results suggest that the PICS is measuring a unique construct from more general benefit findings and that the positive impact of children is not associated with parenting concerns; that is, a mother may have significant concerns about her children throughout the cancer experience and may still report benefit from being a mother while going through cancer.

Table 2

*Psychometric Properties of Psychosocial Scales*

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	$\alpha$	Range		Skew	Kurtosis
					Potential	Actual		
Financial Concerns	133	3.19	2.06	.90	1 – 7	1 – 7	.50	- 1.18
Social Support	133	64.10	17.95	.95	12 – 84	12 – 84	- 1.25	.76
Parenting Concerns*	76	2.16	.99	.92	1 – 5	1 – 4.87	.86	- .10
Reproductive Concerns	132	13.69	9.13	.87	0 – 56	3 – 39	1.03	.11
Hope	141	23.76	4.91	.91	8 – 32	8 – 32	- .78	.76
Benefit Finding	135	42.10	8.13	.88	15 – 60	18 – 60	- .11	- .27
Positive Impact of Children*	76	4.37	.70	.77	1 – 5	2 – 5	- 1.3	1.3
Decision Regret	133	1.77	.96	.90	1 – 5	1 – 5	1.6	2.2
Anxiety	134	8.97	5.30	.91	0 – 21	0 – 21	.24	- .82
Depression	134	5.23	4.47	.87	0 – 21	0 – 20	.91	.48
Fear of Recurrence	134	4.03	1.39	.93	1 – 6	1 – 6	- .32	- .89
Distress	135	2.31	.92	.94	1 – 5	1 – 4.89	.67	- .51
Quality of Life	153	94.33	25.65	.95	0 – 148	22 – 140	- .599	- .12
Life Satisfaction	153	21.82	7.94	.91	5 – 35	5 – 35	- .38	- .88

*Note.* \*These variables include only participants with dependent children at the time of the study. Other discrepancies in the total *n* are attributable to drop-out throughout the course of the survey. Participants were only given a total score if they answered at least 75% of the items on a given scale.

Table 3

*Exploratory Factor Analysis of the PICS*

Item	Factor Loading
Having children helped me focus on the positive.	.88
My children gave me an appreciation for life.	.89
My children gave me a reason to fight the cancer.	.64
My children distracted me from the cancer.	.36
Being a parent helped me identify as more than a cancer patient.	.49

**Analysis of Latent Variables**

Two of the four latent variables were supported by the data, two were rejected based on insufficient model fit and low path estimates. The hypothesized Adaptive Reaction and Distressing Reaction factors were sufficiently supported by the data. Despite multiple theory and data-driven alterations to the latent structure of the Social/Practical Concerns and Biological Concerns factors, the hypothesized structure of these factors was not supported by the data.

The Adaptive Reaction model is just-identified in its number of paths estimated and therefore model fit statistics are not available. The standardized path estimates show that benefit finding is the best predictor of an Adaptive Reaction; hope and the positive impact of children are sufficiently high enough to remain in the model, considering the exploratory nature of this analysis and the relatively small sample size. All path estimates were significant at  $p < .001$ . Standardized path estimates are shown in Figure 2.

The Distressing Reaction model fit the data well:  $\chi^2(3) = 11.51, p < .01, CFI = .97, RMSEA = .15, SRMR = .04$ . All path estimates were significant at  $p \leq .001$ , Standardized path estimates are shown in Figure 3. The path estimate of Decision Regret is lower than .50, suggesting that Decision Regret may not correlate as highly with the

other indicators of Distressing Reactions. However, because very few women scored high on Decision Regret in this sample and more participants will be collected for future analyses, Decision Regret was left in the final model of Distressing Reactions. All other path estimates were greater than .50, indicating that they may be theoretically driven by one underlying construct, named Distressing Reactions for this study.

