SYMPTOM BURDEN, IDENTITY BALANCE, AND EMOTIONAL DISTRESS IN CANCER SURVIVORS

By

LYNNE BENTLEY

BSN, University of Colorado, 1985
MS in Nursing, University of Colorado, 1991
MBA, University of Colorado, 1991

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
Doctor of Philosophy
College of Nursing
2015
This thesis for the Doctor of Philosophy degree by

Lynne Bentley

has been approved for the

College of Nursing

by

Karen Sousa, Chair

Michael Galbraith, Advisor

Regina Fink

Jean Kutner

Date _12/18/2015_
Bentley, Lynne (Ph.D., Doctor of Philosophy College of Nursing)
Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors
Dissertation directed by Associate Professor Michael Galbraith

ABSTRACT

Emotional distress suffuses the experience of cancer survivors and is associated with adverse outcomes. Emotional distress is a response to a circumstance, which threatens the stability of identity. Of the antecedents to emotional distress in cancer patients, symptom burden accounts for the greatest amount of variance. Qualitative studies in populations of cancer survivors have shown that identity affects the experience of emotional distress related to symptom burden. The purpose of this dissertation research was to measure the relationships among symptom burden, identity balance, and emotional distress by testing whether identity balance mediates the relationship between symptom burden and emotional distress in cancer survivors.

The research study framework is structured by a proposed path model, which displays the mediated relationship of identity balance, symptom burden and emotional distress. A cross sectional survey design was used, and mediation analysis was conducted to measure the relationships among the variables. Several cancer centers in the state of Colorado, U.S. were used to disseminate the questionnaire and a link to an online version of the survey was also offered. Data were collected using hard copy questionnaires and SurveyMonkey. Analysis of the mediated effect was conducted using SPSS. Results showed a small partial mediation effect of Identity Balance on the relationship between Symptom Burden and Emotional Distress.

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

Approved: Michael Galbraith
DEDICATION

I dedicate this work to my Dad, who always had faith in me, and my Mom, who always inspired me.

My children, Anders and Zoe, who have rarely known me when I was not in school.

My husband, Anthony, who endured and supported me through the hours, days, months and years of this journey.

My mother-in-law, Margaret, who through her own courageous battle with breast cancer, inspired me to become an oncology nurse.

Dr. Kathy Magilvy, without whose belief in me, I would not have begun this journey, again.

My close friends, Virginia, Sandi, Vicki, Judy, Mindy, Norma, Gabi, Monica, Terry and Stephanie.

Jeremy Geffen who offered a beacon for those cancer patients who are lost in the darkness.

John Fleagle who encouraged and advised me.

And Marybeth.
TABLE OF CONTENTS

CHAPTER

I. INTRODUCTION .......................................................................................................  1

Statement of the Problem ............................................................................................  1

Definitions....................................................................................................................  2

Cancer Survivorship........................................................................................  2

Symptom Burden, Physical ............................................................................  4

Identity Balance (IBL): A Component of Identity ........................................  5

Emotional Distress ..........................................................................................  7

Background ..................................................................................................................  9

Purpose and Rationale for Inquiry............................................................................  11

Theoretical Framework .............................................................................................  12

Contribution to Nursing Science...............................................................................  14

Study Aims .................................................................................................................  15

Partial Mediation........................................................................................................  16

Summary ....................................................................................................................  17

II. REVIEW OF THE LITERATURE ..........................................................................  19

Symptom Burden as an Antecedent to Emotional Distress
in the Context of Cancer............................................................................................  19

Linkages Among Symptom Burden and Identity Balance.......................................  21

Linkages Among Symptom Burden and Emotional Distress ...............................  22

Identity Balance .........................................................................................................  23

Linkages Among Identity Balance and Emotional Distress ...............................  27

Emotional Distress in Adult Cancer Survivors......................................................  28

Summary ....................................................................................................................  30
III. METHODS ................................................................................................................ 33
   Study Design .............................................................................................................. 33
   Sample ........................................................................................................................ 34
      Sampling Strategy .............................................................................................. 35
      Recruitment ....................................................................................................... 36
   Procedure .................................................................................................................... 38
      Consent .......................................................................................................... 39
      Effect Size and Statistical Power ...................................................................... 41
      Mediation .......................................................................................................... 43
   Statistics ...................................................................................................................... 44
      Mediation Analysis ........................................................................................... 44
      Causal Paths ....................................................................................................... 47
   Instruments ................................................................................................................. 49
      Condensed Memorial Symptom Assessment Subscale-Physical (CMSAS-PHYS) .... 50
      Identity Balance Subscale (IBL) of the Identity and Experiences Scale (IES) .... 51
      Profile of Mood States-Brief (POMS-B) ............................................................. 57

IV. RESULTS ................................................................................................................... 60
   Sample Participants Demographics ........................................................................ 60
   Living Arrangements ............................................................................................... 62
   Cancer Type ............................................................................................................ 63
   Procedure .................................................................................................................... 64
      Accruals .............................................................................................................. 64
      Data Preparation .................................................................................................. 65
      Eligibility .............................................................................................................. 66
Missing Data .................................................................................................. 66

Data Analysis .............................................................................................................. 67

Instrument Reliability ................................................................................................. 67

Univariate Descriptive Statistics ............................................................................. 68

Univariate Outliers ..................................................................................................... 69

Linear Regression Assumption Results ................................................................. 72

   Normality ............................................................................................................. 72

   Linearity ............................................................................................................... 74

   Homoscedasticity ................................................................................................. 75

   Multicollinearity .................................................................................................... 77

   Independence ......................................................................................................... 78

Correlational Analysis ................................................................................................. 79

Mediation Analysis ..................................................................................................... 80

   Model fit ............................................................................................................... 81

Hypotheses .................................................................................................................. 81

   Symptom Burden Predicting Emotional Distress ............................................. 82

   Symptom Burden Predicting Identity Balance ............................................... 82

   Identity Balance Predicting Emotional Distress .............................................. 83

   Symptom Burden and Identity Balance Predicting Emotional Distress .... 83

Indirect Effect Analysis ............................................................................................... 84

Qualitative Data ........................................................................................................... 86

Summary ..................................................................................................................... 87

V. DISCUSSION ............................................................................................................ 89

Quantitative Findings ................................................................................................. 89

   Normality ............................................................................................................. 89
# LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Baron and Kenny Mediation Steps</td>
<td>34</td>
</tr>
<tr>
<td>2.</td>
<td>Statistical Power Estimates</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Mediation Analysis Instruments: Summary</td>
<td>49</td>
</tr>
<tr>
<td>4.</td>
<td>Identity Balance Subscale: Validation Instruments and Group Differences</td>
<td>54</td>
</tr>
<tr>
<td>5.</td>
<td>Frequency Distribution of Sample Demographics</td>
<td>61</td>
</tr>
<tr>
<td>6.</td>
<td>Age and Years in the United States</td>
<td>62</td>
</tr>
<tr>
<td>7.</td>
<td>Living Arrangements and Financial Information</td>
<td>62</td>
</tr>
<tr>
<td>8.</td>
<td>Sample Size and Percentage of Sample by Cancer Type</td>
<td>63</td>
</tr>
<tr>
<td>9.</td>
<td>Number and Percentage of Respondents by Site</td>
<td>64</td>
</tr>
<tr>
<td>10.</td>
<td>Univariate Descriptive Statistics and Instrument Reliability</td>
<td>69</td>
</tr>
<tr>
<td>11.</td>
<td>Outlier Statistics and Data Trimming Results</td>
<td>71</td>
</tr>
<tr>
<td>12.</td>
<td>Normality Results</td>
<td>73</td>
</tr>
<tr>
<td>13.</td>
<td>Linearity Statistics</td>
<td>75</td>
</tr>
<tr>
<td>14.</td>
<td>Multicollinearity Statistics</td>
<td>78</td>
</tr>
<tr>
<td>15.</td>
<td>Independence Statistics</td>
<td>78</td>
</tr>
<tr>
<td>16.</td>
<td>Correlation Results</td>
<td>79</td>
</tr>
<tr>
<td>17.</td>
<td>Model Fit Statistics</td>
<td>81</td>
</tr>
<tr>
<td>18.</td>
<td>Baron and Kenny Steps Summary Statistics</td>
<td>83</td>
</tr>
<tr>
<td>19.</td>
<td>Baron and Kenny Mediation Steps</td>
<td>84</td>
</tr>
<tr>
<td>20.</td>
<td>Other Symptoms</td>
<td>87</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

FIGURE

1. Study Path Model ................................................................. 16
2. Path c: The predictor variable X has a causal effect on outcome variable Y ........33
3. Mediation Path Model .............................................................34
4. Path c: Direct Effect of Symptom Burden on Emotional Distress ....................47
5. Path a: Direct Effect of symptom Burden on Identity balance ..........................48
7. Histogram of Residuals ..............................................................73
8. Q-Q plots of Residuals ................................................................73
9. Bivariate Scatter Plot CMSAS and POMSBTS ..................................... 74
10. Bivariate Scatter Plot CMSAS and IBTS ............................................75
11. Bivariate Scatter Plot IBTS and POMSBTS .......................................75
12. Heteroscedasticity ...................................................................77
13. Mediation Diagram with Standardized Coefficients ................................. 87
CHAPTER I
INTRODUCTION

Statement of the Problem

Cancer is a chronic condition with long term side effects that can last for the duration of a person’s life (Witter & LeBas, 2008). Five years after being diagnosed, 68% of adults with cancer are alive and living with the consequences of their experiences (American Cancer Society, 2013). Many cancer survivors experience sequelae from cancer and cancer treatment the rest of their lives. Up to 45% of all cancer patients in North America experience emotional distress (Carlson et al., 2004) and 35.1% of cancer survivors experience higher levels of emotional distress than the general population (Zabora, BrintzenhofeSzoc, Curboe, Hooker, & Piantadosi, 2001; Hoffman, McCarthy, Recklitis, & Ng, 2009). In the U.S., 1.8% to 4.9% of Americans experience psychological distress. Those in the age range of 45 to 64 years exhibited the highest levels (Weissman, Pratt, Miller, Parker, 2015). Even after cancer treatment is completed, cancer survivors experience greater levels of emotional distress than what is found in the general population (Hoffman, McCarthy, Recklitis & Ng, 2009; Zabora, et al., 2001).

Sequelae from cancer and cancer treatment, described in aggregate as symptom burden, cause acute and chronic suffering in cancer survivors. Symptom burden has been categorized into two groupings: physical and psychological. Cleeland (2007) defines symptom burden as the physical and psychological impact of all symptoms that arise from the cancer and/or cancer treatment. Cleeland suggested symptom burden is so widespread and morbid, that it is worthy of outcome measurement in clinical trials and should be considered when the physician makes treatment decisions.
Many types of symptoms cause symptom burden. One of the most distressing symptom to patients was the suffering survivors described from living with malignant wounds. Studied by Lo, Hayter, Hu, Tai, Hsu, and Li, (2011) the authors discovered that the burden of living with an unhealed, malodorous, disfiguring wound left cancer survivors unable to trust their bodies and embarrassed by looking and feeling as if they were not normal. These consequences invoked feelings of fear, mistrust of self, guilt, and a loss or disruption of identity. They reported an overwhelming sense of vulnerability, inability to fulfill role responsibilities, and changes in relationships with family and friends.

Symptom burden for the purposes of this study, focuses on the physical symptoms related to cancer and cancer treatment. Physical symptoms can threaten cancer survivor identity and cause uncertainty and instability in identity balance. When identity is unstable and disrupted, it is imbalanced. A threat to the stability of identity subsequently may lead to the development of, or an increase in, emotional distress. This study investigates the relationship between symptom burden as the antecedent, and emotional distress as the outcome, while measuring any mediating effect presented by identity balance in a sample of cancer survivors.

Definitions

This study uses terminology that can be interpreted differently by the reader. Lexical choices elucidate meaning. In an effort to increase understanding and clarity of vocabulary used in this study, definitions were offered for critical terms.

Cancer survivorship. The National Cancer Institute (n.d.) defines survivorship as encompassing all aspects of the human experience of cancer from diagnosis until the end
of life. It declares that the experience of cancer survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. National Cancer Survivors Day Foundation (n.d.) defines a survivor as any person who is living with a history of cancer and begins at the moment of diagnosis and continues through the remainder of the person’s life. For the purposes of this inquiry, the focus of the cancer survivorship experience was on the emotional response to all aspects of the cancer survivorship journey, and the population under study was specifically defined as those patients who completed adjuvant treatment within the last six to 18 months.

Doyle’s (2008) concept analysis described cancer survivorship in adults as a life changing process that begins with the diagnosis of cancer, is perceived as both positive and negative and includes the experience of living with uncertainty. Doyle believed the consequences of cancer survivorship affect all aspects of health: physical, psychological, social, and spiritual. Little, Paul, Jordens, and Sayers, (2002) defined cancer survivors as individuals who are living, apparently free of cancer, at any time after diagnosis and treatment have been completed. Using that definition, in this study, the cancer survivor population was limited to those patients who have completed adjuvant chemotherapy treatment and have not started second line therapy. Although there are numerous definitions regarding the timing for when cancer survivorship begins, this inquiry was conducted in the context of cancer survivorship measured between six and 18 months after completion of adjuvant chemotherapy and prior to initiation of second line therapy.

Mullan (1985) first elucidated the stages of cancer survival as acute, extended, and permanent. The acute state starts with diagnosis and continues through treatment. The extended stage begins when the person the cancer patient completes adjuvant
treatment or is considered to be in remission. The permanent stage is usually after the person has achieved five years of remission and the likelihood of cancer recurrence is small. Mullan (1985, p. 272) defined the permanent stage of cancer survivorship as a time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.” These circumstances are complex and a person in this stage may continue to encounter social and economic challenges, and suffer from residual symptom burden.

**Symptom burden, physical.** Cancer survivors are living longer, leading to concomitant long term physical symptoms and emotional distress. Cleeland, and Reyes-Gibby (2002) defined symptom burden as disease and/or treatment consequences suffered by cancer patients and survivors. Symptom burden comprises the complex emotional and physical symptoms caused by cancer and cancer treatment. Symptom burden results from the experience of surviving cancer and may involve persistent physical sequelae, emotional distress and ongoing changes in the overarching construct of identity (Burkett & Cleeland, 2007). Symptom burden affects quality of life as a constellation of cancer-related encumbrances borne by the patient. Multiple symptoms usually occur at once, rather than singly. The impact of the multiple symptoms, the severity of symptoms, and the patient’s perception of the circumstances, comprise symptom burden. For the purposes of this dissertation study, only the physical aspects of those cancer and cancer treatment sequelae will be defined as symptom burden.

Symptom burden changes the functional ability of a cancer survivor from that prior to disease and therapy onset and includes the presence, frequency, and severity of physical symptoms. Symptoms may be transient while others persist. Some cancer
survivors contend with effects on large organ system functions such as the genitourinary, gastrointestinal, neurological, pulmonary, musculoskeletal, endocrine, and cognitive abilities for their entire lifetime. Neuropathies, insomnia, and fatigue are also long term physical symptoms. The loss of one or both breasts and painful lymphedema limits mobility. These symptoms are enduring reminders of the experience of cancer, and cause or increase emotional distress.

The emerging emphasis on survivorship is moving toward improving long term health in this population. It is hoped that the knowledge gained in this study may lead to better understanding of how to reduce the effect of symptom burden on the experience of emotional distress in cancer survivors.

**Identity balance (IBL): A component of identity.** Identity, as described by Whitbourne (1986) refers to the overarching construct comprised of three sub-constructs; identity balance, identity accommodation and identity assimilation. To better understand identity balance, it must first be described in the context of the overarching construct of identity. Identity was described in the 1600s by the philosopher John Locke who wrote a seminal treatise on it (Nimbalkar, 2011). His theory viewed identity as the continuity of consciousness a person carries from the past and extends into the present. In his treatise, Locke (1689) wrote that persons are self-aware and that awareness or consciousness is the identity. Locke saw identity as consciousness affected by the state of the body, which suggested a pluralistic belief prior to its popular acceptance in the 20th century. Locke defined identity as awareness of sensibilities, pleasure, pain, happiness, or misery. According to Locke, the identity is self-aware and reflective and is housed within the body.
The overarching construct of identity is a core personality trait providing structure for a person’s life (Erikson, 1980). It represents the amount of self-knowledge, synthesis, and consistency that a person displays over time and in differing circumstances. Erikson suggested that experiencing a crisis affects identity either progressively or regressively. Accordingly, some cancer patients may assimilate their experience and create positive perceptions of identity while others will not.

Erikson (1980) believed that new experiences and information change identity and cause destabilization of identity balance. He explained that the person achieves a sense of mastery by incorporating change into the identity. However, if the new experience is not resolved and incorporated into the identity, the person experiences a sense of inadequacy and imbalance of identity. A person may experience discontinuity in identity after experiencing life changing events (Erikson, 1963). A person’s goals, values, and beliefs are internally consistent and form a coherent sense of self (van Hoof & Raaijmakers, 2002). Applied to cancer survivors, identity balance is the degree to which identity remains stable over changing circumstances.

Weigert (1986) defined identity as a personality reflecting inner character during a certain stage of life within the context of social relationships. Identity is how the person views his/her self in the world. Weigert maintained that the person accepts the predictable reality of change throughout life, the evolution of identity and its continual rebalancing. The experience of cancer may upset this routine process, thus thwarting identity balance.

Côté (1997) discussed social identity and personal identity. Social identity refers to the alignment with groups, and personal identity refers to a person’s character and how the person responds in social situations. Gecas and Burke (1995) defined identity as how
a person responds to others in social situations. The more consistent the self-perception in social situations, the more balanced identity remains over time and circumstance.

Whitbourne (1986) evaluated how individuals adapt their identities in response to changing circumstances, based on theories of Piaget and Erikson. Whitbourne later explained how new experiences affect identity balance in adulthood (Whitbourne, Sneed & Skultety, 2002). Whitbourne posited that healthy adults rebalance identity throughout changing circumstances to maintain a positive perspective of self. However, when the person views circumstances negatively, then the person may have increasing difficulty rebalancing identity.

This inquiry focused on identity balance during changing circumstances. Responses to changing circumstances are reflected in a person’s identity balance. Burke’s Interruption Theory (Burke, 1980) views identity as fluctuating with situational changes. Interruption Theory suggests that greater the disruption to identity, the greater the emotional distress that results. The person adjusts to changing circumstances and rebalances identity to maintain or achieve semantic congruence, which is defined as the standard the person uses to assess how he or she might be viewed by others. People who do not rebalance their identities in response to changing circumstances, experience emotional distress (Burke, 1980). Survivors with an unstable and unbalanced identity retained a negative perception of their experience yielding a lower quality of life with greater emotional distress (Zebrack, 2000).

**Emotional distress.** Emotional distress (ED) in this study is separated from physical symptom burden. It arises from the subjective perception and meaning ascribed to circumstances. The Free Online Dictionary (n.d.) defines the terms emotional and
distress as an experience comprised of intensely unpleasant feelings causing anxiety and suffering, disrupting a person’s sense of self, and needing immediate relief. Emotional distress is subjective and describes feelings that reside in the experience and disrupt the inner world of the person. Moscoso (2010, p. 68) defined emotional distress as “a state marked by feelings that vary in intensity from sadness, insecurity, confusion, and worry, … to anxiety, depression, expression of anger, social isolation, and loss of hope.” The uncertainty about recurrence or any remaining disease creates intrusive thoughts leading to emotional distress.

The National Comprehensive Cancer Network (NCCN) defined emotional distress as “a multi-factorial unpleasant experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (NCCN, n.d.). This meaning was further described as a continuum, from normative feelings of vulnerability, sadness and fear to disabling symptoms of depression, anxiety, panic, social isolation, existential and spiritual crisis (Bultz & Holland, 2006; Thomas, NandaMohan, Nair, Pandy, 2010). According to Vitek, Rosenzweigm, and Stollings (2007, p. 414), the NCCN described the symptoms of distress as: “. . . fear about the future, sadness for loss of health, feeling powerless and angry, poor sleep, poor or decreased appetite, difficulty concentrating, and thoughts of illness and death . . .”.

Emotional distress experienced by cancer survivors negatively affects survival (Brown, Levy, Rosberger, & Edgar, 2003; Faller, Bulzebruck, Schilling, Drings, & Lang, 1996; Hamer, Chida, & Molloy, 2009).
Background

Emotional distress pervades the experience of cancer survivors. Kaiser et al., (2010) analyzed the 2003-2005 National Health Interview Surveys to detect differences in non-somatic distress of those with a history of cancer, those with other chronic health histories, and healthy adults. Their analysis summarized studies reflecting that emotional distress is one of the most common complaints of cancer survivors. Such distress is associated with adverse outcomes, including lower quality of life (QOL), poor compliance with physician recommendations, and increased mortality.

Emotional distress is a response to a circumstance created by a threat to self-identity and is grounded in an interpretive process. Cassell (2002) submits that “…suffering is a distressful state induced by the possibility of losing one’s sense of living as an integrated being” (p. 54-55). Cassell (2002) suggests that emotional distress ensues when a diagnosis of cancer influences “the person’s perception of future events” (p. 213). In chronic situations, emotional distress is accentuated while, in an acute but temporary situation, distress may be reduced because there is a sense that it is finite. Levels of emotional distress depend on how the cancer patient perceives the situation from moment to moment. In the transition to a cancer survivor, the perception of the experience is an identity altering and identity threatening experience. Losing one’s sense of self defines the identity transition. The cancer survivor encounters the prospect of creating an identity that incorporates cancer. Some survivors are more adept at maintaining a balanced identity or reconstituting their identity with resulting lower levels of emotional distress. Others, however, experience higher levels of emotional distress when they are often
unable to reconcile their identity with the reality of their experience of cancer. The consequences impact quality and quantity of life (Adler & Page, 2008).