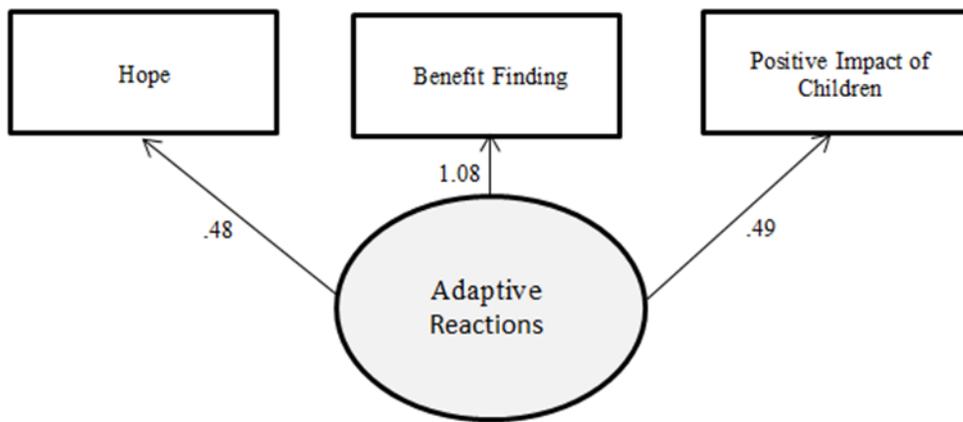


Figure 2

*Measurement Model of Adaptive Reactions*

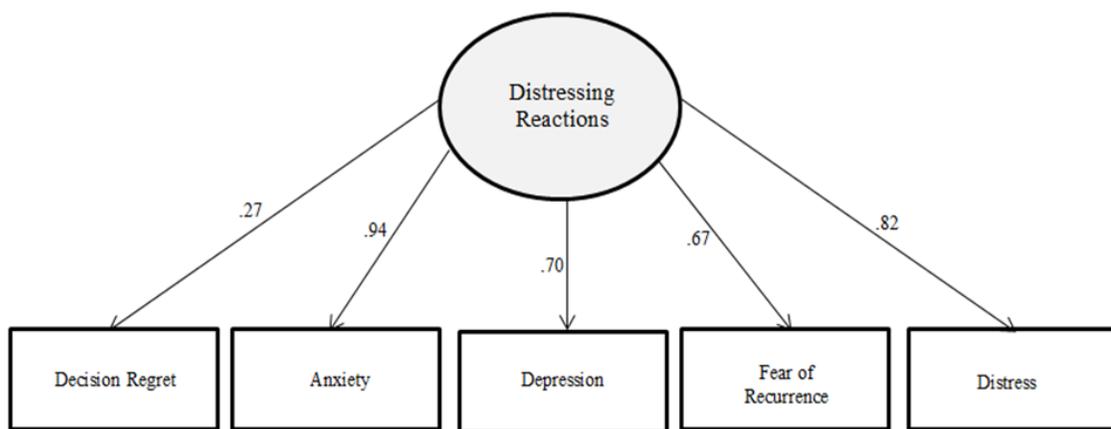


Figure 3

*Measurement Model of Distressing Reactions*

The hypothesized latent structure of Biological Concerns was not supported by the data. More specifically, none of the path estimates were significant for Biological Concerns (all  $p$  values  $\geq .39$ ) and model fit statistics indicated a poor fit. Several iterations of the model were run, including different ways of categorizing Stage (all 5 groups versus “early” or “late” stage), different ways of categorizing comorbidities (continuous versus dichotomized as “zero” or “any”), and including versus excluding Reproductive Concerns. The final model included: 1. Age at diagnosis, 2. Stage, grouped by all 5 stages, 3. Comorbidities, dichotomized as “zero” or “any,” and 4. Time since diagnosis, in years. As mentioned previously, Treatment Decision was not included in the final model because the data revealed that there was no meaningful way to categorize the multiple treatments received. Additionally, Time since diagnosis was not in the original model. However, because of the wide range of years since diagnosis, this was considered an important variable to include along with other disease-related variables. The model was run both with and without Time since diagnosis, and the results were similar. Reproductive Concerns, upon review of the bivariate correlations, correlated better with indicators on the Social/Practical Concerns latent factor and was moved to load on that factor rather than Biological Concerns. Thus, despite multiple iterations of the Biological Concerns variable, these results suggest that the hypothesized indicators do not correlate with each other well enough to consider them one unique construct.

Similarly, the hypothesized latent structure of Social/Practical Concerns was not supported by the data. The model was tested with the following indicators: Parenting Concerns, Social Support, Financial Concerns, and Reproductive Concerns. All path

estimates were less than or equal to .40 for Social/Practical Concerns. These results suggest that, in addition to Biological Concerns, Social/Practical Concerns was not supported as a latent variable driving its hypothesized indicators.

### **Correlations**

Correlations between all predictor variables were examined prior to beginning confirmatory factor analysis, and again afterward. The latter correlations, reflecting the supported latent variables of Adaptive Reactions and Distressing Reactions, are presented in Table 4. Correlations between all predictor variables and the outcomes of Quality of Life and Life Satisfaction are presented in Table 5. Although the latent factors of Biological Concerns and Social/Practical Concerns were not supported by the data, the hypothesized indicators are all significantly related to at least one of the latent variables as well as at least one of the outcome variables. Although the majority of these correlations are somewhat low (i.e., less than .50), they are still theoretically important variables to include in future models.

Table 4

*Correlations between latent and measured variables*

Variable	Adaptive Reaction	Distressing Reaction	Financial	Social Support	Parenting	Fertility	Psych Dx	Age	Stage	CCI	Time Since Dx
Adaptive Reaction	1.00										
Distressing Reaction	-.78**	1.00									
Financial	-.27**	.52***	1.00								
Social Support	.47***	-.45***	-.26**	1.00							
Parenting	.43***	.79***	.48**	-.29*	1.00						
Fertility	.43***	.45***	.05	-.11	.47**	1.00					
Psych Dx	-.09	.29**	.24*	-.11	.29	.16	1.00				
Age	.16	-.24**	-.25	.04	-.18	-.35**	.04	1.00			
Stage	.36***	.28**	.22*	-.01	.28*	.04	.22*	.08	1.00		
CCI	-.39**	.50***	-.13	-.13	.12	.23**	.11	-.10	.17	1.00	
Time Since Dx	.15	-.23*	-.25**	.13	-.07	-.14	.08	.64**	.09	.01	1.00

*Note.* Shaded variables are latent variables.

\*  $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 5

*Correlations between Modeled Variables and Outcomes of Quality of Life and Life Satisfaction*

Variable	Quality of Life	Life Satisfaction
Quality of Life	1.00	
Life Satisfaction	.75**	1.00
Adaptive Reaction	.73***	.88***
Distressing Reaction	-.90***	-.60***
Financial Concerns	-.53**	-.37**
Social Support	.50**	.38**
Parenting Concerns	-.74**	-.62**
Fertility	-.42**	-.39**
Psychological Diagnoses	-.39**	-.28**
Age	.24**	.19*
Stage	-.22**	-.26**
CCI	-.36**	-.32**
Time Since Diagnosis	.25**	.11

\*  $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Revising the Structural Model**

Although the main goal of this study was to test the measurement model of the hypothesized structural model in Figure 1, the results proved useful in revising the model based on the latent factors that were supported (Adaptive Reactions and Distressing Reactions) and those that were not supported by the data (Social/Practical Concerns and Biological Concerns). The revised model is presented in Figure 5. Adaptive Reactions and Distressing Reactions have been retained as they were in the original model. However, although they are still considered conceptually similar, Social/Practical Concerns and Biological Concerns are no longer latent variables; rather, they are now presented as separate measured variables. The absence of latent structure for these latter

variables is communicated by the rectangles present in the revised model, in comparison to the ovals in the original model. Although the individual variables (e.g., Financial Concerns, Social Support, Age, Stage, and so on) are represented under the categorization of Social/Practical Concerns and Biological Concerns, they are no longer considered indicators of latent variables in the revised model.

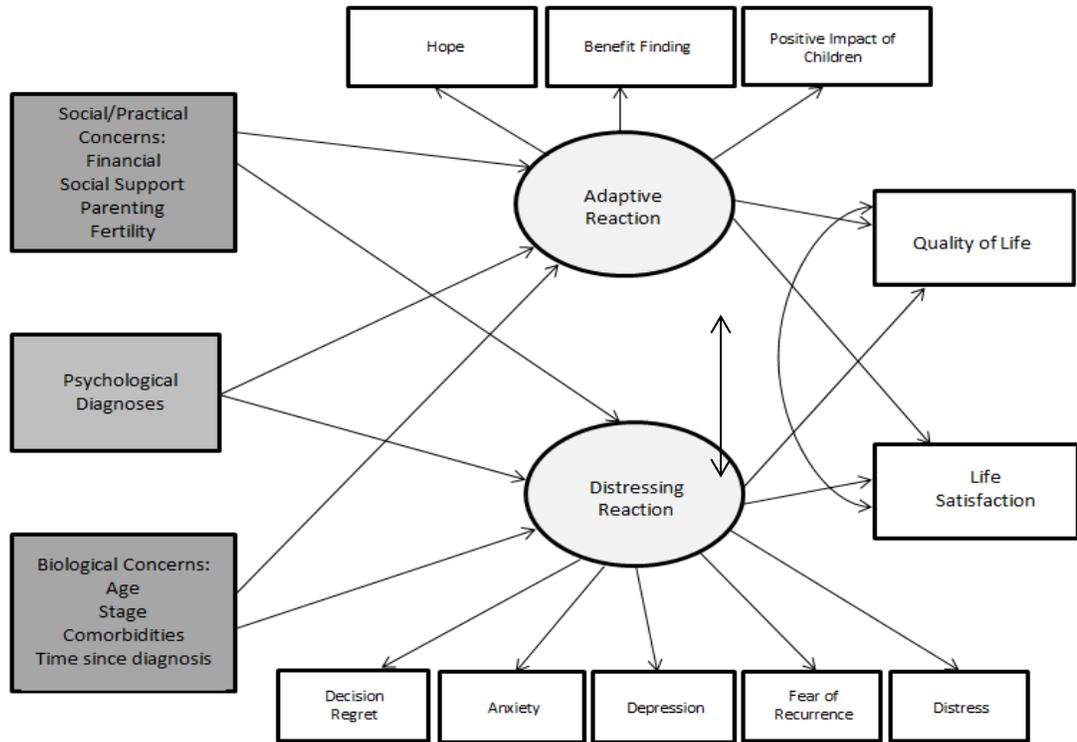


Figure 4

*Revised Structural Model*

## CHAPTER VI

### DISCUSSION AND CONCLUSIONS

Young breast cancer survivors represent a unique population of survivors in that diagnosis and treatment may disrupt their life differently than survivors diagnosed at an older age. More specifically, young survivors are often in the midst of a career, starting a family, and many other life events that are unique to the life-stage of young women. Current research suggests that, in general, young breast cancer survivors have lower quality of life and higher distress levels than their older counterparts.

Numerous studies have explored the specific needs of young breast cancer survivors as well as their distress, quality of life, fear of recurrence, and fertility concerns; the majority of these studies examine these psychosocial outcomes in comparison to older survivors. Studies which focus solely on young survivors often include only a few outcomes or offer conceptual models rather than testable models of the relationships between outcomes (Howard-Anderson et al., 2012). This study builds upon the current literature by describing the relationship between many of the psychosocial variables that have previously been discussed as unique concerns among young breast cancer survivors.

Overall, the young survivors in this sample demonstrated lower levels of global quality of life on the FACT-B than young survivors in other studies using the same instrument. Other studies have found a mean of approximately  $M = 111$  (Avis, Crawford, & Manuel, 2005; Wenzel et al., 1999), whereas the mean in this sample was  $M = 94.33$  ( $SD = 25.65$ ), which is a qualitatively large difference in global quality of life scores. The

discrepancy may be accounted for by the age of this sample in comparison to the age of samples in previous works. Others using the FACT-B included women who were 50 years old or younger, so women diagnosed with breast cancer at an older age were eligible for the other studies. Additionally, it is notable that the sample in this study included women any length of time post-treatment whereas the other studies had a narrower window for inclusion (3 years and 2 months, respectively). It might be expected that the current sample would have higher self-reported quality of life because they are further from treatment. It is possible that the young breast cancer survivors in this sample demonstrated lower quality of life because of some association with recruitment methods (i.e., Facebook) and selection bias, but this warrants further exploration.

In terms of life satisfaction, no studies to date have used the Satisfaction with Life Scale with young survivors of breast cancer. Tate and Forchheimer (2002) found that breast cancer survivors, without restraints on age, demonstrated slightly higher satisfaction with life scores when compared to the present sample of young survivors. Both Tate et al.'s sample and the current sample of young women had satisfaction with life scores lower than the general population (Diener et al., 1985). The findings that quality of life and life satisfaction were both relatively low in this sample suggest that these are important outcomes for further analysis.

The main aim of this study was to test the measurement model of a hypothesized structural model. Confirmatory factor analysis revealed that the latent factors Adaptive Reactions and Distressing Reactions were supported by the data whereas the hypothesized factors of Social/Practical Concerns and Biological Concerns were not.

These findings provide valuable information about the relationships between the measured variables in this study.

Specifically, these results suggest that young breast cancer survivors' self-reported feelings of hope, benefit finding, and the positive impact of children are all associated closely with one another and may be considered together as a positive adaptation to breast cancer survivorship. Not only are hope, benefit finding, and the positive impact of children adaptive at face value, but the factor Adaptive Reaction was also associated with self-reported higher quality of life and life satisfaction in this sample. In other words, these Adaptive Reactions may be considered a protective factor against low quality of life and life dissatisfaction in young breast cancer survivors. Very few studies have examined the positive psychosocial sequelae in young survivors after breast cancer, and this was the first quantitative study to consider hope and the positive impact of having dependent children on survivorship. Notably, benefit finding loaded the most strongly on the latent factor and was the most related to QoL and life satisfaction, suggesting that this may be a more relevant concept for breast cancer survivors, potentially because they are complete with treatment and are able to find benefit from their cancer experience. In terms of the positive impact of children, the majority of mothers' PICS scores were high, suggesting that most of the mothers in this study experienced some positive benefit from having children throughout their experience as a cancer survivor.