An existential crisis in cancer was described by Weisman and Worden in 1975. The plight manifested as perseveration on life and death issues and high levels of emotional distress. Patients who exhibited greater levels of emotional distress were unable to reconcile the changing circumstances attributed to having cancer (Weisman & Worden, 1975). Those patients who were not in a relationship or lacked strong family support, displayed more emotional distress that those with stable marriages and strong support of family and friends. Relieving symptoms associated with cancer and cancer treatments are only part of the solution. The authors suggested that the existential crisis is also based in fear of abandonment, loss of control, loneliness, and fear of the unknown, including an unknown future. Weisman and Worden (1975) suggested that addressing the social and psychological reasons for distress are equally important in relieving the existential plight suffered by cancer patients.

Mathieson and Stam’s (1995) narratives research described how the experience of cancer alters the person’s perception of self-identity; the incongruence between reality and identity fosters emotional distress. Shapiro, Angus, and Davis (1997), in a grounded theory study, compared pre-cancer identity to post diagnosis identity. The subjects reported experiencing an existential threat from cancer that caused an alteration in identity and subsequent emotional distress.

Emotional distress arises from the loss of a future reality which manifests as an incongruence between the identity the person is experiencing and the identity the person expected to experience (Little et al., 2002). The way a person perceives himself prior to
having cancer may constrain his ability to rebalancing identity through incorporating the
cancer experience into his sense of self. Thus, emotional distress decreases as a person
rebalances and re-stabilizes identity.

**Purpose and Rationale for Inquiry**

Health care professionals tend to underestimate emotional distress in cancer
survivors, and this distress is often left untreated Carlson et al. (2004). Patient and
provider assessment of emotional distress align approximately 25% of the time (Linden,
believe they are bound by professional responsibility and moral imperative to address
needs of cancer patients who have been identified by a screening instrument. There is a
significant improvement in outcomes between those who want help for emotional distress
and get it compared to those who want help and do not get it (Ryan, et al., 2005).

Emotional distress affects the quality and quantity (survival) of life for cancer
survivors (Amir, & Ramati, 2002; Bennett, et al., 2010; Houldin, Curtiss, & Haylock,
2006; Rosedale, 2010). Jacobsen and Ransom (2004) report that nearly 50% of adults
with cancer exhibit clinically significant distress. In the late 1990s, the National
Comprehensive Cancer Network (NCCN) targeted efforts to improve the recognition and
treatment of emotional distress in cancer patients. A panel of experts was appointed to
develop practice guidelines to address emotional distress. Consensus-based guidelines
that included standards and clinical pathways of care for managing distress were
developed by the panel. The Commission on Cancer published a new standard, effective
in 2017, requiring oncology programs to demonstrate that cancer patients are screened for
distress. This standard also requires oncology programs to identify issues, such as symptom burden, that can negatively impact treatment and outcomes.

Physical symptom burden is a primary contributor to the experience of emotional distress in cancer survivors. Mao, Armstrong, Bowman, Xie, Kadakia, and Farrar (2007) suggested symptom burden is substantial and affects the emotional status of cancer survivors. Symptom burden also affects the stability of identity in cancer patients and identity imbalance has been established as a cause of emotional distress in cancer survivors (Morse, 1997; Morse & Carter, 1996; Piggin & Jones, 2009; Shapiro et al., 1997). Quantitative studies measuring identity, or its sub-construct identity balance, and emotional distress in cancer survivors were not found. Thus, measuring, and analyzing these relationships are the logical next steps in the trajectory of nursing research. The purpose of this inquiry is to use mediation analysis to measure the relationships among symptom burden, identity balance and emotional distress in cancer survivors. Understanding the relationships among these variables builds knowledge that can be used for future inquiry that may lead to improvements in the lives of those who suffer.

**Theoretical Framework**

Burke’s Interruption Theory, a midrange sociological theory, ties emotional distress to incongruence between the identity of a person and the social environment (Large & Marcussen, 2000). Interruption Theory posits that identity self-regulates by adjusting in response to changing circumstances. This persistent recalibration to maintain identity balance and semantic congruence is defined by Burke as the standard by which a person assesses how he or she might be viewed by others. Interruption Theory assumes the following: interruption of identity increases autonomic activity; greater autonomic
activity results in higher (emotional and physical) distress; the greater the discrepancy between the interruption and the identity, the greater the distress, the greater the discrepancy among ideals; and the greater the depression and subsequent distress, the greater the discrepancy among obligations and the greater the anxiety and subsequent distress (Large & Marcussen, 2000).

Neuman’s System Model evaluated responses to stressors, which for purposes of this inquiry are designated as antecedents of distress (Gigliotti, 1999; Gigliotti, 2001; Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001; Neuman, 1989). Neuman suggested that, in response to stressors, the individual evaluates and implements lines of defense which vary based on the severity of the stressor. When exposed to extreme stressors, the responses may deviate from the normative range. These flexible lines of defense help the individual manage circumstances, return to equilibrium, and reestablish identity balance. Neuman (1989) believed that nurses should understand the individual’s environment, circumstance, and the process of protecting self. Burke’s and Neuman’s models link identity balance and stressors as antecedents to emotional distress. For example if identity balance is destabilized, then there is a direct relationship to the increase in emotional distress, unless something, such as flexible lines of defense, intervenes to reduce or prevent this consequence. This nexus frames an understanding of how emotional distress ensues from responses to changing circumstances, and is influenced by the degree of identity balance.

Survivors rebalance identities as a result of living through cancer (Park, Zlateva, & Blank, 2009). As posited in Burke’s Identity theory, identity is socially constructed in response to changing circumstances through interactions with others. Symptom burden in
cancer survivors is a stressor that unbalances and disrupts identity and causes emotional distress. Thus, according to Interruption Theory, a more balanced identity in cancer survivors may decrease emotional distress.

**Contribution to Nursing Science**

Emotional distress is a response to the human experience of cancer and lies within the scope of nursing practice. According to the Oncology Nursing Society’s *Statement on the Scope and Standards of Oncology Nursing Practice*, oncology nurses should assess patients for coping and comfort, which includes assessment of emotional distress (Brant & Wickham, 2004). When patients undergo high levels of emotional distress it is more difficult for them to express feelings. Expressive suffering, according to Morse (2001), is a necessary step in recovering identity and resolving emotional distress. A better understanding of the relationships among physical symptom burden, and other antecedents to emotional distress, and identity balance may have clinical application for the care of cancer survivors. To effectively care for cancer survivors, nurses must understand the phenomenon of how identity balance is destabilized by a diagnosis of cancer, and the subsequent sequelae. In addition nurses must recognize the effect an unbalanced identity has on the experience of emotional distress in the cancer survivor. Quantitative research on identity and the sub-construct identity balance, and emotional distress has lagged behind the qualitative research of these constructs. Including physical symptom burden as an antecedent to emotional distress adds to the understanding of a significant problem for cancer survivors. By understanding the relationship among symptom burden, identity and emotional distress, a nurse can better evaluate antecedents and identity balance, and determine opportunities to intervene and reduce suffering.
Inpatient nurses often misjudge cancer patients’ emotional distress due to poor understanding of the subjective experience. Martensson, Carlsson, and Lampic (2008) found that nurses who have more education and/or who have spent five days or more caring for a patient, assess emotional distress more accurately than their counterparts with less education or time with a patient. Informed nurses, who are educated to be aware of nuanced patient responses or have a relational experience that sensitizes them to patient responses, are more adept at judging the patients’ subjective perceptions of themselves, and how the cancer experience affects them.

The experience of cancer can be dehumanizing and resulting sequelae further threaten identity balance. Reframing and rebalancing identity is central to enduring assaults of the journey in survivorship. Given the increasing number of cancer survivors suffering with emotional distress, increasing knowledge of the role of identity and its effect on emotional distress builds the body of literature around this phenomenon and informs the epistemic foundation of nursing.

**Study Aims**

Using mediation analysis, this study aims to:

1. Examine the relationship between symptom burden and emotional distress.
2. Examine the relationship between symptom burden and identity balance.
3. Examine the relationship between identity balance and emotional distress.
4. Determine whether identity balance mediates the relationship between symptom burden and emotional distress.
Partial Mediation

Partial mediation occurs when the path from X to Y is reduced in absolute size but is not to zero when the mediator is introduced (Baron & Kenny, 1986). Mediation according to Frazier, Tix and Barron (2004) occurs when the predictor variable (X) influences the mediator (M), which in turn influences the outcome variable (Y). Complete mediation occurs when X no longer affects Y after M has been controlled; thus path $c'$ is zero. The study path model depicted in Figure 1 illustrates the mediated relationship of identity balance on symptom burden and emotional distress (Baron & Kenny, 1986).

Figure 1. Study Path Model. Based on mediation model by Baron and Kenny (1986)
Summary

The human experience of surviving cancer can result in chronic emotional distress creating a decline in the length and quality of life. Cancer survivors are vulnerable to emotional distress by fear of recurrence or death, intrusive thoughts, and the consequential life changes. Knowing more about antecedents of emotional distress may help identify those at risk. Emotional distress results when a cancer survivor is unable to meet his/her own expectations about what life should be. Survivors continue to experience a loss of control over many parts of their lives. They live with reminders of treatment including body image and functional changes and experience post-traumatic stress disorder. Identity is threatened with a cancer diagnosis and again during the transition to cancer survivorship. The threat to identity is reflected in the person’s ability to negotiate the definition of self. Park et al., (2009) noted that as relationships and life priorities change, those survivors who adjust and rebalance their identities and roles while interacting with others and with self, experience lower emotional distress.

Burke’s Interruption Theory posits that self-assessment of life roles and self-image affect the strength of identity and self-esteem. Identity is based on the assessment of how a person believes himself to be perceived by others. When self-assessment is negative, identity and self-esteem deteriorate. Interruption Theory is based on a pluralistic paradigm where an interruption (deterioration) of identity increases autonomic activity; greater autonomic activity results in higher distress. The greater the discrepancy is between the preferred identity and the perceived identity, the greater the autonomic activity, which is experienced as emotional distress (Large & Marcussen, 2000).
Burke’s and Neuman’s theories provide a framework for understanding the experience of emotional distress as a disruption of identity. When individuals face extreme or unexpected stressors they may alter established or normative responses (Neuman, 1989). Incorporating cancer into a survivorship identity may exacerbate stressors such as symptom burden, based on the meaning a person ascribes to the stressors. Physical symptom burden as an antecedent of emotional distress is a potential threat to identity. Changes to the bio-psychosocial aspects of the person add to the disruption and destabilization of identity and foster emotional distress.

A threat to identity balance represents an existential crisis precipitated by a cancer diagnosis. Burke’s Interruption Theory is based on a pluralistic paradigm where a negative disturbance of identity predicts an increase in emotional distress based on the discrepancy caused by the identity disruption. When an extremes stressor such as a cancer diagnosis is encountered, the person may experience an identity disturbance with an autonomic response of emotional distress. Physical symptom burden is described in the literature as the antecedent variable that provides the most variance in emotional distress in cancer patients. Therefore, this study examined the relationship between physical symptom burden (as an antecedent) and emotional distress, using identity balance as a mediator.
CHAPTER II

REVIEW OF THE LITERATURE

This chapter provides a review of the literature on emotional distress, symptom burden, and identity balance in the human experience of cancer and cancer survivorship. Early researchers recognized the connections between these phenomena. Symptom burden and emotional distress were linked when Beecher (1957; 1959) described the emotional component of pain. Goffman (1965) showed that preserving the sense of self aided emotional strength as a final human act of the condemned. In an early effort to understand emotional distress, Worden and Sobel (1978) presented ego strength as promoting positive adaptation and lower emotional distress in response to the changes encountered during the journey of cancer. These studies sketch the trajectory of thought associating symptom burden, emotional distress, and identity.

Symptom Burden as an Antecedent to Emotional Distress in the Context of Cancer

The antecedents of distress in cancer patients most often cited in the literature are cancer diagnosis, low income level, unmarried or un-partnered, low education level, non-native status, younger age, female gender, pain, and symptom burden (Pandey, Thomas, Ramdas, & Nandamohan, 2006; Van Servellen, Sarna, Padilla, & Brecht, 1996). These authors found factors affecting levels of distress included negative life experiences, social support, and disease progression. Negative life events, such as a cancer diagnosis, were viewed as precursors to emotional distress, especially when such events were perceived as beyond the person’s control. Peretz, Baider, Ever-Hadani, and De-Nour (1994) found that patients exposed to prior extreme trauma as Holocaust survivors, had higher levels of distress when diagnosed with cancer than non-Holocaust counterparts. This population
lost the ability to use denial as a coping mechanism, and instead used a dissociative mechanism by compartmentalizing.

Loneliness is included in the category of symptom burden in the context of cancer and cancer survivorship (Rosedale, 2009). Head and neck cancer patients experience emotional distress largely as a result of the psychosocial context in which the patients live (Singer et al., 2011). Those with more distress perceive they have less social support. This is supported by Kugaya et al. (2000), which showed that living alone is a predictor of distress in head and neck cancer patients. Connection with others can reduce emotional distress in cancer patients (Tobin & Begley, 2008). You, Yeh, and Su (2014) identified 34 loneliness-associated genes and verified that cancer patients with high-risk scores had a shorter mean survival time than those with a low-risk score. Their research suggests that cancer patients with lower genetic risk for loneliness, and those with connection to others, may have a survival advantage.

Pandey et al. (2006) studied cancer patients from India and learned that patients who presented with pain and late stage disease, representative of symptom burden, reported higher levels of distress. Kendall, Glaze, Oakland, Hansen, and Parry (2011) investigated cancer patients in an outpatient setting and identified concern over financial difficulties resulting from the expense of cancer treatment as the most prevalent predictor of emotional distress.

Fleer et al. (2005) examined predictors of cancer-related stress symptoms in testicular cancer survivors. They evaluated the role of substantive events (such as hearing the diagnosis) and the emotions evoked by those events to explain differences in the patient experience of distress. This study confirmed previously reported antecedents of
distress including concurrent chronic disease. Of the survivors who were cured, 50% reported few or no distress symptoms associated with their cancer experience.

Clayton, Mishel, and Belyea (2006) tested a model of symptoms, communication, uncertainty, and well-being in breast cancer survivors over age fifty. Managing emotions during the cancer journey is linked to the subjective appraisal process. Cancer and its resultant sequelae, appraised as stressful and negative can be predicted by lower economic status, younger age, lower education level, and higher family distress. Clayton, et al., (2006) found that long term survivors had time to reflect on their experience and appraise its relevant meaning. The study showed that breast cancer survivors with a stronger sense of self, higher age and education exhibited improved well-being and fewer symptoms of distress. According to Clayton et al. (2006), older cancer survivors, who have stable and balanced identities, are able to resolve the experience positively and incorporate it into the context of their life.

**Linkages among Symptom Burden and Identity Balance**

Adverse symptoms from cancer and cancer treatment can impact a person’s perception of self and disrupt identity. Piggin and Jones (2009) studied the impact of symptoms from cancer and cancer treatment on a person’s sense of identity. Their research found that symptoms such as neuropathies, alopecia, loss of organ function, incontinence, impotence, pain, and difficulty concentrating can cause cancer survivors to question who they are.

Molassiotis, Wengstrom, and Kearney (2010) found that body image symptoms negatively affected self-perception. Herth and Cutcliffe (2002) discovered that controlling the burden of symptoms improves an individual’s self-esteem as an aspect of
identity. Symptom burden from a loss of function may cause reliance on others and is associated with a diminished sense of self in cancer survivors (Cousineau, McDowell, Holtz, & Herbert, 2003). This diminished sense of self that unbalances identity and is perceived as a threat results in heightened emotional distress.

**Linkages among Symptom Burden and Emotional Distress**

Symptom burden describes the symptoms that distress survivors. As noted by Mao, Armstrong, Bowman, Xie, Kadakia, and Farrar (2007), 30% of cancer survivors with ongoing symptoms, such as pain and insomnia, experience psychological distress. Physical and psychological symptom burden can lower the quality and quantity of life in cancer survivors. Burkett and Cleeland (2007) defined symptom burden as the subjective assessment of the side effects experienced by a patient. In that context, symptom burden reflects the aggregate impact of disease on the patient’s effectiveness to live as he had prior to becoming aware of the disease, its treatment, and the intensity of symptoms and emotional distress caused by the untreated or unrelieved symptoms (Burkett & Cleeland, 2007). Shi, et al. (2011) suggested that the severity of physical symptoms experienced was significant because higher physical symptom burden caused greater emotional distress.

Somatic sequelae such as pain and fatigue cause emotional distress according to Fossa, Dahl, and Loge (2003). These researchers found that testicular cancer survivors reported chronic fatigue was a distressful sequela of their experience. Non-somatic sequelae cause even greater emotional distress. Relationship tension, loss of sexual functioning, loss of financial stability, change or loss of job, living with fear of recurrence, and alienation describe the unmet supportive care needs of survivors and their
partners resulting in emotional distress (Hodgkinson, Butow, Hobbs, & Wain, (2007).
Butt, et al. (2008) studied cancer and cancer treatment symptoms in an ambulatory cancer patient population. Their findings indicated that relief of symptoms significantly improves quality of life and reduces distress.

Identity Balance

Locke’s philosophical theory about the construct of identity suggests that consciousness is the experience, which creates personal identity. Locke (1689) explained that a person has the properties of being conscious, self-aware, and rational. Consciousness includes current mental states, awareness of our own bodies, and awareness of the past. Identity over time is fixed by awareness of the past. Identity only persists as far back as the person can remember. Each person is the same person insofar as consciousness is the same now as it was in the past. Erikson (1964) offered that the work of identity is to help the ego maintain continuity during times when life circumstances change. “Identity connoted the resiliency of maintaining essential patterns in the process of change” (Erikson, 1964, pp. 95-96). Erikson suggested that the stability of core markers of an identity give indication of how well identity remains balanced over time and changing circumstances.

Identity provides the person with goal-directed behavior based on self-evaluation (Stryker & Serpe, 1982). Stryker examined the linkages of social identities while Burke was interested in self-perception and how the person internally verifies identity. As discussed by Burke (1980), the process of verifying the identity creates and sustains social structures.

Weigert’s (1986) discourse posited that the source of identity is self-awareness
grounded in daily experience. Identity arises from interpretation of the relationships and reflections of social interaction and experience (Weigert, Teitge, & Teitge, 1986). Weigert (1986) described three sources of identity: embodiment, structure and dialectic. The embodiment of the self is expressed by interacting and performing with others. Identity becomes defined by the structures ascribed to it when it is imposed or institutionalized. When circumstances change, identity changes and the cancer survivor is challenged to rebalance and redefine identity based on the new situation.

The connection between physical symptom burden and emotional distress is well documented in existing qualitative literature. Kahn and Steeves (1986) discussed the integration of the physical body and emotions, contributing to the evidence supporting the pluralistic nature of emotional distress. Emotional distress relates to the meaning attributed to the circumstances. Kahn and Steeves (1986) suggested that the anticipation of what the circumstances mean to the person can change self-perception and result in emotional distress, if a negative outcome is perceived. Mathieson and Stam (1995) confirmed the work of Kahn and Steeves (1986). They found that cancer patients rebalance and reconstitute their identities by describing their experiences and reflecting on who they are. Cancer patients continually rebalance their identities in response to the changing circumstances experienced during the journey through cancer.

Identity has multiple domains that relate to the state of being. Hermans, Kempen, and van Loon defined identity as a multidimensional concept comprised of identity elements (1992). Identity balance occurs in response to the person’s subjective assessment of how he is perceived by others (Large & Marcussen, 2000). Identity continually rebalances in response to internal and external influences (Andersen & Chen,
The sense of memory includes future memory, which we use to balance our identity and create our lives (Little et al., 2002). For example, in survivorship, cancer may render a patient infertile. The future memory of having children is eliminated and results in a need to rebalance identity or emotional distress results from the loss and the inability to change or control the consequence. Emotional distress resolves as the future identity is rebalanced and reconfigured to match reality. The continuity of memory contributes to who we are now. This continuity extends to the future. When continuity is disrupted, identity destabilizes, and our lives no longer have meaning for the future.

The drive to construct and reconstruct identity derives from several possibilities. Child development suggests that imitation is a major influence on social development (Sears, Maccoby & Levin, 1957). Psychoanalytic theory posits that conflict and emotional resolutions that lead to ego formation and autonomy drive identity formation (Blos, 1962). Social psychologists argue that self-awareness motivates change. In the cancer experience, identity formation, rebalancing and reconstitution most likely are influenced by dialectic-like processes that emerge from a situation that produces an emotional response to a perceived incompatibility with previous identity. Confronting the situation and the inconsistencies, leads to rebalancing and synthesis of the identity, and resolution of inconsistencies (Adams & Fitch, 1982; Adams, Abraham, & Markstrom, 1987; Markstrom-Adams, Ascione, Braegger & Adams, 1994).

Jones, Parker-Raley and Barczyk (2011) confirmed that adolescent cancer survivors experience an “identity paradox” during the transition from cancer patient to
cancer survivor triggering anxiety. According to Almedon (2005) positive and negative consequences are two sides of the same coin, e.g., recovery and chronic trauma. A number of pathways to rebalance and reconstruct identity are possible during the psychological transition from crisis to either positive or negative aftermath, including being emotionally unharmed.

Zebrack (2000) suggested that reconstruction of identity in cancer survivors requires integrating the experience of cancer and revising the perception of one’s self in the world. The experience of cancer offers the opportunity to expand the perception of self, and open to the possibility of a different role and a new life path.

Cancer is traumatic for a large percentage of the cancer survivor population. Traumatic events can disrupt the normal pattern of human existence and separate self and identity (Gadow, 1982; Cassell, 2002). According to Almedon (2005) the ability to maintain an intact identity in times of trauma may be an innate characteristic. A number of pathways are possible during the psychological transition from crisis to either positive or negative aftermath, including remaining intact. Mental health problems, including depression, may not be as widespread among victims of traumatic experience as assumed because some manage to maintain or rebuild their sense of self or identity (Almedon, 2005).

Helgeson (2011) examined the process of integrating cancer into the self-concept. The extent to which patients define themselves by the disease impacts their adjustment as survivors. The findings revealed that identity is more likely to be fractured if the assimilation of cancer into self-concept was construed as a negative. Cancer survivors who successfully integrate their experience are more likely to have balanced identities
and positive adjustments. When a person who has endured cancer embraces the label of cancer survivor as part of the self-identity, there is a greater likelihood that person will experience decreased anxiety and depression and an improved self-concept (Bell, 2014; Bell & Ristovski-Slijepcevic, 2013).