The indicators of decision regret, depression, anxiety, distress, and fear of recurrence were supported as one concept named Distressing Reactions. Similar to the variables that comprise Adaptive Reactions, this finding supports a concept of general

distress that may be impacted by each of the aforementioned indicators. Although many studies have examined depression, anxiety, and fear of recurrence, this study provides a more broad and inclusive picture of these variables and their relationships with other relevant outcomes. As hypothesized and consistent with the literature on the individual indicators of Distressing Reactions, Distressing Reactions were negatively associated with both quality of life and life satisfaction. In other words, higher levels of Distressing Reactions as measured by decision regret, depression, anxiety, distress, and fear of recurrence, were related to lower levels of quality of life and life satisfaction. Notably, decision regret was not as related as the other indicators of the Distressing Reaction factor, perhaps because a small number of women in this sample endorsed regret about their treatment decision. This finding may be due to the fact that all women in the study were breast cancer survivors and may therefore consider their treatments a success. Anxiety, on the other hand, was the highest loading indicator of a Distressing Reaction.

The Social/Practical Concerns and Biological Concerns latent factors were not supported by the data; the indicators of those variables did not correlate highly enough with one another to consider them one construct. However, considering this study was exploratory in nature, the variables hypothesized as indicators were adequately correlated with the supported latent factors and the outcomes of quality of life and life satisfaction. The variables were all associated with Adaptive Reactions, Distressing Reactions, Quality of Life, and Life Satisfaction in the expected direction based on the literature. Specifically, financial concerns, reproductive concerns, concerns about children, later stage, and comorbidities were all negatively related to quality of life and life satisfaction. Older age, more time since completing treatment, and social support were all related to

higher levels of quality of life and life satisfaction. Although these variables were not associated with each other highly enough to be considered the unique constructs hypothesized in the original model, they are demonstrating relationships consistent with the current literature and are still related to the outcomes of interest. Thus, they were retained in a revised model as individual measured variables rather than latent factors. In the revised model, these variables were still grouped under the subheadings of Social/Practical Concerns and Biological Concerns in order to communicate conceptual similarities between the scales. Interestingly, the variables within biological concerns and psychological diagnoses were the least related to the outcomes of quality of life and life satisfaction in this sample. This finding suggests that the more subjective scores of psychosocial adjustment are more relevant predictors of quality of life and life satisfaction than the more objective measures such as stage, time since diagnosis, comorbidities, and known psychological diagnoses. Further, this is consistent with the fact that anxiety and depression, as measured by the HADS, were not above clinical cut-offs but were still highly related to quality of life and life satisfaction.

There are several limitations to the findings of this study. As with many cohort studies, selection bias presents a potential threat to internal validity. Women were asked about their cancer experience in a retrospective manner, and their responses may be different or less accurate, especially for those who are further from completing treatment. The individual scales were kept in their original formatted time frames; some asked women to reflect on the past week, others on the past month, and so on. Therefore, it is difficult to know if each woman completed the surveys based on the same time-frame.

Because this study utilized a web-based survey and recruitment from numerous sites, the accrual rate of participants is unknown. It is likely that the response rate was low, as indicated by the accrual rate of other web-based studies (Cook, Heath, & Thompson, 2000). It was also impossible to guarantee that each woman completed the study only once, although only one survey was allowed per IP address.

Any findings from this study are limited in terms of generalizability. These findings should not be generalized to patients undergoing active treatment. Also, the majority of survivors were recruited from support groups and advocacy websites; the type of women who are actively seeking support and participating in studies may be a unique subgroup of young survivors. They may be faring better than other survivors in that they are actively involved in a support community. It could also be argued that they may be having more difficulty adjusting to survivorship compared to other survivors because they are still seeking support, or that they identify as a “cancer survivor” more than others might. Additionally, participants were almost entirely Caucasian and of relatively high socioeconomic status (SES); the results may not generalize to minority breast cancer survivors or those of a lower SES. Additionally, the findings should not be generalized to young women with other cancer types or young cancer survivors in general.

Unlike many other studies that examine psychosocial adjustment in young breast cancer survivors, this study does not have a comparison group such as a group of older survivors. Thus, it is not possible to draw conclusions about this group of young survivors in comparison to others. Further, because this study includes women of any stage and any length of time after completing treatment, it is not possible to compare this sample to a different subgroup based on stage or length of time in remission. Such

comparisons are also impossible within this sample because the sample is small and the groups are unevenly distributed.

Despite these limitations, the findings from this study have several implications for researchers and practitioners. Specifically, the support of the Distressing Reactions and Adaptive Reactions factors suggest that adjustment in young breast cancer survivors is complicated and consists of many different relevant psychosocial outcomes. Further research may consider the relationship between the objective disease-related variables and psychosocial adjustment. Specifically, it is interesting that the self-report measures of psychosocial variables were more highly associated with the quality of life and life satisfaction than the stage, comorbidities, psychological diagnoses and time since diagnosis. This finding is also relevant to clinical work; although it might be assumed that someone with Stage 0 or I breast cancer would have less difficulty than someone with later stage breast cancer, this may not be the case. Rather, disease-related variables may be much less relevant to adjustment than the patient's perception of her disease and the impact it has on her life. The fact that the indicators of Distressing Reactions and Adaptive Reactions can be considered conceptually and statistically related suggests that more research should examine the temporal development of these indicators in order to guide screening and intervention strategies. For example, if fear of recurrence preceded depression in the disease trajectory, then screening and interventions targeted toward reducing fear of recurrence might lessen the likelihood of developing subsequent depressive symptoms.

It is notable that this sample of young breast cancer survivors is faring worse in terms of quality of life and life satisfaction than would be expected based on previous

work with similar populations. Although this study focused on testing the relationship between more specific psychosocial indicators of adjustment, future research should continue to explore the relationship among these indicators and the outcomes proposed in the revised model. A better understanding of these complex relationships may be invaluable in designing interventions targeted at the most relevant predictors of quality of life and life satisfaction in young breast cancer survivors.

## REFERENCES

- Alexander, S., Palmer, C., & Stone, P.C. (2010). Evaluation of screening instruments for depression and anxiety in breast cancer survivors. *Breast Cancer Research and Treatment, 122*, 573-578.
- American Cancer Society. (2012). *Breast Cancer Facts and Figures*. Retrieved from <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-030975.pdf>
- Arndt, V., Merxb, H., Stegmaierc, C., Zieglerc, H., & Brennera, H. (2004). Age-specific detriments to quality of life among breast cancer patients one year after diagnosis. *European Journal of Cancer, 5*, 673-680.
- Avis, N.E., Crawford, S., Manuel, J. (2005). Quality of life among younger women with breast cancer. *American Society of Clinical Oncology, 23*(15), 3322-3330.
- Barnes, J., Kroll, L., Burke, O., Lee, J., Jones, A., & Stein, A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. *British Medical Journal, 321*, 479-482.
- Billhult, A. & Segesten, K. (2003). Strength of motherhood: Nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Science, 17*, 122-128.
- Bower, J.E., Low, C.A., Moskowitz, J.T., Sepah, S., & Epel, E. (2008). Benefit finding and physical health: Positive psychological changes and enhanced allostasis. *Social and Personality Psychology Compass, 223-244*.
- Brady, M.J., Cella, D.F., Mo, F., Bonomi, A.E., Tulsky, D.S., Lloyd, S.R., . . . Shiimoto, G. (1997). Reliability and validity of the functional assessment of cancer therapy-breast quality-of-life instrument. *Journal of Clinical Oncology, 15*, 974-986.
- Brennan, J. (2001). Adjustment to cancer- coping of personal transition? *Psycho-oncology, 10*, 1-18.
- Camp-Sorrell, D. (2009). Cancer and its treatment effect on young breast cancer survivors. *Seminars in Oncology Nursing, 25*(4), 251-258.

- Carver, C.S. & Antoni, M.H. (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology, 23*(6), 595-598.
- Charlson, M.E., Pompei, P., Ales, K.L., MacKenzie, C.R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Diseases, 40*(5), 373-383.
- Christianson, S. & Marren, J. (2008). The Impact of Event Scale-Revised (IES-R). *Best Practices in Nursing Care to Older Adults, 19*.
- Cimprich, B., Ronis, D.L., & Martinez-Ramos, G. (2002). Age at diagnosis and quality of life in breast cancer survivors. *American Cancer Society, 10*(2), 85-93.
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology, 20*, 176–185.
- Costanzo, E.S., Ryff, C.D., & Singer, B.H. (2009). Psychosocial adjustment among cancer survivors: Findings from a national survey of health and well-being. *Health Psychology, 28*(2), 147-156.
- Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the Impact of Event Scale-Revised. *Behaviour Research and Therapy, 41*, 1489-1486.
- Diener, E., Emmons, R.A., Larsen, R.J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment, 49*(1), 71-75.
- Fromm, K., Andrykowski, M. A., & Hunt, J. (1996). Positive and negative psychosocial sequelae of bone marrow transplantation: Implications for quality of life assessment. *Journal of Behavioral Medicine, 19*, 221–240.
- Gorman, J.R., Usita, P.M., Madlensky, L., & Pierce, J.P. (2011). Young breast cancer survivors: Their perspectives on treatment decisions and fertility concerns. *Cancer Nursing, 34*(1), 32-40.
- Herrmann, C. (1997). International experiences with the hospital anxiety and depression scale- a review of validation data and clinical results. *Journal of Psychosomatic Research, 42*(1), 17-41.
- Hopwood, P., Haviland, J., Mills, J., Sumo, G., Bliss, J. (2008). The impact of age and clinical factors on quality of life in early breast cancer: an analysis of 2208 women recruited to the UK START Trial (Standardisation of Breast Radiotherapy Trial). *Breast, 17*(1), 115.

- Howard-Anderson, J., Ganz, P.A., Bower, J.E., & Stanton, A.L. (2012). Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: A systematic review. *Journal of the National Cancer Institute, 104*(5), 386-405.
- Kazdin, A.E. (2003). *Research design in clinical psychology: Fourth edition*. Boston, MA: A Pearson Education Company.
- Knobf, M. T. (2006). The influence of endocrine effects of adjuvant therapy on quality of life outcomes in younger breast cancer survivors. *The Oncologist, 11*, 96-110.
- Kroenke, C.H., Rosner, B., Chen, W.Y., Kawachi, I., Colditz, G.A., & Holmes, M.D. (2004). Functional impact of breast cancer by age at diagnosis. *American Society of Clinical Oncology, 22*(10), 1849-1856.
- Land, L.H., Dalton, S.O., Jensen, M., & Ewertz, M. (2010). Comorbidities' impact on survival after treatment for early breast cancer. *Journal of Clinical Oncology, 28*, 15.
- Lechner, S. C., Zakowski, S. G., Antoni, M. H., Greenhawt, M., Block, K., & Block, P. (2003). Do sociodemographic and disease-related variables influence benefit-finding in cancer patients? *Psycho-Oncology, 12*, 491-499.
- Lechner, S.C., Carver, C.S., Antoni, M.H., Weaver, K.E., & Phillips, K.M. (2006). Curvilinear associations between benefit finding and psychosocial adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 74*(5), 828-840.
- Lehman, D. R., Davis, C. G., Delongis, A., Wortman, C. B., Bluck, S., Mandel, D. R., & Ellard, J. H. (1993). Positive and negative life changes following bereavement and their relations to adjustment. *Journal of Social and Clinical Psychology, 12*, 90-112.
- Liu, Y., Perez, M., Schootman, M., Aft, R.L., Gillanders, W.E., Jeffe, D.B. (2011). Correlates of fear of cancer recurrence in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Research & Treatment, 130*, 165-173.
- Matthews, T.J. & Hamilton, B.E. (2009). Delayed childbearing: More women are having their first child later in life. *National Center for Health Statistics, 21*. Retrieved from <http://www.cdc.gov/nchs/data/databriefs/db21.pdf>
- Muriel, A. C., Moore, C.W., Baer, L., Park, E.R., Kornblith, A.B., Pirl, W., . . . Rauch, P.K. (2012). Measuring psychosocial distress and parenting concerns among adults with cancer. *Cancer, 5671-5678*. doi: 10.1002/cncr.27572,