Whitbourne et al. (2002) noted that the ideal state of identity is one of homeostasis or dynamic equilibrium. They described this process as accommodation of the identity to changing circumstances while maintaining core structures and processes. The consistent patterns of identity define the person over time. Although the patterns may shift in response to stressors of changing circumstances, they remain the principal way a person responds. Whitbourne et al., (2002) proposed that a balanced identity is circumscribed as stable, realistic, and with high self-esteem. They elaborated by positing that identity balance liberates the person to respond to change through flexibility and adaptation to new circumstances while retaining inner consistency and stability.

**Linkages among Identity Balance and Emotional Distress**

Charmaz (2002) suggested that chronic illness disrupts the characteristics that differentiate a person from others and alters the person’s way of being in the world. Charmaz (1983) posited that identity is the way people think, feel, and behave (act) habitually. Identity is something a person takes for granted until it is threatened. Charmaz (1983) explained that chronically ill people experience emotional distress as they observe the dissolution of their self-image and become aware of the discrepancy between their perception of identity and the reality of their identity. It is at this point, when identity becomes unstable, that identity balance decreases. Mathieson and Stam’s (1995) narratives research established that the experience of cancer alters the person’s identity
and results in emotional distress. When Shapiro, Angus, and Davis (1997), studied identity and cancer, they found that those patients who re-stabilized their identity, were able to regain identity balance and reduce or resolve their emotional distress.

**Emotional Distress in Adult Cancer Survivors**

Research on emotional distress in cancer has evolved from a general understanding of the phenomenon to investigations into specific dimensions and subdimensions. McCorkle and Young (1978), and Weisman (1989) posited that distress involves the whole person, thus framing a pluralistic paradigm as the foundation for understanding this phenomenon. Kahn and Steeves (1986) advocated that the cancer experience is an existential journey perceived as a personal threat. These authors set the foundation for understanding emotional distress in cancer survivors as a fundamental experience derived from the transition from a non-cancer identity to cancer patient.

The incidence of cancer survivors increased in the 1980s and, as awareness of survivorship increased, it also became apparent that even in cases with few or no physical sequelae, emotional distress persisted. In the 1990s, the National Cancer Institute (NCI) formed the Office of Cancer Survivorship, increasing funding for cancer research and cancer survivorship. The NCI’s research agenda focused on understanding the complex multidimensional nature of emotional distress and on developing tools to measure it.

By the 21st century cancer became known more as a chronic disease than a fatal disease and, in some cases, a curable disease. Research efforts focused on the consequences of living with chronic disease and with the sequelae of emotional and physical trauma in the absence of disease. Researchers’ projects explored Post Traumatic Stress Disorder (PTSD) (Amir & Ramati, 2002; Cordova, Studts, Hann, Jacobsen, &
Andrykowski, 2000), survivor loneliness (Rosedale, 2009; 2010), and how individuals vary in their ability to manage emotional injury from threats to identity. Alfano and Rowland (2006) and Ljungman et al. (2014) reported that some survivors experienced positive effects, including resilience, reprioritization of values, growth in self-confidence, stronger spirituality, and seeing life through new or different perspectives.

Varying degrees of emotional distress experienced by survivors have puzzled researchers. Vivar, Canga, Canga and Arantzamendi (2008), through a review of literature, described the impact of cancer recurrence on survivors and their significant others. Their analysis revealed that survivors who express distress about fear of recurrence enjoy a high quality of life with few intrusive thoughts about recurrence and low emotional distress. This is consistent with Morse (1997) whose research suggested suffering resolves only after a period of expressing feelings.

Understanding how identity is impacted by factors that affect the experience of emotional distress in cancer survivors may provide insight into the relationship between identity and emotional distress. Zebrack (2000, 2009) postulated that to advance the knowledge of the phenomenon of emotional distress and cancer, the following questions should be addressed: (1) Do persons integrate the experience into their identities and, if so, how? (2) What are the differences between those who manage such integration and those who do not? (3) What are the social psychological and social structural factors that impact such integration? and (4) What are the consequences of not integrating the experience?

Zebrack (2000) observed that this process may involve “a depletion of psychological resources, a sense of worthlessness and morbid depression, impairment of
mental functioning or sense of reality, self-destructive acts, preoccupation with punishment and death, or boredom and lack of initiative” (p. 387). For other cancer survivors, “acceptance of a new role and identity as a ‘cancer survivor’ may be associated with new values and ideals that form the foundation for a self that is perceived to be just as good as, if not better than, before cancer” (p. 387).

During their journeys, cancer survivors face reconciling the perception of self with the reality of illness. As advanced by Zebrack (2000, 2009), examining the impact of cancer at various stages during the remainder of a survivor’s life, may advance knowledge about the experience. Zebrack’s qualitative inquiry may be advanced and explored with quantitative research that can measure these postulates.

Summary

The existing qualitative literature suggests the stability of identity balance in cancer survivors mitigates the level of emotional distress experienced as a result of symptom burden (Mathieson & Stam, 1995; Shapiro, Angus & Davis, 1997). Emotional distress in cancer survivors results from a disruption of identity. Identity that is balanced adapts to change and remains coherent. A disruption in identity emerges when cancer is diagnosed and again when transitioning to cancer survivorship. Although symptom burden precipitates emotional distress, it is the subjective interpretation of these sequelae that unbalance and disrupt identity. If the cancer survivor interprets the cancer experience negatively, he or she is more likely to perceive the experience as a threat to self and sense of identity. If the cancer survivor interprets the journey positively, the threat to self, decreases, and identity remains more balanced.
Symptom burden may negatively affect the perception of the experience and how a person defines him or herself. Symptom burden can be stressful, painful, and unpleasant and is not a normal state for the person. Symptom burden changes the way the person perceives him/herself and emotional distress ensues. Emotional distress resolves when the experience of cancer is assimilated and identity is rebalanced and reconstituted, regardless of whether the symptoms from cancer and cancer treatment dissipate.

Identity balance is an indicator of the stability and coherence of identity during changing circumstances in adults (Erikson, 1980; Whitbourne, 1986; 1996). A disrupted identity causes emotional distress. It follows that the more balanced identity remains, the less likely identity will be disrupted. Identity balance provides an indication of the likelihood and degree to which identity will be disrupted.

Emotional distress experienced during the transition from cancer patient to cancer survivor is induced by symptom burden and the reduction of identity balance. Symptom burden is an antecedent to emotional distress; identity balance strengthens that relationship by increasing emotional distress beyond what symptom burden alone would evoke. Identity balance may be reduced during changing circumstances and a decrease in identity balance has been shown to increase emotional distress. Based on the literature, the expected results of the mediation analysis would suggest the lower the identity balance, the greater the influence will be on increasing emotional distress caused by symptom burden. It is anticipated that the mediation model will reflect that when identity balance levels are high, the relationship between symptom burden and emotional distress will be affected by the mediator (identity balance), reducing the effect of symptom burden on emotional distress. The change in identity balance affects the relationship
between symptom burden and emotional distress. I predict that when identity balance levels are low, the effect of symptom burden on emotional distress will increase, resulting in higher levels of emotional distress.

In summary, when identity balance acts as a mediator between symptom burden and emotional distress it should have one of two effects: (1) if identity balance scores are low, it will increase the effect of symptom burden on emotional distress, or (2) if identity balance scores are high, it will decrease the effect of symptom burden on emotional distress. Therefore, identity balance will either increase or decrease the effect that symptom burden has on emotional distress based on the level of identity balance.
CHAPTER III
METHODS

Study Design

A cross-sectional survey design was chosen for this study. The purpose of the study was to examine the relationships among the variables of interest; symptom burden, identity balance, and emotional distress, in the cancer survivor population. These variables of interest are used to construct an \textit{a priori} mediation effect path model. Using the Baron and Kenny procedure, data analysis was analyzed with bivariate linear regression (1986). This method was described by Baron and Kenny (1986) where a causal or predictor variable $X$ is assumed to cause an outcome variable $Y$ (Figure 2). Path $c$ is considered to be the total effect of $X$ on $Y$ (Kenny, n.d.).

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{path_c.png}
\caption{Path $c$: The predictor variable $X$ has a causal effect on outcome variable $Y$}
\end{figure}

When a mediator variable was introduced, the effect of $X$ on $Y$ including the effect of $M$ on that relationship was measured. Kenny (n.d.) discussed how the effect of $X$ on $Y$ would alter path $c$ when a mediator is introduced. When establishing that the mediator variable completely mediates the $X$-$Y$ relationship, the effect of $X$ on $Y$ should be zero. If all four steps of mediation are met, then full mediation has occurred, and the hypothesis that variable $M$ completely mediates the relationship between $X$ and $Y$ has been proven. Kenny cautions though that meeting the four steps may not prove that full mediation was met because other possible models have not been tested. When the mediator is introduced, the new path between $X$ and $Y$ is path $c'$ (Figure 3).
This method assumes that the collected data from the survey are normally distributed. Table 1 shows the steps that were used for this analysis (Baron & Kenny, 1986).

Table 1  
Baron and Kenny Mediation Steps

<table>
<thead>
<tr>
<th>Question</th>
<th>X→Y (path c)</th>
<th>X predicting Y to test for path c, Y = β₀ + β₁X + e</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answers</td>
<td>X→M (path a)</td>
<td>Symptom burden predicting identity balance</td>
</tr>
<tr>
<td>Question</td>
<td>X predicting M to test for path a, M = β₀ + β₁X + e</td>
<td></td>
</tr>
<tr>
<td>Answers</td>
<td>M→Y (path b)</td>
<td>Identity balance predicting emotional distress</td>
</tr>
<tr>
<td>Question</td>
<td>M predicting Y to test the significance of path b, Y = β₀ + β₁M + e</td>
<td></td>
</tr>
<tr>
<td>Answers</td>
<td>X and M predicting Y</td>
<td>Symptom burden and Identity balance predicting emotional distress. Y = β₀ + β₁X + β₂M + e</td>
</tr>
</tbody>
</table>

Sample. The sample population chosen for study was cancer survivors who completed adjuvant chemotherapy within the previous six to 18 months, measured to the month, and had not started new treatment. The rationale for choosing this population is these survivors had experienced the impact of a cancer diagnosis, had been treated with
chemotherapy, and were faced with integrating the experience of cancer into their identity (Andrykowski & Cordova, 1988). The latter period was defined as the extended phase of survivorship (Mullan, 1985). Mullan described this phase as a time of waiting and watching for signs of recurrence. Ethnicity, race, age, gender, income, insurance status, partnership/marriage status, cancer type and education level were captured as demographic information. As noted, due to the likelihood that females are more apt to complete questionnaires, it was anticipated that this study may accrue a larger number of females than males. In addition, currently most cancers are diagnosed in people over age 50, thus it was expected that the sample would be skewed toward those over 50 years of age.

The following categories for ethnicity and race established by Federal guidelines were used: Hispanic, Non-Hispanic; Race: American Indian/Alaska Native, Asian, Black/African American, Native Hawaiian/Pacific Islander, White, two or more races (U.S. Census Bureau, n.d.).

The following overall inclusion criteria were used:

- Can the participant read and understand English?
- Is the participant able to complete this questionnaire by myself without help?
- Is the participant between 18 and 89 years of age?
- Is the participant currently being treated with chemotherapy or radiation therapy?
- Did the participant complete therapy between 6 months and 18 months ago?

**Sampling strategy.** Subjects were accrued at the Comprehensive Cancer Center at Exempla St. Joseph Hospital (ESJH), the Rocky Mountain Cancer Center (RMCC) in
Boulder, Denver Health and Hospital’s (DHH) outpatient oncology clinic, and the Anschutz Cancer Pavilion at the University of Colorado Cancer Center (UCCC). ESJH providers saw approximately 80 patients daily according to practice manager Kamika Kelly (personal communication October 2012). The practice manager of RMCC Boulder, Joey Roth, (personal communication September 2012) noted that clinic providers saw an average of 75 patients daily. The daily number of oncology patients seen at DHH and UCCC was not estimated. ESJH has six medical oncologists, and RMCC Boulder had seven medical oncologists. Each provider had a minimum of one patient each month completing adjuvant chemotherapy treatment. The majority of patients who completed treatment were usually seen every two to six months for follow up care. Subjects were selected from the population of patients who had completed treatment within the past six to 18 months at ESJH and RMCC, DHH and UCCC. Subject accrual continued until an adequate sample size was reached.

Patients who completed adjuvant chemotherapy within the previous six to eighteen months were invited to complete the survey questionnaire. Flyers with an invitation to participate in the survey and offering directions on how to access it were strategically placed in the cancer centers. The respondent marked the boxes for the eligibility criteria and signified agreement to participate in the study by completing the questionnaire. Due to the self-sampling technique, no control was exercised over the ethnic or gender composition of subjects.

Recruitment. The specifics of site, format and sampling technique were chosen in efforts to accrue a homogeneous sample adequate in number for the study. The following sites agreed to offer the questionnaire to eligible cancer survivors: ESJH
Comprehensive Cancer Center, Rocky Mountain Cancer Center Boulder, Denver Health and Hospital’s outpatient infusion center and the Anschutz Cancer Pavilion’s outpatient cancer clinic were invited to participate in this study. A questionnaire format was chosen because it offers a standardized measure in that the same information is gathered from each participant. A non-probability, convenience sampling technique was chosen because this method permits accrual of as many subjects as possible. All patients at the designated cancer centers who match the eligibility criteria were invited to participate in the study.

During a follow up appointment or a survivorship appointment, a patient who had completed adjuvant chemotherapy treatment within the previous six to 18 months was invited to participate in the study by his/her provider or a staff member. Clinic staff including medical assistants, registration staff, nurses, and physicians were trained about the specifics of the study. Each staff member was instructed on how to notify patients about the study and subsequently invite a patient to review the information sheet and the questionnaire.

Flyers were placed in exam rooms, in elevators, and in bathrooms. Potential subjects were invited to participate by completing a paper copy of the questionnaire and depositing it in the drop box provided in the waiting room or by accessing the designated Survey Monkey website listed on flyers available to patients in the waiting room, the exam rooms, bathrooms, and at the scheduling desks. The survey was expected to take less than ten minutes to complete. The patient was given written instructions on how to access the Survey Monkey web site to complete the questionnaire at home or at the cancer center. Computers were available at the cancer center for completion of the questionnaire. A locked drop box was placed next to the questionnaires for anonymous
deposit. A locked drop box marked “Deposit Completed Surveys Here” was located in the reception area for hard copies of the questionnaire. All study data was completed anonymously. The waiting areas all had areas of privacy away from other patients where a respondent could complete the survey privately. All participant information returned was on a voluntary basis. In order to track the overall response rate, each survey was numbered consecutively beginning with 001. Each site was designated on each questionnaire. Questionnaires were regularly collected from each site by the investigator or designee. The paper questionnaires were collected regularly from drop boxes placed in conspicuous places as described above, in each cancer center by the principal investigator or designee. Each participant self-selected for the study.

Accrual of online participants occurred through publishing the website on fliers placed in cancer centers at the study sites, DHH, ESJH, RMCC, and CU. A link to the study was also placed on the web sites of the Colorado Cancer Coalition, ESJH, and RMCC.

Procedure

Participants had a choice about how they could complete the study questionnaire. Questionnaires were provided on line through Survey Monkey or in paper form which was given to participants during a clinic appointment. Participants completing the paper form questionnaire were asked to return the questionnaire at the end of the appointment to the scheduler at checkout or it could have been placed in the box marked “Deposit completed Surveys Here”, on the scheduler’s desk. All questionnaires were completed anonymously. The online version, administered through Survey monkey, was completed on a laptop computer available at the cancer center or at home if the patient preferred. A
web link was provided in an informational flier available to all patients in a variety of places at each survey site; in the bathrooms, at the scheduling desk, in the waiting rooms and in the exam rooms. An information sheet postcard consent form was provided as part of the study introduction and eligibility criteria in both hard copy and electronic forms of administration of the questionnaire. Survey Monkey was chosen for online administration of the questionnaire as it allows for easier data management and secure results to alleviate the danger of being lost or altered. The questionnaires were available for patients who completed adjuvant treatment for cancer within the previous six to 18 months. Adjuvant means in addition to, and adjuvant cancer therapy is defined as treatment for cancer given with curative intent in addition to and after completion of surgery or radiation therapy. The survey contained an invitation to any patient meeting the eligibility criteria. The Survey Monkey version can be found in Appendix D and the hard copy paper version can be found in Appendix E.

The study was approved by Colorado Medical Investigational Review Board (COMIRB) and implied consent was obtained prior to the respondent completing the survey. The study was also approved by the IRB at Exempla Saint Joseph’s hospital in compliance with their requirements. Rocky Mountain Cancer Centers Boulder and Denver Health and Hospital accepted studies approved by COMIRB.

**Consent.** The study provided an information sheet that used implied consent if, after reading, the potential participant chose to complete the questionnaire. The information sheet describes why the study was being done, what happens to the participant who joins the study, any possible discomforts or risks, including phone numbers for the Statewide Crisis Services and Mobile Crisis Outreach services.
study also lists any possible benefits, and that there is no compensation for participation. The information clearly states participation is voluntary and anonymous. The phone number of the principal investigator is listed on the information sheet. The final paragraph is an agreement statement that says the participant has read the information and understands the possible risks and benefits and that being in the study is voluntary.

The study questionnaire was given to a cross section of patients during the transition period from cancer patient to cancer survivor (Appendix A). Each questionnaire had an eligibility statement at the top of the first page of the document. Potential candidates were asked to confirm by marking yes that they met the eligibility requirement of having completed adjuvant chemotherapy within the last six to 18 months.

The five eligibility screening questions were as follows:

1. Do you read and understand English?
2. Are you between 18 and 89 years of age?
3. Are you physically able to complete this questionnaire by yourself without help?
4. Have you completed your chemotherapy?
5. Was your chemotherapy completed within the last six to 18 months?

If you answered no to any of these questions, please stop and do not complete the questionnaire. For more information, you may contact the researcher via text, phone call or email at: 303-868-0054 or lynne.bentley@ucdenver.edu

A final statement advised the person who completed the questionnaire that there is no financial compensation for participation and the respondent may continue if all five questions were answered yes. Demographics were gathered at the end of the
questionnaire, after the three subscales were completed by the participant. The reason for this order of placement was that the information from the questionnaires was most important, and if the subject did not complete the questionnaire it would be least detrimental to eliminate the demographics.

**Effect size and statistical power.** In the context of this study, statistical power determines how likely it is for the analysis to show that identity balance has an effect on the relationship between symptom burden and emotional distress. Adequate power is considered to be 0.8 or greater (Cohen, 1988). Increasing power reduces the chances of a Type II error.

A medium effect size was chosen for this study based on existing literature. Gan, Nasir, Zalilah, and Haziz (2012) conducted a mediation study of the role of psychological factors and disordered eating in which findings indicated distress as a mediator and power estimates to detect a medium effect size using a sample of 237 males was .95, and for the sample of 347 females the power estimate was 0.987. Chang, Casey, Dusek, and Benson (2010) reported a mediation effect of spirituality on psychological outcomes in a cardiac rehab program, which also yielded a medium effect size. For the purposes of this study, the effect size does not involve a life threatening circumstance, nor will it determine if a treatment is beneficial. Effect size will affect the determination of a mediated effect. However, unlike a study in which the dependent variable may be a life threatening event, there is no evidence to suggest that completion of the questionnaire for this study will affect a person’s health. While this study hypothesized that identity balance mediated the relationship between symptom burden and emotional distress, the literature suggested that it was a partial mediation.
Fritz and MacKinnon’s (2007) article on power and effect in mediation studies, which reported empirical estimates of minimum sample sizes for detecting a mediation effect, was used to determine minimum sample size. In their article, Table 3 illustrated the sample size necessary to conduct a mediation study with .8 statistical power for Baron and Kenny’s (1986) tests. According to the table and article text, a tau’ parameter value of .39 and conditions of α = .26 and β = .39 yields a sample size of 124. The conditions of α = .26 and β = .39 were used in this study. These parameter values were chosen because .39 was the designated estimate for a medium effect, and .26 (small-medium) was approximately halfway between the values for small (.14) and medium (.39) effects, as recommended in the literature and illustrated in Table III.2 below (Fritz & McKinnon, 2007). For the purposes of this study and the rationale from Fritz and MacKinnon, the researcher chose to use the values of .14 as small, .26 for small-medium, .39 for medium and .59 for large effect size of the path.

Anomalies relating to statistical power in mediation studies were described by Kenny and Judd (2014). In a model where the indirect effect and the total effect are identical, and for which there is no direct effect, the power used to test total effect can be substantially smaller than that used to test the indirect effect. Additionally, when the predictor variable has a direct causal effect on the outcome variable while controlling for the mediator variable (Table 2), the power of the test of the indirect effect (path a) may be greater than the power of the test of the direct effect (path c) (Kenny & Judd, 2014). This rationale suggested that it is prudent to constrain path a due to the potentially greater effect it may have on the outcome variable.
Table 2
Statistical Power Estimates

<table>
<thead>
<tr>
<th>Effect size</th>
<th>α</th>
<th>Conditions</th>
<th>Power Probability of error (1-β)</th>
<th>Estimated Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medium</td>
<td>0.05</td>
<td>0.26 .39</td>
<td>0.39</td>
<td>0.95</td>
</tr>
</tbody>
</table>

Conditions:
“H”: $a$ is the path between symptom burden and identity balance = 0.26
“M”: $b$ is the path between identity balance and emotional distress = 0.39
tau’ is the path between symptom burden and emotional distress, accounting for the effect of the mediator, identity balance.

Mediation. In mediation analysis, if the predictor variable (X) explains all the variation in the mediator variable (M) there will be no effect of M on the outcome variable (Y). The hypothesis for this study was that identity balance is a partial mediator, and that symptom burden affects identity balance which then affects emotional distress. The presumption for using mediation analysis is that symptom burden acts on identity balance in cancer survivors who have encountered a change in circumstances resulting from the symptoms suffered as a consequence of the cancer experience (Bultz & Holland, 2006).