- National Cancer Institute, Surveillance Epidemiology and End Results. (2011). *SEER Stat Fact Sheets: Breast*. Retrieved from <http://seer.cancer.gov/statfacts/html/breast.html>
- National Cancer Institute. (2012). Breast Cancer Treatment. Retrieved from <http://www.cancer.gov/cancertopics/pdq/treatment/breast/Patient/page5>
- National Institute of Health (2012). *Health and Aging*. Retrieved from <http://www.nia.nih.gov/health/publication/menopause>
- Park, C. L., Cohen, L. H., & Murch, R. L. (1996). Assessment and prediction of stress-related growth. *Journal of Personality*, *64*, 71–105.
- Reich, M., Lesur, A., Perdrizet-Chevallier, C. (2008). Depression, quality of life and breast cancer: A review of the literature. *Breast Cancer Research and Treatment*, *110*, 9-17.
- Rowland, J.H. (1989). Developmental stage and adaptation: adult model. *Handbook of Psychooncology*, 25-43.
- Sammarco, A. (2001). Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. *Cancer Nursing*, *24*(3), 212-219.
- Semple, C.J. & McCance, T. (2010). Parents' experience of cancer who have young children. *Cancer Nursing*, *33*(2), 110-118.
- Snyder, C.R., Harris, C., Anderson, J.R., Holleran, S.A., Irving, L.M., . . . Harney, P. (1991). The will and the ways: Development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, *60*(4), 570-585.
- Stanton, A.L., Danoff-Burg, S., Huggins, M.E. (2002). The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. *Psycho-oncology*, *11*(2), 93-102.
- Stanton, A.L., Ganz, P.A., Kwan, L., Meyerowitz, B.E., Bower, J.E., Krupnick, J.L., . . . Belin, T.R. (2005). Outcomes from the moving beyond cancer psychoeducational, randomized, controlled trial with breast cancer patients. *Journal of Clinical Oncology*, *23*(25), 6009-6018.
- Tabachnik, B.G. & Fidell, L.S. (2012). *Using Multivariate Statistics*. New Jersey: Pearson Education, Inc.
- Tate, D.G. & Forchheimer, M. (2002). Quality of Life, Life Satisfaction, and Spirituality. *American Journal of Physical & Medical Rehabilitation*, *81*(6), 400-410.

- Tomich, P.L. & Helgeson, V. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology, 23*(1), 16-23.
- Vickburg, S.M.J. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *The Society of Behavioral Medicine, 25*(1), 16-24.
- Wenzel, L.B., Fairclough, D.L., Brady, M.J., Cella, D., Garrett, K.M., Klushman, B.C., . . . Marcus, A.C. (1999). Age-related differences in the quality of life of breast carcinoma patients after treatment. *Cancer, 86*, 1768-74.
- Wenzel, L., Dogan-Ates, A., Habbal, R., Berkowitz, R., Goldstein, D.P., Bernstein, M., . . . Cella, D. (2005). Defining and measuring reproductive concerns of female cancer survivors. *Journal of the National Cancer Institute Monographs, 34*, 94-98.
- Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 52*, 30-41.
- Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S. & Berkoff, K.A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 55*, 610-17.

**APPENDIX A**

**FUNCTIONAL ASSESSMENT OF CANCER THERAPY- BREAST**

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

**PHYSICAL WELL-BEING**

Not      A      Som      Quit      Ver  
at      little      e-      ea      y  
all      bit      wha      bit      muc  
                                         t                                           h

G P 1	I have a lack of energy .....	0	1	2	3	4
G P 2	I have nausea .....	0	1	2	3	4
G P 3	Because of my physical condition, I have trouble meeting the needs of my family .....	0	1	2	3	4
G P 4	I have pain .....	0	1	2	3	4

G P 5	I am bothered by side effects of treatment .....	0	1	2	3	4
G P 6	I feel ill .....	0	1	2	3	4
G P 7	I am forced to spend time in bed .....	0	1	2	3	4

	<b><u>SOCIAL/FAMILY WELL-BEING</u></b>	<b>Not</b>	<b>A</b>	<b>Som</b>	<b>Quit</b>	<b>Ver</b>
		<b>at</b>	<b>little</b>	<b>e-</b>	<b>ea</b>	<b>y</b>
		<b>all</b>	<b>bit</b>	<b>wha</b>	<b>bit</b>	<b>muc</b>
				<b>t</b>		<b>h</b>

G S 1	I feel close to my friends .....	0	1	2	3	4
G S 2	I get emotional support from my family .....	0	1	2	3	4
G S 3	I get support from my friends.....	0	1	2	3	4
G S 4	My family has accepted my illness .....	0	1	2	3	4
G S 5	I am satisfied with family communication about my illness.....	0	1	2	3	4
G S	I feel close to my partner (or the person who is my					

6	main support) .....	0	1	2	3	4
Q 1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next section.</i>					
G S 7	I am satisfied with my sex life .....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

**EMOTIONAL WELL-BEING**

Not at all      A little bit      Somewhat      Quite a bit      Very much

G E 1	I feel sad .....	0	1	2	3	4
G E 2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
G E 3	I am losing hope in the fight against my illness .....	0	1	2	3	4
G E 4	I feel nervous .....	0	1	2	3	4
G E 5	I worry about dying .....	0	1	2	3	4
G E 6	I worry that my condition will get worse .....	0	1	2	3	4

**FUNCTIONAL WELL-BEING**

**Not at all**      **A little bit**      **Somewhat**      **Quite a bit**      **Very much**

G F 1	I am able to work (include work at home) .....	0	1	2	3	4
G F 2	My work (include work at home) is fulfilling.....	0	1	2	3	4
G F 3	I am able to enjoy life.....	0	1	2	3	4
G F 4	I have accepted my illness.....	0	1	2	3	4
G F 5	I am sleeping well .....	0	1	2	3	4
G F 6	I am enjoying the things I usually do for fun .....	0	1	2	3	4
G F 7	I am content with the quality of my life right now.....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

**ADDITIONAL CONCERNS**

Not at all      A little bit      Somewhat      Quite a bit      Very much

B 1	I have been short of breath .....	0	1	2	3	4
B 2	I am self-conscious about the way I dress.....	0	1	2	3	4
B 3	One or both of my arms are swollen or tender .....	0	1	2	3	4
B 4	I feel sexually attractive .....	0	1	2	3	4
B 5	I am bothered by hair loss .....	0	1	2	3	4
B 6	I worry that other members of my family might someday get the same illness I have.....	0	1	2	3	4
B 7	I worry about the effect of stress on my illness.....	0	1	2	3	4
B 8	I am bothered by a change in weight.....	0	1	2	3	4
B 9	I am able to feel like a woman .....	0	1	2	3	4

P  
2

I have certain parts of my body where I experience

0

1

2

3

4

pain .....

## APPENDIX B

### SATISFACTION WITH LIFE SCALE (SWLS)

Below are five statements that you may agree or disagree with. Using the 1 – 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 – Strongly agree
- 6 – Agree
- 5 – Slightly agree
- 4 – Neither agree nor disagree
- 3 – Slightly disagree
- 2 – Disagree
- 1 – Strongly disagree

\_\_\_\_ In most ways my life is close to my ideal.

\_\_\_\_ The conditions of my life are excellent.

\_\_\_\_ I am satisfied with my life.

\_\_\_\_ So far I have gotten the important things I want in life.

\_\_\_\_ If I could live my life over, I would change almost nothing.

- 31 – 35 Extremely satisfied

- 26 – 30 Satisfied
- 21 – 25 Slightly satisfied
- 20 Neutral
- 15 – 19 Slightly dissatisfied
- 10 – 14 Dissatisfied
- 5 - 9 Extremely dissatisfied

## APPENDIX C

### BENEFIT FINDING MEASURE (Tomich & Helgeson, 2004)

Having had breast cancer:

1. has made me more sensitive to family issues.
2. has led me to be more accepting of things.
3. has taught me how to adjust to things I cannot change.
4. has given my family a sense of continuity, a sense of history.
5. has made me a more responsible person.
6. has made me realize the importance of planning for my family's future.
7. has brought my family closer together.
8. has made me more productive.
9. has helped me take things as they come.
10. has helped me to budget my time better.
11. has made me more grateful for each day.
12. has taught me to be patient.
13. has taught me to control my temper.
14. has renewed my interest in participating in different activities.
15. has led me to cope better with stress and problems.

## APPENDIX D

### HOPE SCALE

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1 = Definitely False    2 = Mostly False    3 = Mostly True    4 = Definitely True

1. I can think of many ways to get out of a jam. (Pathways)
2. I energetically pursue my goals. (Agency)
3. I feel tired most of the time. (Filler)
4. There are lots of ways around any problem. (Pathways)
5. I am easily downed in an argument. (Filler)
6. I can think of many ways to get the things in life that are most important to me. (Pathways)
7. I worry about my health. (Filler)
8. Even when others get discouraged, I know I can find a way to solve the problem. (Pathways)
9. My past experiences have prepared me well for my future. (Agency)
10. I've been pretty successful in life. (Agency)
11. I usually find myself worrying about something. (Filler)
12. I meet the goals that I set for myself. (Agency)

## APPENDIX E

### IMPACT OF EVENTS SCALE- REVISED (IES-R)

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to \_\_\_\_\_, which occurred on \_\_\_\_\_. How much were you distressed or bothered by these difficulties?

Item Response Anchors are 0 = Not at all; 1 = A little bit; 2 = Moderately; 3 = Quite a bit; 4 = Extremely.

The Intrusion subscale is the MEAN item response of items 1, 2, 3, 6, 9, 14, 16, 20. Thus, scores can range from 0 through 4.

The Avoidance subscale is the MEAN item response of items 5, 7, 8, 11, 12, 13, 17, 22. Thus, scores can range from 0 through 4.

The Hyperarousal subscale is the MEAN item response of items 4, 10, 15, 18, 19, 21. Thus, scores can range from 0 through 4.

1. Any reminder brought back feelings about it.
2. I had trouble staying asleep.

3. Other things kept making me think about it.
4. I felt irritable and angry.
5. I avoided letting myself get upset when I thought about it or was reminded of it.
6. I thought about it when I didn't mean to.
7. I felt as if it hadn't happened or wasn't real..
8. I stayed away from reminders of it.
9. Pictures about it popped into my mind.
10. I was jumpy and easily startled.
11. I tried not to think about it.
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.
13. My feelings about it were kind of numb.
14. I found myself acting or feeling like I was back at that time.
15. I had trouble falling asleep.
16. I had waves of strong feelings about it.
17. I tried to remove it from my memory.
18. I had trouble concentrating.
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.
20. I had dreams about it.
21. I felt watchful and on-guard.
22. I tried not to talk about it.

Total IES-R score: \_\_\_\_\_





## APPENDIX G

### HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Instruct the patient to answer how it currently describes their feelings.