Logic dictates that it would be most prudent to assign a more conservative estimate to path $a$ than path $b$. As noted in Frazier, Tix and Barron (2004) mediation occurs when the mediator variable (M) acts as the means through which the predictor variable (X) influences the outcome variable (Y). In addition, extant substantive evidence indicated that symptom burden (X) affected a person’s identity. Identity balance (M) affects emotional distress (Y) primarily if altered by symptom burden (X). If symptom burden (X) has little or no effect on identity balance (M), there is little or no effect on emotional distress (Y) (Morse, 1997). However, if symptom burden (Y) has a large effect on identity balance (M), there is a subsequent stronger effect on emotional distress (Y).
due to inability to rebalance and reconstitute identity in cancer survivors (Bultz & Holland, 2006; Morse, 1997; Morse & Carter, 1996; Piggin & Jones, 2009; Shapiro et al., 1997). If identity balance (M) remains stable over changing circumstances, the literature suggests that cancer survivors experience a lower intensity of emotional distress (Y) despite enduring symptom burden (X) resulting from their cancer journey (Kahn & Steeves, 1986; Morse, 1997; Bultz & Holland, 2006). Based on the literature, and the above analysis, a sample size of 124 and using Fritz and MacKinnon’s (2007) rationale, a medium effect size of .39 with an alpha of 0.05 was used in this study.

Statistics

**Mediation analysis.** Simple mediation, described by Kenny (n.d.), considers a variable X that causes variable Y. The path between these two variables is labeled path c. Path c is called the direct effect. An intervening variable is called the mediator, M. When M is introduced and intervenes in the relationship between X and Y, the new path is labeled c’. Complete mediation occurs when the predictor or causal variable X, symptom burden, no longer affects the outcome variable, Y, emotional distress after accounting for the mediator or intervening variable, identity balance. Thus, path c’ is zero. Partial mediation occurs when path c decreased, yet different from zero when the mediator is presented. Kenny’s (n.d) macro for mediation, MedText, uses the sample size of the study and the number of covariates in each of the steps to complete a power analysis that will achieve a medium effect size of .3 (r = .3). For the test of step 1 (path c) complete mediation is assumed and r = .09 (.3 * .3) as the effect size measures.

The test for assumption violations for regression first assessed the standardized residual using EXPLORE in SPSS using variables specific to each step in the Baron and
Kenny (1986) mediation analysis model, and then confirmed by using the MedText.SPS syntax macro in SPSSv22 (Kenny, 2014). Several steps were taken to analyze the model using linear and multiple regression. The four assumptions of linear regression models were assessed: 1) linearity of the relationship between the predictor and the criterion variable, 2) independence of observations, 3) homogeneity of variance, and 4) normal distribution. Violations of any one of these assumptions suggest inaccuracies in the regression model. If normality is violated, the calculation of confidence intervals may be either too wide or too narrow (Field, 2009). Normality of data is commonly tested by using the Shapiro-Wilks Test, skewness, kurtosis, and visual inspection of either the histogram or Q-Q plots. A nonlinear transformation may be used when normality violations occur (Field, 2009).

This study used a mediation analysis to measure the relationships among variables. Mediation analysis was chosen based on the relationships among the variables under investigation, identified in the literature. A mediational effect describes the relationship between an endogenous and exogenous variables. For the purposes of this study, symptom burden, the antecedent of emotional distress, was classified as the exogenous variable. Identity balance is the mediating variable. The independent variable (symptom burden) and the mediating variable (identity balance) affect the dependent variable (emotional distress). Total scores for the POMS-B and IBL, and average scores for the CMSAS-PHY were used in analysis as indicated in the instruments’ manuals or confirmed by the instrument developer via email prior to analysis.

When the proposed model has been appropriately specified, multiple regression is used to estimate the first three steps (paths $c$, $a$, and $b$). The contemporary method
measures the indirect effect which can be defined as: total effect = direct effect + indirect effect or \( c = c' + ab \). The indirect effect is a measure of how much of the effect of \( X \) on \( Y \) that is being mediated. The indirect effect is equal to the decrease of the effect of the causal variable on the outcome or \( ab = c - c' \) (Kenny, n.d.).

Kenny developed a syntax macro (MedText.SPS) to run the indirect effect, which allows for one causal variable, a mediator and an outcome variable. The macro computes the indirect effect by calculating the product of coefficients. The mediator and outcome must be continuous, measured on an interval scale.

If mediation analysis results reveal non-significant findings at any step, then the requirements for a mediation effect are not met. A three variable recursive model was used which has two causal paths to an exogenous variable and is pictured in the following path model (refer to figure III.1)

There are four steps to satisfy, for a completely mediated effect.

1. The effect of \( X \) on \( Y \) is significant.
2. The effect of \( X \) on \( M \) is significant.
3. The effect of \( M \) on \( Y \) controlled for \( X \) is significant.
4. The direct effect of \( X \) on \( Y \) adjusted for \( M \) is non-significant in a completely mediated model. In a partially mediated effect the direct effect of \( X \) on \( Y \) adjusted for \( M \) is diminished.

The hypotheses for this study were:

1. There is a relationship between symptom burden and identity balance.
2. There is a causal relationship between symptom burden and emotional distress.
3. There is a causal relationship between identity balance and emotional distress.

4. Identity balance mediates the relationship between symptom burden and emotional distress.

**Causal paths.** There are two causal paths:

1. There is a causal relationship between symptom burden and emotional distress.

2. There is a causal relationship between identity balance and emotional distress.

When the study controls for identity balance, the relationship between symptom burden and emotional distress is changed (mediated). Identity balance was predicted to be the mediator of the relationship between symptom burden and emotional distress. This study used a recursive model based on the literature, therefore these functionalities provided the most appropriate and meaningful estimates for the aims of this study.

Extant literature suggests symptom burden has a direct effect on emotional distress; the greater the symptom burden, the greater the emotional distress (Figure 4).

**Figure 4.** Path c: Direct Effect of Symptom Burden on Emotional Distress
Symptom burden has an inverse effect on identity balance; the greater the symptom burden the lower the identity balance score (Figure 5).

**Figure 5.** Path *a*: Direct Effect of Symptom Burden on Identity Balance

Identity balance has an inverse effect on emotional distress; the lower the identity balance score, the higher the emotional distress (Figure 6).

**Figure 6.** Path *b*: Inverse Effect of Identity Balance on Emotional Distress
Instruments

This study used a questionnaire that included three validated tools: (1) the Identity Balance subscale (IBL) of the Identity and Experiences Scale (IES) to measure identity balance, (2) the Brief Profile of Mood States (POMS-B) to measure the global domain of emotional distress, and (3) the Condensed Memorial Symptom Assessment Scale—Physical (CMSAS-PHYS) to measure symptom burden. Each of these instruments was designed for patient self-assessment (Kirkova et al., 2006; Vodermaier, Linden, & Siu, 2009). Table 3 provides a summary of psychometric properties for mediation analysis instruments.

Table 3
Mediation Analysis Instruments: Summary

<table>
<thead>
<tr>
<th>Instrument Title</th>
<th>Date(s)</th>
<th>Purpose</th>
<th>Construct(s) Measured</th>
<th>Population for which Designed</th>
<th>Number of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condensed Memorial Symptom Assessment Scale—Physical (CMSAS-PHYS)</td>
<td>2004</td>
<td>Measures symptom distress or frequency for physical symptoms</td>
<td>Symptom burden</td>
<td>Patients who suffer cancer-related symptoms</td>
<td>11</td>
<td>α = 0.84</td>
<td>r = -.43 to -.76</td>
</tr>
<tr>
<td>Identity Balance Subscale (IBL)</td>
<td>2010, 2003</td>
<td>Assess the extent to which the individual approaches experiences with a consistent sense of self, but with the flexibility to incorporate discrepant information about the self into identity as the situation demands.</td>
<td>Identity Balance</td>
<td>Adults 18+ years of age</td>
<td>11</td>
<td>α = 0.84-0.86</td>
<td>r = .45 to -.26</td>
</tr>
</tbody>
</table>
(Table 3 continued)

<table>
<thead>
<tr>
<th>Instrument Title</th>
<th>Date</th>
<th>Purpose</th>
<th>Construct(s) Measured</th>
<th>Population for which Designed</th>
<th>Number of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brief Profile of Mood States (POMS-B)</td>
<td>1987</td>
<td>Measures tension (anxiety), depression, anger, fatigue, confusion and vigor.</td>
<td>Mood states</td>
<td>18+ years of age</td>
<td>11</td>
<td>α = 0.93</td>
<td>r = .56 to .77</td>
</tr>
</tbody>
</table>

**Condensed Memorial Symptom Assessment subscale-Physical (CMSAS-PHYS).** The Condensed Memorial Symptom Assessment Survey is the condensed version of the Memorial Symptom Assessment Survey. The subscale, Condensed Memorial Symptom Assessment Survey- Physical (CMSAS-PHYS), was used to measure physical symptom burden. The CMSAS-PHYS assesses the severity of multiple physical symptoms and their impact on daily functioning (Chang, Hwang, Kasimis, & Thaler, 2004). The CMSAS-PHYS subscale is comprised of 11 items and contains no reverse coding. The Likert type scale measures whether a symptom was present in the last seven days, and if so, how much it bothered the person bothered the person. Scores range from not at all to very much. There are no items with reverse scoring. This variable is dichotomous with the first question asking if the symptom was present or not in the last seven days. If the symptom was present but not bothersome the participant marked a 0 which then given a weighted score of 0.8. A symptom that scored a one, for a physical symptom that caused little bit of distress in the last 7 days, was weighted with a score of 1.6; 2.4 was the weighted score for a physical symptom that was marked as a two, somewhat distressful in the last 7 days; 3.2 was the weighted score for a symptom marked as a three, that caused quite a bit of distress in the last 7 days, and 4.0 was the weighted score given for a mark of four given when a physical symptom caused very
much distress in the last 7 days. Thus a score of 0 = 0.8, 1 = 1.6, 2 = 2.4, 3 = 3.2, and 4 = 4.0. For the study statistical calculations, the CMSAS-PHYS average score was used.

The CMSAS was developed as a rapid symptom assessment scale that was easy to complete, takes approximately five minutes to complete, while still giving an accurate measure of symptom burden. Chang et al. (2004) measured the CMSAS against the Fact-G, and the Memorial Symptom Assessment Scale-Short Form. Reliability of the subscale CMSAS-PHYS was tested and Chronbach’s alpha was 0.72. The measure reportedly took about five minutes to complete. Lam, et al. (2008) validated the CMSAS in a sample of 256 Chinese cancer patients and found that the Chronbach’s alphas score for the CMSAS-PHYS subscale of the CMSAS was 0.84, suggesting a high level of internal consistency (Appendix C).

**Identity Balance sub-scale (IBL) of the Identity and Experience Scale (IES).**

Whitbourne’s Identity and Experience Scale (IES) assesses the individual’s use of identity processes when adapting to change. Sneed and Whitbourne (2003) studied changes experienced by adults throughout time. Normal physical, psychological and social role changes naturally occur throughout adulthood, and characterize circumstances specific to each person. These changes challenge the person’s own sense of identity. Whitbourne’s IES measured the fluctuation of identity indicators over changing circumstances. All three IES measures are intended for use with adults 18 and older (Whitbourne, 2002).

Coding for the Identity Balance subscale of the Identity and Experience Scale (Whitbourne, 2002) is included in the manual in Appendix A (Whitbourne, 2002). The manual states the tool uses no reverse scoring. The coding scheme used for the IBL
subscale ranges from 1 = not like me to 7 = completely like me. Participants rate each of the 11 items in the IBL subscale on the 7-point Likert type scale.

For this dissertation study, identity was measured using the Identity Balance subscale (IBL) (Whitbourne, Sneed, & Skultety, 2002). The items of the IBL assessed how consistent identity remained throughout changing circumstances, by measuring a patient’s flexibility to incorporate discrepant information about the self into identity. Whitbourne’s study (1986) showed that, during changing circumstances, there was identity balance variation among subjects and that identity balance was positively related to the ability to incorporate changes into the identity while maintaining a consistent and positive view of the self. Further, the IBL subscale measured the extent to which the individual approached experiences with a consistent sense of self, and with the flexibility to incorporate discrepant information about the self into identity as the situation demanded. IBL evaluated the consistency of identity during change.

The IBL subscale contained 11 items such as: “Try to keep a steady course in life but am open to new ideas” and “Am not afraid to confront my failures”. Participants rate each of 11 items on a 7-point Likert scale ranging from “not like me” to “completely like me.” There is no weighting or reverse scoring used. Scores were analyzed with total subscale scores ranging from 3 to 33. This tool can be completed in five minutes or less (Whitbourne, Sneed, & Skultety, 2009).

The IBL had been tested for validity and reliability in several studies to date. Whitbourne and Collins (1998) developed the initial scale of identity processes to assess how participants reacted to specific age-related changes. The sample comprised 81 male and 161 female participants (n=242) ranging in age from 40 to 89 years old (M= 63.31,
Principal axis factoring revealed three distinct factors corresponding to accommodation, assimilation and balance using the overall sample, as well as two separate subsamples. Reliability specific to the IBL was satisfactory for both subsamples; under 65 ($r = .68; n = 103$) and over 65 ($r = .69; n = 112$). Contrary to expectation, correlation results with the Rosenberg Self-Esteem Questionnaire (SEQ; Rosenberg, 1965) revealed identity balance was negatively related to self-esteem.

In subsequent studies, various analyses were used to condense the items and examine relationships between the IES subscales and self-esteem, depression, and defense mechanisms, as well as age and gender differences. Detailed summary statistics including IBL validation estimates can be found in Table 3 below. Reliability for the IBL ranged from .73 to .90 (Sneed & Whitbourne, 2001; Sneed & Whitbourne, 2003; Weinberger & Whitbourne, 2010; Whitbourne et al., 2002; Whitbourne et al., 2009; Whitbourne & Collins, 1998).

Adequate construct validity, as measured by factor analysis, internal consistency reliability, and inter-correlation with numerous validity instruments were reported (Weinberger & Whitbourne, 2010; Whitbourne et al., 2009). Construct validity was estimated by calculating the correlation between the IBL and the Self-Esteem Questionnaire (SEQ; Rosenberg, 1965), the Center for Epidemiological Studies Depression Scale-20 (CESD-20; Radloff, 1977), and five subscales from the Defense Mechanisms Inventory (DMI; Gleser & Ihilevich, 1969) with summary statistics displayed in Table 4. Group differences were also tested by correlation between age and IBL items (Whitbourne et al., 2009), as well as gender and IBL items (Sneed & Whitbourne, 2003). It was determined that, overall, the items measured the
same construct, and all indicators of the construct were represented in each subscale
(Sneed & Whitbourne, 2001; Sneed & Whitbourne, 2003; Weinberger & Whitbourne, 2010; Whitbourne et al., 2002; Whitbourne & Collins, 1998).

Table 4
Identity Balance Subscale (IBL): Validation Instruments and Group Differences

<table>
<thead>
<tr>
<th>Study first author</th>
<th>Validity Instrument or Group Differences</th>
<th>Purpose</th>
<th>Construct(s) Measured</th>
<th>Population Tested</th>
<th>Number of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weinberger (2010)</td>
<td>Center for Epidemiological Studies: Depression Scale-20 (CESD-20; Radloff, 1977)</td>
<td>Assessment of depressive affect symptoms</td>
<td>Depressed mood, feeling of worthlessness feelings of hopelessness, loss of appetite, poor concentration, and sleep disturbance</td>
<td>n = 68; 67% (F); age 66-91 yrs.</td>
<td>20; self report</td>
<td>α = .73-.90</td>
<td>r = -.13</td>
</tr>
<tr>
<td>Sneed (2013)</td>
<td>Gender</td>
<td>Measures Identity Balance by Age</td>
<td>Explore relationship between IBL and gender</td>
<td>n = 173; 62% (F); age 42-85 yrs.</td>
<td>NA</td>
<td>α = .86</td>
<td>r = -.11</td>
</tr>
<tr>
<td>Whitbourne (2002)</td>
<td>Age</td>
<td>Explore relationship between IBL and Age split by gender</td>
<td>Identity Balance by Age</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>10</td>
<td>α = .86</td>
<td>rAGE-M = -.14, rAGE-F = .07</td>
</tr>
</tbody>
</table>
(Table 4 continued)

<table>
<thead>
<tr>
<th>Study author</th>
<th>Validity Instrument or Group Differences</th>
<th>Purpose</th>
<th>Construct(s) Measured</th>
<th>Population Tested</th>
<th>Number of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whitbourne (2002)</td>
<td>Principalization subscale (PRN) from the Defense Mechanism Inventory (DMI; Gleser &amp; Ihilevich, 1969)</td>
<td>Assesses intellectualization, rationalization, and isolation of affect</td>
<td>Principalization defense mechanisms</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>200 (overall DMI)</td>
<td>α = .86</td>
<td>rPRN-M = .21 rPRN -F = .24*</td>
</tr>
<tr>
<td>Whitbourne (2002)</td>
<td>Reversal subscale (REV) from the Defense Mechanism Inventory (DMI; Gleser &amp; Ihilevich, 1969)</td>
<td>Measures denial, negation, reaction formation, and repression</td>
<td>Reversal defense mechanism</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>200 (overall DMI)</td>
<td>α = .86</td>
<td>rREV-M = .15 rPRN F = -.16</td>
</tr>
<tr>
<td>Whitbourne (2002)</td>
<td>Projection subscale (PRO) from the Defense Mechanism Inventory (DMI; Gleser &amp; Ihilevich, 1969)</td>
<td>Assesses attributing undesirable aspects of the self to others.</td>
<td>Projection defense mechanism</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>200 (overall DMI)</td>
<td>α = .86</td>
<td>rPRO = M -.15 rPRO F = -.16</td>
</tr>
<tr>
<td>Whitbourne (2002)</td>
<td>Turning Against Object subscale (PRO) from the Defense Mechanism Inventory (DMI; Gleser &amp; Ihilevich, 1969)</td>
<td>Measures identification with the aggressor and displacement</td>
<td>Turning Against Object defense mechanism</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>200 (overall DMI)</td>
<td>α = .86</td>
<td>rTAO-M = .26 rTAO -F = -.19</td>
</tr>
</tbody>
</table>
(Table 4 continued)

<table>
<thead>
<tr>
<th>Study first author</th>
<th>Validity Instrument or Group Differences</th>
<th>Purpose</th>
<th>Construct(s) Measured</th>
<th>Population Tested</th>
<th>Number of Items</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whitbourne (2002)</td>
<td>Turning Against Self subscale (PRO) from the Defense Mechanism Inventory (DMI; Gleser &amp; Ihilevich, 1969)</td>
<td>Assesses self handicap, pessimism, and masochism.</td>
<td>Turning Against Self defense mechanism</td>
<td>n = 147; 63% (F) age 40-95</td>
<td>200 (overall DMI)</td>
<td>α = .86</td>
<td>rTAS-M = .13; rTAS - F = .09</td>
</tr>
</tbody>
</table>
Of the three IES subscales, the IBL was chosen for use in this study because it measured how consistent identity remains over changing circumstances, which was in alignment with the aims of this study. For the study statistical calculations the IBL total score was used. Permission was received from the author, Dr. Susan Whitbourne, to use the IBL separately and to renumber this subscale from one to 11 for clarity and consistency.

**Profile of Mood States-Brief (POMS-B).** The Brief Profile of Mood States (POMS-B) (Cella et al., 1987) was chosen as a global measure of emotional distress and was validated with a sample of cancer patients. It is derived from the original Profile of
Mood States developed by McNair, Lorr, and Droppleman (1971). The full POMS contains 65 words or statements that describe feelings people have. The POMS contains subscales measuring vigor and friendliness which are reverse scored. The POMS Brief features 11 words describing mood states and can be completed in less than five minutes. The POMSB is scaled the same as the POMS, except that the items with reverse scoring were removed from the POMS B (Cella, et al., 1987; Norcross, Guadagnoli, & Prochaska, 1984; Yeun & Shin-Park, 2006). The response format used a five point Likert scale ranging from 0 to 5 where: 0 = not at all; 1 = a little; 2 = moderately; 3 = quite a bit; and 4 = extremely. These responses were scored in six-factor analytically derived mood dimensions. The scores are the sums of item ratings for each dimension. A zero rating means the mood is not present, whereas four conveys that the mood is felt extremely. There is no weighted scoring.

This tool was selected over the full measure of emotional distress due to the ease of completion and the highly satisfactory internal consistency (Cella et al., 1987). The tool measured tension (anxiety), depression, anger, fatigue, confusion and vigor. Cella et al. (1987) noted that the subscales of the POMS (tension, depression, anger, fatigue, confusion, and vigor) did not reliably exhibit discriminate validities. The overlap of domains was significant, with constructs such as anxiety and depression being highly inter-correlated. Of note, POMS had high anxiety (tension) to depression inter-correlations ranging from 0.56 to 0.77. Of the inter-correlations between the five distress subscales, the mean and median coefficient was 0.60. Due to the inter-correlations of the POMS, the authors used a principal components factor analysis to determine that the 58 item POMS could be reduced to one factor reflecting distress.
The POMS-Brief resulted by instituting a cut off score of 0.65 for factor loadings. Cronbach’s alpha was not significantly different for the POMS-B at 0.91 and the POMS at 0.93. The tool was also validated by Baker, Denniston, Zabora, Polland, and Dudley (2002) in cancer patients awaiting bone marrow transplant. The authors reported their analysis provided evidence of convergent and discriminant validity (subcategories of construct validity) of the Brief POMS. Convergent validity refers to how well measures of constructs correlate with each other and how well dissimilar constructs can be discriminated.

The Brief POMS was chosen when evidence suggested that the greatest contributor to emotional distress results from one factor. Thus, the authors concluded the POMS- B score was a reliable global measure of emotional distress in cancer survivors. (Appendix B). For the study statistical calculations the POMS B total score was used.
CHAPTER IV

RESULTS

The role of identity balance in the experience of emotional distress in cancer survivors had only been studied qualitatively prior to this investigation. This study was undertaken as a first step in the quantitative understanding of the role of identity balance in mediating the relationship between symptom burden and emotional distress in a cross section of the cancer survivor population.

Sample Participants Demographics

A sample of 128 adjuvant cancer patients, 68.8% females, 28.1% males, and 3.8% unknown gender, participated in this study. The study sample was 16.4% Hispanic, 72.7% non-Hispanic, and 10.9% unknown. Ethnicity reporting showed 2.3% Native American, 3.1% Asian, 2.3% African American, 74.2% European American, 8.6% representing two or more ethnicities, and 9.5% not reporting an ethnicity. Nearly 60% of respondents completed some college with 29% having completed college and/or graduate education. Of the 115 participants who answered, one completed a doctoral degree (.8%), five completed a master’s degree (3.9%), thirty-one completed a four year college degree (24.2%), seventeen completed a two year college degree (13.3%), Thirty-four completed high school or received a GED (29.6%), twelve completed some high school (9.4%), two completed middle school (1.7%), and all respondents completed grade school. Overall, seventy-two of the 115 respondents acquired some higher education (56.3%).

Age of participants ranged from 24 years to 83 years. The modal age was 48 and the median age was 55 years. The mean was 54.88 years with a standard deviation of 12.48 years. Years in the U.S. ranged from less than one to 83. The mode for years in the
U.S. was 53 years and the median number of years in the U.S. was 54.50 years. The mean was 52.99 years. For this sample, the mean age of participants was 54.88 years with a mean number of years in the U.S.* of 52.99. While there were participants who were not native to the U.S., the results show that the majority were. All data were self-reported.

See Tables 5 and 6 for summary statistics.

Table 5
Frequency Distribution of Sample Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>36</td>
<td>28.1</td>
</tr>
<tr>
<td>Female</td>
<td>88</td>
<td>68.8</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>21</td>
<td>16.4</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>93</td>
<td>72.7</td>
</tr>
<tr>
<td>Missing</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native American</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>3.1</td>
</tr>
<tr>
<td>African American</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>European American</td>
<td>95</td>
<td>74.2</td>
</tr>
<tr>
<td>Two or more races</td>
<td>11</td>
<td>8.6</td>
</tr>
<tr>
<td>Missing</td>
<td>12</td>
<td>8.8</td>
</tr>
<tr>
<td>Education: highest level some or completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle school</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>High school</td>
<td>34</td>
<td>26.6</td>
</tr>
<tr>
<td>College</td>
<td>66</td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Doctorate</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Middle school</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Missing</td>
<td>8</td>
<td>6.3</td>
</tr>
</tbody>
</table>

Note: All data were self-reported. Total sample size differences were due to non-responses.
Table 6
*Age and Years in United States*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mode</th>
<th>Median</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48</td>
<td>55</td>
<td>54.88</td>
<td>12.48</td>
<td>123</td>
</tr>
<tr>
<td>Years in United States (U.S)</td>
<td>53</td>
<td>54.5</td>
<td>52.99</td>
<td>15.99</td>
<td>112</td>
</tr>
</tbody>
</table>

Note: Multiple modes existed. Smallest value is shown.

**Living Arrangements and Financial Information**

Further sample descriptive statistics are displayed in Table 7. Of the sample population, 55.5% lived with others. Participants who lived alone made up nearly one third of the sample at 32.8%. Eleven % of participants did not answer the question.

Participants who were married or in a partnership comprised 58% of the sample, while 25.8% were single. Twenty-one participants, 16.4%, did not answer the question regarding living arrangements. One hundred and five participants (82%) answered yes and 17 answered no to whether or not income was sufficient for their needs. With regard to having medical insurance, 108 respondents answered yes and five answered no. Of those who responded to the question about financial assistance, 19 answered yes, they had financial assistance with healthcare bills and four answered no, however, 105 participants did not answer this question.

Table 7
*Living Arrangements and Financial Information*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I live alone</td>
<td>42</td>
<td>32.8</td>
</tr>
<tr>
<td>I live with others</td>
<td>71</td>
<td>55.5</td>
</tr>
<tr>
<td>Partnership/ Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/ Unmarried Partnership</td>
<td>74</td>
<td>57.8</td>
</tr>
<tr>
<td>Single</td>
<td>33</td>
<td>25.8</td>
</tr>
</tbody>
</table>
Note: All data were self-reported. Total sample size differences were due to non-responses.

**Cancer Type**

Females in this study comprised 68.8% of all participants, and 40% of all participants responded that they had breast cancer. Colorectal cancer was the second most reported cancer type in this study at 10.2%. Gynecological cancer was reported by 8.6% of participants, and 7.8% of respondents reported having lymphoma or leukemia.

Distribution by cancer type can be found in Table 8.

**Table 8**

*Sample Size and Percentage of Sample by Cancer Type*

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>52</td>
<td>40.6</td>
</tr>
<tr>
<td>Colorectal</td>
<td>13</td>
<td>10.2</td>
</tr>
<tr>
<td>Ovarian</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Endometrial</td>
<td>8</td>
<td>6.3</td>
</tr>
<tr>
<td>Uterine</td>
<td>7</td>
<td>5.5</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>6</td>
<td>4.7</td>
</tr>
<tr>
<td>Thyroid</td>
<td>3</td>
<td>2.3</td>
</tr>
<tr>
<td>Prostate</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Skin or melanoma</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>H &amp; N</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Missing</td>
<td>17</td>
<td>13.3</td>
</tr>
<tr>
<td>Total</td>
<td>128</td>
<td>100</td>
</tr>
</tbody>
</table>

(Table 7 continued)
Procedure

**Accruals.** Participants were accrued from three sites and online as shown in Table 9. Fliers were placed in strategic locations in each study site to include elevators, bathrooms, exam rooms, and reception areas. Each site had a site coordinator who, with the principal investigator, conducted training sessions for staff, which included secured distribution, clarification, and collection of questionnaires. Paper questionnaires were offered by trained employees at the front/reception desk and in exam rooms. Participants deposited completed paper questionnaires in a locked collection box located in the waiting areas. For participants who preferred to complete the survey online, a flier with instructions on how to access the survey monkey form of the questionnaire was provided. Of the eligible participants with useable questionnaires, one participant was accrued from DHH and five participants were accrued from RMCC. Seventy-nine participants were accrued at the Comprehensive Cancer Center at Exempla St. Joseph Hospital (ESJH), and forty-three were accrued online. The University of Colorado had no participants who completed hardcopy questionnaires. It is known, however, that one online participant learned of the study from a flyer in the Anschutz Cancer Center. That participant contacted the Principal Investigator by phone and subsequently accessed the online study questionnaire.

<table>
<thead>
<tr>
<th>Site</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESJH</td>
<td>79</td>
<td>61.7</td>
</tr>
<tr>
<td>RMCC</td>
<td>5</td>
<td>3.9</td>
</tr>
<tr>
<td>DHHA</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>OL</td>
<td>43</td>
<td>33.6</td>
</tr>
<tr>
<td>Total</td>
<td>128</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 9
*Number and Percentage of Respondents by Site*
After acquiring 128 eligible participants who had successfully completed the questionnaire, accruals were closed. Accrual sites were notified that participant numbers had been met and were requested to remove the link to the survey-monkey questionnaire from their websites. All unused questionnaires and the locked collection boxes were picked up by the principal investigator. The questionnaires were shredded and the boxes were returned to the investigator’s home office. Three additional hardcopy questionnaires had been successfully completed at the Exempla St. Joseph site, and were collected by the principal investigator. Flyers that had been placed at sites in bathrooms and in exam rooms were removed by the principal investigator and onsite study coordinators.

**Data preparation.** The data from Survey Monkey were downloaded and exported into an excel spreadsheet and cleaned. To clean the data, the columns consisting of the non-relevant data such as IP addresses and the sequence number of the participant were removed. Anticipating that the online and hardcopy data sets would be merged, the columns for the online data set were arranged in the same order as those on the hardcopy spreadsheet. The answers were then coded to be consistent with the codebook used for the hardcopy questionnaire. To assure accuracy, each column was coded separately according to the required designation listed in the code book.

Initially 189 cases comprised the overall data file. There were a total of 103 online and 86 hardcopy questionnaire cases. Sixty-one out of 103 online cases (60%) were ineligible leaving 42 online, eligible cases. All of the 86 hardcopy questionnaires collected, met the five eligibility criteria. This was possibly due to participant self-exclusion. This resulted in a total of 128 (67.7%) useable cases overall.
Coding was rechecked for accuracy and consistency with the codebook. Hardcopy and Survey Monkey data sets were checked for congruence. The columns were ordered exactly alike starting with site, accrual number, eligibility criteria, followed by the variables of interest; Symptom Burden (CMSAS-PHYS), Identity Balance, (IBL), and Emotional Distress (POMS-B) responses. Responses to the open ended question about other symptoms was inserted after the Emotional Distress (POMS-B) responses, followed by the demographics data. After completing the ordering of the data, the online and hardcopy sets were merged into the same spreadsheet. Then data were re-inspected and checked again for accuracy. Upon completion of this process, these data were reviewed for participant eligibility, data accuracy, and regression assumptions.

**Eligibility.** Participant eligibility for both hardcopy and online questionnaires was pre-determined by the questionnaire eligibility criteria. Any participant who did not answer yes to all of the five eligibility questions for the online questionnaire automatically bypassed the study questions and was taken to the end of the questionnaire. Nonresponse to any one of the five eligibility questions determined ineligibility and removal of responses from the final data set. Nonresponse to demographics questions did not constitute ineligibility. Of the total 189 participants, 128 questionnaires (or 67.7%) fulfilled the requirements for inclusion in the study and 65 questionnaires were found to have inadequate number of responses or did not meet the eligibility criteria of the study. The 65 questionnaires that did not meet the minimum requirements for accurate data accrual were removed.

**Missing Data.** Upon examination, data entry was highly scrutinized due to respondent self-report. The researcher reviewed the data file and found 30 missing data
points. Next the researcher calculated the percentage of missing data points which was only 1% (30/4,224). Following recommendations from Tabachnick and Fidell (2013), if there are five percent or less missing data points in a random pattern, nearly any procedure for handling missing values yields similar results. Therefore missing data were recoded as 999 as is acceptable practice according to current data preparation analysis standards (Field, 2009). The researcher determined there were an adequate number of data points to continue with analysis.

Data Analysis

Instrument reliability. Internal consistency of each subscale was analyzed to determine reliability in the sample of cancer patients (n = 128). The POMS-B, IBL, CMSAS-PHYS (symptoms), and CMSAS-PHYS (present/not) subscales were assessed separately to determine reliability. This was followed by evaluation of the overall CMSAS-PHYS measure. Results ranged from very strong to excellent except for the CMSAS-PHYS overall (αCMSAS-PHYSsymptoms = .87, αCMSAS-PHYSpresent/not = .81, α IBL = .93; α POMS-B = .95; α). The developers of the tool and those who independently validated results for the CMSAS-PHYS explained that the overall measurement of the physical symptoms was the score to be used in analyses. However, the variable is dichotomous with the first question asking if the symptom is present. Therefore, a weighted scoring method was used for the physical symptoms subscale to differentiate the answers. There was the possibility of a respondent noting that yes the symptom was present, however that symptom had not bothered them for the last seven days. The other possibility was that the symptom was not present at all and therefore did not bother the person. To account for the difference, those that experienced the symptom but it did not bother them were
assigned a weighted score of .8 and those who did not experience the symptom at all were scored with a zero. The remaining response options were assigned the following scores: a little bit (1.6), somewhat (2.4), quite a bit (.2), and very much (4.0). By doing this, the developers of the tool determined it was not necessary to use the CMSAS-PHYS (present/not present) subscale in the final analysis.

In addition, the subscale authors, Chang, Hwang, Kasimis, and Thaler (2004), determined the weighted average score was the true overall indicator of the presence of Symptom Burden, rather than the use of a summed total score, as used for the Identity Balance scale (IBL) and the Emotional Distress scale (POMS-B). Instrument reliability and validity estimates support this conclusion both in this sample and in prior use (Cella, et al., 1987). It should be noted that estimates for the Symptom Burden variable may appear to be imprecise on initial examination. However, the reader is reminded that these estimates are indeed accurate.

**Univariate descriptive statistics.** Summary statistics can be found in Table 10. No values were outside the expected range as indicated by minimum and maximum statistics. For instance, the constructed minimum value and the sample minimum value for Symptom Burden (SB) was 0.8, whereas the constructed maximum value was 4.0, but the sample minimum was 3.2. It is reasonable that the highest possible value of 4.0 (very much) was not shown. For Symptom Burden (SB), absolute minimum score was 0 and maximum was 44 and the sample minimum was .8 and the maximum was 3.2. The mean of 1.44 is reasonable and nearly midway between .8 and 3.2. The absolute minimum for Identity Balance (IBL) was 7 and absolute maximum 77. For the sample the minimum score was 30 and the maximum was 77. The mean of 59.07 is reasonable for these scores.
Results showed the sample minimum was 59.07. Absolute minimum for Emotional Distress (ED) was 0 and an absolute maximum score was 44. The mean for ED was 10.20 with a SD of 9.77. This might be slightly lower than expected but with a SD of nearly 10 the mean could be as high as 22 which would be the median between 0 and 44. The scores for each of the variables are reasonable and fit within the absolute ranges (Tabachnick & Fidell, 2013).

The means and standard deviations for the three variables used in the mediation analysis were as follows: SB (M=1.44, SD = .75), IBL (M = 59.07, SD = 10.49), and ED (M=10.20, SD = 9.77). See Table 10 below for instrument reliability results. These values are reasonable upon consideration of the selective sample and the stage of the cancer journey. Participants were currently six to 18 months post adjuvant curative (hopefully) treatment. This stage of the journey is fraught with emotion that includes a range from joy to completing treatment and possible cure, to fear of recurrence.

Table 10
Univariate Descriptive Statistics and Instrument Reliability

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
<th>Chronbach's α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom Burden (CMSAS-PHYS)</td>
<td>0.8</td>
<td>3.2</td>
<td>1.44</td>
<td>0.75</td>
<td>0.87</td>
</tr>
<tr>
<td>Identity Balance (IBL)</td>
<td>30</td>
<td>77</td>
<td>59.07</td>
<td>10.49</td>
<td>0.93</td>
</tr>
<tr>
<td>Emotional Distress (POMS-B)</td>
<td>0</td>
<td>41</td>
<td>10.20</td>
<td>9.77</td>
<td>0.95</td>
</tr>
</tbody>
</table>

Univariate outliers. Cook’s Distance was computed using SPSS syntax, and 10 outliers were identified. This must be considered in interpreting results. These outliers may contribute to violations of normality or linearity, and may distort the accuracy and precision of regression coefficients.
Cook’s D is a general, overall assessment of influence which measures the effect of deleting an outlier (IDRE Institute for Digital Research in Education at UCLA, n.d.). The conventional cut-off point is computed by $4/n$ (IDRE Institute for Digital Research in Education at UCLA, n.d.). For this sample that translates to $4/128$ or .031. The higher the estimate, the more influential the data point is, with the lowest value being zero. The ten outliers were identified using this criterion (Table 11). The following strategies were used to reduce their impact: 1) data entry was re-checked on two separate occasions in which no errors were detected, 2) consideration that one variable may be responsible for most of the outliers, however, all three variables were critical to the mediation analysis, therefore, all were retained, 3) data trimming by removal of cases (below), and 4) data transformation (Kenny, n.d.; Tabachnick & Fidell, 2013).

Many attempts were made to correct for the influence of the outliers using methods for data trimming (Tabachnick & Fidell, 2013). Ten different combinations and iterations of outlier removal were attempted, deleting one outlier at a time with each iteration. Results revealed no improvement in normality. Interestingly, results revealed more severe violations of normality with each iteration (Table 11).

This may have been because the sample population is very specific, participant experiences and attitudes are unique, diverse and personalized. One participant may feel extreme burden from symptoms that then caused heightened emotional distress, while a second participant’s perception of SB might have been influenced by support systems contributing to a stable IBL, which buffered or mitigated emotional distress. The literature clearly identified antecedents to and buffers of emotional distress in cancer patients. Cancer survivors with few resources that help mitigate emotional distress who
are plagued by extreme pain and loss of function from symptoms such as neuropathies may experience more extreme emotional distress.

In addition, other authors use Cook’s distance cutoff values > 1 to carefully check data points, and Cook’s distance values > 4 as indication of potentially serious outliers (Regression Diagnostics, n.d.; Stevens, 2002). The researcher determined it was essential to retain all outlier cases to ensure the overall data would capture the breadth and depth of participants’ perspectives and experiences (Tabachnick & Fidell, 2013). Thus, the researcher reported the initial results throughout, and did proceed with the remainder of the analyses.

Table 11

Outlier Statistics and Data Trimming Results

<table>
<thead>
<tr>
<th>Case Number</th>
<th>Cook’s D</th>
<th>Sig F</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Shapiro-Wilk Statistic</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>all 128 cases</td>
<td>-</td>
<td>-</td>
<td>0.82</td>
<td>2.65</td>
<td>0.94</td>
<td>128</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>68</td>
<td>0.172</td>
<td>0.915</td>
<td>0.81</td>
<td>2.95</td>
<td>0.939</td>
<td>127</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>29</td>
<td>0.112</td>
<td>0.953</td>
<td>0.89</td>
<td>3.08</td>
<td>0.935</td>
<td>126</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>2</td>
<td>0.103</td>
<td>0.958</td>
<td>0.97</td>
<td>3.19</td>
<td>0.931</td>
<td>125</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>82</td>
<td>0.102</td>
<td>0.959</td>
<td>1</td>
<td>3.54</td>
<td>0.924</td>
<td>124</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>9</td>
<td>0.091</td>
<td>0.965</td>
<td>1.33</td>
<td>3.68</td>
<td>0.914</td>
<td>123</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>94</td>
<td>0.09</td>
<td>0.965</td>
<td>0.88</td>
<td>2.18</td>
<td>0.949</td>
<td>122</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>126</td>
<td>0.062</td>
<td>0.98</td>
<td>0.65</td>
<td>1.49</td>
<td>0.968</td>
<td>121</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>119</td>
<td>0.059</td>
<td>0.981</td>
<td>0.29</td>
<td>0.19</td>
<td>0.981</td>
<td>120</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>80</td>
<td>0.058</td>
<td>0.982</td>
<td>-0.27</td>
<td>0.06</td>
<td>0.983</td>
<td>119</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>91</td>
<td>0.045</td>
<td>0.987</td>
<td>0.35</td>
<td>0.02</td>
<td>0.977</td>
<td>118</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>68 &amp; 2</td>
<td>-</td>
<td>-</td>
<td>0.893</td>
<td>3.05</td>
<td>0.934</td>
<td>126</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>29 &amp; 82</td>
<td>-</td>
<td>-</td>
<td>0.9</td>
<td>3.05</td>
<td>0.935</td>
<td>126</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Note: The first 10 data trimmings were inclusive as indicated by the df statistic. The last two table entries included the removal of the last two specified cases only.
**Linear regression assumptions results.** These results include normality, linearity, homoscedasticity and multicollinearity. Violations are explained in chapter five.

**Normality.** Tests for the normality assumptions were conducted first. Normality was assessed by skewness and kurtosis estimates of the residuals, as well as visual inspection of the Q-Q plots and the histograms (IDRE, n.d.). Summary statistics can be found in Table 12.

Skewness is the extent to which a distribution of values deviates around the mean. A value of zero means the distribution is symmetric. If the statistic is greater than 1.0 (or less than -1.0), then the distribution is skewed and not symmetrical. Positive skew is shown by the tail extending to the right and negative skew is shown by the tail extending to the left. Kurtosis measures the peakedness or flatness or a distribution. A value near zero indicates a shape near normal distribution. A negative value is flatter and a positive value is more peaked with -3 to +3 as an acceptable range (Kenny, n.d.).

Visual inspection of the histogram (Figure 7) and the Q-Q plots (Figure 8) displayed normal distribution including the previously noted outliers. Skewness and kurtosis were within normal range at 0.82 and 2.65 respectively. The Shapiro-Wilk test, however, indicated violation of normal distribution. According to Field (2009) this may be due to outlier influence and conventionally accepted sensitivity to large sample size. Current interpretation of Shapiro-Wilk is assessed with the understanding that statistical significance is easy to obtain with 1) sample size larger than 100, and 2) small deviations from normality, both of which appear in these data (Field, 2009). Based on these results, the residuals from this regression conform to the assumption of normal distribution (IDRE, Institute for Digital Research and Education at UCLA, n.d.).
Table 12

**Normality Results**

<table>
<thead>
<tr>
<th>Outcome Variable</th>
<th>Population Mean</th>
<th>SE</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Shapiro-Wilk Statistic</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>POMS-B Residuals</td>
<td>0.00</td>
<td>6.43</td>
<td>0.82</td>
<td>2.65</td>
<td>0.94</td>
<td>128.00</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

**Figure 7.** Histogram of Residuals

**Figure 8.** Q-Q plots of Residuals
**Linearity.** The linearity assumption was tested by visual inspection of the scatter plots including a fit line and correlation analysis, which can be seen in Figure 9, 10, 11 and Table 13 (IDRE, n. d.). The scatterplot of the relationship between the variables is as follows: 1) the SB and ED, plot displayed a linear relationship, 2) the SB and IBL plot displayed a loosely defined linear relationship with possible violation, and 3) the IBL and ED plot showed a linear relationship.

In order to interpret these observations more accurately, a regression line was added to the scatterplots and regression correlation test was conducted. Analysis revealed a statistically significant correlation among all variables of interest. Linear regression results revealed a strong positive correlation between SB and ED ($r = .69, p < .001$), a moderate negative correlation between SB and IB ($r = -.47, p < .001$), a strong negative correlation between the IBL and ED ($r = -.59, p < .001$).

![Figure 9. Bivariate Scatter Plot CMSAS and POMSBTS](image)
Figure 10. Bivariate Scatter Plot CMSAS and IBTS

Figure 11. Bivariate Scatter Plot IBTS and POMSBTS

Table 13

<table>
<thead>
<tr>
<th>Path</th>
<th>R</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>SB → ED</td>
<td>0.69</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>SB → IBL</td>
<td>-0.47</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>IBL → ED</td>
<td>-0.59</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

*Homoscedasticity.* Testing for violations of homoscedasticity (i.e. heteroscedasticity) is important in linear regression, because violations make it difficult
to gauge true standard deviation, and resulting in inaccurate confidence intervals, that are too wide or narrow. If the variance of the errors increases over time, confidence intervals for out-of-sample predictions may be too narrow (Tabachnick and Fidell, 2013).

To assess for heteroscedasticity, a scatterplot (Figure 12) was created in SPSS as shown below. The Standardized residuals are plotted against the standardized predicted values. If there is homoscedasticity, there should be no pattern seen in the residuals plotted against the predicted values. With heteroscedasticity it is typical to see the data more tightly grouped together at the left and gradually fanning out to the right. The plot was inspected and did show residuals that grow larger to the right, which is a typical pattern of heteroscedasticity. Heteroscedasticity may occur when the values of the independent variable become more extreme in either the negative or positive. In this study there were greater numbers of low scores of SB than middle values. The more extreme the values of the predictor variable are, the more likely there is to be heteroscedasticity. Heteroscedasticity may also be a byproduct of other violations of assumptions. Outliers may also influence heteroscedasticity, therefore, this result was not unexpected. Unless heteroscedasticity is rather great, significance tests are unlikely to be affected. These study data showed a violation of homoscedasticity.
Multicollinearity. Tabachnick and Fidell (2013) use the Condition Index paired with Variance Proportion for a given dimension to understand collinearity. Condition index is a measure of dependency of one variable on another. Variance inflation of the parameter estimate is associated with a high condition index. When the standard error of the parameter estimate is large, the parameter estimate is very uncertain. Because each dimension accounts for some part of the variance of each parameter estimated, a collinearity problem occurs when a dimension with a high condition index contributes strongly to the variance of two or more variables. Criteria used for multicollinearity were a condition index greater than 30 paired with variance proportion greater than 0.50 for a given dimension (Belsey, Kuh, & Welsch, 1980; Tabachnick & Fidell, 2013). Results revealed no Condition Indices greater than 30 (Condition Index Dimension 1 = 1.00; Condition Index Dimension 2 = 4.64; Condition Index Dimension 3 = 17.65). Therefore, there was no evidence of multicollinearity. Table 14 displays summary statistics.
Table 14
*Multicollinearity Statistics*

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Eigenvalue</th>
<th>Condition Index</th>
<th>Variance Proportions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Constant</td>
</tr>
<tr>
<td>1</td>
<td>0.69</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>-0.49</td>
<td>4.64</td>
<td>0.01</td>
</tr>
<tr>
<td>3</td>
<td>0.75</td>
<td>17.65</td>
<td>0.99</td>
</tr>
</tbody>
</table>

*Independence.* Independence of observations was assumed in the analysis of the models for each regression. In addition, the Durbin-Watson test was conducted to assess independence on each of the four Baron and Kenny (1986) steps with a value near two as indication of independence (Durbin & Watson, 1951). For the purpose of this study, the conservative parameters for independence violation were $3 > \text{Durbin-Watson} > 1$ (Field, 2009). No violation of independence was indicated with these data ($\text{SB} \rightarrow \text{ED} = 1.70; \text{SB} \rightarrow \text{IBL} = 1.76; \text{IBL} \rightarrow \text{ED} = 1.70; \text{SB and IBL} \rightarrow \text{ED} = 1.78$). Table 15 below provides a summary of estimates.

Table 15
*Independence Statistics*

<table>
<thead>
<tr>
<th>Path</th>
<th>Durbin-Watson</th>
</tr>
</thead>
<tbody>
<tr>
<td>$\text{SB} \rightarrow \text{ED}$</td>
<td>1.71</td>
</tr>
<tr>
<td>$\text{SB} \rightarrow \text{IBL}$</td>
<td>1.78</td>
</tr>
<tr>
<td>$\text{IBL} \rightarrow \text{ED}$</td>
<td>1.69</td>
</tr>
<tr>
<td>$\text{SB and IBL} \rightarrow \text{ED}$</td>
<td>1.77</td>
</tr>
</tbody>
</table>

*Transformations.* No univariate transformations were applied due to Kenny’s (n.d) Medtext.SPS analysis results, data trimming results, as well as the strong indication and clear connection between the cases with extreme scores and the rest of the cases. According to Tabachnick & Fidell (2013), this is an indication that the outliers are a legitimate part of the sample and should remain.
However, Kenny’s (n.d.) Medtext.SPS analysis results showed a violation of linearity between SB and IBL. To analyze the effect of SB on IBL, a curvilinear regression revealed a statistically significant quadratic effect with a coefficient $b_2$ value of 6.709 ($p < .01$). A quadratic transformation was applied based on MedText.SPS results prior to mediation analysis.

**Correlational analysis.** Correlation measures the strength and direction of the relationships between the study variables. A strong correlation yields a correlation coefficient with an absolute value of $r \geq .70$, a moderate correlation is indicated by an $r$ statistic between .30 and .70, whereas weak correlation coefficient is between 0 and .30. A negative sign (-) indicates an inverse relationship.

Results indicated the correlations were in the expected directions with the highest correlation between Symptom Burden (X) and the Emotional Distress (Y), followed by the Identity Balance (M) and the Emotional Distress (Y), and finally the Symptom Burden (X) and Identity Balance (M). Correlation estimates were statistically significant at the $p < .001$ level for all three measures. As displayed in Table 16, results revealed a strong positive correlation between the Symptom Burden and Emotional Distress, which was expected due to an overlap in the constructs ($r = .69, p < .001$). Symptom Burden was moderately inversely correlated with Identity Balance ($r = -0.51, p < .001$). Identity Balance was moderately inversely correlated with Emotional Distress ($r = - .59, p < .001$).
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Emotional Distress</th>
<th>Symptom Burden</th>
<th>Identity Balance</th>
</tr>
</thead>
<tbody>
<tr>
<td>(CMSAS-PHYS)</td>
<td>0.69</td>
<td>1.00</td>
<td>-0.49</td>
</tr>
<tr>
<td>Identity Balance (IBL)</td>
<td>-0.59</td>
<td>-0.49</td>
<td>1.00</td>
</tr>
</tbody>
</table>

**Mediation analysis.** Mediation analysis was conducted using bivariate linear regression as the data analysis technique for paths $a$, $b$, $c$ and $c'$. After these four linear equations were completed, path $a$ revealed a violation of non-linearity. Subsequently a quadratic regression was also used for path $a$. An *a priori* mediational path model hypothesized that the independent variable (symptom burden) was related to the mediator variable (identity balance), which was related to the dependent variable (emotional distress), and that identity balance affected the relationship between symptom burden and emotional distress.

While the analysis for this dissertation relied on the work of Baron and Kenny (1986), testing the difference of $c - c'$, or the indirect effect $ab$, is the contemporary method used to accomplish a direct test of mediation (Hayes & Preacher, 2014; Kenny, 2014; Preacher, & Hayes, 2008). The macro provided by Kenny (n.d.) on his website uses the contemporary method for mediation analysis of testing described above.

For the purposes of this study, both methods were used to test the four hypotheses, and are explained below. Each hypothesis is listed first, followed by the specific path analysis used to test it based on the Baron and Kenny (1986) model. Theoretically, if complete mediation were found, then the effect of Symptom Burden on
Emotional Distress controlling for Identity would be equal to zero. The following assumptions were made in order to ensure valid estimates: 1) there is no measurement error in Symptom Burden and Identity Balance, 2) there are no unmeasured common causes of Symptom Burden and Identity Balance, or of Identity Balance and Emotional Distress, 3) Identity Balance does not cause Symptom Burden and Emotional Distress does not cause Identity Balance, and 4) Identity Balance and Symptom Burden do not interact to cause Emotional Distress. A 95% confidence interval (CI) was used for all analyses. Summary statistics can be found in Table IV 12.

**Model fit.** Overall fit for each path model was assessed prior to inferential analysis to assess the generalizability of each path model. Results revealed the difference between the $R^2$ and adjusted $R^2$ statistics was small for each of the four path models as displayed in Table 16 (SB $\rightarrow$ ED = .004; SB $\rightarrow$ IBL = .006; IBL $\rightarrow$ ED = .005; SB and IBL $\rightarrow$ ED = .007). This shrinkage means that if the models were derived from the population rather than a sample they would account for approximately 0.4%, 0.6%, 0.5%, and 0.7% less variance in the outcome (Benning, Patrick, Blonigen, Hicks, & Iacono, 2005; Field, 2009). Thus, the researcher concluded that the generalizability of the four path models was adequate.

<table>
<thead>
<tr>
<th>Table 17 Model Fit</th>
<th>Path</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$F$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SB $\rightarrow$ ED</td>
<td>0.471</td>
<td>0.467</td>
<td>112.34</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>SB $\rightarrow$ IBL</td>
<td>0.235</td>
<td>0.229</td>
<td>38.75</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>IBL $\rightarrow$ ED</td>
<td>0.351</td>
<td>0.346</td>
<td>68.08</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>SB and IBL $\rightarrow$ ED</td>
<td>0.559</td>
<td>0.552</td>
<td>79.31</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Hypotheses

H1: There is a relationship between symptom burden and identity balance

**Symptom burden predicting emotional distress.** Step 1: X→Y (path c); X predicting Y to test for path c, Y = β₀ + β₁X + e

Results: The effect of path c, Symptom Burden (X) on Emotional Distress (Y), was passed with a large effect size (r = 11.16, CI [9.09, 13.24], β = .69, p < .001). This high beta coefficient suggested there may be overlap in the constructs being measured.

H2: There is a causal relationship between symptom burden and emotional distress

**Symptom burden predicting identity balance.** Step 2: X→M (path a); X predicting M to test for path a, M = β₀ + β₁X+e

Results: The effect of Symptom Burden (X) on Identity Balance (M), path a, was initially tested as a linear relationship and appeared to pass according to estimates displayed in Table 17 (r = -8.17, CI [-10.881, -5.47], β = -.47, p < .001). However, the relationship was complicated. A scatterplot of the data suggested there was a slight u-shaped curve. In addition, the summary created by the macro cautioned that the relationship between symptom burden and identity balance was nonlinear. Therefore, the data were tested for a quadratic relationship using curvilinear regression which uses the equation y = ax² + bx + c.

Step 2: X→M (path a); X predicting M to test for path a, M = β₀ + β₁X + β₂X²+e

Results: The quadratic effect of X² (Symptom Burden) on M (Identity Balance) was statistically significant, (β₂ = 6.71, R² = .287, p < .001). Therefore, according to this
analysis, 28.7% of the variation in Identity Balance can be explained by Symptom Burden using curvilinear analysis. This step was passed.

H3: There is a causal relationship between identity balance and emotional distress

**Identity balance predicting emotional distress.** Step 3: M→Y (path b); M predicting Y to test the significance of path b. \[ Y = \beta_0 + \beta_1 M + e \]

Results: The effect of Identity Balance (M) on Emotional Distress (Y) controlling for Symptom Burden (X) was passed \( (r = -.32, CI [-.44, -.20], \beta = -.35, p < .001) \). There was a medium effect size for path b \( (r = -.59; ES = -.42) \).

H4: Identity balance mediates the relationship between symptom burden and emotional distress.

**Symptom burden and identity balance predicting emotional distress.** Step 4: XM→Y (path c'); X and M predicting Y to test the significance of c'.

\[ Y = \beta_0 + \beta_1 X + \beta_2 M + e \]

Results: For path c', the effect of Symptom Burden (X) on Emotional Distress (Y) controlling for Identity Balance (M) was not passed \( (R = 8.54, CI [6.397, 10.677], \beta = .53, p < .001) \). This was a large effect size \( (r = .577) \) (Figure 13).

Summarization of the results of these steps is shown in Tables 18 and 19.

---

**Table 18**

*Baron and Kenny Steps Summary Statistics*

<table>
<thead>
<tr>
<th>Step</th>
<th>Path</th>
<th>Estimate</th>
<th>95% CI</th>
<th>Beta</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>c</td>
<td>11.16</td>
<td>9.09 to 13.24</td>
<td>0.69</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>2</td>
<td>a</td>
<td>-8.17</td>
<td>-10.88 to -5.47</td>
<td>-0.47</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>3</td>
<td>b</td>
<td>-0.32</td>
<td>-.44 to -.20</td>
<td>-0.35</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>4</td>
<td>c'</td>
<td>8.54</td>
<td>6.40 to 10.68</td>
<td>0.53</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Table 19</td>
<td>Baron and Kenny Mediation Steps (1986)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Answers Question 1</strong></td>
<td><strong>X→Y (path c)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there a relationship</td>
<td>X predicting Y to test for path c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>between symptom burden</td>
<td>H₁: There is a relationship between symptom burden and identity balance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and identity balance</td>
<td>Y = β₀ + β₁X + e</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Passed</strong></td>
<td><strong>r = 11.16  p &lt; .001, 95% CI [9.09, 13.24]</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>large effect size r = .69</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Answers Question 2</strong></td>
<td><strong>X→M (path a)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there a causal</td>
<td>X predicting M to test for path a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationship between</td>
<td>H₂: There is a causal relationship between symptom burden and emotional distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>symptom burden</td>
<td>M = β₀ + β₁X + e</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and emotional distress</td>
<td>r = -8.17  p &lt; .001, 95% CI [-10.88, -5.47]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Passed (with a violation of linearity)</strong></td>
<td>medium effect size r = -.47</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Answers Question 3</strong></td>
<td><strong>M→Y (path b)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there a causal</td>
<td>M predicting Y to test the significance of path b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationship between</td>
<td>Identity balance predicting emotional distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>identity and</td>
<td>Y = β₀ + β₁M + e</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>emotional distress</td>
<td>r = -.32  p &lt; .001, 95% CI [-.44, -.20]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Passed</strong></td>
<td>medium effect size r = -.42</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Answers Question 4</strong></td>
<td><strong>X and M predicting Y (path c')</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does identity balance</td>
<td>Symptom burden and Identity balance predicting emotional distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mediate the relationship</td>
<td>Y = β₀ + β₁X + β₂M + e</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of symptom burden and</td>
<td>R = 8.54, 95% CI [6.397, 10.677], β = .53, p &lt; .001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>emotional distress?</td>
<td>large effect size r = .58</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Not Passed</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Indirect Effect Analysis**

In the application of the indirect effect analysis method, using Kenny’s (n.d.) MedText.SPS macro, effect sizes are partial correlations (r) where the predictor is polytomous (interval level). The indirect effect is computed as the product of two effect sizes, thus the effect size is the product of partial correlations (r*r).
In this study, the indirect effect ($a \times b$) of Symptom Burden ($X$) on Emotional Distress ($Y$) was equal to 2.63, a very small effect size ($r^2 = -.29$), whereas, the direct effect was equal to 8.54. This model showed the percentage of the total effect ($c' + ab$) that was mediated was equal to 23.53%. According to Hoyle and Kenny (1999), the mediator is said to be proximal, meaning the standardized path $a$ estimate was greater than the standardized path $b$ estimate. Thus, Identity Balance was "closer" to Symptom Burden than to Emotional Distress. The $Z$ statistic of the indirect effect was computed using the Sobel standard error (Sobel SE = .672, $Z = 3.910, p < .001$). Therefore, it was concluded that the indirect effect was significantly different from zero, because the Sobel test was statistically significant.

In accordance with Preacher and Hayes (2008), the bootstrap method was applied which resulted in an estimated indirect effect of 2.61 (SE = .66, $p < .001$). The 95% bias corrected bootstrap confidence interval (5000 trials) was from 1.567 to 4.280. Zero was not in the confidence interval, therefore, it was concluded that the indirect effect was different from zero. (In contemporary analyses, the bootstrapped test, and not the Sobel test, is reported.)

Path $a$ and path $b$ showed inverse relationships between the variables. The coefficient for path $c$ was greater than $path c'$ which suggested there was a mediated effect from identity balance (Figure 13).
The study also asked an open ended question about other symptoms experienced by the participant. This question titled, Symptoms-Other, was intended to give respondents an opportunity to list any symptoms not contained within the questionnaire. Thirty-nine of 128 participants responded. One response was “none” and 38 participants responded with one or more symptoms. The largest number of responses fell within the category of neurological with five answers. The second largest category was emotional. There were three categories that fell into the third largest grouping and included GI, constitutional and musculoskeletal symptoms. See Table 20 for the complete listing of symptoms.
Table 20

**Other Symptoms**

<table>
<thead>
<tr>
<th>Symptom Category</th>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>GI</td>
<td>Diarrhea</td>
</tr>
<tr>
<td></td>
<td>Food tastes off</td>
</tr>
<tr>
<td>Lung</td>
<td>Pneumonia</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom Category</th>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological</td>
<td>Neuropathy right side especially in right arm and hand, muscle twitching</td>
</tr>
<tr>
<td></td>
<td>Tingling in fingers, ringing ears</td>
</tr>
<tr>
<td></td>
<td>Tingling in hands</td>
</tr>
<tr>
<td></td>
<td>Numbness in hands</td>
</tr>
<tr>
<td></td>
<td>Hearing loss</td>
</tr>
<tr>
<td>Hormonal</td>
<td>Impotence</td>
</tr>
<tr>
<td></td>
<td>Hot flashes</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Loss of memory. Can't seem to remember things that are mentioned to me</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Leg cramps</td>
</tr>
<tr>
<td></td>
<td>Fingers and legs hurt, ache</td>
</tr>
<tr>
<td>Emotional</td>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
<td>Irritable</td>
</tr>
<tr>
<td></td>
<td>Irritable</td>
</tr>
<tr>
<td>Constitutional</td>
<td>Feel chilled</td>
</tr>
</tbody>
</table>

**Summary**

These results from this study indicated that the mediating variable (Identity Balance) accounted for some, but not all, of the relationship between the independent variable, Symptom Burden, and the dependent variable, Emotional Distress. Path $a$ was nonlinear and the relationship between X and M was complicated and appeared to be quadratic. However, there was quantitative evidence of a statistically significant relationship between the mediator, IBL and the dependent variable, ED, and there was a statistically significant direct relationship between the independent variable, SB and the
dependent variable, ED. This study did not show that there was a significant indirect relationship between the independent and dependent variables.

The variable, other symptoms, returned responses in nine categories. Neurological logged the largest number of complaints and presumably was the most bothersome as they warranted note. Interestingly, while the sample participants were not actively engaged in treatment, the symptoms persisted and continued to be bothersome.

According to the American Cancer Society (ACS) (2015), breast cancer will be the most diagnosed cancer in women in the United States at 29%. For males, it is prostate cancer at 26%. The largest volume of patients in the study, 40.6%, reported having been treated for breast cancer. Gynecological cancers including ovarian, endometrial, uterine and cervical were the second most reported cancers in females in this study at 8%. Colorectal cancer was the second most reported cancer overall in this study at 10.2%. However, at 6.3% of the sample, thyroid cancer was reported more than the national average of 3.8% (National Cancer Institute, n.d.). The higher volume of patients with colorectal cancer, whose treatment can cause severe neuropathies, may have influenced the responses to the open ended question regarding other bothersome symptoms not captured by the questionnaire. Neurological symptoms were the most often reported for the open ended question. One participant responded to the open ended question by reporting that hot flashes and irritability were troublesome.
CHAPTER V

DISCUSSION

This study sought to determine if identity balance mediated the relationship between symptom burden and emotional distress. While results showed that there was possibly a small partially mediated effect, the findings are not convincing. Many variables beyond those tested, may influence the experience of emotional distress in cancer survivors, and any one of them potentially could have an effect on outcomes.

Quantitative Findings

**Linear regression assumptions.** The following are explanations of violations of assumptions. Violations were considered within the context of this study.

*Normality.* The effect of a violation of normality may be related to how inconstant the variance of Y is, or how skewed the Y population distribution is. There was positive skew in the data for symptom burden and emotional distress and a slight negative skew in the data for identity balance which may have affected normality. The data for each of the variables revealed outliers. Removing the outliers using a casewise technique was minimally effective in normalizing the data.

*Linearity.* The violation of linearity occurred in path $a$, and a quadratic transformation was applied. This revealed a curvilinear relationship. When outliers are present, the linear regression goodness of fit test may not be the most informative as results that include outliers could affect the difference in detecting a linear fit. The impact of the violation on the linear regression results depends on the extent of the violation. Small violations caused by outliers may have little or no effect as shown by the Cook’s D
analysis. Therefore, a quadratic transformation was used and revealed statistical significance.

Neuman’s (1989) theory of nursing and the background on identity from Erikson (1980) may offer insight into this result. According to Neuman (1989), the person maintains flexible lines of defense which offer a buffer of protection. When a person is under assault from illness and its consequences, flexible lines of defense may serve to protect and preserve identity balance as a sub-construct of identity. Erikson (1980) submitted that identity is a core construct that is formed early in life and whose fundamental structure is maintained throughout life. This premise suggests that while there are transitory changes to identity balance as a sub-construct of identity, the core structure remains unchanged. The results suggest that there may be some effect of symptom burden on identity balance, and that the effect is not consistent or permanently damaging to the core construct.

**Homoscedasticity.** There was a violation of homoscedasticity in this study sample. According to Tabachnick and Fidell (2013) homoscedasticity occurs when the variability in scores for one variable (interval level) is similar at all values of another interval level variable. A violation suggests there may be a problem with normality of one or both of the variables. Violations of homoscedasticity are more common in cross sectional studies than in time series data. This could suggest bias so that results of hypothesis testing may have errors. According to Tabachnick and Fidell (2013), when analysis is performed on heteroscedastic data there may be a biased standard error estimation leading to a type II error, where the researcher fails to reject the null hypothesis when it is not true.
Skewness, which is present in each variable, is a source of heteroscedasticity. As a consequence, the test of model fit may be affected. According to Tabachnick and Fidell (2013), heteroscedasticity may weaken the analyses but may not invalidate them.

The demographic data show that the sample was comprised of 40% female breast cancer patients, and 10.2% colon or rectal patients. In addition, 55% of the respondents lived with others and 57% lived with a partner or spouse. All patients reported having enough financial resources to meet their needs. It is known that having a support system and financial resources sufficient to meet needs can mitigate emotional distress and could have had an influence on results.

It is known that the variance in emotional distress results from multifactorial sources (Holland & Reznik, 2005; Bultz & Holland, 2006; Cleeland (2007). These data may have been affected by intervening variables not included in this study.

**Independence.** These data showed no violations of independence. Therefore in each of the comparisons, the independent variables, symptom burden and identity balance, independently matched the corresponding Y value (emotional distress) (Tabachnick & Fidell, 2013). Each observation was independent of, and not influenced by any other observation in this study.

**Synopsis.** As was hypothesized, this study was able to show that identity balance partially mediated the relationship between symptom burden and emotional distress. However, the mediation effect was small. The other finding was that path a was curvilinear rather than linear.

In reviewing the theoretical framework, there may have been some indications that this complicated relationship between symptom burden and identity balance
described by path \( a \), may occur. Neuman’s theory of flexible lines of defense could explain why path \( a \) was curvilinear rather than linear. As symptom burden increased past a certain point, identity balance responded differently. Rather than decreasing as hypothesized, it started to increase. This suggested that symptom burden no longer exhibited the same effect, possibly because flexible lines of defense (Neuman, 1989) bolstered the person’s ability to retain a stable and balanced identity.

**Causal relationship between symptom burden and emotional distress: path c \((X \rightarrow Y)\).**

Symptom burden and emotional distress are highly correlated, possibly because there may be overlap in one or more constructs being measured. Emotional distress is itself considered as one of the symptoms measured in the full Memorial Symptom Assessment Scale. The Condensed version, used in this study, did not specifically measure emotional distress, instead it measured physical symptoms. There are several physical symptoms, such as lack of energy, feeling drowsy, and difficulty sleeping, which could be construed as symptoms resulting from emotional distress.

The coefficient of determination designated by \( R^2 \) is .474 for path c. It is the explained variation divided by the total variation and is between 0 and 100%. When the value is 0%, the model explains none of the variability of the response data around its mean, and 100% indicates that the model explains all the variability. In this case, 47.4% is explained. According to this model, symptom burden accounts for 47% of the variance in emotional distress, which is a large amount of the variance to be accounted for by symptom burden.

**Causal relationship between symptom burden and identity balance: Path a \((X \rightarrow M)\).** This study hypothesized that there is a relationship between symptom burden
(X) and Identity Balance (M) based on review of the literature (Mathieson & Stam, 1995; Zebrack, 2000). This study confirms that there is a relationship between these variables.

Path $a (X \rightarrow M)$ showed a violation of linearity although results were statistically significant. Because of the violation, a quadratic transformation was applied and results showed a significant curvilinear relationship. The relationship between the two variables appeared to have been complicated as evidenced by significance in both the linear and nonlinear relationships. There are several possible explanations; bias could have been introduced, as a self-selected sample, error could have occurred, or something might have intervened to stabilize identity balance.

Erikson (1963), and Locke (1689) describe identity as a core construct formed early in life that is unlikely to change. Mathieson and Stam (1995) report that locus of control is removed from the patient during the existential crisis experienced by the cancer journey. Rather than a change to core identity, perhaps the curvilinear relationship between symptom burden and identity balance could be explained in part by a temporary loss of locus of control (Mathieson & Stam, 1995; Weisman & Worden, 1975).

Considering identity balance a first order variable, means identity in adults formed prior to the cancer diagnosis. Hence, identity may be unbalanced by the experience but not fundamentally changed. The changes undergone by identity under this premise, would result in a second order change to identity. This suggests that identity balance may change temporarily and then return to a stable state with the fundamental identity intact. It is reasonable to assume that a person may have had any number of identity altering experiences prior to a diagnosis of cancer. If that were so, re-stabilization of identity may previously have occurred, however, it may not have been in response to
an existential crisis. The existential crisis of cancer presents differently than an existential crisis of an acute traumatic experience. Generally, while the person may feel poorly, there is rarely an immediate danger in the cancer experience. The change in identity balance discussed in the qualitative literature may have referred to a second order change or alteration of an already formed identity rather than a complete rebuild and re-stabilization of identity. A full reconstitution of identity is not necessary, and probably is impossible. Rather, incorporating the experience and altering identity in some way still leaves the fundamental identity intact. The ability to rebalance and re-stabilize an identity that has endured and assault may be related to the resilience of the individual.

If identity, and for the purposes of this study, identity balance, is considered a first order construct, then the mediation model would be: identity balance → symptom burden → emotional distress. The question would then change to: does symptom burden mediate the relationship between identity balance and emotional distress. A larger sample size may reveal more about the relationships between symptom burden and emotional distress.

*Causal relationship between identity balance and emotional distress: Path b (M \( \rightarrow \) Y).* These variables exhibited a strong inverse relationship with a correlation coefficient of -.592. This statistic is supported by the current literature. A balanced identity is suggestive of a balanced or stable personality which may exhibit greater resiliency in the face of threats to self. The coefficient of determination (\( R^2 \)) was .351 which indicates that 35% of the variation in emotional distress was accounted for by identity balance in this model. The adjusted \( R^2 \) that accounted for error, was .346. The model was significant at the .000 level.
**Mediation of identity balance on symptom burden and emotional distress: Path**

$c'(X \rightarrow Y)$. This path revealed statistical significance for linearity. However, it must be considered that path $a$ was nonlinear and that there were violations of normality in the data that could have influences the mediation results.

The coefficient of determination ($R^2$) was .567, thus 56% of the variance in emotional distress was accounted for by the two predictor variables, symptom burden and identity balance. The model was significant at the .000 level. Consideration must be given also to the violations of assumptions due to non-normality in the variables and a violation of linearity in path $a$.

The relationships between these variables show that identity balance has a small effect on the relationship between symptom burden and emotional distress. This suggests that identity balance contributes a small partial mediation between symptom burden and emotional distress.

**Qualitative Findings**

The open ended question about symptoms gave participants an opportunity to express what was most bothersome. That certain categories of symptoms were reported for the qualitative variable question several times, suggests they were more troubling to the participant. Studying these specific categories of symptoms and how they affected the relationships among the variables of interest may be an opportunity for future study. It may be possible that a symptom such as impotence may affect identity in males differently than does hair loss or nausea or neuropathy. Using moderation might be a possible means to better understand the importance of these symptoms and their effect on the relationships among these study variables. The qualitative variable most reported was
neurotoxicity. This side effect is remarkable for its extreme pain and that it endures over time. Years after treatment, cancer survivors continue to complain and even seek treatment for symptoms related to chemotherapy induced neurotoxicity. Hearing loss is also considered a neurological side effect and two participants noted it. Simple daily tasks can be made nearly impossible by neuropathy. Hand neuropathy can limit use of fingers which makes everyday tasks like buttoning shirts and writing with a pencil, difficult and painful.

Hormonal symptoms reported included impotence and hot flashes. These effects may influence gender identity which could affect identity balance. While hot flashes are uncomfortable, they may signify a loss of femininity; impotence, a loss of masculinity. Mood alterations including anxiety and irritability were noted by three participants. While this is a small number, there are also questions within the subscales addressing these emotional constructs. That the participant felt these were worth mentioning again was notable. Knowing that these symptoms are vexing, caregivers might consider early patient education and interventions to lessen the impact of their severity.

**Demographic Findings and Limitations.** The uncontrollable factors that affect the quality of this research are identified as follows:

**Gender.** In this study an evenly distributed number of both genders was not accrued, therefore, there may be a bias toward one gender. Several reasons for this are the large number of female breast cancer patients who completed the study, and that women are more likely to complete a questionnaire than men. Both of these factors could influence the sway to a female bias. This may have affected the outcome of this study because gender could have biased any or all of the variables. For example, depression is
known to be a dimension of distress. In the existing literature, females are more likely than males to seek help for depression (Piccinelli & Wilkinson, 2000). While this may not have precisely reflected the % age of males to females who experience depression, the trend suggested that females are more prone to depression (Piccinelli & Wilkinson, 2000). Another example is that the literature suggested females were more likely to complete surveys and questionnaires than males (Smith, 2008). This study was completed primarily by females; therefore, the results may have been affected by a female bias.

**Age.** Age is known to affect the experience of emotional distress (Strong et al., 2007). In this sample, the median age of respondents was 55 with a range of 24 – 83 years, captured in the demographics section. While cancer afflicts people of all ages, there is a greater prevalence in middle and late age. The sample of cancer survivors was skewed toward an age over 50, which predisposed this population to age related functional limitations and comorbidities (Mao et al., 2010). Due to practical and temporal constraints, a pretreatment functional assessment was beyond the scope of this analysis. These limitations may have affected measurement of symptom burden.

**Years in U.S.** The study primarily captured participants who were native or had lived in the U.S. for a long period of time as shown by the mean number of years in the U.S., which was 52.99 and the mean age of respondents at 54.88 years. Ashing-Giwa and Lim (2011) found that indicators of less favorable emotional outcomes and greater emotional distress in cancer patients were Latino ethnicity, lower income, lower education, lack of employment, non-English speaking, and younger age.

**Financial resources.** Few participants responded to the question about finances. Of those that responded, four answered they did not have financial resources adequate for
their needs and nineteen responded yes, that they had financial resources adequate for their needs.

**Living arrangements.** Regarding living arrangements and partnership status, a little more than two thirds (73) of participants revealed they were in a partnership or were married, and seventy-one participants reported they lived with others. Living with others may offer support and help to reduce or mitigate emotional distress.

**Education.** The majority of respondents had achieved some college or higher. Denver is a college town and a large number of respondents participated online which may have contributed to accruing participants with higher education levels and access to a computer. Higher educational levels achieved by participants may have influenced responses. Higher education has been shown to correlate with lower levels of distress.

**Ethnicity and race.** Ethnicity and race were somewhat homogenous with 93 or 80.47% of respondents selecting non-Hispanic, and 95 participants (74.22%) marking White for Race. The sample was not reflective of the more heterogeneous population of cancer survivors.

**Language.** Language presented another limitation. This study was only open to those people able to read and understand English. Approximately 25% of patients seen at ESJH CCC are Hispanic which suggests there may have been non-English speaking patients who were unable to complete the survey due to a language barrier. The English language requirement for this study excluded potential participants from the population of candidates. Using a sample that was not economically as diverse as the population of cancer survivors for each site was another limitation. This may have been due to the language barrier, or possibly related to lack of easy access to a computer. The population
of oncology survivors from the Boulder site was expected to reflect the local population demographics represented by middle and upper class, white, and female. The sample was too small to accurately assess for these attributes, however the overall sample reflected these demographic attributes.

Methodological Challenges

**Instrument.** The instrument used to gather the data, was a self-report questionnaire and, while the questionnaire is completely anonymous, honest answers from respondents cannot be guaranteed. Computers were available at the cancer center for respondents to use to complete the questionnaire online through Survey Monkey, and potential respondents were also given the Survey Monkey web site and offered the option to complete the questionnaire at home. This introduced additional opportunity for error. The questionnaire was offered online through Survey Monkey and as a paper document. Two options were provided in an attempt to reach more respondents by increasing accessibility. The two options for accessing and completing the survey resulted in variations in administration and which may have invited inconsistent responses. Completion of the paper document was required during the patient visit to the cancer center; no mail in questionnaires were received nor accepted. The Survey Monkey option was available at the cancer center and could also be accessed from a home computer. There was no way to prevent someone from taking the survey more than once, however there was no compensation or reward for doing so.

**Sample.** The nonrandom convenience sampling technique prohibits results from being generalized to other populations, thus compromising the strength of the survey
design. The self-report method for administration of the questionnaire was another weakness of the survey design.

It was also discovered that when the site had an active survivorship clinic, it was easier to garner accruals. Additionally, when the study was started, there was a pool of potential eligible respondents. After those initial potential respondents had been invited to participate, the pool of potentially eligible respondents dwindled which was reflected in a slower accrual rate.

Implications of Results

Nurses may impact the experience of emotional distress by helping survivors find value in their experience and change their perception of themselves. Research has identified internal resources, such as optimism, hope, coherence, acceptance, transcendence, and meaning, which have not been studied in aggregate in measuring the cancer survivor’s capacity to mitigate emotional distress. Once a full model is created, the next research opportunity lies in identifying and measuring the capacity to manage and mitigate emotional distress. Measuring personal resources and intervening to bolster where resources are lacking may provide opportunities to translate the foundational research on identity balance and emotional distress into interventions that restore an individual’s emotional capacity to withstand the cancer journey and thrive in survivorship.

Discovering how identity balance is affected throughout the cancer journey may offer insights into the part that identity balance plays at different points in the journey. Generating knowledge about the relationships among symptom burden, identity balance and emotional distress can lead to deeper understandings about how to sustain identity
balance during the existential crisis of a cancer diagnosis, and throughout the journey of cancer. Ultimately it may offer insight into ways to reduce suffering and improve the quality of life of cancer patients.

**Possible Future Directions for Inquiry**

Due to the changes experienced throughout the journey of cancer, patients continually adjust their identities as they adapt their understanding of who they are and what they represent (Mathieson & Stam, 1995). However, the results of the study suggest that core identity factors remain stable although outward manifestations of personality may vary temporarily. Identity and identity balance have not been thoroughly studied in cancer populations at any stage of the journey and this offers opportunity for further research.

Survivorship, by definition, requires the incorporation of cancer into the identity. This is a time of transition, of resolving the question of who am I, to include the experience of cancer. Mathieson and Stam’s (1995) and work suggested that cancer strikes the person’s sense of control, self-image, and self-esteem. Peretz, Baider, Ever-Hadani, and De-Nour (1994) note that loss of control initiates or heightens emotional distress which can lead to dissociative coping. Dissociation can include changing the person’s sense of self. Due to the documented effect on the balance of a cancer patient’s life, how emotional distress is linked to identity, and how the experience of cancer survivorship is integrated into identity, are clearly worthy of future inquiry (Zebrack, 2000).

Greer (2008) who introduced research positing that emotional distress in patients with advanced cancer appears to be caused by low levels of positive effect, concluded
that studying the effects of positive psychological states, such as optimism and hope, and those internal, personal resources that lead to such states may be of benefit in advancing the science. These intrinsic identity constructs may help the person strengthen flexible lines of defense against stressors and protect the stability of a person’s identity. Research has identified internal resources that are useful in dispelling emotional distress. Strengthening the internal and personal resources and thus the flexible lines of defense against stressors, may build the capacity of the person to mitigate emotional distress. Future inquiries could focus on the value of identity measures to predict emotional distress in a sample of cancer survivors.

Another opportunity for future inquiry lies in further exploring identity in cancer survivors and how internal and external factors affect identity. Measuring these personal resources and intervening to bolster where resources are lacking may provide opportunities to translate the foundational research on identity and emotional distress into interventions that restore an individual’s emotional capacity to withstand the assaults of the cancer journey and survivorship. Future inquiry that will improve understanding of the phenomena should include measuring the additional antecedents of emotional distress, and additional domains of identity. Including symptoms noted in the qualitative question as moderators is another possible avenue for future research.

Conclusion

The interdependent relationships among these variables are highly complex. Understanding the mitigating factors is critical to a full understanding of the phenomenon and for how to translate knowledge into clinical practice. Measurement and analysis of
the interdependency of the many variables affecting the experience of emotional distress in cancer survivors is an important area of exploration for future inquiry.

Identity balance as a first order construct would go through symptom burden resulting in the experience of emotional distress rather than having symptom burden act as the first order construct that would change identity balance. Instead it would be the fundamental identity that would act on symptom burden. If identity balance were not a core personality construct as with children and adolescents, there may have been a greater amount of mediation seen; identity balance would have been affected more by symptom burden as a second order construct. It would be more malleable, more likely to be reconstructed completely. That the mediation was minimal in this study, suggested that identity balance may be a first order construct and thus less likely to change. The nature of the experience of cancer, being an existential threat, may be a great enough insult to identity that it does effect a small amount of fundamental change. However, not enough to fully mediate the relationship between symptom burden and emotional distress. This suggests that identity balance is a first order construct. As such, it goes through symptom burden and effects the experience of emotional distress. It would not however, effect a significant change in identity balance. This is consistent with the theoretical underpinning.

Neuman’s theory shows an outer flexible line of defense through which stressors may penetrate. If so, the next is a normal line of defense followed by lines of resistance. The open structure suggested that there is an adaptive response to stressors as the individual evaluates and implements lines of defense which vary based on the severity of the stressor. Burke’s and Neuman’s models link stressors, in this study symptom burden,
as antecedents to identity balance and emotional distress. An existential threat such as cancer may be considered an extreme stressor. In such a case, Neuman (1989) notes that the responses may deviate from the normative range. The complexity seen in the relationships among the variables may be related to a deviation from the normative range in the context of an extreme stressor. The person uses the flexible lines of defense to manage circumstances with the goal of returning to equilibrium, and reestablishing identity balance. According to Neuman, previous experience, support systems, and life circumstances, such as age, education level and financial stability, figure into the person’s process of protecting self from stressors. Neuman asserts that when there is adequate energy, the system is reconstituted and the line of defense is restored. Similarly, identity balance can be re-stabilized in response to the stressors of symptom burden. The ability to re-stabilize identity varies based on the internal and external context of the person’s experience.

Many cancers are highly survivable (ACS, 2015) due to earlier diagnosis, and advances in treatment. With durable responses, symptom burden related to cancer and cancer treatment will affect levels of emotional distress in cancer survivors for a lengthy period of time if not for the rest of their lives. Therefore, it is likely that the reduction of symptom burden through management of the suffering of emotional distress will continue to be a focus of nursing care.

As a first attempt to measure identity balance, a sub-construct of identity, this study shows the complexities and the need for constraining the sample to increase homogeneity. It also revealed that using a more robust data analysis technique, such as structural equation modeling that can account for the multifactorial nature of these
phenomena, may yield other insights. The study shows the strong correlations among these variables and continuing research into the role identity plays in emotional distress may add valuable knowledge about the experience of cancer survivors.

An interesting finding occurred that shows respondents retaining a relatively high identity balance and lower than expected emotional distress. The clinic at St. Joseph’s Hospital employees an onsite psychosocial oncology team that meets with every treatment patient. Additionally, every patient is screened for distress and appropriate intervention is offered. Further research and measurement of these variables, and other influencing factors may uncover additional knowledge that improves understanding of the study phenomena.
REFERENCES


APPENDIX A

THE IDENTITY AND EXPERIENCES SCALE (IES)

The Identity and Experiences Scale (IES) assesses the individual’s use of identity processes in response to change. Whitbourne’s Identity Process Theory (IPT) (Whitbourne, 1986; 1996) suggests individuals adapt to changing circumstances by altering their sense of identity. Identity Balance (IBL), accounts for the ability to gradually alter identity while retaining its consistency. IBL items measure the extent to which the individual approaches experiences with a consistent sense of self, but with the flexibility to incorporate discrepant information about the self into identity as the situation demands.

IBL

Questions: 9, 17, 19, 20, 22, 26, 29, 30, 31, 32, 33

Permission to use the IBL subscale and to renumber the items was granted by Dr. Susan Whitbourne on 1-13-2013 via email correspondence received to my University of Colorado email account. Dr. Whitbourne approved my use of the IBL as a subscale by itself and she approved the renumbering of the items, keeping item order intact.

Please circle the number next to each item that best describes yourself as you are in general. Read each item carefully and think about your answer before you respond. Answers range from 1 (not like me) to 7 (completely like me). There are 11 items on this scale. Please answer all eleven items.
<table>
<thead>
<tr>
<th></th>
<th>1 = Not like me</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Try to be flexible but also try to maintain my goals.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Am challenged but not overwhelmed by change.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Feel I can handle disappointments about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Try to keep a steady course in life but am open to new ideas.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Have had my share of experiences in which I’ve learned about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feel confident in “who” I am but am willing to learn more about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Often take stock of what I have or have not accomplished.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Have a clear sense of my goals but am willing to consider alternatives.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Am always looking for ways to improve myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Am not afraid to confront my failures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Have very few doubts or questions about myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B

PROFILE OF MOOD STATES-BRIEF

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle ONE answer to the right, which best describes how you have been feeling during the past 24 hours.

The numbers refer to these phrases:

<table>
<thead>
<tr>
<th></th>
<th>0 = not at all</th>
<th>1 = a little</th>
<th>2 = moderately</th>
<th>3 = quite a bit</th>
<th>4 = extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Discouraged</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Bewildered</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Miserable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Gloomy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Weary</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. On Edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Muddled</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Uneasy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Unhappy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
APPENDIX C

CONDENSED MEMORIAL SYMPTOM ASSESSMENT SCALE (CMSAS)

Instructions: Below is a list of symptoms. Please circle either Y or N to indicate whether or not you have experienced the symptom during the last week. If YES, please circle the number that best describes how much this symptom has bothered you in the past 7 days.

If the symptom is present, please indicate how much the symptom bothered you.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Present?</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of energy</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Pain</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling drowsy</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Constipation</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Nausea</td>
<td>Y N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Other: Please list any other symptom(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
You are being asked to be in a research study. This form provides you with information about the study. A member of the research team will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don’t understand before deciding whether or not to take part.

Why is this study being done?
This study plans to learn more about your thoughts and feelings regarding your experience with cancer and cancer treatment. You are being asked to be in this research study because you are a cancer survivor. Up to 200 people will participate in the study.

What happens if I join this study?
If you join the study, you will be asked to answer a short questionnaire. You have the choice to take it on paper or on the internet. Your participation will take 15 minutes.

What are the possible discomforts or risks?
Discomforts you may experience while in this study includes revisiting your cancer experience.

Other possible risks include feelings of sadness, grief, or loss. The study may also include risks that are unknown at this time.

If you experience these feelings and need to talk with someone you can call the Tri-County Mental Health hotline numbers:
- Statewide Crisis Services: 1-888-568-1112

You may discontinue participation at any time and it will not affect your treatment or your care.

What are the possible benefits of the study?
This study is designed for the researcher to learn more about how to improve the quality of life of cancer survivors by reducing emotional distress. The goal is to
better understand how a cancer survivor’s sense of self affects emotional distress that is caused by symptoms related to the cancer journey and treatment. By participating you may also benefit from the chance to resolve feelings, reduce emotional distress and improve your quality of life with the help of healthcare professionals.

**Will I be paid for being in the study?** You will not be paid to be in the study.

**Will I have to pay for anything?** It will not cost you anything to be in the study.

**Is my participation voluntary?**
Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled.

**Who do I call if I have questions?**
The researcher carrying out this study is Lynne Bentley, RN, MSN. You may ask any questions you have now. If you have questions later, you may call or email *Lynne Bentley at 303-318-1316 or lynne.bentley@ucdenver.edu.*

You may have questions about your rights as someone in this study. You can call or email Lynne Bentley, RN, MSN at 303-318-1316 or lynne.bentley@ucdenver.edu. You can also call the Multiple Institutional Review Board (IRB). You can call them at 303-724-1055.

**Who will see my research information?**
We will do everything we can to keep your records a secret. It cannot be guaranteed.
Both the records that identify you and the consent form signed by you may be looked at by others.

- Federal agencies that monitor human subject research
- Human Subject Research Committee
- The group doing the study
- The group paying for the study
- Regulatory officials from the institution where the research is being conducted who want to make sure the research is safe
  The results from the research may be shared at a meeting. The results from the research may be in published articles. Your name will be kept private when information is presented.

Some things we cannot keep private: If you tell us you are going to physically hurt yourself or someone else, we have to report that to the Colorado department of health and human services. Also, if we get a court order to turn over your study records, we will have to do that.
Agreement to be in this study
I have read this paper about the study. I understand the possible risks and benefits of this study. I know that being in this study is voluntary.

You may request an extra copy of this information sheet to take home.

You are invited to participate in the Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors research study. Please answer the Eligibility Questions below by marking the box with the answer that best describes you.

If you answer YES to all eligibility questions, please complete the questionnaire, and upon completion return it to the locked collection box in the reception area.

If you answer NO to any eligibility questions, please do not complete the questionnaire, and return it to the locked collection box in the reception area.
# Eligibility Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can read and understand English.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am able to complete this questionnaire by myself without help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am between 18 and 89 years of age.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am not currently being treated with chemotherapy or radiation therapy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I completed treatment within the last 6 to 18 months.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Identity Balance Subscale of the Identity and Experience Scale

Please circle the number next to each item that best describes yourself as you are in general. Read each item carefully and think about your answer before you respond.

Answers range from 1 (not like me) to 7 (completely like me).

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Try to be flexible but also try to maintain my goals.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Am challenged but not overwhelmed by change.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Feel I can handle disappointments about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Try to keep a steady course in life but am open to new ideas.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Have had my share of experiences in which I’ve learned about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feel confident in “who” I am but am willing to learn more about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Often take stock of what I have or have not accomplished.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Have a clear sense of my goals but am willing to consider alternatives.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Am not afraid to confront my failures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Have very few doubts or questions about myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### PROFILE OF MOOD STATES-BRIEF

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle ONE answer to the right, which best describes how you have been feeling during the past 24 hours.

<table>
<thead>
<tr>
<th>The numbers refer to these phrases:</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = not at all  1 = a little  2 = moderately  3 = quite a bit  4 = extremely</td>
</tr>
</tbody>
</table>

Circle ONE answer which best describes how you have been feeling during the past 24 hours.

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Discouraged</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Bewildered</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Miserable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Gloomy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Weary</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. On Edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Muddled</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Uneasy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Unhappy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**Condensed Memorial Symptom Assessment Scale (CMSAS)**

Instructions: Below is a list of symptoms. Please circle either Y or N to indicate whether or not you have experienced the symptom during the last week. If YES, please circle the number that best describes how much this symptom has bothered you in the past 7 days. If the symptom is present, please indicate how much the symptom bothered you.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Present</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Lack of energy</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Lack of appetite</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Pain</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Dry mouth</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Weight Loss</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Feeling drowsy</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Shortness of breath</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Constipation</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Difficulty sleeping</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Difficulty concentrating</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Nausea</td>
<td>Y  N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Other: Please list any other symptom(s) that bother you.

**DEMOGRAPHICS**

What is your age in years? ____________

How many years have you lived in the U.S.? ____________

What type of cancer did you have? ___________________________________________
Financial Circumstances: Mark one.

My household income is sufficient for my needs.

☐ Yes
☐ No

Insurance: Mark all that apply

☐ I have health insurance

☐ I have some type of financial assistance to help pay my healthcare bills.

☐ I do not have health insurance.

☐ I do not have some type of financial assistance to help pay my healthcare bills.

Living Arrangements: Mark one.

☐ I live alone

☐ I live with others (family/friends)

☐ I live in assisted living
☐ I live in a skilled nursing facility

**Current Partnership/Marital Status: Mark one.**

☐ I am married

☐ I am in an unmarried partnership

☐ I am single (Currently I do not have a partner or a spouse)

**Education: Mark the highest level of education you have completed.**

☐ Some elementary school (K-5)

☐ Completed elementary school (grade 5)

☐ Some middle school (6-8)

☐ Completed middle school (grade 8)

☐ Some high school (9-12)

☐ Completed high school (grade 12) or GED

☐ Some college

☐ 2 year college degree (associate’s)

☐ 4 year college degree (BS, BA)

☐ Master’s degree

☐ Doctoral degree

☐ Professional degree (MD, JD)
Gender: Mark one.

☐ Male
☐ Female
☐ Other

Ethnicity: Mark one.

☐ Hispanic
☐ Non-Hispanic

Race: Mark all that apply.

☐ American Indian/Native American
☐ Asian
☐ Black/African American
☐ Native Hawaiian/Pacific Islander
☐ White
☐ Two or more races
APPENDIX E

ONLINE PATIENT INFORMATION FORM AND QUESTIONNAIRE

Principal Investigator: Lynne Bentley
COMIRB No: 13-2212
Version Date: 11-2-2013
Study Title: Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors

You are being asked to be in a research study. This form provides you with information about the study. A member of the research team will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don’t understand before deciding whether or not to take part.

Why is this study being done?
This study plans to learn more about your thoughts and feelings regarding your experience with cancer and cancer treatment. You are being asked to be in this research study because you are a cancer survivor. Up to 200 people will participate in the study.

What happens if I join this study?
If you join the study, you will be asked to answer a short questionnaire. You have the choice to take it on paper or on the internet. Your participation will take 15 minutes.

What are the possible discomforts or risks?
Discomforts you may experience while in this study includes revisiting your cancer experience.

Other possible risks include feelings of sadness, grief, or loss. The study may also include risks that are unknown at this time.

If you experience these feelings and need to talk with someone you can call the Tri-County Mental Health hotline numbers:

- Statewide Crisis Services: 1-888-568-1112

You may discontinue participation at any time and it will not affect your treatment or your care.

What are the possible benefits of the study?
This study is designed for the researcher to learn more about how to improve the quality of life of cancer survivors by reducing emotional distress. The goal is to
better understand how a cancer survivor’s sense of self affects emotional distress that is caused by symptoms related to the cancer journey and treatment. By participating you may also benefit from the chance to resolve feelings, reduce emotional distress and improve your quality of life with the help of healthcare professionals.

**Will I be paid for being in the study?** You will not be paid to be in the study.

**Will I have to pay for anything?** It will not cost you anything to be in the study.

**Is my participation voluntary?**
Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled.

**Who do I call if I have questions?**
The researcher carrying out this study is Lynne Bentley, RN, MSN. You may ask any questions you have now. If you have questions later, you may call or email Lynne Bentley at 303-318-1316 or lynne.bentley@ucdenver.edu.

You may have questions about your rights as someone in this study. You can call or email Lynne Bentley, RN, MSN at 303-318-1316 or lynne.bentley@ucdenver.edu. You can also call the Multiple Institutional Review Board (IRB). You can call them at 303-724-1055.

**Who will see my research information?**
We will do everything we can to keep your records a secret. It cannot be guaranteed.
Both the records that identify you and the consent form signed by you may be looked at by others.

- Federal agencies that monitor human subject research
- Human Subject Research Committee
- The group doing the study
- The group paying for the study
- Regulatory officials from the institution where the research is being conducted who want to make sure the research is safe

The results from the research may be shared at a meeting. The results from the research may be in published articles. Your name will be kept private when information is presented.
Some things we cannot keep private: If you tell us you are going to physically hurt yourself or someone else, we have to report that to the Colorado department of health and human services. Also, if we get a court order to turn over your study records, we will have to do that.

**Agreement to be in this study**
I have read this paper about the study. I understand the possible risks and benefits of this study. I know that being in this study is voluntary.
Please answer the Eligibility Questions below by marking the box with the answer that best describes you.

If one or more of your answers does not meet the requirements of this research study, you will be taken to the end of the questionnaire.

**Eligibility Questions**

<table>
<thead>
<tr>
<th>Eligibility Questions</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can read and understand English.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am able to complete this questionnaire by myself without help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am between 18 and 89 years of age.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am not currently being treated with chemotherapy or radiation therapy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I completed treatment within the last 6 to 18 months.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Identity Balance Subscale of the Identity and Experience Scale

Please circle the number next to each item that *best* describes yourself as you are in general. Read each item carefully and think about your answer before you respond.

Answers range from 1 (not like me) to 7 (completely like me).

<table>
<thead>
<tr>
<th></th>
<th>1 = Not like me</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Try to be flexible but also try to maintain my goals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2. Am challenged but not overwhelmed by change.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. Feel I can handle disappointments about myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4. Try to keep a steady course in life but am open to new ideas.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5. Have had my share of experiences in which I’ve learned about myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6. Feel confident in “who” I am but am willing to learn more about myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7. Often take stock of what I have or have not accomplished.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8. Have a clear sense of my goals but am willing to consider alternatives.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9. Am always looking for ways to improve myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10. Am not afraid to confront my failures.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11. Have very few doubts or questions about myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
**PROFILE OF MOOD STATES-BRIEF**

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle ONE answer to the right, which best describes how you have been feeling during the past 24 hours.

<table>
<thead>
<tr>
<th>The numbers refer to these phrases:</th>
<th>0 = not at all</th>
<th>1 = a little</th>
<th>2 = moderately</th>
<th>3 = quite a bit</th>
<th>4 = extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circle ONE answer which best describes how you have been feeling during the past 24 hours.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Discouraged</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Bewildered</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Miserable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Gloomy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Weary</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. On Edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Muddled</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Uneasy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Unhappy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Condensed Memorial Symptom Assessment Scale (CMSAS)

Instructions: Below is a list of symptoms. Please circle either Y or N to indicate whether or not you have experienced the symptom during the last week. If YES, please circle the number that best describes how much this symptom has bothered you in the past 7 days. If the symptom is present, please indicate how much the symptom bothered you.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Present</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Lack of energy</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Lack of appetite</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Pain</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Dry mouth</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Weight Loss</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling drowsy</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Shortness of breath</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Constipation</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Difficulty sleeping</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Difficulty concentrating</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Nausea</td>
<td>Y</td>
<td>N</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Other: Please list any other symptom(s) that bother you.

DEMOGRAPHICS

What is your age in years? ______________

How many years have you lived in the U.S.? ___________

What type of cancer did you have? ___________________________

Financial Circumstances: Mark one.

My household income is sufficient for my needs.

☐ Yes
☐ No
Insurance: Mark all that apply

☐ I have health insurance

☐ I have some type of financial assistance to help pay my healthcare bills.

☐ I do not have health insurance.

☐ I do not have some type of financial assistance to help pay my healthcare bills.

Living Arrangements: Mark one.

☐ I live alone

☐ I live with others (family/friends)

☐ I live in assisted living

☐ I live in a skilled nursing facility

Current Partnership/Marital Status: Mark one.

☐ I am married

☐ I am in an unmarried partnership

☐ I am single (Currently I do not have a partner or a spouse)

Education: Mark the highest level of education you have completed.

☐ Some elementary school (K-5)

☐ Completed elementary school (grade 5)

☐ Some middle school (6-8)

☐ Completed middle school (grade 8)

☐ Some high school (9-12)

☐ Completed high school (grade 12) or GED
☐ Some college

☐ 2 year college degree (associate’s)

☐ 4 year college degree (BS, BA)

☐ Master’s degree

☐ Doctoral degree

☐ Professional degree (MD, JD)

Gender: Mark one.

☐ Male

☐ Female

☐ Other

Ethnicity: Mark one.

☐ Hispanic

☐ Non-Hispanic

Race: Mark all that apply.

☐ American Indian/Alaska Native

☐ Asian

☐ Black/African American

☐ Native Hawaiian/Pacific Islander

☐ White

☐ Two or more races
APPENDIX F

COMIRB CERTIFICATE OF APPROVAL #1

Certificate of Approval

23-Jan-2014

Investigator: Lynne Bentley

Subject: COMIRB Protocol 13-2212 Initial Application

Effective Date: 27-Dec-2013

Expiration Date: 26-Dec-2014

Expedited Category: 7

Title: Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors

Submission ID: APP01-4

Description:

All COMIRB Approved Investigators must comply with the following:

- For the duration of your protocol, any change in the experimental design/consent and/or assent form must be approved by the COMIRB before implementation of the changes.
- Use only a copy of the COMIRB signed and dated Consent and/or Assent Form. The investigator bears the responsibility for obtaining from all subjects "Informed Consent" as approved by the COMIRB. The COMIRB REQUIRES that the subject be given a copy of the consent and/or assent form. Consent and/or assent forms must include the name and telephone number of the investigator.
- Provide non-English speaking subjects with a certified translation of the approved Consent and/or Assent Form in the subject's first language.
- The investigator also bears the responsibility for informing the COMIRB immediately of any Unanticipated Problems that are unexpected and related to the study in accordance with COMIRB Policy and Procedures.
- Obtain COMIRB approval for all advertisements, questionnaires and surveys before use.
- Federal regulations require a Continuing Review to renew approval of this project within a 12-month period from the last approval date unless otherwise indicated in the review cycle listed below. If you have a restricted/high risk protocol, specific details will be outlined in this letter. Non-compliance with Continuing Review will result in the termination of this study.

You will be sent a Continuing Review reminder 75 days prior to the expiration date. Any questions regarding this COMIRB action can be referred to the Coordinator at 303-724-1056 or UCHSC Box F-490.

Review Comments:

APP01-4 has been APPROVED.

The following documents have been stamped APPROVED/NOTED as part of this approval:

1. Application for Protocol Review: version 12/13/13 (Please note that the COMIRB Coordinator administratively updated the version date on the stamped APPROVED version of this document and sent a copy to the PI)
- Includes Attachment M – Waiver of Written Documentation of Consent: Determined to meet criteria for waiver of consent for written documentation of consent.
- Includes Attachment O – Full Waiver of HIPAA Authorization Approved: Determined to meet criteria for full waiver of HIPAA authorization
2. FRMS Letter
3. I cnized Cover Letter
4. Flyer
5. Personnel - Section C Form
6. Research Study Information Sheet (Post Card Consent); version 12/13/13
7. COMIRB Protocol
8. Identity Balance Subscale of the Identity and Experience Scale
9. Response Letter; version 11/02/13

Affiliated Sites: University of Colorado Hospital, UCD Anschutz Medical Campus, Denver Health (Acknowledgement Letter Received)

Unaffiliated Sites: 2

Please note that COMIRB will no longer be E-mailing approved documents. Stamped, approved documents can be retrieved in the eRA (InfoEd) system, Please click here to access instructions on finding these approved documents.

Sincerely,

UCD Panel D

Please provide your feedback on IRB processes and support
APPENDIX G

COMIRB CERTIFICATE OF APPROVAL #2

Certificate of Approval

09-Jan-2015

Investigator: Lynne Bentley
Sponsor(s):
Subject: COMIRB Protocol 13-2212 Continuing Review
Effective Date: 23-Dec-2014
Expiration Date: 22-Dec-2015
Expedited Category: 7
Title: Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors

Submission ID: CRV001-2
Description:
CRV001-2
Status: Enrolling
Response to incomplete submission

CRV001-1
Status: Enrolling

All COMIRB Approved Investigators must comply with the following:

- For the duration of your protocol, any change in the experimental design/consent and/or assent form must be approved by the COMIRB before implementation of the changes.
- Use only a copy of the COMIRB-approved, stamped Consent and/or Assent Form. The investigator bears the responsibility for obtaining from all subjects “Informed Consent” as approved by the COMIRB. The COMIRB requires that the subject be given a copy of the consent and/or assent form after it is signed. Consent and/or assent forms must include the name and telephone number of the investigator.
- Provide non-English speaking subjects with a certified translation of the approved Consent and/or Assent Form in the subject’s first language.
- The investigator also bears the responsibility for informing the COMIRB immediately of any Unanticipated Problems that are unexpected and related to the study in accordance with COMIRB Policy and Procedures.
- Obtain COMIRB approval for all advertisements, questionnaires and surveys before use.
- Federal regulations require a Continuing Review to renew approval of this project within a 12-month period from the last approval date unless otherwise indicated in the review cycle listed below. If you have a restricted/high risk protocol, specific details will be outlined in this letter. Non-compliance with Continuing Review will result in the...
You will be sent a Continuing Review reminder 75 days prior to the expiration date. Any questions regarding this COMIRB action can be referred to the Coordinator at 303-724-1055 or UCHSC Box F-490.

**Review Comments:**

CRV001-2
The following documents have been reviewed and stamped APPROVED or NOTED as part of this approval:
Continuing review form (CRV001-2)
Postcard consent form, version date: 12.13.13
Application for protocol review with attachments A, F, M: Waiver of Documentation of Consent—Determined to meet criteria for waiver of documentation of consent.
Full Waiver of HIPAA Authorization—Determined to meet criteria for waiver of HIPAA authorization and Section C: Personnel, version date: 12.13.13
Protocol, no date
Table 3, no date
Exempla IRB approval letter, version date: 3.10.14
Cover letter, no version date

Please note that COMIRB will no longer be emailing approved documents. Stamped, approved documents can be retrieved in the eRA (InfoEd) system. [Please click here](#) to access instructions on finding these approved documents.

Sincerely,

UCD Panel D
APPENDIX H
EXEMPLA APPROVAL

March 18, 2014

Lyane Hanley, RN, MSN, MBA
Director, Comprehensive Cancer Center
1823 Market St.
Denver, CO 80218

Re: IRB # 201405, Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors

Dear Mr. Hanley:

The above-named study has undergone Expedited review and the clarification and requested changes have been received. The study received approval as of March 18, 2014 under HHS 45 CFR 46.101 and FDA 21 CFR 56.110, Category 7. The study is approved for no more than twelve (12) months. Approval will expire on 03/08/2015.

The following are included in this approval:
1. Protocol, Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors (no version 1 or date provided)
2. Waiver of Informed Consent approved
3. Research Study Information Sheet, including surveys, approved (no version 4 provided)
4. Exempla IRB Free Waiver, approved

Please note the study approval does not include the Comprehensive Cancer Centers at FLMC, or GESMC, signed Department Agreements will need to be submitted to the IRB in order to add these locations.

As a reminder, written approval from the IRB must be obtained prior to initiating any changes/modifications to this study. This includes but is not limited to changes in procedures, concomitant medications, consent forms, protocols, participants, and advertising materials, and investigator brochures unless a change is necessary to diminish the extent or severity of the risk to the participants in the study (See IRB Policies and Standard Operating Procedures and Submission Forms*).

Any unanticipated problems, serious adverse events, breach of privacy or serious protocol deviations that may occur in the course of this study must be reported promptly. Promptly for internal events means a telephone verbal notification within 2 business days and a written report within 5 business days for external events (See IRB Policies and Standard Operating Procedures*).

If you have any questions, please contact the IRB Office at (303) 877-6579.

Thank you.

[Signature]

Philip Noji, MD
Chair, Exempla Healthcare IRB

*The Exempla Healthcare IRB Policies and Standard Operating Procedures and all submission forms are located on the Exempla Portal and on the U7 Drive. A paper copy will be mailed upon electronic version will be available upon request. Please call 303-877-6579 or email Glen Lind, IRB Coordinator, at Glen.Lind@SCLHealth.com

Institutional Review Board
1805 Franklin Street • Denver, CO 80218-1191 • Ph 303-437-6629 • F 303-437-6527 • www.exempla.org
APPENDIX I: SLC HEALTH SYSTEM APPROVAL

March 11, 2015

Lynea Bentley, RN, PhD
SHI – COC
1825 Marion St.
Denver, CO 80218

IRB: Study # 201403, Symptom Burden, Identity Balance and Emotional Distress in Cancer Survivors

Dear Dr. Bentley:
The continuing review of research report for the above-mentioned study has been reviewed and approved as expedited research, under 45 CFR 46.110 and FDA 21 CFR 56.110. The study has been approved for one year. Approval will expire on 3/9/2016.

The following are included in this approval:


2. The IRB Continuing Review of Research fee has been waived.

As a reminder, a study closure report needs to be submitted to the IRB once the local study is ready to close. Until the study is closed, written approval from the IRB must be obtained prior to initiating any changes/modifications in this study. This includes but is not limited to changes in procedures, co-investigators, funding agencies, consent forms, protocols, participant and advertising materials, and investigator brochures unless a change is necessary to eliminate an apparent hazard to the participants in the study (See IRB Policies and Standard Operating Procedures and Submission Forms*).

Any unanticipated problems, adverse events, breach of privacy or serious protocol deviations that may occur in the course of this study must be reported promptly. Promptly for internal events means a phone or email notification within 5 business days and a written report within 5 business days; for external events promptly means within 5 business days (See IRB Policies and Standard Operating Procedures*).

If you have any questions, please contact the IRB Office, at (303) 812-6488.

Thank you,

Cami Lind, CIP
IRB Manager
SLH Health-Provider Institutional Review Board

*The SCLH IRB Policies and Standard Operating Procedures and all submission forms are available electronically or paper copy will be mailed upon request. Please call 303-812-6488 or email Cami Lind at Cami.Lind@SCLH.net

SCL Health-Provider Institutional Review Board

APPENDIX I

146