(1) I feel tense or 'wound up':

Most of the time 3

A lot of the time 2

From time to time, occasionally 1

Not at all 0

(D) I still enjoy the things I used to enjoy:

Definitely as much 0

Not quite so much 1

Only a little 2

Hardly at all 3

(1) I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly 3

Yes, but not too badly 2

A little, but it doesn't worry me 1

Not at all 0

(D) I can laugh and see the funny side of things:

As much as I always could 0

Not quite so much now 1

Definitely not so much now 2

Not at all 3

(1) Worrying thoughts go through my mind:

A great deal of the time 3

A lot of the time 2

From time to time, but not too often 1

Only occasionally 0

(D) I feel cheerful:

Not at all 3

Not often 2

Sometimes 1

Most of the time 0

(1) I can sit at ease and feel relaxed:

Definitely 0

Usually 1

Not Often 2

Not at all 3

(D) I feel as if I am slowed down:

Nearly all the time 3

Very often 2

Sometimes 1

Not at all 0

(1) I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all 0

Occasionally 1

Quite Often 2

Very Often 3

(D) I have lost interest in my appearance:

Definitely 3

I don't take as much care as I should 2

I may not take quite as much care 1

I take just as much care as ever 0

(1) I feel restless as I have to be on the move:

Very much indeed 3

Quite a lot 2

Not very much 1

Not at all 0

(D) I look forward with enjoyment to things:

As much as I ever did 0

Rather less than I used to 1

Definitely less than I used to 2

Hardly at all 3

(1) I get sudden feelings of panic:

Very often indeed 3

Quite often 2

Not very often 1

Not at all 0

(D) I can enjoy a good book or radio or TV program:

Often 0

Sometimes 1

Not often 2

Very seldom 3

Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.

0-7 = Normal

8-10 = Borderline abnormal

11-21 = Abnormal

## **APPENDIX H**

### **DECISION REGRET SCALE**

Please reflect on the [first decision that you made about hormone therapy after talking with your family physician.] Please show how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about your decision.

1- Strongly Agree, 2- Agree, 3- Neither Agree nor Disagree, 4-Disagree, 5. Strongly Disagree

1. It was the right decision
2. I regret the choice that was made
3. I would go for the same choice
4. The choice did me a lot of harm
5. The decision was a wise one

## **APPENDIX I**

### **FINANCIAL PROBLEMS SUBSCALE OF THE QLACS**

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

1. You had financial problems because of the cost of cancer surgery or treatment.
2. You had problems with insurance because of cancer.
3. You had money problems that arose because you had cancer.
4. You had financial problems due to a loss of income as a result of cancer.

## APPENDIX J

### REPRODUCTIVE CONCERNS SCALE

REPRODUCTIVE CONCERNS SCALE [IF AGE > 45, SKIP TO PAGE XX]

The next statements reflect possible feelings or thoughts about pregnancy, fertility (ability to get pregnant), & reproduction (having children). Please rate how true each one has been for you during the past month. If you do not feel that the statement is relevant to you, please answer “Not at all”

During the past month:

Not at all

A little bit

Some-what

Quite a bit

Very much

1. I have concerns about my ability to have children.
2. I am content with the number of children that I have.
3. I feel less of a woman because of reproductive problems.
4. An illness/disease has affected my ability to have children.
5. I am angry that my ability to have children has been affected.
6. I am able to talk openly about fertility or reproductive concerns.
7. Others are to blame for my reproductive problems.

8. I am sad that my ability to have children has been affected.
9. I have had control over my reproductive future.
10. I feel guilt about my reproductive problems.
11. I have mourned the loss of my ability to have children.
12. I blame myself for my reproductive problems.
13. I am frustrated that my ability to have children has been affected.
14. I am less satisfied with my life because of reproductive problems.

## APPENDIX K

### MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you Very Strongly Disagree

Circle the “2” if you Strongly Disagree

Circle the “3” if you Mildly Disagree

Circle the “4” if you are Neutral

Circle the “5” if you Mildly Agree

Circle the “6” if you Strongly Agree

Circle the “7” if you Very Strongly Agree

1. There is a special person who is around when I am in need. (SO)
2. There is a special person with whom I can share my joys and sorrows. (SO)
3. My family really tries to help me. (Fam)
4. I get the emotional help and support I need from my family. (Fam)
5. I have a special person who is a real source of comfort to me. (SO)
6. My friends really try to help me. (Fri)
7. I can count on my friends when things go wrong. (Fri)
8. I can talk about my problems with my family. (Fam)
9. I have friends with whom I can share my joys and sorrows. (Fri)
10. There is a special person in my life who cares about my feelings. (SO)

11. My family is willing to help me make decisions. (Fam)

12. I can talk about my problems with my friends. (Fri)

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

## APPENDIX

### CHARLSON COMORBIDITY INDEX

**Table 1. Charlson Comorbidity Index Scoring System**

Score	Condition
1	Myocardial infarction (history, not ECG changes only) Congestive heart failure Peripheral vascular disease (includes aortic aneurysm $\geq 6$ cm) Cerebrovascular disease: CVA with mild or no residua or TIA Dementia Chronic pulmonary disease Connective tissue disease Peptic ulcer disease Mild liver disease (without portal hypertension, includes chronic hepatitis) Diabetes without end-organ damage (excludes diet-controlled alone)
2	Hemiplegia Moderate or severe renal disease Diabetes with end-organ damage (retinopathy, neuropathy, nephropathy, or brittle diabetes) Tumor without metastases (exclude if $>5$ y from diagnosis) Leukemia (acute or chronic) Lymphoma
3	Moderate or severe liver disease
6	Metastatic solid tumor AIDS (not just HIV positive)

NOTE. For each decade  $> 40$  years of age, a score of 1 is added to the above score.

Abbreviations: ECG, electrocardiogram; CVA, cerebrovascular accident; TIA, transient ischemic attack; AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus.