

2013-04-23

# Evaluation of the Impact of Coping Skills Groups on Quality of Life in Cancer Survivors and Co-Survivors

Erin S. Cornelius

*University of Miami*, [schweers@post.harvard.edu](mailto:schweers@post.harvard.edu)

Follow this and additional works at: [http://scholarlyrepository.miami.edu/oa\\_dissertations](http://scholarlyrepository.miami.edu/oa_dissertations)

---

## Recommended Citation

Cornelius, Erin S., "Evaluation of the Impact of Coping Skills Groups on Quality of Life in Cancer Survivors and Co-Survivors" (2013). *Open Access Dissertations*. 987.

[http://scholarlyrepository.miami.edu/oa\\_dissertations/987](http://scholarlyrepository.miami.edu/oa_dissertations/987)

This Open access is brought to you for free and open access by the Electronic Theses and Dissertations at Scholarly Repository. It has been accepted for inclusion in Open Access Dissertations by an authorized administrator of Scholarly Repository. For more information, please contact [repository.library@miami.edu](mailto:repository.library@miami.edu).

UNIVERSITY OF MIAMI

EVALUATION OF THE IMPACT OF COPING SKILLS GROUPS ON QUALITY OF  
LIFE IN CANCER SURVIVORS AND CO-SURVIVORS

By

Erin Schweers Cornelius

A DISSERTATION

Submitted to the Faculty  
of the University of Miami  
in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

Coral Gables, Florida

May 2013

©2013  
Erin Schweers Cornelius  
All Rights Reserved

UNIVERSITY OF MIAMI

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

EVALUATION OF THE IMPACT OF COPING SKILLS GROUPS ON QUALITY OF  
LIFE IN CANCER SURVIVORS AND CO-SURVIVORS

Erin Schweers Cornelius

Approved:

---

Kent Burnett, Ph.D.  
Associate Professor  
Educational and Psychological Studies

---

M. Brian Blake, Ph.D.  
Dean of the Graduate School

---

Margaret Crosbie-Burnett, Ph.D.  
Associate Professor Emerita  
Educational and Psychological Studies

---

Etiony Aldarondo, Ph.D.  
Associate Dean for Research and  
Director of CEW Center

---

Peggy Rios, Ph.D.  
Lecturer Educational and Psychological  
Studies and Program Director, Cancer Support  
Community of Greater Miami

CORNELIUS, ERIN SCHWEERS  
Evaluation of the Impact of Coping Skills  
Groups on Quality of Life in Cancer  
Survivors and Co-Survivors

(Ph.D., Counseling Psychology)  
(May 2013)

Abstract of a dissertation at the University of Miami.

Dissertation supervised by Professor Kent Burnett.  
No. of pages in text. (127)

A coping skills group intervention for cancer survivors and co-survivors was developed based upon the APPLES Indicators of Healing. The group was a six week intervention aimed at teaching specific coping skills hypothesized to improve the participants' quality of life. Variables including illness-related distress, illness-related coping, and illness-related resilience were examined in their relation to quality of life prior to the start of the intervention, midway through the intervention, and after the intervention concluded. It was predicted that participation in the APPLES coping skills group intervention would significantly improve cancer survivors' and co-survivors' resiliency, quality of life, and use of positive coping skills, while lessening distress and use of negative coping skills. It was concluded that during the group there was an increase in feelings of distress and use of substances; however, by the end of the group the participants showed an increase in posttraumatic growth and feelings of resiliency and a decrease in symptoms of PTSD, specifically feelings of detachment.

## ACKNOWLEDGEMENT

Completing this dissertation and my doctoral degree would not have been possible without the support, time, commitment, patience, humor, and care of those important people in my life.

I would like to thank Dr. Kent Burnett, my committee chair, for working with me for many years to visualize this project and bring it to fruition. His guidance has been invaluable. I would also like to thank Dr. Margaret Crosbie-Burnett, Dr. Etiony Aldarondo, and Dr. Peggy Rios for their time, effort, and guidance in the dissertation defense process.

My doctoral degree would not have been possible without the unwavering support of my family and friends. Thank you to Doug Schweers, Judy Schweers, and Laurie Branch for their financial and emotional support as well as enthusiastic cheerleading, especially when it felt like the finish line kept moving. Thank you to my amazing friends who encouraged me at every corner and provided much needed distractions at times. I would also like to thank my amazing husband, Sean Cornelius, for believing I could do this and helping me to find the time and energy when it seemed like life would always get in the way. And last but not least, thank you to my son, Harrison, for surprising me with your arrival and reminding me that life is what happens when you are busy working on your graduate degree.

## TABLE OF CONTENTS

	Page
LIST OF FIGURES.....	vii
LIST OF TABLES.....	viii
Chapter	
I INTRODUCTION	
General Overview.....	1
Cancer as a Chronic Illness.....	1
Unique Issues for Cancer Survivors .....	3
Unique Issues for Cancer Co-Survivors.....	3
Cancer and Coping.....	4
Quality of Life.....	5
Psychological Interventions for Cancer Survivors and Co-Survivors.....	7
Need for New Psychological Interventions for Cancer Survivors and Co-Survivors.....	8
Focus of the Present Study.....	9
II BACKGROUND	
Scope of the Literature Review.....	11
Cancer as a Chronic Illness.....	11
Distress in Cancer Survivors.....	13
Distress in Cancer Co-Survivors.....	16
Cancer and Coping.....	18
Quality of Life.....	23
Psychological Interventions for Cancer Survivors and Co-Survivors .....	27
Overview.....	27
Education .....	28
Coping.....	31
Emotional Support .....	34
Psychotherapy.....	39
Summary of Literature.....	42
Need for New Psychological Interventions for Cancer Survivors and Co-Survivors .....	43
Research Questions, Hypotheses, and Overview of the Study .....	44
Research Question 1a.....	44
Hypothesis 1a.....	44
Research Question 1b .....	44
Hypothesis 1b.....	44
Research Question 2a.....	45
Hypothesis 2a.....	45

Chapter		
II	Research Question 2b .....	45
	Hypothesis 2b.....	45
	Research Question 3a.....	45
	Hypothesis 3a.....	45
	Research Question 3b .....	45
	Hypothesis 3b.....	46
	Research Question 4a.....	46
	Hypothesis 4a.....	46
	Research Question 4b .....	46
	Hypothesis 4b.....	46
	Research Question 5a.....	46
	Hypothesis 5a.....	46
	Research Question 5b .....	46
	Hypothesis 5b.....	46
	Research Question 6a.....	47
	Hypothesis 6a.....	47
	Research Question 6b .....	47
	Hypothesis 6b.....	47
	Research Question 7a.....	47
	Hypothesis 7a.....	47
	Research Question 7b .....	47
	Hypothesis 7b.....	47
III	METHODOLOGY .....	
	Methodology .....	48
	Participants.....	49
	Inclusion Criteria .....	49
	Exclusion Criteria .....	50
	Recruitment.....	50
	Sample Characteristics.....	52
	Procedures and Measures.....	52
	Screening Instruments.....	54
	Cancer Support Community Greater Miami Intake Form .....	54
	Assessment Battery.....	55
	Demographic Questionnaire .....	55
	Injury Distress Index.....	55
	Injury Coping Index .....	56
	Injury Resilience Index.....	56
	Quality of Life Inventory .....	57
	Data Collection .....	58
IV	RESULTS .....	
	Demographics .....	59
	Analysis of the Results.....	62
	Missing Data .....	62



Chapter		
IV	Descriptives.....	64
	Hypothesis Testing.....	66
	Post-Hoc Analysis.....	72
V	DISCUSSION	
	Review of Research Questions .....	74
	Review of Research Findings .....	76
	Implications of Research Findings.....	80
	Strengths and Limitations .....	81
	Recommendations for Future Research .....	84
	REFERENCES.....	88
	APPENDIX A.....	103
	APPENDIX B.....	126
	APPENDIX C.....	127

## LIST OF FIGURES

	Page
Figure 1: Cancer Survivor Adaptation Model.....	12
Figure 2: CASIO Model of Quality of Life.....	25

## LIST OF TABLES

	Page
Table 1: APPLES Group Administration Schedule.....	49
Table 2: APPLES Group Session Outline .....	53
Table 3: Research Support for the APPLES Indicators of Healing.....	54
Table 4: Demographics of Cancer Survivor Group.....	61
Table 5: Demographics of Cancer Co-Survivor Group.....	62
Table 6: Attrition Rate throughout Study.....	63
Table 7: Mean, Standard Deviation, and Range of Assessment Measures.....	65
Table 8: Correlations of Assessment Measures .....	66

## CHAPTER I

### **Introduction**

#### **General Overview**

Approximately 569,490 people will die of cancer this year and another 1,529,560 people will be diagnosed with cancer in the US. Furthermore, the National Cancer Institute estimates that about 11.4 million people were alive with cancer in January 2006; this is an additional 600,000 people from the estimates just two years prior (American Cancer Society, 2010). The trauma of being diagnosed with a life-threatening illness can lead to a multitude of changes in one's life and the impact is far-reaching (Classen, et al., 2001). Coping with an illness of this magnitude requires support, guidance, and resources, for both the cancer patient and their family members (Couper, Bloch, Love, Duchesne, MacVean, & Kissane, 2009; Danhauer, Crawford, Farmer, & Avis, 2009; Manne, et al., 2008).

Researchers and clinicians are beginning to recognize that a cancer diagnosis is a traumatic experience (Classen, et al., 2001; Nijboer, Tempelaar, & Sanderman, 1998). It is now listed in the Diagnostic and Statistical Manual of Mental Disorders-IV under Posttraumatic Stress Disorder as meeting the criteria of "exposure to an extreme traumatic stressor" (Classen, et al., 2001). Thus, it is important for physicians and clinicians to focus not only on the physical condition but also the emotional and mental condition of the cancer patient.

#### **Cancer as a Chronic Illness**

"Up through the 1950s and 1960s, cancer carried a stigma for the patient and the family, partly owing to the poor survival rate, enforcing a silence on all concerned" (Holland & Lewis, 2000). However, in the 1970s this began to shift with the introduction

of patient's rights. As patients and their families began to talk about the diagnosis and become more active in advocating for their needs, the general attitude towards cancer began to change.

Currently, all cancers diagnosed between 1999-2005 have a five year survival rate of 68%, which is up from the 1975-1977 rate of 50% (American Cancer Society, 2010). Thus, over the last thirty years cancer has shifted from an acute disease to a chronic illness. With this change in mindset comes a change in practice as clinicians are no longer focused on short term care, but rather promoting long term survivorship.

Forty to fifty years ago cancer was synonymous with a death sentence and doctors aimed to prolong the inevitable. However, as we have made significant medical advances it is possible, and in a lot of cases probable, that cancer survivors can live for many years without any evidence of illness. With this advancement has come a new set of challenges, as cancer survivors are plagued with worries about recurrence in later years or of the impact of late effects (Northouse, Kershaw, Mood, & Schafenacker, 2005; Rehse & Pukrop, 2003). Symptom abatement or remission is no longer a sufficient endpoint to a cancer diagnosis. Chemotherapy, radiation, and surgery are no longer the only treatment options, but they are now paired with individual therapy, support groups, exercise, and mind-body wellness programs.

Conceptualizing cancer as a chronic illness has led to a more comprehensive approach to cancer treatment. This more inclusive model of cancer has helped to shift our understanding of how people deal with a cancer diagnosis. According to research, chronic illness should be perceived in terms of a) the disruption of the "normal" life experience, b) an intimidating new situation, c) limited opportunities for control, d) ambiguity in the

experience, e) lack of explanation or justification, and f) change in patient/partner dynamics in order to compensate for the lack of control/understanding (Morgan, Fogel, Rose, Barnett, Mock, & Davis, 2005).

### **Unique Issues for Cancer Survivors**

Cancer survivors are faced with many obstacles upon diagnosis. Treatment decisions, cost of care, loss of functioning, mortality, and the impact on relationships are just a few of the many new challenges that cancer survivors face. Therefore, it is not surprising that as many as 50% of patients are distressed enough to qualify for a diagnosis of anxiety or depression (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999).

Research findings over the past decade indicate that the cancer survivor's physical health and mental health are to some extent linked. Some studies have found an increase in recurrence amongst patients experiencing significant distress (Molassiotis, 1997). However, cancer patients who are able to express their emotions are better able to cope with the disease and have a better prognosis (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999). Therefore, psychological treatment for cancer survivors has become an integral part of a comprehensive treatment model for a cancer diagnosis.

### **Unique Issues for Cancer Co-Survivors**

Cancer is an invasive and pervasive disease that not only affects those battling the illness, but also those who are unexpectedly asked to care for a sick or dying loved one (Kuijjer, Buunk, De Jong, Ybema, & Sanderman, 2004). Caring for a loved one with cancer can be very stressing and distressing. Beyond the obvious duty of providing care and support for the sick person, there are other changes that occur. For example, financial

obligations related to medical costs and a potential change in household income, adjustments to daily routines, disruption in a couple's social life related to the partner's illness, coping with your loved one's emotional distress as well as your own, and the uncertainty related to treatment and recurrence of cancer (Baider & Bengel, 2001).

Multiple self-report studies have found that between 20-30% of caregivers are probable cases of psychiatric morbidity (Pitceathly & Maguire, 2003). Distress may be extended due to the caregivers' disregard for their own emotional needs while focusing on their loved one's well-being. Caregivers are less likely than patients to discuss their concerns and only half with serious psychological problems will seek help (Pitceathly & Maguire, 2003).

### **Cancer and Coping**

According to Lazarus and Folkman, coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Simply put, coping is adapting to demanding situations. Coping is influenced by a person's cognitive appraisal of the situation as well as their emotional arousal in response to the appraisal. Thus, the coping strategies that one employs will be influenced by one's interpretation of the perceived threat. And, as demonstrated in multiple studies, cancer is perceived as a significant threat to the well-being of a large number of people (American Cancer Society, 2010; Classen, et al., 2001; Fawzy, Fawzy, Arndt, & Pasnau, 1995).

Further, coping styles can be broken down into problem-focused coping (i.e. looking for a solution to a practical issue) or emotion-focused coping (i.e. using strategies

to minimize emotional distress). Emotion-focused and problem-focused coping have been found to be two distinct constructs, and thus it is possible to utilize both at the same time (Schmitz & Crystal, 2000). However, coping with a life-threatening situation, such as a cancer diagnosis, requires strategies different from those used to cope with everyday life situations (Baider & Bengel, 2001). It has even been suggested that cancer survivors who use active coping strategies such as restructuring, processing, expression, and acceptance have better quality of life than those who employ passive coping strategies such as avoidance and minimization (Danahauer, Crawford, Farmer, & Avis, 2009). Thus, information about coping as well as guidance on the use of strategies becomes more important for the survivors and co-survivors who face a battle with cancer.

### **Quality of Life**

“Quality of life (QOL) refers to the degree of excellence in life (or living) relative to some expressed or implied standard of comparison, such as most people in a particular society” (Frisch M. B., 1998, p. 19). The term “quality of life” is very broad based and has been used to describe many different phenomena. It has been equated with well-being, life satisfaction, engaging in particular behaviors, objective living conditions, symptom abatement, mental health, years of survival, and many others (Frisch M. B., 1998). The lack of agreement about the definition of quality of life has led to a confusing body of literature which sites improvement in quality of life amongst a multitude of groups, yet has measured very different concepts. While some researchers have made attempts to tease out smaller components of quality of life, other researchers have decided to develop an integrative model that includes many different elements (Frisch M. B., 1998; Frisch, et al., 2005; Frisch, Cornell, & Villanueva, 1992).



The CASIO Model of Quality of Life is a linear integrative model of life satisfaction that is based on the sum of satisfaction in particular life domains that are deemed important by the individual (Frisch M. B., 2006). An individual's satisfaction in a specific area of life (e.g. work, family life, romantic relationships, etc.) is determined by 1) objective characteristics of the domain, 2) the individual's perception of the domain, 3) the individual's evaluation of whether their needs have been met in that domain, and 4) the individual's determination of personal value and importance of the domain (Frisch M. B., 1998). These four components lead to overall satisfaction, as outlined in the CASIO Model of Quality of Life.

Frisch's model of quality of life is conceptually sophisticated as it incorporates a component of clinical significance such that an individual is able to decide how important a particular component is to *their* life. It is assumed that in general people value the same things in life; however, the subjective importance of these areas is very different. Therefore, a model that allows for a multitude of areas as well as a subjective significance rating provides the most inclusive definition of quality of life. According to Frisch, the sixteen areas of life that make up "quality of life" include: health, self-esteem, goals and values, standard of living, work, recreation, learning, creativity, helping or social service/civic action, love relationship, friendships, relationships with children, relationships with relatives, home, neighborhood, and community (Frisch M. B., 1998). For cancer survivors and co-survivors, every one of these sixteen domains is vulnerable to a cancer diagnosis.

## **Psychological Interventions for Cancer Survivors and Co-Survivors**

Group psychotherapy has been repeatedly offered as a treatment for illness-related distress in cancer patients (Edelman & Kidman, 1999; Meyer & Mark, 1995; Petersen, Bull, Propst, Dettinger, & Detwiler, 2005; Uitterhoeve, et al., 2004). This treatment modality offers many advantages over individual therapy such as easy accessibility, peer contact, and cost effectiveness. Additionally, living in a society so focused on managed care, it is important to note that group therapy produces results for a fraction of the cost of individual therapy (Frisch M.B., 1998).

Multiple studies have looked at many different types of groups including, coping skills, supportive, educational, and psychotherapeutic groups. The findings are mixed with some authors stating that cognitive-behaviorally based groups are the most effective, while others state that those groups just scratch the surface of the difficulties that face cancer patients (Bottomley A., 1997a; Coyne, Lepore, & Palmer, 2006; Fobair, 1997a). Additional researchers have found that groups that combine cognitive-behavioral techniques with supportive-expressive and psychoeducational methods have the best results with cancer patients (Classen, et al., 2001; Barsevick, Sweeney, Haney, & Chung, 2002; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004; McLean, 1995; Meyer & Mark, 1995). When reviews of these studies were conducted, it was found that the conflicting findings were the result of assessing the impact of the group on many different objectives (Barsevick, Sweeney, Haney, & Chung, 2002; Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; DeVine & Westlake, 1995; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Newell, Sanson-Fisher, & Savolainen, 2002; Owen, Klapow, Hicken, &

Tucker, 2001; Sheard & Maguire, 1999; Trijsburgvan, van Knippenberg, & Rijpma, 1992; Uitterhoeve, et al., 2004).

Research has also suggested that group therapy is a feasible and effective way to address the stress and distress cancer co-survivors are facing. In a recent research review of group therapy with cancer co-survivors the author concluded that one way group therapy is helpful is through the facilitation of “efforts to find and share meaning in the crisis of cancer” (Sherman, 2008, p. 415). In addition, other researchers have found that the majority of those who do not talk about role and relationship changes after cancer had a negative experience while couples who talked about changes adapted more effectively to those changes (Pitceathly & Maguire, 2003; Vess, Moreland, & Schwebel, 1985).

#### **Need for New Psychological Interventions for Cancer Survivors and Co-Survivors**

The current research on psychotherapy for cancer survivors and caregivers is confusing at best. The literature is incredibly contradictory; while some researchers claim that CBT based groups are the most effective, others have found that they are simply symptom based and do not adequately treat long term effects (Bottomley A. , 1996a; Petersen, Bull, Propst, Dettinger, & Detwiler, 2005). Furthermore, some researchers claim that supportive-expressive based groups have larger effect sizes than CBT groups on emotional and functional adjustment (Classen, et al., 2001; Meyer & Mark, 1995). And still other researchers claim that psychoeducational interventions used in conjunction with these other types of groups provide the best method for reducing distress in cancer patients (Barsevick, Sweeney, Haney, & Chung, 2002). In addition, the outcomes that these groups are measured on are very broad and most studies are difficult to compare (Fawzy, Fawzy, Arndt, & Pasnau, 1995; Owen, Klapow, Hicken, & Tucker, 2001).

Most researchers would agree that group psychotherapy is more cost effective and able to reach more people than individual therapy (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Edelman & Kidman, 1999). In addition, group therapy provides a level of support and connection with others in a similar situation that one would not be able to have in an individual setting (Spiegel, Bloom, & Yalom, 1981). However, there is significant confusion over the best type of group to facilitate improvement in quality of life for both cancer survivors and caregivers.

### **Focus of the Present Study**

Despite the general support for the use of group therapy with cancer survivors and co-survivors, controlled investigations of the impact of coping skills focused group therapy on quality of life are rare. The reasons for this include ethical considerations related to withholding treatment to patients, a lack of clear consensus about the effectiveness of these specific group modalities, and practical concerns related to sample size. Groups work best with about eight participants in each group and to generate large enough samples of both cancer survivors and co-survivors would be above and beyond most researchers' resources. For all of the reasons listed above, the present research does not involve a controlled comparison of treatment approaches.

Rather, the goal of the present study is to evaluate changes in quality of life associated with participation in a coping skills-focused support group for cancer survivors and co-survivors and to investigate the mechanisms that link coping to changes in quality of life. The evaluation will utilize Frisch's CASIO Model of Quality of Life, as well as distress, coping, and resiliency measures specifically designed for measuring response to illness (or injury). At the macro-level, it is hypothesized that participation in

a coping skills-focused support group for cancer survivors and co-survivors will be associated with improvement in reported quality of life. At a more individual level, it is hypothesized that improvement in coping skills will be associated with improvements in reported quality of life.

The current research was funded by the John C. Mitchell Fellowship in Psychological Trauma, Counseling Psychology Program, Department of Educational and Psychological Studies, University of Miami. The fellowship was awarded for the 2009-2010 academic year.

## CHAPTER II

### **Background**

#### **Scope of the Literature Review**

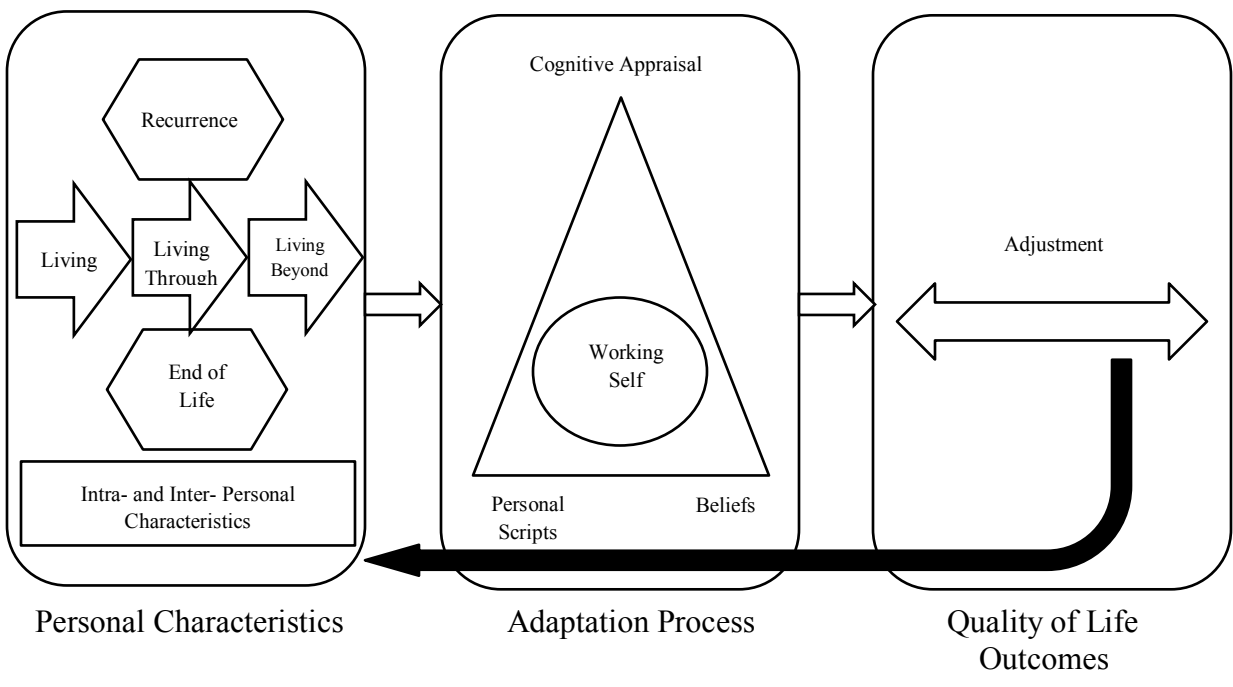
Computer-assisted searches of electronic databases were used to collect journal articles, books, and related publications on the topics of cancer as a chronic illness, coping, cancer co-survivors, quality of life, psychological interventions for cancer survivors/co-survivors, and group interventions. A variety of search engines were used, including PSYCINFO, OVID, MEDLINE, PUBMED, GOOGLE, SCIENCE DIRECT, EBSCOHOST, and ERIC. Sources that were written in or translated into English, included human subjects, and were primarily published within the last twenty years were included.

#### **Cancer as a Chronic Illness**

With an estimated 1.43 million new cases of cancer diagnosed in the United States each year and over 10.8 million living survivors, cancer has shifted from being a certain death sentence to a chronic disease (American Cancer Society, 2010). Little (2004) argues that cancer falls under the rubric of “chronic illness” based upon the trajectory of the illness. Thirty percent of cancer survivors experience distress when they are disease-free for at least two years. In addition, the documented late effects of chemotherapy treatment, difficulty reintegrating into the workforce, problems with future insurance coverage, and the fear of possible cancer recurrence, make cancer an illness that goes far beyond the boundaries of active disease. Furthermore, the term “cancer survivor” is employed from the moment diagnosis is made, thus, this label sticks with the person for life, making cancer a chronic illness (Little, 2004).

The Cancer Survivor Adaptation (CSA) model views cancer survivorship as a dynamic process involving personal characteristics, cognitive appraisal, and quality of life outcomes. The feedback loop created by the interaction of these three domains proposes that the trajectory of cancer survivorship continues throughout the survivor's lifetime (Naus, Ishler, Parrott, & Kovacs, 2009). "It is the continual cyclical interaction of quality of life outcomes and personal context within the adaptation process that provides the multidimensional and dynamic conceptualization of cancer as a chronic illness" (Naus, Ishler, Parrott, & Kovacs, 2009, p. 1355). This view of cancer as a chronic illness stresses the importance of continual evaluation of cancer survivors over time, as distress adaptation and coping skills are dynamic processes that go far beyond basic physical and emotional adjustment to cancer (Naus, Ishler, Parrott, & Kovacs, 2009). The CSA model is shown below in Figure 1.

Figure 1: Cancer Survivor Adaptation Model



## **Distress in Cancer Survivors**

It has long been argued that a cancer diagnosis is a stressing and distressing event (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; Carver, et al., 1993; Fawzy, Fawzy, Arndt, & Pasnau, 1995). Cancer-related distress has been defined as “an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment” (National Comprehensive Cancer Network, 1999, p. 119). And while it is estimated that approximately 35% of cancer survivors will experience some distress (Faul, Jim, Williams, Loftus, & Jacobsen, 2010), only about 33% of those will actually receive some kind of mental health treatment for it (Clark, Bostwick, & Rummans, 2003).

In the general population, distress is linked with having a chronic medical condition, no health insurance, lower educational levels, being single or divorced, and being a woman (Kaiser, Hartoonian, & Owen, 2010). Cancer survivors contend with all of these potential distress-related problems, as well as lower quality of life, poor medical adherence, and increased morbidity and mortality rates (Kaiser, Hartoonian, & Owen, 2010). The researchers propose that the current information on distress in cancer survivors has been derived from studies with small sample sizes and homogenous populations. Thus, the researchers conducted a study to address the lack of information on distress in cancer survivors with varying disease types to help create a cancer-specific model of distress. Through the 2003-2005 National Health Interview Surveys the researchers had 93,606 participants, of which 5,150 were cancer survivors, 55,154 had other chronic medical conditions, and 33,302 were healthy participants. The researchers found that cancer survivors, as compared to those with other chronic medical conditions



and healthy participants, had significantly higher levels of distress (Kaiser, Hartoonian, & Owen, 2010). In addition, cancer survivors and those with other chronic medical conditions had more risk factors for developing distress than healthy participants. These included ethnicity, having children, experiencing pain, and having fewer elders in the home. Furthermore, cancer type was also significantly associated with distress, with survivors of female reproductive cancer and lung cancer being at the greatest risk for distress (Kaiser, Hartoonian, & Owen, 2010). Thus, the researchers propose that there is something distinctive about cancer-related distress, as opposed to other health conditions, and treatments should be tailored accordingly.

Despite the impact of cancer-related distress, evidence suggests that it remains unrecognized in those that are suffering (Couper, Bloch, Love, Duchesne, MacVean, & Kissane, 2009; Kelly, Ghazi, & Caldwell, 2002; Seelert, Hill, Rigdon, & Schwenzfeier, 1999; Thomas, Thomas, Nandamohan, Nair, & Pandey, 2009). Current tools utilize cutoff scores for both depression and anxiety as measures of distress. The researchers argue that distress exists on a continuum from general feelings of sadness to disabling grief and despair, but is identifiable before the criteria for anxiety and depression are reached (Thomas, Thomas, Nandamohan, Nair, & Pandey, 2009). Thus, Thomas, Thomas, Nandamohan, and Pandey (2009) propose that there is a need for an appropriate distress screening tool for use with cancer survivors. The researchers conducted two phases of the study with 240 participants in the first validation phase and 495 in the second phase. Through factor analysis, the researchers developed the Distress Inventory for Cancer Version 2 (DIC 2) with six factors: Emotional Distress, Familial Distress, Social Distress, Spiritual Distress, Medical Distress, and Activities of Daily Living.

While the researchers noted some overlap between depression and anxiety symptoms, distress was shown to be a distinct entity with significant implications for cancer survivors (Thomas, Thomas, Nandamohan, Nair, & Pandey, 2009). However, a major limitation of this study was the sample used, as more than 50% of the participants had been diagnosed with head and neck cancer. Therefore, more research on cancer-related distress in populations with varying types and stages of cancer is needed.

Most studies of breast cancer-related distress show that the greatest impact is in the first year after diagnosis with gradual improvement thereafter (Barez, Blasco, Fernandez-Castro, & Viladrich, 2007; Millar, Purushotham, McLatchie, George, & Murray, 2005). However, past researchers have looked at group differences with little consideration for individual variation. Using Bonanno's (2004) model of four distinct trajectories, Henselmans, Helgeson, Seltman, de Vries, Sanderman, and Ranchor (2010) recruited 171 women with a suspicion of breast cancer from six different Dutch hospitals and administered the General Health Questionnaire-12 to assess levels of distress at five different timepoints (diagnosis, surgery, chemotherapy/radiation, two months after end of treatment, and six months after end of treatment). The researchers concluded that 36% of the sample never experienced any distress, 33% experienced distress immediately following diagnosis but then recovered, 15% experienced distress after the end of treatment, and 15% experienced chronic distress throughout treatment and survivorship (Henselmans, Helgeson, Seltman, de Vries, Sanderman, & Ranchor, 2010). These findings highlight the importance of an individual experience of cancer diagnosis, treatment, and survivorship and point to the need for tailored treatments to address these concerns.

### **Distress in Cancer Co-Survivors**

Cancer co-survivors, or caregivers, have a unique role in the illness trajectory of the cancer patient. In some cases the caregiver provides significant financial, physical, emotional, and logistical support in the management of the illness. With the consequences of a cancer diagnosis being long-term, the burden placed on caregivers can be substantial. Furthermore, the focus of care is typically on the survivor, leaving the caregiver to cope with the emotional, physical, and financial toll on their own. Due to the varying demands on caregivers, as well as the unpredictable course of the illness, the literature on caregiver distress is inconsistent.

In a large national study of terminally ill patients, researchers found that 34.7% reported moderate to substantial care needs in terms of nursing, transportation, personal care, and home-making (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). High care needs were significantly related to serious economic burdens in 44.9% of the population, with extra expenses related to health care costs requiring the sale of assets, procuring a loan, or finding an additional job. In addition, 31.4% of caregivers of terminally ill patients reported depressive symptoms and stated that caregiving was “interfering with their family or personal life” (Emanuel, Fairclough, Slutsman, & Emanuel, 2000, p. 457).

Some studies have shown that approximately 55% of the care provided for cancer survivors comes from family caregivers (Nijboer, Tempelaar, & Sanderman, 1998). Partners are reported to provide the most comprehensive care with females and partners considered to be the most vulnerable groups of caregivers in terms of psychological distress (Nijboer, Tempelaar, & Sanderman, 1998). Furthermore, these groups are least

likely to receive assistance for their distress as caregiving can be very time-consuming and personal care for the caregiver is no longer a priority.

In a review of caregiver distress, Pitceathly and Maguire (2003) also found that female caregivers are a particularly vulnerable group. In addition, the researchers state that psychological distress can be prolonged due to disregard for personal needs, an inability to disclose their personal concerns, and poor coping skills. Progression of the illness can further exacerbate caregiver distress and lead to denial or avoidance strategies. Pitceathly and Maguire (2003) report that caregivers who seek support, either from partners/spouses or formal settings, experience lower levels of psychological distress. While interventions for caregivers have been implemented, there is a lack of sound theory, randomized controlled design, and standardization of methodology behind these interventions which has led to inconsistency in findings (Pitceathly & Maguire, 2003).

In a 2001 review of gender difference in cancer caregiving, Baider and Bengel found that the available information on psychological distress is contradictory at best. The researchers report that some studies found higher levels of distress in caregivers as compared to their spouses (Ell, Nishimoto, Mantell, & Hamovitch, 1998; Haddad, 1994; Kaye & Gracely, 1993), yet other studies found the opposite to be true, while still other studies found no difference at all (Hannun, Giese-Davis, & Harding, 1991). Baider and Bengel (2001) report that these findings are further complicated by gender differences in caregivers and survivors. Female survivors are reported to be more anxious and depressed than male counterparts. Furthermore, following a negative marital event (i.e., a cancer diagnosis) 36% of women were found to experience clinical depression, twice as much as men (Baider & Bengel, 2001).

Other researchers at the University of Melbourne conducted a study with 103 partners of men diagnosed with localized and metastatic prostate cancer (Couper, Bloch, Love, Duchesne, MacVean, & Kissane, 2009). The researchers observed psychological distress, marital satisfaction, family functioning, and coping longitudinally over six months. Couper et al. (2009) found high levels of distress, sometimes surpassing the threshold for psychiatric diagnosis, in women with no psychological intervention. Researchers propose that “a suitably designed therapy program [may have] a meaningful role in reducing overall distress” (Couper, Bloch, Love, Duchesne, MacVean, & Kissane, 2009, p. 381).

In a study by McCorkle and Pasacreata (2001), the researchers claim the role of the caregiver is changing. As the prognosis of cancer shifts from a certain death sentence to long-term survivorship, caregivers have extensive and shifting responsibilities. The Patient and Caregiver Outcomes Research Team at Yale University conducted numerous studies over 25 years looking at various interventions for caregivers. In one particular study, Heinrich and Schag (1985) developed a stress management intervention for cancer patients and spouses. The six-week small group intervention found improvement in knowledge and coping skills in patients and spouses in both the intervention and control groups. The authors note the small number of subjects and the need for replication of findings.

### **Cancer and Coping**

The field of coping and stress-related research was closely tied to psychoanalytic and developmental theories that postulated a connection between defensive style and developmental stage (Lazarus R. S., 1993). These theoretical interpretations dominated

coping and stress-related research until the 1970s when new developments led to a change in perspective. The new approach viewed coping as a process in which “coping changes over time and in accordance with situational contexts in which it occurs” (Lazarus R. S., 1993, p. 235). Therefore, coping strategies are no longer universally healthy or collectively pathologic, but rather they are fluid practices that are individually derived and situationally specific. With this in mind, Lazarus and Folkman propose that coping is considered a process in which a threat is perceived, a response is formed, and subsequently executed (Lazarus & Folkman, 1984; Morgan M. A., 2009).

Lazarus and Folkman (1984) propose that there are five main principles of the process approach to coping. First, thoughts and actions associated with coping must be measured separately from outcomes in order to assess their adaptiveness as there are “no universally good or bad coping processes, though some might more often be better or worse than others” (Lazarus R. S., 1993, p. 235). Second, how a person copes is dependent on the context in which the stressor occurs and this is expected to change over time as the stressor itself changes. Therefore, when researching coping strategies, it is important to specify the “threats of immediate concern” rather than focusing on the overall illness, injury, or trauma (Lazarus R. S., 1993, p. 236). Third, research designed to assess coping strategies needs to “describe what a person is thinking and doing in the effort to cope with stressful encounters,” both across time and across situations (Lazarus R. S., 1993, p. 236). This diverse method allows researchers to explore both state and trait aspects of coping strategies. Fourth, coping is defined as “ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus R. S., 1993, p. 237). And

lastly, the theory of coping as a process states that the two main functions of coping are emotion-focused and problem-focused. Problem-focused coping relies on the individual's ability to change the environment itself while emotion-focused coping changes either the way the individual interprets their relationship with the environment or how they choose to attend to it. Western values tend to celebrate and encourage the problem-focused strategies; however, in situations in which nothing can be done to change the situation, problem-focused coping strategies can be “counterproductive and result in chronic distress when they fail” (Lazarus R. S., 1993, p. 238).

With these principles in mind, the current literature further classifies coping strategies as either active/approach-based or passive/avoidance-based (Park, Edmondson, Fenster, & Blank, 2008; Stanton, et al., 2000). Approach-based strategies include emotion processing, support seeking, positive reinterpretation, and active coping while avoidance-based strategies include self-blame, denial, and behavioral disengagement (Bellizzi & Blank, 2006). In a study of 215 breast cancer survivors, Bellizzi and Blank (2006) looked at variables that influence posttraumatic growth after completing treatment, including coping strategies. After conducting a higher order factor analysis of the Brief COPE, the researchers found two distinct factors, Active Adaptive Coping and Maladaptive or Escapist Coping, which accounted for 34% and 14% of the variance, respectively. This finding further supports the distinction of active/approach-based and passive/avoidance-based coping strategies. While these findings are theoretically important, there are generalizability limitations which include the majority of the respondents being Caucasian, highly educated, and from the upper tier of socioeconomic

status. In addition, this study only looked at the coping strategies of breast cancer survivors which may be different from survivors of other types of malignancy.

An active coping strategy that has received a lot of attention recently is the use of humor. In a 2005 review article (Christie & Moore, 2005) on the use of humor as a medical intervention, the authors reviewed 20 studies, of which four focused on cancer survivors (Bennett & Lengacher, 1999; Ferrell, Taylor, Grant, Fowler, & Corbisiero, 1993; Gray, Fitch, Davis, & Phillips, 1997; Johnson P., 2002). The studies suggest that humor can reduce negative health issues as well as have a positive effect on the immune system. In addition, humor was found to be an effective coping strategy by decreasing anxiety and encouraging open discussion of illness-related issues (Christie & Moore, 2005). In one study in particular, the authors conducted interviews with nine breast cancer survivors and found that the use of humor by nurses helped to create more trusting relationships with the survivors (Johnson P., 2002). In addition, laughter was seen as a positive coping strategy which encouraged reinterpretation of events in 64% of terminally ill patients (Joshua, Cotroneo, & Clarke, 2005). One participant stated that “if you can laugh and take away from the seriousness of it, you really are a survivor at that point” (Johnson P., 2002, p. 693). Further research on this coping strategy needs to be conducted in order to support the trends shown in previous research with smaller samples.

Another benefit of approach-based coping strategies is the impact on positive health behavior changes. Research has shown that cancer survivors engage in risky health behaviors at about the same rate as the general population (Bellizzi, Rowland, Jeffrey, & McNeel, 2005). Park et al. (2008) propose that health behavior change should be looked at from a stress and coping perspective that incorporates the understanding that cancer



survivors experience a heightened sense of vulnerability following a cancer diagnosis, and this stress and distress can have a negative impact on their ability to implement positive health behavior changes. The researchers sent questionnaires to 250 male and female cancer survivors to assess locus of control, social support, meaning in life, health behavior changes, and coping. The coping questionnaire utilized the previously mentioned two-factor approach (Bellizzi & Blank, 2006) that focuses on “active/adaptive” and “maladaptive/avoidant” strategies. The results of the study support the stress and coping model and propose that a cancer diagnosis is a “teachable moment” for adaptive health behavior change (Park, Edmondson, Fenster, & Blank, 2008).

Research supports the claim that active coping strategies enhance psychological adjustment in cancer survivors while avoidant or passive strategies can impede adjustment (Carver, et al., 1993; Stanton, et al., 2000). Interventions which encourage participants to write or talk about stressful experiences have seen increases in both psychological and physical health (Smyth, 1998); thus, researchers are exploring the use of these emotional expression-based interventions with cancer survivors (Stanton, et al., 2000). In a study of 92 female breast cancer survivors, Stanton et al. (2000) found that participants who engaged in emotional expression-based coping experienced lower psychological distress, fewer cancer-related medical appointments, and higher levels of vigor and self-perceived health status. However, researchers did not see a significant change in quality of life amongst participants engaged in emotional expression-based coping (Stanton, et al., 2000). While these findings are encouraging, this study is limited due to its use of female breast cancer survivors as the only participants. In addition,

emotional expression-based coping was assessed via questionnaire only, and there is some concern about the participants' interpretation of these concepts.

Research also supports the claim that approach-based coping strategies are effective for couples coping with a cancer diagnosis (Baider & Bengel, 2001; Manne, Ostroff, Norton, Fox, Goldstein, & Grana, 2006; Morgan M. A., 2009; Morgan, Fogel, Rose, Barnett, Mock, & Davis, 2005). Research by Morgan (2009) proposes that the cancer diagnosis has an impact on both the survivor and the co-survivor, thus coping skills should focus on using the relationship as a source of support for both the patient and the partner. Survivors and co-survivors who engage in avoidance-based coping strategies reported higher levels of distress and poorer adjustment to diagnosis and treatment (Baider & Bengel, 2001; Morgan M. A., 2009). Thus, communication researchers suggest that approach-based strategies should be adapted to meet the needs of dyads struggling with a life-threatening illness (Manne, Ostroff, Norton, Fox, Goldstein, & Grana, 2006).

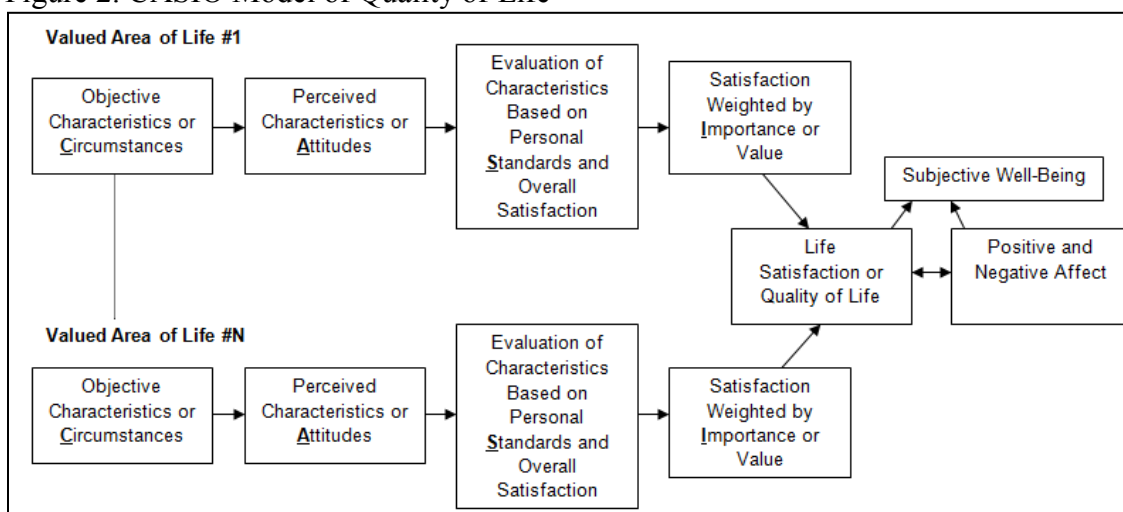
### **Quality of Life**

The term "quality of life" (QOL) has multiple definitions that combine both the objective and subjective components of daily life (Camfield & Skevington, 2008). From the objective standpoint, quality of life comprises activities of daily living, functional status, relationship quantity, financial status, and occupational status while subjective components of quality of life revolve around happiness and life satisfaction (Camfield & Skevington, 2008). For many years quality of life research has focused on the objective, and more measurable, perspective (Campbell, Converse, & Rogers, 1976); however, this has begun to shift. The World Health Organization (WHO) proposed that the definition of

quality of life needs to be more broad and all-encompassing with a consideration for cross-cultural differences. The WHOQOL Group defines quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997, p. 1). The WHOQOL Group also states that the concept of quality of life is extensive, multifaceted, and impacted by one’s “physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment” (World Health Organization, 1997, p. 1). In addition, a sixth domain, religiousness and spirituality, was also added to this definition.

As society has continued to make advances in the field of medicine, efforts towards promoting *quality* of life have begun to overshadow the previous emphasis on *quantity* of life (Frisch M. B., 1998; Gladis, Gosch, Dishuk, & Crits-Christoph, 1999). Through years of research, Frisch (1998) has proposed the CASIO model of quality of life which suggests that overall life satisfaction is comprised of subjective satisfaction and importance ratings on multiple domains. The model assumes that “people tend to want the same things, although the particular areas valued by an individual as well as their subjective importance to that individual’s overall life satisfaction will vary” (Frisch M. B., 1998, p. 25). The 16 domains of quality of life are: Health, Self-esteem, Goals and values, Standard of living, Work, Recreation, Learning, Creativity, Helping, Love relationship, Friendships, Relationships with children, Relationships with relatives, Home, Neighborhood, and Community. The model is listed below in Figure 2.

Figure 2. CASIO Model of Quality of Life



Under the assumption that quality of life is a subjective construct with varying importance for different populations, cancer site and stage can have a large impact on overall life satisfaction. In a review of quality of life for bladder cancer survivors, the authors claim that bladder cancer provides a unique opportunity for quality of life research since this particular cancer impacts both men and women's genitourinary and sexual health (Botteman, Pashos, Hauser, Laskin, & Redaelli, 2003). In addition, there are multiple surgical options for bladder cancer treatment; however, the impact of these surgeries on future quality of life is unknown. The authors further state that methodology is an issue and findings are questionable due to "small sample size, use of retrospective data collection, heterogeneous patient populations, use of non-sensitive instruments, and lack of instrument standardization" (Botteman, Pashos, Hauser, Laskin, & Redaelli, 2003, p. 680). Therefore, it is difficult to translate the current knowledge on quality of life and bladder cancer into a useful tool in patient surgical decision-making. The authors conclude that there is a serious need for more sound research on quality of life in cancer survivors in order to guide both pre- and post-treatment medical decisions.

In a meta-analysis of interventions for improving quality of life in cancer survivors, researchers looked at the impact of social cognitive theory (SCT) components on the effectiveness of the intervention (Graves, 2003). The author proposed that interventions with more social cognitive theory components would have a larger effect than those studies with minimal or no SCT components. Social cognitive theory components included relaxation training, coping (physical, affect, and spiritual), practicing new skills outside of the intervention, role-playing, modeling of behavior, cognitive restructuring, self-monitoring of skills, goal setting, setting realistic expectations, cancer survivor testimony, bibliotherapy, and problem solving (Graves, 2003). The author used 38 studies with a total of 3,216 participants for the meta-analysis and found that studies that used SCT components in their interventions had a significantly larger effect on quality of life than studies that did not incorporate these techniques. The author concludes that SCT components maximize the quality of life improvement in adult cancer survivors and should be incorporated into future interventions (Graves, 2003).

In a study of the effects of a family intervention on quality of life in breast cancer survivors and their caregivers, the researchers assessed the effectiveness of the FOCUS program as compared to usual care (Northouse, Kershaw, Mood, & Schafenacker, 2005). The FOCUS program consisted of three monthly home visits and two booster phone call sessions to focus on family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. One hundred thirty-four dyads participated in this study through the six month follow-up assessment. The researchers found that the family caregivers reported significantly fewer negative feelings about

caregiving than controls. In addition, breast cancer survivors reported significantly less negative appraisals and feelings of hopelessness than controls. However, while these findings were sustained through the three-month assessment, they had disappeared for both groups by the six month assessment (Northouse, Kershaw, Mood, & Schafenacker, 2005).

In another study of the impact of cancer on caregivers' quality of life, researchers conducted a large study of 373 couples with various cancer diagnoses (Bergelt, Koch, & Petersen, 2008). The researchers measured quality of life, social support, quality of partner relationship, and disease/treatment variables. When reporting the results, the researchers broke up the participants into three diseases-site groups, digestive organs (n = 150), breast (n = 153), and male genital organs (n = 70). After analysis, the data showed that male caregivers reported significantly better quality of life than female caregivers; however both caregivers' mental quality of life was significantly lower than the general population. Furthermore, in patients/caregivers in the digestive organ and breast groups, higher relationship quality predicted better mental quality of life. None of these results were found in the male genital organ group (Bergelt, Koch, & Petersen, 2008). While this research is one of the largest studies on caregiver quality of life, the one time assessment necessitates further research on the longevity of these findings.

### **Psychological Interventions for Cancer Survivors and Co-Survivors**

**Overview.** There have been multiple reviews conducted on the benefits of group psychotherapy interventions with cancer survivors and co-survivors (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; Edelman & Kidman, 1999; Fawzy F. I., 1999; Fawzy & Fawzy, 1998; Fawzy, Fawzy, Arndt, & Pasnau, 1995;

Lepore & Coyne, 2006; Newell, Sanson-Fisher, & Savolainen, 2002). The majority of these interventions fall into four distinct categories: education, coping, emotional support, and psychotherapy (Fawzy F. I., 1999). There are many studies on each of these types of psychotherapeutic group intervention encompassing various populations, settings, treatments, and modalities. And while these reviews have not looked at all of the same studies, the overarching message is the same: drawing any general conclusions from the literature is a difficult task, as the results are inconsistent and contradictory (Lepore & Coyne, 2006).

**Education.** In one of the first empirically derived studies of group therapy with cancer patients, Ferlic, Goldman, and Kennedy (1979) developed a crisis intervention program with a strong educational component. The researchers proposed that going beyond the traditional support group was necessary to examine the patient's adjustment to illness, communication, cancer-related knowledge, psychological adjustment to illness, and self-concept (Ferlic, Goldman, & Kennedy, 1979). Using a manualized treatment, researchers met with the group for six 90 minute sessions. The groups were led by a social worker and each week co-led by a different professional depending on the topic of the session. Subjects included newly diagnosed patients with advanced cancer with a final group of 60 participants. These participants were randomized and thirty were in the experimental group and 30 were in the control group. The researchers found that the experimental group had significantly higher scores on cancer knowledge at the end of the group; however, there was not enough of a response at the six month follow up to report the data. In addition, the group participants had an increase in self-concept as compared to the control group, but this change did not last through the six month follow up. The

researchers state that group counseling provided a significant benefit to the participants of the group and that more groups with an educational focus are needed, especially in the areas of nutrition and sexuality (Ferlic, Goldman, & Kennedy, 1979).

For many treatment facilities, education has been an integral component of a program in comprehensive patient care. Researchers at the University of Minnesota hospitals proposed that a group intervention is a cost effective and feasible format for relaying information about cancer rehabilitation (Johnson J. , 1982). Researchers recruited 52 participants for the study, of which half attended a four week, 8-session intervention entitled “I Can Cope.” Participants’ anxiety, meaningfulness in life, and knowledge of cancer were measured and compared to those in the control group. In addition, participants in the group were also provided access to a resource library which had books, audiotapes, videotapes, and informational brochures on a variety of topics. The researchers found that there is a significant relationship between the experimental group’s utilization of learning resources and changes in anxiety, meaningfulness, and knowledge scores (Johnson J., 1982).

In another study by Cunningham and Tocco (1989), the authors looked at the effectiveness of a psychoeducational group intervention with a supportive component as compared to a strictly supportive group. The groups lasted for six weeks and were two hours in length. The researchers had 53 participants split between the two groups, with between seven and ten members in a group at a time. Participants had a variety of cancer diagnoses and were in different stages of disease. Participants’ mood (POMS) and symptomatology (SCL-90-R) were assessed at baseline, at the end of the group and three weeks post-group. The researchers found that there was a statistically significant



improvement in the global scores on both the POMS and SCL-90-R for the psychoeducational and supportive control group, with a greater change in the psychoeducational group. The results of this study support the development of brief behaviorally-oriented group interventions for cancer survivors (Cunningham & Tocco, 1989).

In a recent review of psychoeducational group interventions for cancer patients suffering from symptoms of depression, a psychoeducational intervention was defined as “therapeutic approaches that involve processes, such as information giving and receiving, discussion of concerns, problem solving, coping skills training, expression of emotion, and social support” (Barsevick, Sweeney, Haney, & Chung, 2002, p. 74). Articles published between 1980 and 2000 in which depression was a major outcome variable were included. Fifty five studies were included in the final analyses with 36 randomized clinical trials, 7 quasi-experimental studies, 5 descriptive studies, 3 meta-analyses, and 3 qualitative reviews. The authors found that in 63% of the studies there was significant evidence to support the utility of psychoeducational groups as an intervention for depression in cancer patients. The authors further recommend that oncology nurses conduct brief screening for depression and distress in all patients and make referrals as necessary (Barsevick, Sweeney, Haney, & Chung, 2002).

Cancer co-survivors can also benefit from psychoeducational group interventions, as evidence by Manne, Babb, Pinover, Horwitz, and Ebbert’s (2004) study. The researchers recruited wives of prostate cancer survivors to participate in a six week group intervention. The authors reasoned that the distress level of the caregivers was an important component to the overall care of the cancer survivor, as the caregivers provide

a necessary level of support during cancer treatment (Manne, Babb, Pinover, Horwitz, & Ebbert, 2004). There were 60 participants in the study with half in the psychoeducational group and the other half in a control condition with standard care (i.e. access to a social worker and referrals in the community). Participants were assessed on measures of psychological distress, cancer-specific distress, coping skills, post-traumatic growth, and cancer-specific marital interactions. The researchers found that the psychoeducational group intervention did not have a significant impact on reducing levels of caregiver distress as compared to the control condition. However, the researchers also found that the wives who participated in the intervention did have high levels of positive reappraisal and post-traumatic growth as compared to the control participants. Thus, the researchers suggest that further study is warranted on interventions for caregivers of cancer survivors (Manne, Babb, Pinover, Horwitz, & Ebbert, 2004).

**Coping.** Psychotherapy groups with a focus on coping skills and strategies are another avenue for delivering care to cancer survivors and co-survivors. Researchers have stated that about one-third to one-half of cancer survivors will experience clinically significant levels of distress during the course of their illness, and coping skills groups are an effective means of treatment (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; Faul, Jim, Williams, Loftus, & Jacobsen, 2010).

A particularly stressful component of cancer care is chemotherapy treatment and coping skills such as relaxation and stress management training have proven useful in managing anticipatory nausea (Faul, Jim, Williams, Loftus, & Jacobsen, 2010). Researchers hypothesized that pre-treatment coping skill level would reduce distress and increase quality of life (Faul, Jim, Williams, Loftus, & Jacobsen, 2010). One hundred and

ten adults with various stages and types of cancer were recruited to participate in a survey study. The researchers found that the participants with more coping skills prior to chemotherapy treatment had lower levels of distress and higher quality of life post-chemotherapy treatment. The researchers state that these findings are important for the development of psychosocial services for cancer patients, particularly coping skills training (Faul, Jim, Williams, Loftus, & Jacobsen, 2010).

Another avenue for coping skills training with advanced stage cancer patients is the use of a coping and communication telephone support intervention. Researchers proposed that the telephone would be a feasible way for advanced stage cancer patients to receive care without the strain of traveling to a hospital (Radziewicz, Rose, Bowman, Berlia, O'Toole, & Given, 2009; Rose, Radziewicz, Bowman, & O'Toole, 2008). Eighty-two male and female cancer patients with a prognosis of less than a year were recruited to participate in this intervention. The first stage involved a home visit in which the participant identified a family caregiver to participate in the study with them. Following the home visit, participants received a tailored intervention schedule of at least monthly phone calls to monitor distress levels, prepare for future treatments, foster independence, provide support, and address emotional and practical problems (Rose, Radziewicz, Bowman, & O'Toole, 2008). The initial results revealed that in the first six weeks of intervention, at least 50% of the participants reported symptom issues, practical problems, and psychological problems and the majority requested supportive listening, cognitive/problem solving, and educational assistance to manage these obstacles (Rose, Radziewicz, Bowman, & O'Toole, 2008).

Young adult cancer survivors are a special population due to physical and psychological changes related to developmental stage. In addition, uncertainty is a huge concern for this population as recurrence and second site cancers are more common (Santacroce & Lee, 2006). In a study conducted by Santacroce, Asmus, Kadan-Lottick, and Grey (2010), the researchers compared a manualized combination of coping skills training (CST) and a previously validated model of the positive impact of uncertainty, HEROS PLUS (Mishel, 1988), with the original HEROS program, to treat young adult cancer survivors. The HEROS PLUS intervention consisted of seven, 30-minute, telephone sessions designed to help participants manage stressors related to survivorship. This included relaxation skills training, cognitive reframing, self-talk, communication skills, and problem-solving skills. However, the study did not have good recruitment and retention rates (46%) and due to this statistical analysis of the results was prohibited (Santacroce, Asmus, Kadan-Lottick, & Grey, 2010). Therefore, the authors report preliminary trends in the data which show that the HEROS PLUS intervention is a feasible and effective way for providing support to survivors of childhood cancer (Santacroce, Asmus, Kadan-Lottick, & Grey, 2010).

Coping skills groups are also a useful intervention for caregivers and co-survivors suffering from increased distress and decreased quality of life due to a loved one's illness (Bowman, Rose, Radziewicz, O'Toole, & Berila, 2009; Kurtz, Kurtz, Given, & Given, 2005; McMillan, Small, & Weitzner, 2006). In a study on a mixed methods coping skills group, the researchers proposed five in-person sessions and five phone sessions over a 20 week period. Participants were 237 dyads of caregivers and survivors, with 118 in the intervention group and 119 in the control group (Kurtz, Kurtz, Given, & Given, 2005).

The researchers found no significant differences in depression, symptom management, or physical and social functioning. However, the researchers proposed further investigation into the delivery mechanism for the coping skills information, noting that the length of intervention or length of follow-up assessment may have impacted the results (Kurtz, Kurtz, Given, & Given, 2005).

In another study of coping skills interventions for caregivers, the researchers recruited 354 caregivers of advanced stage cancer patients who were randomized to the control group (n =109), a group that received standard care plus three supportive visits (n =109), or a group that received standard care plus three coping skills focused supportive visits (n =111) (McMillan, Small, & Weitzner, 2006). The researchers assessed caregiver quality of life, caregiver burden, and caregiver mastery. At the 30 day follow up assessment, the researchers found that the caregivers that participated in the group that received coping skills focused supportive visits reported significantly improved quality of life and less caregiver burden. There was no difference in caregiver mastery in any of the group interventions.

**Emotional Support.** Another group intervention that has been studied is the use of emotional support groups for cancer survivors and co-survivors. These groups have been difficult to study as the term “support group” has been used to describe a whole host of group formats (Bottomley A. , 1997a; Goodwin, Leszcz, Ennis, & Koopmans, 2001; Helgeson & Cohen, 1996; McLean, 1995). These groups can be professionally administered or led by a peer survivor; they can be closed and structured or open and unstructured; they can also be focused on informational support as opposed to emotional

support. Due to the lack of consistency, information on support groups has been questionable at best.

In a comprehensive review of discussion, education, and combination group interventions, Helgeson and Cohen (1996) found that “the literature is neither large enough nor methodologically sound enough to reach any definitive conclusions” about the utility of these groups (Helgeson & Cohen, 1996, p. 143). However, the authors do state that they feel the research provides “strong hints” that educational groups offer higher levels of support than discussion groups when comparing brief interventions.

In another review of cancer support groups, Bottomley (1997) found plenty of potential limitations of cancer support groups that may explain the reported lack of effectiveness. These include inadequate control groups for comparison, pharmacological effects, unmatched controls on disease, stage, and course of treatment, sociodemographic differences, personality characteristics of participants, using unstandardized measures, heterogeneous groups, differences in facilitators, and insufficient assessment of outcome variables (Bottomley A., 1997a). Considering all of these factors, Bottomley reports that it is difficult to come to any conclusions and that randomized controlled trials with larger sample sizes and sound methodological design are needed.

With these critiques in mind, some researchers have reported beneficial psychological and survival benefits for group participation. Spiegel, Bloom, and Yalom’s (1981) study on lowering mood disturbances is one of them. In this seminal study 34 women with metastatic breast cancer were randomly assigned to participate in a weekly year long support group while 24 women were assigned to the control condition. The group was unstructured and had no end date, remaining available to participants

throughout the year data was collected. The researchers used measures at four different timepoints to assess health locus of control, mood, self-esteem, maladaptive coping responses, phobias, and level of denial. Due to the nature of the participants' illness, there was only complete data on 30 of the 54 participants. The researchers found that women who participated in the support group reported lower levels of mood disturbance, had fewer phobias, and used less maladaptive coping responses as compared to the control group (Spiegel, Bloom, & Yalom, 1981).

The work that Spiegel, Bloom, and Yalom (1981) did on the previous study led to their most controversial finding to date. In a 1989 research study the authors stated that they had found a survival benefit for breast cancer patients who participated in a psychosocial support group (Spiegel D. , Bloom, Kraemer, & Gottheil, 1989). This finding led to an explosion in research on therapeutic support groups and the results have been mixed. Researchers have reported some survival benefit in studies on gastrointestinal cancer and early stage melanoma; however, these studies are rife with limitations. The facilitators of some of these groups were not trained professionals, groups varied in length and duration, and most importantly, the actual intervention varied significantly amongst the studies (Goodwin, 2005). Furthermore, with one exception (Andersen, et al., 2008), no study has yet been able to replicate the original findings. However, Goodwin's (2005) review does highlight that while all of the studies on survival benefits are inconclusive, the researchers have been able to adequately show that support groups provide a psychological advantage for breast cancer survivors.

One study that attempted to replicate Spiegel et al.'s 1989 findings was conducted using supportive-expressive group therapy with metastatic breast cancer patients

(Goodwin, Leszcz, Ennis, & Koopmans, 2001). The authors recruited 235 women with metastatic breast cancer who were expected to survive for at least three months to participate in the study. Two-thirds of the participants were assigned to the supportive-expressive intervention group and one-third was assigned to the control group. The main outcome variable of interest was survival; however, the researchers also looked at mood and pain measures used in Spiegel et al.'s (1989) original study. The researchers found a significant interaction between baseline scores and effect of treatment, which showed that women who were more distressed at the start of the study had more benefit from participation in the intervention group. In addition, the women in the intervention group reported that their psychological pain worsened at a slower rate than the women in the control group. Lastly, the researchers found that the median survival rate in the control group was 176 months while the intervention group was 179 months, a difference that is not statistically significant. Therefore, the authors conclude that supportive-expressive group therapy does offer many important benefits to participants, yet prolonged survival is not one of them (Goodwin, Leszcz, Ennis, & Koopmans, 2001).

In other studies of supportive-expressive group therapy with women diagnosed with metastatic breast cancer, similar results have been found (Classen, et al., 2001; Giese-Davis, et al., 2002). Classen et al.'s study (2001) reported similar methodology to Goodwin, Leszcz, Ennis, and Koopmans (2001) and also found that participation in the intervention group led to lower rates of traumatic stress and overall mood disturbance in the intervention group as compared to the control group. Another study (Giese-Davis, et al., 2002) from the same group of participants looked at the impact of supportive-expressive group therapy on emotion regulation and affect in metastatic breast cancer



survivors. Again, researchers found that participation in the group yielded positive outcomes for the research subjects. Specifically, women who participated in the intervention group reported less suppression of negative emotions and greater restraint of hostile and aggressive behavior as compared to the control group (Giese-Davis, et al., 2002). These findings also support the utility of support groups for cancer survivors.

One of the main criticisms of this branch of research is the focus on female breast cancer patients. In an effort to provide information on a more heterogeneous sample, Cella, Sarafian, Snider, Yellen, and Winicour (1993) conducted an evaluation study of an eight week support group for cancer survivors. The authors recruited 105 subjects to participate in the group and found that post-intervention quality of life scores significantly improved as compared to baseline scores. The authors state that while the study was limited due to the non-randomized design, they were able to offer support to previous findings as well as advance the research on a non-breast cancer population (Cella, Sarafian, Snider, Yellen, & Winicour, 1993).

Caregivers, like survivors, are also faced with a traumatic experience when a loved one is diagnosed with cancer. Therefore, support groups aimed at the unique issues that co-survivors face are also an integral component of oncology care. Hudson (2004) conducted a review of supportive interventions for family members of palliative care cancer patients. The author found five studies with “reasonable methodological approaches” that addressed this issue (Hudson, 2004, p. 80). Of these studies, two used an individual approach, two used home visits and phone calls, and only one study (Pascareta, Barg, Nuamah, & McCorkle, 2000) used a group intervention. Hudson reports that this study lacked a comparison group and due to the self-selection method of group

participation, may also be over-stating the results they found. Therefore, Hudson suggests that further research with rigorous methodology on caregiver support in palliative care is needed (Hudson, 2004).

**Psychotherapy.** Multiple reviews have shown that group psychotherapy, including cognitive-behavioral, informational, nonbehavioral, social support, and unusual treatments such as music and art therapy, are useful and beneficial in supporting cancer survivors and co-survivors throughout the trajectory of the illness (Bottomley A. , 1996a; Bottomley A. , 1996b; Edelman & Kidman, 1999; Meyer & Mark, 1995; Uitterhoeve, et al., 2004). However, the data on which interventions yield the greatest impacts in different populations is, at best, mixed.

In a comprehensive meta-analysis of psychosocial interventions for cancer survivors (Meyer & Mark, 1995), the authors looked at effect sizes for the main dependent measures including emotional adjustment, functional adjustment, symptoms, medical outcomes, and compound/global outcomes. The authors found there was no significant effect for medical outcomes in any of the intervention modalities mentioned above. However, the authors did find that supportive-expressive group therapy had a significantly larger effect than cognitive-behavioral therapy on emotional adjustment, functional adjustment, and compound/global outcomes. The authors believe that these findings are noteworthy and should lead to further study (Meyer & Mark, 1995).

In multiple articles on the benefits of group cognitive-behavioral therapy, Bottomley has reported that it has a considerable impact on cancer survivors and if conducted properly, should be a first line of defense for illness-related distress (Bottomley A., 1996a; Bottomley A., 1996b). The researcher states that effective

cognitive-behavioral groups will draw on established theory by Beck (1976) and Ellis (1962) as well as integrate components of social support. In addition, groups will be time limited, have between six and ten participants, take place in a convenient and safe location, and use homogenous samples of gender, cancer type, and prognosis (Bottomley A. , 1996b). In his own study on the topic, Bottomley (1996) reports that after comparing a CBT group (n = 9) with a support group (n = 8) and a standard treatment group (n =14) he found that those survivors that participated in the CBT group had significantly improved on measures of depression, coping styles, and social support. However, due to the small sample size these results are not conclusive.

In yet another study of group cognitive behavioral therapy with cancer survivors, the authors propose that previous studies used a hybrid model of Beck (1976) and Ellis's (1962) theories (Edelman & Kidman, 1999), thus yielding mixed results. In an effort to clarify these findings, the researchers recruited 60 breast cancer survivors to participate in either a 12 session manualized CBT treatment program or a supportive discussion group. The authors found that the survivors who participated in the CBT group had significantly higher self-esteem, quality of life, vigor, and social support immediately post-treatment as compared to the supportive group. However, these group differences disappeared at the four month follow-up (Edelman & Kidman, 1999).

Another study (Antoni, et al., 2006) of group cognitive behavioral therapy combined the traditional treatment with a stress management program that highlights relaxation techniques (Antoni M. H., 2003). The authors recruited 199 women with nonmetastatic breast cancer to be randomized to either the CBT + stress management group or a one-day seminar control group. The group met for 10 two-hour sessions and

participants were evaluated at baseline, six months, and twelve months post-recruitment. The researchers found that the participants in the CBT + stress management group had significantly increased levels of benefit finding, lifestyle change, positive affect, and positive states of mind and decreased levels of social disruption as compared to the control group (Antoni, et al., 2006). The authors report that the findings of this randomized and controlled study dispute previous claims that the evidence to support the effectiveness of group psychotherapy for cancer patients is inconclusive and encourage further studies (Carver, 2005).

A different approach to group psychotherapy is the use of it to manage symptoms of pain. Researchers at Stanford University developed a group intervention that combined supportive-expressive therapy with hypnosis to manage cancer pain (Butler, et al., 2009). The researchers recruited 124 women with metastatic breast cancer to participate in a year-long group intervention of supportive-expressive therapy + hypnosis or a self-directed educational control group. After one year of assessment the researchers found that the women in the intervention group reported significantly less increase in pain and suffering as compared to the women in the control group. This effect size was in the small to moderate range. However, the researchers also found that there was no significant difference in pain constancy or frequency between the two groups (Butler, et al., 2009). Therefore, the authors suggest that this type of intervention can be useful for women with cancer related pain; yet further research needs to be done on other populations.

A less researched treatment option is the use of narrative-expressive therapy for the long term treatment of cancer survivors and co-survivors (Petersen, Bull, Propst,

Dettinger, & Detwiler, 2005). The authors propose that the cognitive, behavioral, educational, and social support groups that are commonly used are effective for short term coping with illness; however, they have not been shown to have a long term impact on the underlying stress of being a cancer survivor or co-survivor. Currently, after groups end “patients are left with the problem of integrating a significant stressor into their lives, reprioritizing, reappraising, and bringing a sense of coherence to the experience without assistance” (Petersen, Bull, Propst, Dettinger, & Detwiler, 2005, p. 42). With this in mind, the authors developed a manualized intervention designed to help prevent PTSD in patients with a traumatic illness. To date, the authors have not been able to conduct this research due to the belief “that when a person is sick or has limited energy, it may be too taxing” to participate in a group (Petersen, Bull, Propst, Dettinger, & Detwiler, 2005, p. 45).

### **Summary of Literature**

Cancer is a both an invasive and pervasive disease. It has a far-reaching impact that goes well beyond the initial stage of active disease. The current understanding and treatment of cancer is a vast difference from the care of 50 years ago. Advances in medicine, the patient’s rights movement, and the development of the field of psycho-oncology have all contributed to the more recent view of cancer as a chronic illness.

A cancer diagnosis is a very distressing event for both the cancer survivor and their loved ones. Research has shown that while between 30-50% of people faced with this disease develop some distress, only a small percentage actually receives mental health care (Baider & Bengel, 2001; Ell, Nishimoto, Mantell, & Hamovitch, 1998; Faul, Jim, Williams, Loftus, & Jacobsen, 2010). Coping with a chronic illness requires the

survivor and co-survivor to have a multitude of skills to make it from diagnosis through treatment to survivorship. And while coping does have a personal component to it, there are specific skills and techniques that have proven more effective than others.

It has become widely accepted that group psychotherapy is a cost effective and efficient modality for teaching cancer-related coping skills and improving quality of life. Psychoeducational, coping skills, emotional support, and psychotherapy based groups are the main types of group interventions used with cancer survivors and co-survivors. Many researchers have found some success with these interventions, yet there are still many questions to be answered. Despite the copious amount of research conducted, the only thing that the authors can agree on is that drawing any conclusions from the literature is difficult to do as the results are inconsistent and contradictory (Lepore & Coyne, 2006).

#### **Need for New Psychological Interventions for Cancer Survivors and Co-Survivors**

As demonstrated in the previous review of literature, there have been many studies on the impact of cancer related interventions on the quality of life and well being of cancer survivors and co-survivors. However, these studies are rife with problems necessitating new research to address some of the previous shortfalls. Many reviews have shown that the results of intervention studies are conflicting at best (Bottomley A. , 1996a; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Harding & Higginson, 2003; Newell, Sanson-Fisher, & Savolainen, 2002; Rehse & Pukrop, 2003). In addition, a large portion of research has been conducted on women diagnosed with breast cancer and some researchers have unsuccessfully attempted to translate these results to other groups of cancer survivors. Furthermore, few interventions specifically target the caregiver, and those that do tend to limit the definition of caregiver to spouse or partner of the patient,

therefore neglecting the less traditional family dynamic. And lastly, methodological shortcomings such as sample size, duration of the intervention, delivery of the intervention, training of the group facilitator, and use of appropriate assessment tools has led to a need for more research.

### **Research Questions, Hypotheses, and Overview of the Study**

The present study is designed to evaluate changes in quality of life associated with participation in a coping skills-focused support group for cancer survivors and co-survivors. In addition, this study will examine the mechanisms that link coping to changes in quality of life. This will be done by utilizing Frisch's CASIO Model of Quality of Life (Frisch M. B., 2006), as well as resiliency, distress, and coping measures specifically designed for measuring response to illness (Burnett, Victorson, Gela, & Ouellette, 2008; Victorson, Burnett, & Gela, 2008; Victorson D. , Enders, Burnett, Farmer, Barocas, & Lauzon, 2004; Victorson D. E., Enders, Burnett, & Ouellette, 2008). The research questions as well as the hypotheses for this study are presented below.

**Research Question 1a.** Will cancer survivors have significantly higher post-treatment scores on quality of life scales when compared to pre-treatment scores?

*Hypothesis 1a.* Cancer survivors' post-treatment quality of life scores will be significantly higher than their pre-treatment quality of life scores.

**Research Question 1b.** Will cancer co-survivors have significantly higher post-treatment scores on quality of life scales when compared to pre-treatment scores?

*Hypothesis 1b.* Cancer co-survivors' post-treatment quality of life scores will be significantly higher than their pre-treatment quality of life scores.

**Research Question 2a.** Will cancer survivors have significantly higher post-treatment scores on illness-related resiliency scales when compared to pre-treatment scores?

*Hypothesis 2a.* Cancer survivors' post-treatment illness-related resiliency scores will be significantly higher than their pre-treatment illness-related resiliency scores.

**Research Question 2b.** Will cancer co-survivors have significantly higher post-treatment scores on illness-related resiliency scales when compared to pre-treatment scores?

*Hypothesis 2b.* Cancer co-survivors' post-treatment illness-related resiliency scores will be significantly higher than their pre-treatment illness-related resiliency scores.

**Research Question 3a.** Will cancer survivors have significantly higher post-treatment scores on illness-related coping skills scales when compared to pre-treatment scores?

*Hypothesis 3a.* Cancer survivors' post-treatment illness-related coping skills scores will be significantly higher than their pre-treatment illness-related coping skills scores.

**Research Question 3b.** Will cancer co-survivors have significantly higher post-treatment scores on illness-related coping skills scales when compared to pre-treatment scores?



**Hypothesis 3b.** Cancer co-survivors' post-treatment illness-related coping skills scores will be significantly higher than their pre-treatment illness-related coping skills scores.

**Research Question 4a.** Will cancer survivors have significantly lower post-treatment scores on illness-related distress scales when compared to pre-treatment scores?

**Hypothesis 4a.** Cancer survivors' post-treatment illness-related distress scores will be significantly lower than their pre-treatment illness-related distress scores.

**Research Question 4b.** Will cancer co-survivors have significantly lower post-treatment scores on illness-related distress scales when compared to pre-treatment scores?

**Hypothesis 4b.** Cancer co-survivors' post-treatment illness-related distress scores will be significantly lower than their pre-treatment illness-related distress scores.

**Research Question 5a.** Will cancer survivors' illness-related resiliency scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

**Hypothesis 5a.** Cancer survivors' illness-related resiliency scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

**Research Question 5b.** Will cancer co-survivors' illness-related resiliency scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

**Hypothesis 5b.** Cancer co-survivors' illness-related resiliency scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

**Research Question 6a.** Will cancer survivors' illness-related coping skills scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

*Hypothesis 6a.* Cancer survivors' illness-related coping skills scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

**Research Question 6b.** Will cancer co-survivors' illness-related coping skills scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

*Hypothesis 6b.* Cancer co-survivors' illness-related coping skills scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

**Research Question 7a.** Will cancer survivors' illness-related distress scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

*Hypothesis 7a.* Cancer survivors' illness-related distress scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

**Research Question 7b.** Will cancer co-survivors' illness-related distress scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

*Hypothesis 7b.* Cancer co-survivors' illness-related distress scores will be significantly related to quality of life scores at baseline, 3-week and 6-week assessment.

## CHAPTER III

### **Methodology**

There are 100 worldwide locations of Cancer Support Community (formerly The Wellness Community) in which free support in a community setting is provided to cancer survivors and co-survivors. Cancer Support Community Greater Miami offers support groups, education, individual psychotherapy, and nutrition/exercise programs. Cancer Support Community Greater Miami was founded in 1982 and uses the “Patient Active Concept” as a guiding principle in all of their work. This standard states that “people with cancer who participate in their fight for recovery from cancer will improve their quality of life and may enhance the possibility of their recovery” (Cancer Support Community Greater Miami, 2010, p. 1).

Based upon work by Drs. Kent Burnett and Margaret Crosbie-Burnett, a coping skills group curriculum was developed specifically aimed at cancer survivors and co-survivors (Appendix A). The group curriculum was designed to encompass the APPLES model of well-being which consists of six indicators of healing in relation to coping with traumatic injury, illness, or disaster (Burnett & Crosbie-Burnett, 2012). The indicators are: **A**cceptance and **A**ppropriate Grieving for Loss and Reality of Loss, **P**ositive Reframing, **P**ositive Action, **L**aughter, **E**motional Support Seeking, and **S**tress Tolerance.

Beginning in January 2010, a six-week cancer support group for cancer survivors and a six-week cancer support group for cancer co-survivors were offered at Cancer Support Community of Greater Miami in South Miami, Florida. Enrollment in each group was capped at a maximum of 13 members. Each group met once a week for six

weeks and each session lasted for 90 minutes. The survivor and co-survivor groups were run on the same six-week schedule to encourage adult family members, friends, and caregivers to participate in the groups. Both the survivor and the co-survivor groups were each offered in January, April, and June in order to accommodate the largest number of cancer survivors and co-survivors. All groups were limited to adults and the groups were both mixed gender and mixed diagnosis groups. Cancer survivors and co-survivors were placed in separate groups to facilitate open and honest conversation. The aim of this study is to examine the impact of cancer-specific group therapy on distress, coping skills, resiliency, and quality of life.

Table 1: APPLES Group Administration Schedule

	January 2010		April 2010		June 2010	
Type	Survivor	Co-Survivor	Survivor	Co-Survivor	Survivor	Co-Survivor
<b>Facilitator</b>	EC	DR	DR	EC	AD	JR
<b>Session 1</b>	1/20/10	1/20/10	4/7/10	4/7/10	6/3/10	6/3/10
<b>Session 2</b>	1/27/10	1/27/10	4/14/10	4/14/10	6/10/10	6/17/10
<b>Session 3</b>	2/3/10	2/3/10	4/21/10	4/21/10	6/17/10	6/24/10
<b>Session 4</b>	2/10/10	2/10/10	4/28/10	4/28/10	6/24/10	7/1/10
<b>Session 5</b>	2/17/10	2/17/10	5/5/10	5/5/10	7/15/10	7/15/10
<b>Session 6</b>	2/24/10	2/24/10	5/12/10	5/12/10	7/22/10	7/22/10

## Participants

**Inclusion criteria.** Inclusion criteria for participation in this study were that participants must be 18 years of age or older, able to read, write, and speak English, and be a registered participant at Cancer Support Center of South Miami, Florida. The age

requirement of this study ensured that the participant is of age to give consent for participation. Because all of the assessment measures are in English, the cancer survivor and co-survivor had to be able to read and write English. In addition, the cancer-specific therapy groups were conducted in English and therefore all participants in those groups had to be able to speak English. And lastly, because the aim of this study was to evaluate the impact of the cancer-specific support group, all participants in the research study had to be enrolled in and participating in the group.

**Exclusion Criteria.** Potential participants were excluded from this study if they were unable to adequately communicate in English with the facilitators and other group members. Potential participants were also excluded from the study for serious mental illness (i.e. active bipolar disorder, schizophrenia). This was determined by an in-depth clinical interview conducted by the Director of the Cancer Support Community Greater Miami during the orientation session. Also, potential participants were excluded from the study if they opted not to participate in the questionnaire battery; however, they were allowed to remain in the group as all data collection was conducted either before or after the group session.

**Recruitment.** Eligible participants were recruited through Cancer Support Community Greater Miami by direct contact during center orientation, through flyers posted throughout the Cancer Support Community Greater Miami facility, via email notification, on the Cancer Support Community Greater Miami bimonthly calendar of events, or by telephone recruitment. One month prior to the start of each session (i.e. December 2009, March 2010, and May 2010) Cancer Support Community Greater Miami would distribute its bimonthly calendar of events to all members of the mailing

list. Participation in at least one event at Cancer Support Community Greater Miami would place participants on the mailing list. The Coping Skills groups for Survivors and Co-survivors were highlighted on the calendar each month. Interested participants were asked to RSVP to Cancer Support Community Greater Miami to sign up for the groups. In addition, a separate email flyer (Appendix B) describing the coping skills groups was sent to all Cancer Support Community Greater Miami members who had attended at least one group/event in the previous three months. Again, interested participants were asked to RSVP to Cancer Support Community Greater Miami to sign up for the groups. All Cancer Support Community Greater Miami members who had attended at least one group/event in the previous three months and who had not provided an email address for contact were called on the phone and offered information about the groups. In addition, all new members of Cancer Support Community Greater Miami are required to participate in a one-hour orientation session to become familiar with the resources and programs offered at the facility. During this orientation session upcoming programs are highlighted that may be relevant to the new participant. The Coping Skills groups were discussed in all new orientation sessions. And lastly, Cancer Support Community Greater Miami placed flyers throughout the facility advertising upcoming groups and events. Again, interested participants were asked to RSVP.

Once potential participants expressed interest in the groups, the facilitator contacted them by phone and verified that they met the eligibility criteria of the study. In addition, the facilitator answered any questions the participants had about the groups or the study.

Prior to starting the first group session, all participants were given a copy of the informed consent form and the study was explained. Participants were told that participation was completely voluntary and they could withdraw from the study at any time and still remain in the group. Participants were also told that it was important to try to attend all six sessions of the group as the material discussed would build upon the material discussed in previous weeks. The facilitator explained that due to the health situation of the survivors and co-survivors it was understandable that medical issues may arise that prevent their attendance. In these cases, if the participant did not call the facilitator ahead of time to let them know, the facilitator would call the participant to check in on them. Once everyone signed the consent form the first session began.

**Sample characteristics.** Participants were over the age of 18 and from a wide variety of racial and ethnic groups. Participants in the survivor groups had a wide range of cancers with varying diagnoses. In addition, survivors were in various stages of the disease from newly diagnosed to 19 years post-treatment. Participants in the co-survivor groups were spouses, friends, adult children, and siblings of a cancer survivor. The persons being cared for had various diagnoses. It was not necessary to have a loved one in the survivor group in order to join the co-survivor group and vice versa.

### **Procedures and Measures**

Researchers were graduate students at the University of Miami and/or group facilitators at Cancer Support Community Greater Miami. There were four facilitators (EC, DR, AD, and JR) including the lead investigator (EC). Prior to the start of each six week segment the lead investigator met with all of the group facilitators to train them on

the manualized therapy. Throughout the groups the lead investigator met weekly with the group facilitators to provide supervision and discuss any issues that arose in the group sessions.

Prior to the start of the first session the facilitator consented the participants into the study. The purpose of the study was explained and all potential participants were given an opportunity to ask questions. Potential participants did not have to participate in the research study in order to participate in the coping skills group; however, all potential participants chose to enroll in the study.

After consenting to participate in the group and the research study, all participants were asked to fill out a baseline assessment battery (described in the sections below) before beginning the discussion in the first session. Group sessions were led by the facilitator and participants were encouraged to actively contribute. Each session was dedicated to one of the “indicators of healing” described in Table 2.

Table 2: APPLES Group Session Outline

<b>Session</b>	<b>Topic</b>	<b>Assessment</b>
Session 1	Introduction	Baseline (before session)
Session 2	Acceptance and Appropriate Grieving for Loss and the Reality of Loss	
Session 3	Positive Reframing	3-Week (after session)
Session 4	Positive Action	
Session 5	Laughter/Emotional Support Seeking	
Session 6	Stress Tolerance	6-Week (after session)



The choice to focus on these indicators of healing was the result of Burnett's (Burnett, Victorson, Gela, & Ouellette, 2008) recognition that the Injury Coping Index's (ICI) factor structure was consistent with a large body of other research on adaptive coping following injury, illness, and disaster, described in Table 3 below. The full manual for the groups is in Appendix A.

Table 3: Research Support for the APPLES Indicators of Healing

<b>Indicator of Healing</b>	<b>Research Support</b>
Acceptance and Appropriate Grieving for Loss and the Reality of Loss	(Maciejewski, Zhang, Block, & Prigerson, 2007; Pitceathly & Maguire, 2003)
Positive Reframing	(Fawzy, Cousins, Fawzy, Kemeny, Elashoff, & Morton, 1990)
Positive Action	(Edelman & Kidman, 1999)
Laughter	(Bennett, Zeller, Rosenberg, & McCann, 2003; Christie & Moore, 2005)
Emotional Support Seeking	(Classen, et al., 2001)
Stress Tolerance	(Antoni M. H., 2003; Lepore & Coyne, 2006; Schmitz & Crystal, 2000)

**Screening instruments.** Screening instruments were used to determine if participants were eligible to take part in the research study by being of the appropriate age, being able to read, write, and speak English, and not suffer from severe psychopathology. The screening instrument used in this study was the Cancer Support Community Greater Miami Intake Form.

***Cancer Support Community Greater Miami Intake Form.*** The Cancer Support Community Greater Miami Intake Form is a brief self-report questionnaire that is given to all new members of Cancer Support Community Greater Miami. This questionnaire is filled out during the mandatory orientation session for use of the Cancer Support Community Greater Miami facilities. This form provides information about preferred

language of communication, along with interest in particular resources, and contact information. Data from this form are used for recruitment purposes only.

**Assessment battery.** The battery of assessments included: (a) the Demographic Questionnaire (DQ) as an assessment of basic information about the participant; (b) the Injury Distress Index (IDI) to assess self-reported distress following a traumatic physical illness; (c) the Injury Coping Index (ICI) to measure self-reported coping strategies specifically related to experiencing a traumatic physical illness; (d) the Injury Resilience Index (IRI), a self-report measure to assess one's ability to "bounce back" from trauma; and (e) the Quality of Life Inventory (QOLI) a self-report measure of life satisfaction designed to complement symptom inventories. The assessment battery took approximately 15-20 minutes to complete at each administration. Each of these measures is described in the paragraphs below.

***Demographic Questionnaire (DQ).*** The Demographic Questionnaire is a brief 12-item self-report measure to assess basic information about the participant. The measure includes items about age, marital status, income, education level, employment, and cancer treatment history. The survivor version asks questions about diagnosis, current stage of treatment, and insurance coverage. The co-survivor version asks about the relationship with the survivor as well as specific information about the survivor's cancer diagnosis and current stage of treatment.

***Injury Distress Index (IDI).*** The Injury Distress Index is a brief 32-item self report measure designed to assess injury-related distress after a traumatic physical illness diagnosis (Victorson D. E., Enders, Burnett, & Ouellette, 2008). Items are rated on a five-

point Likert scale ranging from 0 “strongly disagree” to 4 “strongly agree”. The prompt for the survivor version of the measure is “since the cancer diagnosis...” and the prompt for the co-survivor version is “since my loved one’s cancer diagnosis...” Sample items include “I am watchful for anything bad that might happen” and “I get more nervous than normal when something reminds me of the illness.” There are seven subscales (Re-experience, Avoidance and numbing, Hyperarousal, Posttraumatic stress, Depression, Anxiety, and Pain) and a total IDI score. Cronbach’s  $\alpha$  for the subscales ranges from 0.75 to 0.86 and the total score is 0.92. The IDI has shown acceptable convergent and discriminant validity with other highly used measures of distress (Victorson D. E., Enders, Burnett, & Ouellette, 2008).

***Injury Coping Index (ICI).*** The Injury Coping Index is a 19-item self-report measure designed to assess the presence of distress as well as the use of coping strategies when faced with a trauma (Burnett, Victorson, Gela, & Ouellette, 2008). Items are rated on a five-point Likert scale ranging from 0 “strongly disagree” to 4 “strongly agree”. The prompt for the survivor version of the measure is “since the cancer diagnosis...” and the prompt for the co-survivor version is “since my loved one’s cancer diagnosis...” Sample items include “I joke around about things that have happened to me as a result of the illness” and “I try to view the illness in a positive light.” There are six subscales of the ICI (Transformational coping, Use of social support, Use of humor, Behavioral avoidance, Use of distraction, and Use of substances). Cronbach’s  $\alpha$  for the subscales ranges from 0.75 to 0.93.

***Injury Resilience Index (IRI).*** The Injury Resilience Index is a 19 item self-report measure designed to assess psychological resilience or the ability of someone to

“bounce back” from a traumatic experience (Victorson, Burnett, & Gela, 2008). Items are rated on a five-point Likert scale ranging from 0 “strongly disagree” to 4 “strongly agree”. The prompt for the survivor version of the measure is “since the cancer diagnosis...” and the prompt for the co-survivor version is “since my loved one’s cancer diagnosis...” Sample items include “I think something positive will come out of this” and “I can rely on others for emotional support if I need them.” There are five subscales of the IRI (Hardiness, Social support and satisfaction, Posttraumatic growth, Optimism, and Coping self-efficacy). Cronbach’s  $\alpha$  for the subscales ranges from 0.70 to 0.85 (Victorson, Burnett, & Gela, 2008). Both convergent and discriminant validity were acceptable with positive correlations on well-validated measures.

***Quality of Life Inventory (QOLI).*** The Quality of Life Inventory (QOLI) is a brief 32-item self-report measure designed to assess both importance of and satisfaction with specific areas of life. The measure has been empirically validated and tested with multiple populations, both clinical and non-clinical (Frisch, Cornell, Villanueva, & Retzlaff, 1992). There are 16 areas assessed by the QOLI with each area specifically defined. For each area, respondents are asked how important it is to their happiness and how satisfied they are. The 16 areas are: Health, Self-esteem, Goals and values, Standard of living, Work, Recreation, Learning, Creativity, Helping, Love relationship, Friendships, Relationships with children, Relationships with relatives, Home, Neighborhood, and Community. The importance items are rated on a three-point Likert scale ranging from 0 “not important” to 2 “very important”. The satisfaction items are rated on a six-point Likert scale ranging from -3 “very dissatisfied” to +3 “very satisfied” (Frisch M. B., 1998). The total score on the measure represents a participant’s

satisfaction in only the areas of life that they have deemed important. The questionnaire is the same for both survivors and caregivers. Validation testing was conducted with four different samples, a VA inpatient sample, a VA recovered sample, undergraduates, and a counseling center sample. Cronbach's  $\alpha$  for all four samples ranged from 0.77 for the undergraduates to 0.89 for the VA recovered sample. The authors also report significant correlations between the QOLI scores and widely used measures of life satisfaction and subjective well-being (Frisch, Cornell, Villanueva, & Retzlaff, 1992).

### **Data Collection**

Researchers were graduate students in psychology and licensed mental health professionals at Cancer Support Community Greater Miami. Prior to data collection, all researchers met with the investigator (EC) for training in the group curriculum. Researchers administered the baseline assessment battery in a group format prior to beginning Session One of the coping skills group. The 3-week assessment was collected immediately following Session Three and the 6-week assessment was collected immediately following the final session. Researchers informed participants about the structure of the assessment battery and the time needed to complete. Researchers clarified the prompts for the battery as there are slight wording differences for survivors and co-survivors. Participants were told to read each item carefully and to choose the answer that best described their response. Researchers were present while the participants were completing the battery to answer any questions. Administration of the questionnaires lasted approximately 15-20 minutes.

## CHAPTER IV

### Results

#### Demographics

Twenty six cancer survivors (11.5% male, n = 3; 88.5% female, n = 23) and 16 cancer co-survivors (62.5% male, n = 10; 37.5% female, n = 6) participated in this research study. Participants in the survivor groups were from various racial (96.2% White/Caucasian and 3.8% Black/African American) and ethnic (50% Hispanic and 50% Non-Hispanic) backgrounds while participants in the co-survivor groups were also from various racial (86.7% White/Caucasian and 13.3% Mixed Race/Other) and ethnic (40% Hispanic and 60% Non-Hispanic) backgrounds. The majority of participants in the survivor groups were married or living with a partner (57.7%), with some single (7.7%), divorced (19.2%), or widowed (15.4%). In the co-survivor groups, 87.5% were married or living with a partner while 6.3% were single and another 6.3% were divorced. Participants in the survivor groups were between the ages of 39 to 88 (mean age = 59.2) and in the co-survivors groups participants were between the ages of 43 to 73 (mean age = 60.27).

In the survivor groups, participants indicated they had multiple types of cancer with some indicating more than one type. These included appendix (3.4%), blood (3.4%), breast (37.9%), colon (13.9%), gastric (3.4%), head and neck (3.4%), lung (13.9%), ovarian (13.9%), pancreatic (3.4%), and prostate (3.4%). The stage of disease varied across participants with the survivor groups having some participants in active treatment (38.5%), some in remission (42.3%), some with recurrent/metastatic disease (11.5%) and

some not sure of their stage (7.7%). In the co-survivor groups participants indicated their loved ones had been diagnosed with multiple types of cancer with some participants indicating more than one type. These included appendix (6.3%), breast (31.2%), colon (12.5%), head and neck (6.3%), liver (6.3%), lung (12.5%), ovarian (12.5%), prostate (6.3%), and thyroid (6.3%). In addition, the stage of disease also varied with the participant's loved ones being newly diagnosed (12.5%), in active treatment (31.3%), in remission (25.0%), having recurrent/metastatic disease (18.8%), and some not sure of the stage of disease (12.5%). The mean age of diagnosis for cancer survivors was 55.48 years (range 30-77 years) and the mean age of co-survivors at the time of their loved one's diagnosis was 56.80 years (range 40-73 years). Participants in the co-survivor groups did not necessarily have a loved one in the survivor group and vice versa, thus there is not a correlation between the types of cancer reported in each group.

Participants in the survivor groups tended to be employed (53.8%), but were also retired (30.8%), disabled (11.5%), and homemakers (3.8%). The education level of survivors was varied (15.4% partial college; 11.5% two-year college; 38.5% four-year college; 34.6% graduate degree) and the household income was varied as well with the majority of survivors having over \$50,000 of yearly income. The majority of participants in the co-survivor groups were employed (66.7%) or retired (26.7%) with most attending at least two years of college (37.5% two-year college; 12.5% four-year college; 37.5% graduate degree). The household income of co-survivors ranged from \$30,000-\$49,999 (37.5%), \$50,000-\$69,999 (31.5%), to over \$90,000 (31.5%).

Table 4. Demographics of Cancer Survivor Group (N=26)

<b>Sex</b>	<b>N (%)</b> <i>Male 3 (11.5)</i>	<b>N (%)</b> <i>Female 23 (88.5)</i>
<b>Race</b>	<b>N (%)</b> <i>White 25 (96.2)</i>	<b>N (%)</b> <i>Black 1 (3.8)</i>
<b>Ethnicity</b>	<b>N (%)</b> <i>Hispanic 13 (50)</i>	<b>N (%)</b> <i>Non-Hispanic 13 (50)</i>
<b>Employment Status</b>	<b>N (%)</b> <i>Employed 14 (53.8)</i> <i>Disabled 3 (11.5)</i>	<b>N (%)</b> <i>Homemaker 1 (3.8)</i> <i>Retired 8 (30.8)</i>
<b>Marital Status</b>	<b>N (%)</b> <i>Married 15 (57.7)</i> <i>Divorced 5 (19.2)</i>	<b>N (%)</b> <i>Single 2 (7.7)</i> <i>Widowed 4 (15.4)</i>
<b>Education</b>	<b>N (%)</b> <i>Partial College 4 (15.4)</i> <i>2-Year College 3 (11.5)</i>	<b>N (%)</b> <i>4-Year College 10 (38.5)</i> <i>Graduate Degree 9 (34.6)</i>
<b>Household Income</b>	<b>N (%)</b> <i>&lt; \$10,000 2 (7.7)</i> <i>\$30,000-\$49,999 4 (15.4)</i> <i>\$70,000-\$89,999 5 (19.2)</i>	<b>N (%)</b> <i>\$10,000-\$29,999 1 (3.8)</i> <i>\$50,000-\$69,999 6 (23.1)</i> <i>&gt;\$90,000 6 (23.1)</i>
<b>Type of Cancer*</b>	<b>N (%)</b> <i>Appendix 1 (3.4)</i> <i>Breast 11 (37.9)</i> <i>Gastric 1 (3.4)</i> <i>Lung 4 (13.9)</i> <i>Pancreatic 1 (3.4)</i>	<b>N (%)</b> <i>Blood 1 (3.4)</i> <i>Colon 4 (13.9)</i> <i>Head and Neck 1 (3.4)</i> <i>Ovarian 4 (13.9)</i> <i>Prostate 1 (3.4)</i>
<b>Stage of Treatment</b>	<b>N (%)</b> <i>Active Treatment 10 (38.5)</i> <i>Recurrent/Metastatic 3 (11.5)</i>	<b>N (%)</b> <i>Remission 11 (42.3)</i> <i>Not Sure 2 (7.7)</i>
<b>Mean Age of Survivors 59.20 (39-88)</b>		
<b>Mean Age at Diagnosis 55.48 (30-77)</b>		

\*Some patients identified more than one type of cancer.



Table 5. Demographics of Cancer Co-Survivor Group (N = 16)

<b>Sex</b>	<b>N (%)</b> <i>Male</i> 10 (62.5)	<b>N (%)</b> <i>Female</i> 6 (37.5)
<b>Race</b>	<b>N (%)</b> <i>White</i> 13 (86.7)	<b>N (%)</b> <i>Mixed Race/Other</i> 3 (13.3)
<b>Ethnicity</b>	<b>N (%)</b> <i>Hispanic</i> 6 (40)	<b>N (%)</b> <i>Non-Hispanic</i> 9 (60)
<b>Employment Status</b>	<b>N (%)</b> <i>Employed</i> 10 (66.7) <i>Retired</i> 4 (26.7)	<b>N (%)</b> <i>Unemployed</i> 1 (6.7)
<b>Marital Status</b>	<b>N (%)</b> <i>Married</i> 14 (87.5) <i>Divorced</i> 1 (6.3)	<b>N (%)</b> <i>Single</i> 1 (6.3)
<b>Education</b>	<b>N (%)</b> <i>High School/GED</i> 1 (6.3) <i>2-Year College</i> 6 (37.5) <i>Graduate Degree</i> 6 (37.5)	<b>N (%)</b> <i>Partial College</i> 1 (6.3) <i>4-Year College</i> 2 (12.5)
<b>Household Income</b>	<b>N (%)</b> <i>\$30,000-\$49,999</i> 6 (37.5) <i>&gt;\$90,000</i> 5 (31.5)	<b>N (%)</b> <i>\$50,000-\$69,999</i> 5 (31.5)
<b>Type of Loved One's Cancer</b>	<b>N (%)</b> <i>Appendix</i> 1 (6.3) <i>Colon</i> 2 (12.5) <i>Liver</i> 1 (6.3) <i>Ovarian</i> 2 (12.5) <i>Thyroid</i> 1 (6.3)	<b>N (%)</b> <i>Breast</i> 5 (31.2) <i>Head and Neck</i> 1 (6.3) <i>Lung</i> 2 (12.5) <i>Prostate</i> 1 (6.3)
<b>Stage of Loved One's Treatment</b>	<b>N (%)</b> <i>Newly Diagnosed</i> 2 (12.5) <i>Remission</i> 4 (25.0) <i>Not Sure</i> 2 (12.5)	<b>N (%)</b> <i>Active Treatment</i> 5 (31.3) <i>Recurrent/Metastatic</i> 3 (18.8)
<b>Mean Age of Co-Survivors</b> 60.27 (43-73)		
<b>Mean Age at Loved One's Diagnosis</b> 56.80 (40-73)		

\*Some patients identified more than one type of cancer.

### Analysis of the Results

**Missing Data.** Descriptive statistics were run to check the integrity of the data entry. Due to the longitudinal nature of the intervention, attrition was an issue. The participants were struggling with an unpredictable disease, thus some participants were lost due to disease progression as well as competing priorities in their lives. At baseline measurement there were 42 participants (26 Survivors and 16 Co-Survivors), at the 3-

week midpoint assessment there were 26 participants (16 Survivors and 10 Co-Survivors) and at the 6-week assessment there were 19 participants (13 Survivors and 6 Co-Survivors). For analyses that compared participants across all three timepoints, only participants who completed all three assessment batteries (n = 19) were included.

Table 6. Attrition Rate throughout Study

	Survivors	Co-Survivors
Baseline	N = 26	N = 16
3-Week	N = 16	N = 10
6-Week	N = 13	N = 6

When the data were collected from participants, a researcher was present at all times. Participants were encouraged to answer each and every question on the assessment battery. Of the completed batteries, very few responses were omitted. In the rare circumstance where a question was skipped on a measure, an average was calculated based on responses in that particular subscale. For example, if a subscale contained five items, four of which were answered and one was skipped, an average of the four responses on that subscale was calculated and inserted for the one missing response. Due to strict data collection methods, there was never a circumstance where more than one response on a subscale was omitted. There was one participant who did not participate in the 3-week assessment but did complete the 6-week assessment. That participant's responses are included in the baseline and 6-week analyses. There was also one participant who skipped an entire measure during one administration and that participant's data were omitted from analysis for that particular measure but included for other measures.

Due to attrition in this study, chi-square analyses were conducted on demographic data of participants who completed all three assessments in the study versus participants who only completed one or two assessments in the study. Results showed that there were no significant differences on sex, ethnicity, racial group, marital status, education level, occupational status, socioeconomic status, type of insurance, and stage of disease. A one-way ANOVA was conducted to look at differences in age amongst participants who completed all three assessments in the study versus participants who only completed one or two assessments in the study and no significant difference was found.

**Descriptives.** Listed in Table 7 is descriptive information on the Illness Distress Index, the Illness Resiliency Index, the positive coping scale of the Illness Coping Index, the negative coping scale of the Illness Coping Index, and the Quality of Life Inventory. Table 8 lists correlations for these five measures as well.

Table 7. Mean, Standard Deviation, and Range of Assessment Measures

<b>Baseline Assessment</b>			
<b>Measure</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
Illness Distress Index	49.85	24.43	0-106
Illness Resiliency Index	55.50	12.05	17-73
Illness Coping Index			
Positive Coping	31.35	6.65	15-48
Negative Coping	3.12	3.03	0-11
Quality of Life Index	1.63	1.02	0-3
<b>3-Week Assessment</b>			
<b>Measure</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
Illness Distress Index	47.83	23.82	9-88
Illness Resiliency Index	56.23	11.65	29-76
Illness Coping Index			
Positive Coping	32.37	6.14	20-44
Negative Coping	3.81	3.51	0-12
Quality of Life Index	1.65	1.20	0-3
<b>6-Week Assessment</b>			
<b>Measure</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
Illness Distress Index	43.68	26.84	0-78
Illness Resiliency Index	58.50	10.94	34-76
Illness Coping Index			
Positive Coping	34.42	7.48	16-47
Negative Coping	3.32	3.22	0-9
Quality of Life Index	1.60	1.05	0-3

Table 8. Correlations of Assessment Measures

<b>Baseline Assessment</b>					
	Illness Distress Index	Illness Resiliency Index	ICI: Positive Coping	ICI: Negative Coping	Quality of Life Index
Illness Distress Index	X	-.224	-.128	.505**	-.305
Illness Resiliency Index		X	.771**	-.240	.424**
ICI: Positive Coping			X	-.119	.304
ICI: Negative Coping				X	-.090
Quality of Life Index					X
<b>3-Week Assessment</b>					
	Illness Distress Index	Illness Resiliency Index	ICI: Positive Coping	ICI: Negative Coping	Quality of Life Index
Illness Distress Index	X	-.334	-.345	.603**	-.551**
Illness Resiliency Index		X	.739**	-.297	.399*
ICI: Positive Coping			X	-.312	.273
ICI: Negative Coping				X	-.425*
Quality of Life Index					X
<b>6-Week Assessment</b>					
	Illness Distress Index	Illness Resiliency Index	ICI: Positive Coping	ICI: Negative Coping	Quality of Life Index
Illness Distress Index	X	-.453	.001	.785**	-.424
Illness Resiliency Index		X	.470*	-.344	.510*
ICI: Positive Coping			X	.153	-.103
ICI: Negative Coping				X	-.282
Quality of Life Index					X

\*Correlation is significant at .05 level; \*\*Correlation is significant at .01 level

**Hypothesis Testing.** The first hypothesis stated that cancer survivors' post-treatment quality of life scores will be significantly higher than their pre-treatment quality of life scores. Quality of life was measured using the Quality of Life Inventory (QOLI). The QOLI yields an overall quality of life score rated as "very low," "low," "average," and "high." In order to test this a repeated measures ANOVA was run on the cancer

survivors who completed all three assessment measures ( $N = 13$ ). The mean score for quality of life in cancer survivors was not significantly different over time ( $F(2, 24) = 1.45, p = .255$ ).

The first hypothesis also stated that cancer co-survivors' post-treatment quality of life scores will be significantly higher than their pre-treatment quality of life scores. In order to test this a repeated measures ANOVA was run on the cancer co-survivors who completed all three assessment measures ( $N = 6$ ). The mean score for quality of life in cancer co-survivors was not significantly different over time with a Greenhouse-Geisser correction ( $F(1, 5) = 1.00, p = .363$ ).

The second hypothesis stated that cancer survivors' post-treatment illness-related resiliency scores will be significantly higher than their pre-treatment illness-related resiliency scores. Illness-related resiliency was measured using the Illness Resiliency Index (IRI). The IRI has five subscales (Hardiness, Social Support, Growth, Optimism, and Self-Efficacy) and also yields a total resiliency score. In order to test this hypothesis, the total resiliency score was used and a repeated measures ANOVA was run on the cancer survivors who completed all three assessment measures ( $N = 13$ ). The mean score for illness-related resiliency in cancer survivors was not significantly different over time ( $F(2, 24) = 1.56, p = .231$ ).

The second hypothesis also stated that cancer co-survivors' post-treatment illness-related resiliency scores will be significantly higher than their pre-treatment illness-related resiliency scores. In order to test this hypothesis, the total resiliency score was used and a repeated measures ANOVA was run on the cancer co-survivors who

completed all three assessment measures ( $N = 6$ ). The mean score for illness-related resiliency in cancer co-survivors was not significantly different over time ( $F(2, 10) = 2.33, p = .148$ ).

The third hypothesis stated that cancer survivors' post-treatment illness-related positive coping scores will be significantly higher than their pre-treatment illness-related positive coping scores and their post-treatment illness-related negative coping scores will be significantly lower than their pre-treatment illness-related negative coping scores. Illness-related coping was measured using the Illness Coping Index (ICI). The ICI has six subscales (Behavioral Avoidance, Social Support, Humor, Transformational Coping, Use of Substances, and Distraction), yet it does not yield an overall coping score. Therefore, in order to test this hypothesis a positive coping score was created based on the three positive subscales (Social Support, Humor, and Transformational Coping) and a negative coping score was created based on the two negative subscales (Behavioral Avoidance and Use of Substances). The Distraction subscale was not included in either score due to its ability to be both positive and negative. In order to test the first part of this hypothesis, the positive coping score was used and a repeated measures ANOVA was run on the cancer survivors that completed all three assessment measures ( $N = 12$ ). The mean score for illness-related positive coping in cancer survivors was not significantly different over time ( $F(2, 22) = 0.50, p = .614$ ). In order to test the second part of this hypothesis, the negative coping score was used and a repeated measures ANOVA was run on the cancer survivors that completed all three assessment measures ( $N = 12$ ). The mean score for illness-related negative coping in cancer survivors was not significantly different over time ( $F(2, 22) = 2.96, p = .073$ ).

The third hypothesis also stated that cancer co-survivors' post-treatment illness-related positive coping scores will be significantly higher than their pre-treatment illness-related positive coping scores and their post-treatment illness-related negative coping scores will be significantly lower than their pre-treatment illness-related negative coping scores. In order to test the first part of this hypothesis, the positive coping score was used and a repeated measures ANOVA was run on the cancer co-survivors that completed all three assessment measures ( $N = 6$ ). The mean score for illness-related positive coping in cancer co-survivors was not significantly different over time ( $F(2, 10) = 1.76, p = .222$ ). In order to test the second part of this hypothesis, the negative coping score was used and a repeated measures ANOVA was run on the cancer co-survivors that completed all three assessment measures ( $N = 6$ ). The mean score for illness-related negative coping in cancer co-survivors was not significantly different over time ( $F(2, 10) = .32, p = .734$ ).

The fourth hypothesis stated that cancer survivors' post-treatment illness-related distress scores will be significantly lower than their pre-treatment illness-related distress scores. Illness-related distress was measured using the Illness Distress Index (IDI). The IDI has four subscales (PTSD, Depression, Anxiety, and Pain) and also yields a total distress score. In order to test this hypothesis, the total distress score was used and a repeated measures ANOVA was run on the cancer survivors who completed all three assessment measures ( $N = 13$ ). The mean score for illness-related distress in cancer survivors was not significantly different over time ( $F(2, 24) = 0.97, p = .393$ ).

The fourth hypothesis also stated that cancer co-survivors' post-treatment illness-related distress scores will be significantly lower than their pre-treatment illness-related distress scores. In order to test this hypothesis the total distress score was used and a



repeated measures ANOVA was run on the cancer co-survivors who completed all three assessment measures ( $N = 6$ ). The mean score for illness-related distress in cancer co-survivors was not significantly different over time ( $F(2, 10) = 2.92, p = .100$ ).

The fifth, sixth, and seventh hypotheses tested the relationship of illness-related resiliency, coping, and distress with overall quality of life. In order to test this, Pearson product-moment correlations were run on cancer survivors, cancer co-survivors, and a combined group of both at baseline, 3-week, and 6-week assessment. In addition, chi-square analyses were run to examine the differences between participant status (i.e. cancer survivors and cancer co-survivors) on overall quality of life at baseline, 3-week, and 6-week assessment.

The fifth hypothesis stated that cancer survivors' and cancer co-survivors' illness-related resiliency scores will be significantly related to quality of life scores at baseline, 3-week, and 6-week assessment. The total resiliency score was used for these analyses. For cancer survivors there was no significant relationship between illness-related resiliency and overall quality of life at baseline, 3-week, or 6-week assessment. For cancer co-survivors, there was also no significant relationship between illness-related resiliency and overall quality of life at baseline, 3-week, or 6-week assessment. When the groups were combined, there was a significant positive correlation at baseline assessment ( $r(40) = .42, p < .01$ ), 3-week assessment ( $r(24) = .40, p < .05$ ), and 6-week assessment ( $r(18) = .51, p < .05$ ) between illness-related resiliency and overall quality of life.

The sixth hypothesis stated that cancer survivors' and cancer co-survivors' illness-related coping scores will be significantly related to quality of life scores at

baseline, 3-week, and 6-week assessment. Both positive and negative coping scores were used for these analyses. For cancer survivors there was no significant relationship between illness-related positive coping, illness-related negative coping and overall quality of life at baseline, 3-week, or 6-week assessment. For cancer co-survivors, there was a significant relationship between illness-related positive coping and overall quality of life at baseline ( $r(15) = .56, p < .05$ ) but no significant relationships between illness-related positive coping, illness-related negative coping, and overall quality of life at 3-week or 6-week assessment. When the groups were combined, there was a significant relationship between illness-related negative coping and overall quality of life at the 3-week assessment ( $r(26) = -.43, p < .05$ ). There were no significant relationships between illness-related positive coping, illness-related negative coping, and overall quality of life at baseline or 6-week assessment.

The seventh, and final, hypothesis stated that cancer survivors' and cancer co-survivors' illness-related distress scores will be significantly related to quality of life scores at baseline, 3-week, and 6-week assessment. The total distress score was used for these analyses. For cancer survivors, there was no significant relationship between illness-related distress and overall quality of life at baseline, 3-week, and 6-week assessment. For cancer co-survivors, there was a significant negative correlation at 3-week assessment between illness-related distress and overall quality of life ( $r(8) = -.89, p < .001$ ). This relationship was not present at baseline or 6-week assessment. When the groups were combined, there was a significant negative correlation at 3-week assessment between illness-related distress and overall quality of life ( $r(24) = -.55, p < .01$ ).

Chi-square analyses were run to examine the differences in overall quality of life by participant status (i.e. cancer survivors and cancer co-survivors) at baseline, 3-week, and 6-week assessment. Quality of life scores were combined into a LOW category, which was made up of scores on the QOLI in the “very low and low” groups, and a HIGH category, which was made up of scores on the QOLI in the “average” and “high” groups. This was necessary to generate valid results due to attrition and the sample size in the 6-week assessment group. The chi-square analyses showed that the level of overall quality of life at baseline significantly differed by participant status,  $\chi^2(1, N = 41) = 5.11$ ,  $p = .024$ . Cancer survivors reported a higher level of overall quality of life at baseline assessment than cancer co-survivors. The level of overall quality of life at 3-week assessment also significantly differed by participant status,  $\chi^2(1, N = 26) = 6.52$ ,  $p = .011$ . Again, cancer survivors reported a higher level of overall quality of life at 3-week assessment than cancer co-survivors. The level of overall quality of life at 6-week assessment did not significantly differ by participant status,  $p = .303$ , two-tailed Fisher’s Exact Test, Cramer’s  $V = 0.286$ .

**Post-Hoc Analysis.** Post-hoc tests were run on subscales of the Illness Resiliency Index (IRI), the Illness Coping Index (ICI), and the Illness Distress Index (IDI). Participants’ data were grouped together (survivors and co-survivors) and repeated measures ANOVAs were conducted on a combined group of 19 participants who completed all three assessment batteries.

On the IRI, five subscales (Hardiness, Social Support, Growth, Optimism, and Self-Efficacy) were analyzed and the results show that there was a significant difference in posttraumatic growth over time with a Greenhouse-Geisser correction ( $F(1.468, 9.535)$

= 5.40,  $p < .05$ ). Post-hoc tests using the Bonferroni correction revealed that posttraumatic growth increased from baseline assessment to 6-week assessment (baseline scores of  $7.89 \pm 3.14$  versus 6-week assessment scores of  $9.11 \pm 3.18$ ), which was statistically significant ( $p < .05$ ).

On the ICI, six subscales (Behavioral Avoidance, Social Support, Humor, Transformational Coping, Use of Substances, and Distraction) were analyzed and the results show that there is a significant difference in use of substances over time ( $F(2, 2.722) = 3.87, p < .05$ ). Post-hoc tests using the Bonferroni correction revealed that substance use increased from baseline assessment to 3-week assessment (baseline scores of  $0.44 \pm 1.10$  versus 3-week assessment scores of  $1.06 \pm 1.35$ ), which was statistically significant ( $p < .05$ ).

On the IDI, four subscales (PTSD, Depression, Anxiety, and Pain) were analyzed and the results show that there is a significant difference in PTSD scores over time ( $F(2, 136.346) = 5.09, p < .05$ ). Post-hoc tests using the Bonferroni correction revealed that PTSD symptoms decreased from baseline assessment to 6-week assessment (baseline scores of  $26.53 \pm 13.15$  versus 6-week assessment scores of  $21.21 \pm 12.96$ ), which was statistically significant ( $p < .05$ ). Within the PTSD subscale on the IDI, there are three subscales (Detached, Hypervigilant, and Intrusion) to describe the symptoms of PTSD. Repeated measures ANOVAs were run on all three PTSD subscales and the results showed that there were significantly less feelings of detachment over time ( $F(2, 23.741) = 3.91, p < .05$ ).

## CHAPTER V

### **Discussion**

This study aims to address an under-researched but growing body of literature on psychological treatment for cancer survivors and co-survivors. Based on the fundamental principles of psychology, combined with theories on the treatment of chronic illness, this study attempts to present a new treatment option for community care. In this section a review of the original research questions will be presented along with a review of the significant research findings and implications of those findings. Methodological issues will be discussed at the end of the section and recommendations for future research will be presented.

#### **Review of Research Questions**

Below are the original seven research questions with a specific question for cancer survivors and cancer co-survivors.

1a. Will cancer survivors have significantly higher post-treatment scores on quality of life scales when compared to pre-treatment scores?

1b. Will cancer co-survivors have significantly higher post-treatment scores on quality of life scales when compared to pre-treatment scores?

2a. Will cancer survivors have significantly higher post-treatment scores on illness-related resiliency scales when compared to pre-treatment scores?

2b. Will cancer co-survivors have significantly higher post-treatment scores on illness-related resiliency scales when compared to pre-treatment scores?

3a. Will cancer survivors have significantly higher post-treatment scores on illness-related positive and negative coping skills scales when compared to pre-treatment scores?

3b. Will cancer co-survivors have significantly higher post-treatment scores on illness-related positive and negative coping skills scales when compared to pre-treatment scores?

4a. Will cancer survivors have significantly lower post-treatment scores on illness-related distress scales when compared to pre-treatment scores?

4b. Will cancer co-survivors have significantly lower post-treatment scores on illness-related distress scales when compared to pre-treatment scores?

5a. Will cancer survivors' illness-related resiliency scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

5b. Will cancer co-survivors' illness-related resiliency scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

6a. Will cancer survivors' illness-related coping skills scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

6b. Will cancer co-survivors' illness-related coping skills scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

7a. Will cancer survivors' illness-related distress scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

7b. Will cancer co-survivors' illness-related distress scores be significantly related to quality of life at baseline, 3-week and 6-week assessment?

### **Review of Research Findings**

After participating in the APPLES Coping Skills group, the 13 cancer survivors who completed all three assessment timepoints showed no significant change in quality of life over time. In addition, of the six co-survivors who completed all three assessment timepoints, there was no significant change in quality of life over time. This finding was surprising given the stressors both cancer survivors and cancer co-survivors report experiencing throughout the course of their illness. However, chi-square analyses comparing cancer survivors' and co-survivors' quality of life scores at the three different timepoints revealed significant differences between groups at baseline and 3-week assessment. At both times cancer survivors reported a higher level of overall quality of life as compared to cancer co-survivors. So, while there may not have been a significant increase in reported quality of life for cancer survivors and co-survivors throughout the duration of the group, it is important to note that cancer survivors experienced higher overall levels of quality of life at baseline and 3-week assessment as compared to co-survivors. Thus, while cancer survivors are struggling with a physical illness, those who care for them may be feeling more of a psychological impact.

Individual analyses of the 13 cancer survivors and six co-survivors who completed the entire APPLES Coping Skills group curriculum showed no significant differences in illness-related resiliency or illness-related distress over time. However, when the sample was combined in the post-hoc analyses there was a significant increase

in post-traumatic growth from baseline to 6-week assessment. Thus, APPLES Coping Skills group participants, regardless of survivor status, had a more positive psychological experience after dealing with the traumatic event of being diagnosed with and battling cancer. In addition, within the combined group, posttraumatic stress disorder (PTSD) symptoms decreased from baseline to 6-week assessment. When the three subscales of PTSD symptoms (Detachment, Hypervigilant, and Intrusion) were further analyzed, it was the feelings of detachment that drove the significant finding. Thus, both cancer survivors and co-survivors experienced less detachment from other people and/or their cancer experience after participating in the APPLES Coping Skills group. This may highlight the beneficial component of group participation as opposed to individual treatment. Connection to others as well as oneself may be a consequence of participation in the APPLES Coping Skills group.

Again, individual analyses of the 13 cancer survivors and six cancer co-survivors who completed every assessment in the APPLES Coping Skills group showed no significant difference in the use of positive coping skills or negative coping skills over time. However, when the cancer survivors and co-survivors were combined in the post-hoc analyses, there was a significant increase in the use of negative coping skills, specifically the use of substances (alcohol and un-prescribed medication), from baseline to 3-week assessment.

It is possible that the opportunity to face the reality of the situation may have contributed to the use of negative coping skills. For example, in the co-survivor group there was a wide range of time from diagnosis to participation in the group. One co-survivor was 20 years post-initial diagnosis and facing a recurrence of the disease in their



loved one. Another member's loved one had been diagnosed for the first time weeks before the group started and yet another co-survivor was experiencing placing her husband in hospice care. Based upon clinical experience with the group, this researcher believes that those that were new to cancer co-survivorship may have utilized more negative coping skills (i.e. use of substances) at the beginning of the group as they were learning more about the co-survivor journey from other group members. It is possible that the use of substances decreased as more coping skills were introduced in the group. More research needs to be done better understand this phenomenon.

Analyses were also run to look at the relationship of illness-related resiliency to quality of life at baseline, 3-week, and 6-week assessment. There was no significant relationship for the 13 cancer survivors or the six cancer co-survivors when analyzed separately. However, when the groups were combined there was a significant positive relationship between resiliency and quality of life at all three timepoints. Thus, as illness-related resiliency increased so did the APPLES Coping Skills group participants' perceived quality of life, showing that the more resilient a person is the more satisfied they feel in the areas of their life that they deemed to be important. Therefore, it may be that while actual quality of life may not have changed or improved, one's feelings of resiliency influenced their improved perception of their quality of life through participation in a coping skills group.

Analyses were also run to look at the relationship of illness-related positive coping skills and illness-related negative coping skills to quality of life at baseline, 3-week, and 6-week assessment. There was no significant relationship for the 13 cancer survivors. However, for the six co-survivors, there was a positive relationship between

illness-related positive coping skills and quality of life at baseline, but not 3-week or 6-week assessment. When the groups were combined in the post-hoc analyses, there was a significant relationship between the use of negative coping skills and quality of life at the 3-week assessment. This finding coincides with the increase in the use of substances at the 3-week assessment.

Lastly, analyses were run to look at the relationship of illness-related distress to quality of life at baseline, 3-week, and 6-week assessment. Of the 13 cancer survivors that completed the APPLES Coping Skills group, there was no significant relationship over time. However, of the six co-survivors that completed the APPLES Coping Skills group over time, there was a significant negative relationship between illness-related distress and quality of life at the 3-week assessment. Thus, as illness-related distress increased, cancer co-survivors reported a decrease in their perceived quality of life at the midpoint of the group. When the participants were combined into one group for the post-hoc analyses this finding held true. This also coincides with the increase in negative coping skills and the use of substances. Thus, it appears that midway through the group the participants experienced feelings of distress as they worked to process their/their loved one's illness and its impact on their life. Subsequently, the use of substances increased at this timepoint. This may indicate that the coping skills taught in later sessions of the group (i.e. emotional support seeking and stress tolerance) may be better utilized at the beginning of the group.

In summary, the findings show that at the midpoint (3-week) assessment there is an increase in feelings of distress and the use of substances (alcohol and un-prescribed medication) as well as a decrease in the participants' perceived quality of life. The

findings also show that by the end of the group (6-week assessment), participants report an increase in posttraumatic growth and feelings of resiliency and a decrease in symptoms of PTSD, specifically feelings of detachment.

### **Implications of Research Findings**

The APPLES Coping Skills group manual was developed following the guidelines of Dr. Kent Burnett and Dr. Margaret Crosbie-Burnett's research into psychological well-being. The curriculum clearly used the concepts of (1) **Acceptance** and appropriate grieving for loss and the reality of loss, (2) **Positive reframing**, (3) **Positive action**, (4) **Laughter**, (5) **Emotional support seeking**, and (6) **Stress tolerance** to teach cancer survivors and cancer co-survivors about healing, self-care, and the power of community support.

The findings of this study support the idea that developing group therapy models to address the impact of chronic illness on survivors and co-survivors is an avenue of important future research. As the clinical mindset shifts to view cancer as an ever-present illness instead of a predetermined death sentence, psychological treatment needs to make adjustments as well. Recognizing that the cancer survivor's psychological well-being plays an important role in their physical well-being is an important first step. However, this study demonstrates the negative impact having a loved one with a chronic illness has on those who take care of them. In some situations, it appears that co-survivors have more psychological symptoms than survivors. Based on clinical observation, it appears that the increase in daily demands on co-survivors, coupled with the sense of duty and obligation to focus on the physically ill loved one, may make it more likely that the co-

survivor does not seek support of their own. This allows psychological symptoms to worsen. In addition, the physical medical evidence available to support a diagnosis exists with cancer; however, there is no blood test for anxiety and depression. This may allow those suffering to dismiss their symptoms to focus on the survivor. More advocacy and research is needed to reduce the stigma associated with mental health care and increase the public's knowledge about psychological suffering in the caregiver role.

### **Strengths and Limitations**

There were multiple strengths to this study. First and foremost, being able to offer supportive treatment in a community setting facilitated the participation of a variety of people, ranging in age, ethnicity, gender, and socioeconomic status. While this was important for research purposes, it also allowed participants who may not have been able to afford to pay for treatment or access treatment to engage in the group. Another strength of the study was being able to conduct multiple groups over a six month time period. The group was offered on three separate occasions in January 2010, April 2010, and June 2010. This again contributed to diversity in participants, but also allowed cancer survivors who could not participate in the first offering due to health concerns to engage in the group at a later date. In addition, the multiple group offerings contributed to increasing the sample size and giving more power to the research findings.

In addition, the longitudinal design of the study provided important information about change over time. Assessing the participants before the start of the group, midway through the group, and after the last session provided important information that is not always collected. Instead of having a snapshot in time, this study allowed for the

investigation of changes over the course of the group. The midway data point proved to be highly informative as it seems that group participants experienced a decrease in well-being and an increase in negative coping before being able to experience positive change. Another strength of this study was the decision to use four different group facilitators to run both the survivor and co-survivor groups. This helped to eliminate the possible impact of the administrator on the group participants. The design of this study included creating a manualized treatment that was intended to be administered by multiple providers. Not only does this help with treatment fidelity, but it also makes it possible for other therapists to run APPLES Coping Skills groups in different settings in the future.

One of the most important strengths of the study was the combination of psychoeducation and social support in the group treatment manual. Offering pertinent information on the impact of stress on physical and psychological well-being, as well as providing group participants with concrete stress relaxation exercises, makes it possible for them to engage in these activities long after the group has ended. In addition, by using the group format, participants were “forced” to interact with other group members. This may have helped to reinforce the notion that struggling alone is not the only option when faced with chronic illness, but rather relating to others may facilitate your own recovery.

While this study certainly had its strengths, it was not without its limitations. Attrition was the biggest problem faced in this study. At the first session, 42 participants joined the groups (26 survivors and 16 co-survivors). By the midpoint assessment, both groups had lost 38% of the participants (16 survivors and 10 co-survivors remained) and by the final assessment the survivor group had lost half of its participants (13 survivors completed the group) and the co-survivor group had lost 62% of its participants (6 co-

survivors completed the group). The rate of attrition was somewhat alarming; however, past research has shown that follow through is difficult for this group. This may be related to the nature of the illness, competing demands for time, and a disregard for mental health in the face of a physical health crisis. Due to the attrition, some statistical analyses were difficult to conduct, therefore post-hoc analyses were run on a combined group of APPLES Coping Skills participants, regardless of survivor status, to give pertinent information about the effectiveness of the group.

Another limitation of this study was the inability to follow group participants after the group ended to look at the sustainability of any changes. The final assessment was collected immediately following the end of the sixth group session. Therefore, whether or not the decrease in feelings of detachment, increase in posttraumatic growth, and increase in feelings of resiliency will persist days, weeks, or months after the end of the group is unknown. This limitation was due to funding and timing issues; however, future research may be able to address this concern.

This study also used measurement tools to assess distress, coping, and resiliency that have not been used in a cancer population before. The measures were originally constructed to assess injury-related distress, coping, and resiliency in a population experiencing physical trauma. Due to the shift in perspective about cancer being considered a chronic illness, it was suggested that these measurement tools may be appropriate to assess this population. Because this is the first use with the cancer population, there is no existing research with which to compare the findings.

And lastly, the treatment manual was constructed to offer a six week group therapy experience to address very important topics for cancer survivors and co-survivors. The length of the treatment offered was based both on the existing literature as well as the experience and recommendation of the Cancer Support Community Greater Miami. It would have been more ideal to offer a longer group to address the concepts of the APPLES Coping Skills groups on a deeper and more involved level, however, that was not possible. The rate of attrition supported the decision to make the group shorter, yet the depth with which each component of the group was addressed was less than ideal.

### **Recommendations for Future Research**

The findings of this study are useful in helping to tailor psychological treatments for cancer survivors and co-survivors. However, there are opportunities for future research that take the findings of this study and build off of them. First, while the 6-week group format was based off of existing literature and the recommendation of the Cancer Support Community Greater Miami, there are other options for the length of the group. On one hand a more intensive group, either in number of sessions or length of the existing six sessions, would provide the participants the opportunity to explore the APPLES concepts more in depth. While the current format addresses all six concepts, at times the group felt to be “a mile wide and an inch deep” as each component of the group deserved serious exploration, conversation, and integration that may not have been possible in six 90 minute sessions.

Another alternative would be to create one to two session workshops that comprehensively deal with a single component of the APPLES group. These workshops

could be offered in community centers like the Cancer Support Community Greater Miami, as well as in hospitals, clinics, and doctor's offices. By offering the workshops in more settings, survivors in active treatment would be able to participate. Additionally, co-survivors assisting loved ones in active treatment would be a captive audience, thus facilitating their participation in their own mental health care. An example of this would be offering APPLES based workshops in chemotherapy treatment rooms which usually provide treatment for 6-8 patients at a time with room for a caregiver with each survivor. Another component of these proposed workshops would be supplying each participant with take-home literature on each of the APPLES concepts. This could possibly facilitate further conversation outside of the group as well as a way to reinforce the concepts beyond the group.

Another possibility for future research would be to conduct the groups with more participants. Attrition was the biggest threat to this study and a larger pool of participants would allow for additional statistical analyses. The current study recruited participants from one community center. It would be beneficial in future studies to partner with other community centers or agencies to offer the groups in multiple settings in order to increase participation. This would also increase diversity of participants and generalizability of the findings. In addition, with a larger pool of participants, it may be possible to have the groups focused on a specific type of cancer (i.e. breast cancer). This may be beneficial to participants as it was found that having the same or similar diagnosis to another participant fostered camaraderie and connectedness.

Another avenue for future research would be to offer separate survivor and co-survivor groups with matched/paired participants. One of the findings of this study was



that co-survivors typically coped worse with the illness and were less resilient. Research that looks at APPLES Coping Skills group co-survivors matched with their survivor would be able to explore the interaction between the two. Does a poorly coping co-survivor impact the quality of life of a survivor? Or vice versa? Paired groups would be able to offer insight into this phenomenon.

In addition, while this study provided longitudinal data that is not typically available in these studies, long term follow up was not conducted. It would be beneficial to look at the lasting impact of the group one, three, or even six months post-participation. Do changes last or do survivors and co-survivors revert back to baseline levels of resiliency, coping, distress, and quality of life? Research that is able to show a sustainable impact would be instrumental in furthering the availability of positive psychology wellness-based psychotherapy groups. Furthermore, the trajectory of the cancer diagnosis is not wholly predictable and the fear of recurrence, emergence of late effects, and challenges of reentry after treatment are real obstacles. Long term follow up would be able to address the impact of these hurdles on individual as well as relational health.

Lastly, the APPLES Coping Skills groups were designed to address the unique challenges that face survivors and co-survivors of chronic illness. While cancer is now considered a chronic illness, there are many other avenues to explore. For example, the APPLES Coping Skills group would be appropriate for patients diagnosed with HIV/AIDS as well as their family members and loved ones. Additionally, the groups would also be useful for children coping with chronic illness and their parents and siblings. Providing positive psychology based group psychotherapy for children would

help to create support networks that may continue through their development. Also, recognizing the impact that having a sick sibling has on the childhood experience of both the patient and their loved one is an untapped area of research. And probably most relevant in this day and age, would be the opportunity to offer the APPLES Coping Skills groups to wounded veterans and their family members. Veterans returning from war zones face the challenges of physical and mental/emotional wounds and it is imperative that we recognize the impact that these new burdens create. The APPLES Coping Skills group would provide an avenue to learn coping skills and offer information and support to the veterans and their loved ones. This is an important area of future research given the number and scope of physical injuries and epidemic levels of post-traumatic stress disorder related to being a combat veteran.

## References

- U.S. Cancer Statistics Working Group. (2009 1-January). *United States Cancer Statistics: 1999-2005 Incidence and Mortality Web-based Report*. Retrieved 2010, 23-February from U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).
- American Cancer Society. (2010). *Cancer Facts & Figures 2010*. Atlanta: American Cancer Society.
- American Cancer Society. (2008 November). *Making Treatment Decisions: Humor Therapy*. Retrieved 2010, 15-February from [www.cancer.org](http://www.cancer.org)
- Andersen, B. L. (1992). Psychological interventions for cancer patients to enhance the quality of life. *Journal of Consulting and Clinical Psychology, 60*, 552-568.
- Andersen, B. L., Yang, H. C., Farrar, W. B., Golden-Kreutz, D. M., Emery, C. F., Thornton, L. M., Young, D. C., Carson, W. E. (2008). Psychologic intervention improves survival for breast cancer patients: A randomized clinical trial. *Cancer, 113*(12), 3450-3458.
- Andrykowski, M. A., & Manne, S. L. (2006). Are psychological interventions effective and accepted by cancer patients? I. Standards and levels of evidence. *Annals of Behavioral Medicine, 32* (2), 93-97.
- Antoni, M. H. (2003). *Stress management intervention for women with breast cancer*. Washington, DC: American Psychological Association.
- Antoni, M. H., Lechner, S. C., Kazi, A., Wimberly, S. R., Sifre, T., Urcuyo, K. R., et al. (2006). How stress management improves quality of life after treatment for breast cancer. *Journal of Consulting and Clinical Psychology, 74* (6), 1143-1152.
- Baider, L., & Bengel, J. (2001). Cancer and the spouse: Gender-related differences in dealing with health care and illness. *Critical Reviews in Oncology/Hematology, 40*, 115-123.
- Barez, M., Blasco, T., Fernandez-Castro, J., & Viladrich, C. (2007). A structural model of the relationships between perceived control and adaptation to illness in women with breast cancer. *Journal of Psychosocial Oncology, 25*, 21-43.
- Barsevick, A. M., Sweeney, C., Haney, E., & Chung, E. (2002). A systematic qualitative analysis of psychoeducational interventions for depression in patients with cancer. *Oncology Nursing Forum, 29* (1), 73-86.

- Beck, A. T. (1976). *Cognitive therapy and emotional disorders*. New York: International Universities Press.
- Bellizzi, K. M., & Blank, T. O. (2006). Predicting posttraumatic growth in breast cancer survivors. *Health Psychology, 25* (1), 47-56.
- Bellizzi, K. M., & Blank, T. O. (2006). Understanding the dynamics of post-traumatic growth in breast cancer survivors. *Health Psychology, 25*, 47-56.
- Bellizzi, K. M., Rowland, J. H., Jeffrey, D. D., & McNeel, T. (2005). Health behaviors of cancer survivors: Examining opportunities for cancer control intervention. *Journal of Clinical Oncology, 23*, 8884-8893.
- Bennett, M. P., Zeller, J. M., Rosenberg, L., & McCann, J. (2003). The effect of mirthful laughter on stress and natural killer cell activity. *Alternative Therapies in Health and Medicine, 9* (2), 38-44.
- Bennett, M., & Lengacher, C. (1999). Use of complementary therapies in a rural cancer population. *Oncology Nursing Forum, 26*, 1287-1294.
- Bergelt, C., Koch, U., & Petersen, C. (2008). Quality of life in partners of patients with cancer. *Quality of Life Research, 17*, 653-663.
- Berglund, G., Bolund, C., Gustafsson, U.-L., & Sjoden, P.-O. (1994). A randomized study of a rehabilitation program for cancer patients: The "Starting Again" group. *Psycho-Oncology, 3*, 109-120.
- Blake-Mortimer, J., Gore-Felton, C., Kimerling, R., Turner-Cobb, J. M., & Spiegel, D. (1999). Improving the quality and quantity of life among patients with cancer: A review of the effectiveness of group psychotherapy. *European Journal of Cancer, 35* (11), 1581-1586.
- Bonanno, G. A. (2004). Loss, trauma, and human resilience. Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist, 59*, 20-28.
- Botteman, M. F., Pashos, C. L., Hauser, R. S., Laskin, B. L., & Redaelli, A. (2003). Quality of life aspects of bladder cancer: A review of the literature. *Quality of Life Research, 12*, 675-688.
- Bottomley, A. (1997a). Cancer support groups: Are they effective? *European Journal of Cancer, 6*, 11-17.
- Bottomley, A. (1996a). Group cognitive behavioural therapy interventions with cancer patients: A review of the literature. *European Journal of Cancer, 5*, 143-146.

- Bottomley, A. (1996b). Group cognitive behavioural therapy: An intervention for cancer patients. *International Journal of Palliative Nursing*, 2 (3), 131-136.
- Bottomley, A. (1997b). Where are we now? Evaluating two decades of group interventions with adult cancer patients. *Journal of Psychiatric and Mental Health Nursing*, 4, 251-265.
- Bowman, K. F., Rose, J. H., Radziewicz, R. M., O'Toole, E. E., & Berila, R. A. (2009). Family caregiver engagement in a coping and communication support intervention tailored to advanced cancer patients and families. *Cancer Nursing*, 32 (1), 73-81.
- Bredart, A., Cayrou, S., & Dolbeault, S. (2002). Re: Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute*, 94 (23), 1810-1811.
- Bredin, M., Corner, J., Krishnasamy, M., Plant, H., Bailey, C., & A'Hern, R. (1999). Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer. *BMJ*, 318, 901-905.
- Burnett, K. (October, 2008). Indicators of healing in survivors of illness, injury, and disaster. Presented at the University of Miami School of Education Faculty Retreat. Key Largo, FL.
- Burnett, K. F., Victorson, D. E., Gela, N. R., & Ouellette, E. A. (2008). Injury Coping Index: Initial Psychometric Findings. *Poster presented at the annual conference of the Society of Behavioral Medicine*. San Diego.
- Burnett, K. & Crosbie-Burnett, M. (2012). *Sowing the Seeds of Well-Being*. West Palm Beach; FL: Seeds of Well-Being, LLC.
- Butler, L. D., Koopman, C., Neri, E., Giese-Davis, J., Palesh, O., Thorne-Yocam, K. A., et al. (2009). Effects of supportive-expressive group therapy on pain in women with metastatic breast cancer. *Health Psychology*, 28 (5), 579-587.
- Cain, E. N., Kohorn, E. I., Quinlan, D. M., Latimer, K., & Schwartz, P. E. (1986). Psychosocial benefits of a cancer support group. *Cancer*, 57, 183-189.
- Caldwell, J. (2009). *Online Relaxation Exercises*. Retrieved 2009, 9-October from Georgia Southern University:  
<http://students.georgiasouthern.edu/counseling/relax/OnlineRelax07.htm>
- Camfield, L., & Skevington, S. M. (2008). On subjective well-being and quality of life. *Journal of Health Psychology*, 13, 764-775.

- Campbell, A., Converse, P. E., & Rogers, W. L. (1976). *The quality of American life*. New York: Russell Sage.
- Cancer Support Community Greater Miami. (2010). *About the Cancer Support Community of Greater Miami*. Retrieved 2010, 9-July from Cancer Support Community of Greater Miami:  
<http://cancersupportcommunitymiami.org/aboutus.htm>
- Carver, C. S. (2005). Enhancing adaptation during treatment and the role of individual differences. *Cancer, 104* (11), 2602-2607.
- Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., et al. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65*, 375-390.
- Cella, D. F., Sarafian, B., Snider, P. R., Yellen, S. B., & Winicour, P. (1993). Evaluation of a community-based cancer support group. *Psycho-Oncology, 2*, 123-132.
- Cella, D., Peterman, A., Passik, S., Jacobsen, P., & Breitbart, W. (1998). Progress toward guidelines for management of fatigue. *Oncology (Huntington), 12*, 369-377.
- Christie, W., & Moore, C. (2005). The impact of humor on patients with cancer. *Clinical Journal of Oncology Nursing, 9* (2), 211-218.
- Clark, D. M. (2004). Developing new treatments: On the interplay between theories, experimental science and clinical innovation. *Behaviour Research and Therapy, 42*, 1089-1104.
- Clark, M. M., Bostwick, M., & Rummans, T. A. (2003). Group and individual treatment strategies for distress in cancer patients. *Mayo Clinic Proceedings, 78*, 1538-1543.
- Classen, C., Butler, L. D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., et al. (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer. *Archives of General Psychiatry, 58*, 494-501.
- Corner, J., Plant, H., A'Hern, R., & Bailey, C. (1996). Non-pharmacological intervention for breathlessness in lung cancer. *Palliative Medicine, 10*, 299-305.
- Couper, J., Bloch, S., Love, A., Duchesne, G., MacVean, M., & Kissane, D. (2009). Coping patterns and psychosocial distress in female partners of prostate cancer patients. *Psychosomatics, 50* (4), 375-382.

- Coyne, J. C., & Lepore, S. J. (2006). Rebuttal: The black swan fallacy in evaluating psychological interventions for distress in cancer patients. *Annals of Behavioral Medicine, 32* (2), 115-118.
- Coyne, J. C., Lepore, S. J., & Palmer, S. C. (2006). Efficacy of psychosocial interventions in cancer care: Evidence is weaker than it first looks. *Annals of Behavioral Medicine, 32* (2), 104-110.
- Cunningham, A. J., & Tocco, E. K. (1989). A randomized trial of group psychoeducational therapy for cancer patients. *Patient Education and Counseling, 14*, 101-114.
- Danhauer, S. C., Crawford, S. L., Farmer, D. F., & Avis, N. E. (2009). A longitudinal investigation of coping strategies and quality of life among younger women with breast cancer. *Journal of Behavioral Medicine, 32*, 371-379.
- DeVine, E. C., & Westlake, S. K. (1995). The effects of psychoeducational care provided to adults with cancer: Meta-analysis of 116 studies. *Oncology Nursing Forum, 22*, 1369-1381.
- Diggle, P. J., Liang, K. Y., & Zeger, S. L. (1994). *Analysis of longitudinal data*. Oxford: Clarendon Press.
- Edelman, S., & Kidman, A. D. (1999). Description of a group cognitive behaviour therapy programme with cancer patients. *Psycho-Oncology, 8*, 306-314.
- Edelman, S., Craig, A., & Kidman, A. D. (2000). Group interventions with cancer patients: Efficacy of psychoeducational versus supportive groups. *Journal of Psychosocial Oncology, 18* (3), 67-85.
- Ell, K. O., Nishimoto, R. H., Mantell, J., & Hamovitch, M. (1998). Psychological adaptation to cancer: A comparison among patients, spouses, and non-spouses. *Fam Syst Med, 6*, 335-348.
- Ellis, A. (1962). *Reason and emotion in psychotherapy*. Seacaucus, NJ: Citadel.
- Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine, 132*, 451-459.
- Entwistle, V., Tritter, J. Q., & Calnan, M. (2002). Researching experiences of cancer: The importance of methodology. *European Journal of Cancer Care, 11*, 232-237.
- Eune, B. (2009 йил September/October). Four steps to successful survivorship. *Stanford Magazine*.

- Fahey, T., Insel, P., & Roth, W. (2005). Relaxation techniques: Progressive muscle relaxation and imagery. In T. Fahey, P. Insel, & W. Roth, *Fit and Well: Core Concepts and Labs in Physical Fitness and Wellness*. New York: McGraw Hill and Companies.
- Faul, L. A., Jim, H. S., Williams, C., Loftus, L., & Jacobsen, P. B. (2010). Relationship of stress management skill to psychological distress and quality of life in adults with cancer. *Psycho-Oncology*, *19*, 102-109.
- Fawzy, F. I. (1999). Psychosocial interventions for patients with cancer: What works and what doesn't. *European Journal of Cancer*, *35* (11), 1559-1564.
- Fawzy, F. I., & Fawzy, N. W. (1998). Group therapy in the cancer setting. *Journal of Psychosomatic Research*, *45* (3), 191-200.
- Fawzy, F. I., Cousins, N., Fawzy, N. W., Kemeny, M. E., Elashoff, R., & Morton, D. (1990). A structured psychiatric intervention for cancer patients. I. Changes over time in methods of coping and affective disturbance. *Archives of General Psychiatry*, *47*, 720-725.
- Fawzy, F. I., Fawzy, N. W., Arndt, L. A., & Pasnau, R. O. (1995). Critical review of psychosocial interventions in cancer care. *Archives of General Psychiatry*, *52*, 100-113.
- Ferlic, M., Goldman, A., & Kennedy, B. J. (1979). Group counseling in adult patients with advanced cancer. *Cancer*, *43*, 760-766.
- Ferrell, B., Taylor, E. J., Grant, M., Fowler, M., & Corbisiero, R. M. (1993). Pain management at home. Struggle, comfort, and mission. *Cancer Nursing*, *16*, 169-178.
- Fobair, P. (1997a). Cancer support groups and group therapies: Part I: Historical and theoretical background and research on effectiveness. *Journal of Psychosocial Oncology*, *15* (1), 63-81.
- Fobair, P. (1997b). Cancer support groups and group therapies: Part II. process, organizational, leadership, and patient issues. *Journal of Psychosocial Oncology*, *15* (3-4), 123-147.
- Frisch, M. B. (1998). Quality of life therapy and assessment in health care. *Clinical Psychology: Science and Practice*, *5* (1), 19-40.
- Frisch, M. B. (2006). *Quality of life therapy: Applying a life satisfaction approach to positive psychology and cognitive therapy*. Hoboken: John Wiley and Sons.



- Frisch, M. B., Clark, M. P., Rouse, S. V., Rudd, M. D., Paweleck, J. K., Greenstone, A., et al. (2005). Predictive and treatment validity of life satisfaction and the quality of life inventory. *Assessment, 12*, 66-78.
- Frisch, M. B., Cornell, J., & Villanueva, M. (1992). Clinical validation of the quality of life inventory: A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment, 4* (1), 92-101.
- Frisch, M. B., Cornell, J., Villanueva, M., & Retzlaff, P. J. (1992). Clinical validation of the quality of life inventory: A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment, 4* (1), 92-101.
- Giese-Davis, J., Koopman, C., Butler, L. D., Classen, C., Cordova, M., Fobair, P., et al. (2002). Change in emotion-regulation strategy for women with metastatic breast cancer following supportive-expressive group therapy. *Journal of Consulting and Clinical Psychology, 70* (4), 916-925.
- Gladis, M. M., Gosch, E. A., Dishuk, N. M., & Crits-Christoph, P. (1999). Quality of life: Expanding the scope of clinical significance. *Journal of Consulting and Clinical Psychology, 67* (3), 320-331.
- Goodwin, P. J. (2005). Support groups in advanced breast cancer: Living better if not longer. *Cancer, 104* (11), 2596-2601.
- Goodwin, P. J., Leszcz, M., Ennis, M., & Koopmans, J. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine, 345* (24), 1719-1727.
- Graves, K. D. (2003). Social cognitive theory and cancer patients' quality of life: A meta-analysis of psychosocial intervention components. *Health Psychology, 22* (2), 210-219.
- Gray, R., Fitch, M., Davis, C., & Phillips, C. (1997). A qualitative study of breast cancer self-help groups. *Psycho-Oncology, 6*, 279-289.
- Haddad, P. (1994). *Affective disorder amongst partners of cancer patients*. Manchester, England: University of Manchester.
- Hannun, J. W., Giese-Davis, J., & Harding, K. (1991). Effects of individual and marital variables on coping with cancer. *Journal of Psychosocial Oncology, 9*, 1-20.
- Harding, R., & Higginson, I. J. (2003). What is the best way to help FCGs in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine, 17*, 63-74.

- Heinrich, R. L., & Schag, S. C. (1985). Stress activity management: Group treatment for cancer patients and spouses. *J Consult Clin Psychol*, *43*, 439-446.
- Helgeson, V. S., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, *15* (2), 135-148.
- Henselmans, I., Helgeson, V. S., Seltman, H., de Vries, J., Sanderman, R., & Ranchor, A. V. (2010). Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. *Health Psychology*, *29* (2), 160-168.
- Hilton, B. A., Crawford, J. A., & Tarko, M. A. (2000). Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. *Western Journal of Nursing Research*, *22* (4), 438-459.
- Holland, J. C., & Lewis, S. (2000). *The Human Side of Cancer*. New York: Harper Collins.
- Hudson, P. (2004). A critical review of supportive interventions for family FCGs of palliative stage cancer patients. *Journal of Psychosocial Oncology*, *22*, 77-93.
- Inner Health Studio. (2009). *East Relaxation Techniques*. Retrieved 2009, 9-October from <http://www.innerhealthstudio.com/>
- Jacobsen, P. B. (2006). Lost in translation: The need for clinically relevant research on psychological interventions for distress in cancer patients. *Annals of Behavioral Medicine*, *32* (2), 119-120.
- Johnson, J. (1982). The effects of a patient education course on persons with a chronic illness. *Cancer Nursing*, 117-123.
- Johnson, P. (2002). The use of humor and its influences on spirituality and coping in breast cancer survivors. *Oncology Nursing Forum*, *29* (4), 691-695.
- Joshua, A. M., Cotroneo, A., & Clarke, S. (2005). Humor and oncology. *Journal of Clinical Oncology*, *23* (3), 645-648.
- Kaiser, N. C., Hartoonian, N., & Owen, J. E. (2010). Toward a cancer-specific model of psychological distress: Population data from the 2003-2005 National Health Interview Surveys. *J Cancer Surviv*, *4*, 291-302.
- Kaye, J., & Gracely, E. (1993). Psychological distress in cancer patients and their spouses. *J Cancer Ed*, *8*, 47-52.

- Kelly, C., Ghazi, F., & Caldwell, K. (2002). Psychological distress of cancer and clinical trial participation: A review of the literature. *Eur J Cancer Care (Engl)*, *11*, 6-15.
- Kitrungrote, L., & Cohen, M. Z. (2006). Quality of life of FCGs of patients with cancer: A literature review. *Oncology Nursing Forum*, *33*, 624-632.
- Kuijjer, R. G., Buunk, B. P., De Jong, G. M., Ybema, J. F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners of feelings of inequity, relationship quality and psychological distress. *Psychooncology*, *13*, 321-334.
- Kurtz, M. E., Given, B., Kurtz, J. C., & Given, C. W. (1994). The interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families. *Cancer*, *74* (7 Suppl), 2071-2078.
- Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2005). A randomized controlled trial of patient/caregiver symptoms control intervention: Effects on depressive symptomatology of caregivers of cancer patients. *Journal of Pain and Symptom Management*, *30*, 111-122.
- Lacovino, V., & Reesor, K. (1997). Literature on interventions to address cancer patients' psychosocial needs. *Journal of Psychosocial Oncology*, *15* (2), 47-71.
- Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, *55*, 234-247.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lepore, S. J., & Coyne, J. C. (2006). Psychological interventions for distress in cancer patients: A review of reviews. *Annals of Behavioral Medicine*, *32* (2), 85-92.
- Little, M. (2004). Chronic illness and the experience of surviving cancer. *Internal Medicine Journal*, *34*, 201-202.
- Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). An empirical examination of the stage theory of grief. *JAMA*, *297* (7), 716-724.
- Manne, S. L., & Andrykowski, M. A. (2006). Are psychological interventions effective and accepted by cancer patients? II. Using empirically supported therapy guidelines to decide. *Annals of Behavioral Medicine*, *32* (2), 98-103.
- Manne, S. L., & Andrykowski, M. A. (2006). Seeing the forest for the trees: A rebuttal. *Annals of Behavioral Medicine*, *32* (2), 111-114.

- Manne, S. L., Winkel, G., Rubin, S., Edelson, M., Rosenblum, N., Bergman, C., et al. (2008). Mediators of a coping and communication-enhancing intervention and a supportive counseling intervention among women diagnosed with gynecological cancers. *Journal of Consulting and Clinical Psychology, 76* (6), 1034-1045.
- Manne, S., Babb, J., Pinover, W., Horwitz, E., & Ebbert, J. (2004). Psychoeducational group intervention for wives of men with prostate cancer. *Psycho-Oncology, 13*, 37-46.
- Manne, S., Ostroff, J., Norton, T., Fox, K., Goldstein, L., & Grana, G. (2006). Cancer-related relationship communication in couples coping with early stage breast cancer. *Psycho-Oncology, 15* (3), 234-247.
- McCorkle, R., & Pasacrete, J. V. (2001). Enhancing FCG outcomes in palliative care. *Cancer Control, 8*, 36-45.
- McLean, B. (1995). Social support, support groups, and breast cancer: A literature review. *Canadian Journal of Community Mental Health, 14* (2), 207-227.
- McLean, B. (1995). Social support, support groups, and breast cancer: A literature review. *Canadian Journal of Community Mental Health, 14* (2), 207-225.
- McMillan, S. C., Small, B. J., & Weitzner, M. (2006). Impact of a coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106*, 214-222.
- Meyer, T. J., & Mark, M. M. (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology, 14* (2), 101-108.
- Millar, K., Purushotham, A. D., McLatchie, E., George, W. D., & Murray, G. D. (2005). A 1-year prospective study of longitudinal variation in distress, and illness perceptions, after treatment for breast cancer. *Journal of Psychosomatic Research, 58*, 335-342.
- Mishel, M. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship, 20*, 225-232.
- Molassiotis, A. (1997). Psychosocial transitions in long-term survivors of bone marrow transplantation. *European Journal of Cancer Care, 6*, 100-107.
- Morgan, M. A. (2009). Considering the patient-partner relationship in cancer care: Coping strategies for couples. *Clinical Journal of Oncology Nursing, 13* (1), 65-72.

- Morgan, P. D., Fogel, J., Rose, L., Barnett, K., Mock, V., & Davis, B. L. (2005). African American couples merging strengths to successfully cope with breast cancer. *Oncology Nursing Forum*, 32 (5), 979-987.
- Mullin, P. A., Lohr, K. N., Bresnahan, B. W., & McNulty, P. (2000). Applying cognitive design principles to format HRQOL instruments. *Quality of Life Research*, 9, 13-27.
- National Comprehensive Cancer Network. (1999). NCCN practice guidelines for the management of psychosocial distress. *Oncology (Huntingt)*, 13 (5A), 113-147.
- Naus, M. J., Ishler, M. D., Parrott, C. E., & Kovacs, S. A. (2009). Cancer Survivor Adaptation Model: Conceptualizing cancer as a chronic illness. *Journal of Clinical Psychology*, 65 (12), 1350-1359.
- Newell, S. A., Sanson-Fisher, R. W., & Savolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute*, 94 (8), 558-584.
- Nijboer, C., Tempelaar, R., & Sanderman, R. (1998). Cancer and caregiving: The impact on the FCG's health. *Psychooncology*, 7, 3-13.
- Northouse, L., Kershaw, T., Mood, D., & Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their FCGs. *Psychooncology*, 14, 478-491.
- Osoba, D., Rodrigues, G., Myles, J., Zee, B., & Pater, J. (1998). Interpreting the significance of changes in health-related quality-of-life scores. *Journal of Clinical Oncology*, 16 (1), 139-144.
- Owen, J. E., Klapow, J. C., Hicken, B., & Tucker, D. C. (2001). Psychosocial interventions for cancer: Review and analysis using a three-tiered outcomes model. *Psycho-Oncology*, 10, 218-230.
- Oxlad, M., Wade, T. D., Hallsworth, L., & Koczwara, B. (2007). 'I'm living with a chronic illness, not...dying with cancer': A qualitative study of Australian women's self-identified concerns and needs following primary treatment for breast cancer. *European Journal of Cancer Care*, 17, 157-166.
- Park, C. L., Edmondson, D., Fenster, J. R., & Blank, T. O. (2008). Positive and negative health behavior changes in cancer survivors: A stress and coping perspective. *Journal of Health Psychology*, 13 (8), 1198-1206.

- Pascareta, J., Barg, F., Nuamah, I., & McCorkle, R. (2000). Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nursing, 23*, 295-303.
- Penson, R. T., Partridge, R. A., Rudd, P., Seiden, M., Nelson, J., Chabner, B., et al. (2005). Laughter: The best medicine? *The Oncologist, 10* (8), 651-660.
- Penson, R. T., Talsania, S. H., Chabner, B. A., & Lynch, T. J. (2004). Help me help you: Support groups in cancer therapy. *The Oncologist, 9*, 217-225.
- Petersen, S., Bull, C., Propst, O., Dettinger, S., & Detwiler, L. (2005). Narrative therapy to prevent illness-related stress disorder. *Journal of Counseling & Development, 83*, 41-47.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer, 39* (11), 1517-1524.
- Poppen, R. (1998). *Behavioral relaxation training and assessment* (2nd ed.). London: SAGE Publications.
- Radziewicz, R. M., Rose, J. H., Bowman, K. F., Berlia, R. A., O'Toole, E. E., & Given, B. (2009). Establishing treatment fidelity in a coping and communication support telephone intervention for aging patients with advanced cancer and their family caregivers. *Cancer Nursing, 32* (3), 193-202.
- Rehse, B., & Pukrop, R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: Meta analysis of 37 published controlled outcome studies. *Patient Education and Counseling, 50*, 179-186.
- Rose, J. H., Radziewicz, R. M., Bowman, K. F., & O'Toole, E. E. (2008). A coping and communication support intervention tailored to older patients diagnosed with late stage cancer. *Clin Interventions Aging, 3*, 83-101.
- Ross, L., Boesen, E. H., Dalton, S. O., & Johansen, C. (2002). Mind and cancer: Does psychosocial intervention improve survival and psychological well-being. *European Journal of Cancer, 38*, 1447-1457.
- Santacroce, S. J., & Lee, Y. L. (2006). Uncertainty, posttraumatic stress and health behaviors in young adult childhood cancer survivors. *Nursing Research, 55*, 259-266.

- Santacroce, S. J., Asmus, K., Kadan-Lottick, N., & Grey, M. (2010). Feasibility and preliminary outcomes from a pilot study of coping skills training for adolescent-young adult survivors of childhood cancer and their parents. *Journal of Pediatric Oncology Nursing, 27* (1), 10-20.
- Schmitz, M. F., & Crystal, S. (2000). Social relations, coping, and psychological distress among persons with HIV/AIDS. *Journal of Applied Social Psychology, 30*, 665-683.
- Seelert, K. R., Hill, R. D., Rigdon, M. A., & Schwenzfeier, E. (1999). Measuring patient distress in primary care. *Family Medicine, 31*, 483-487.
- Sheard, T., & Maguire, P. (1999). The effect of psychological interventions on anxiety and depression in cancer patients: Results of two meta-analyses. *British Journal of Cancer, 80*, 1770-1780.
- Sherman, A. C. (2008). Mechanisms of change in group interventions for cancer patients. *International Journal of Group Psychotherapy, 58* (3), 413-418.
- Sherman, A. C., Mosier, J., Leszcz, M., Burlingame, G. M., Ulman, K. H., Cleary, T., et al. (2004). Group interventions for patients with cancer and HIV disease: Part I: Effects on psychosocial and functional outcomes at different phases of illness. *International Journal of Group Psychotherapy, 54* (1), 29-82.
- Sivesind, D., & Baile, W. F. (2001). The psychologic distress in patients with cancer. *Nurs Clin North Am, 36*, 809-825.
- Smith, J. C. (1999). *ABC relaxation theory: An evidence-based approach*. New York: Springer.
- Smyth, J. M. (1998). Written emotional expression: Effect sizes, outcome types, and moderating variables. *Journal of Consulting and Clinical Psychology, 66*, 174-184.
- Sorenson, S. S., Pinqart, M., Habil, D., & Duberstein, P. (2002). How effective are interventions with FCGs? An updated meta-analysis. *Gerontologist, 42*, 356-372.
- Spiegel, D., Bloom, J. R., & Yalom, I. (1981). Group support for patients with metastatic cancer. *Archives of General Psychiatry, 38*, 527-533.
- Spiegel, D., Bloom, J. R., Kraemer, H. C., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet, 2*, 888-891.

- Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., et al. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 68*, 875-882.
- Tedeschi, R. G., & Calhoun, L. (2004). Posttraumatic growth: A new perspective on psychotraumatology. *Psychiatric Times, 58*.
- Thomas, B. C., Thomas, I., Nandamohan, M., Nair, K., & Pandey, M. (2009). Screening for distress can predict loss of follow-up and treatment in cancer patients: Results of development and validation of the Distress Inventory for Cancer Version 2. *Psycho-Oncology, 18*, 524-533.
- Thornton, A. A., Perez, M. A., & Meyerowitz, B. E. (2004). Patient and partner quality of life and psychosocial adjustment following radical prostatectomy. *Journal of Clinical Psychology in Medical Settings, 11* (1), 15-30.
- Trijsburgvan, R. W., van Knippenberg, F. C., & Rijpma, S. E. (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine, 54*, 489-517.
- Tritter, J. Q., & Calnan, M. (2002). Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care, 11*, 161-165.
- Turner, J., Zapart, S., Pedersen, K., Rankin, N., Luxford, K., & Fletcher, J. (2005). Clinical practice guidelines for the psychosocial care of adults with cancer. *Psycho-Oncology, 14*, 159-173.
- Uitterhoeve, R. J., Vernooy, M., Litjens, M., Potting, K., Bensing, J., De Mulder, P., et al. (2004). Psychosocial interventions for patients with advanced cancer: A systematic review of the literature. *British Journal of Cancer, 91*, 1050-1062.
- Vess, J., Moreland, J., & Schwebel, A. (1985). An empirical assessment of the effects of cancer on family role functioning. *Journal of Psychosocial Oncology, 3*, 1-16.
- Victorson, D. E., Burnett, K. F., & Gela, N. R. (2008). The Injury Resilience Index: Development and Psychometric Characteristics. *Poster presented at the annual convention of the Society of Behavioral Medicine*. San Diego.
- Victorson, D. E., Enders, C. K., Burnett, K. F., & Ouellette, E. A. (2008). The Injury Distress Index: Development and validation. *Archives of Physical Medicine Rehabilitation, 89*, 1893-1902.



- Victorson, D., Enders, C., Burnett, K., Farmer, L., Barocas, J., & Lauzon, J. (2004). Assessing peritraumatic responses following traumatic physical injury: Development of the injury evaluation index (IEI). *Poster presented at the annual meeting of the International Society for Traumatic Stress Studies*. New Orleans.
- Victorson, D., Farmer, L., Burnett, K., Ouelette, A., & Barocas, J. (2005). Maladaptive coping strategies and injury-related distress following traumatic physical injury. *Rehabilitation Psychology, 50* (4), 408-415.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: W. W. Norton & Company.
- Wood, P. E., Milligan, M., Christ, D., & Liff, D. (1978). Group counseling for cancer patients in a community hospital. *Psychosomatics, 19* (9), 555-561.
- World Health Organization. (1997). *WHOQOL: Measuring quality of life*. Geneva, Switzerland: World Health Organization.
- Zakowski, S. G., Harris, C., Krueger, N., Laubmeier, K. K., Garrett, S., Flanigan, R., et al. (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *British Journal of Health Psychology, 8*, 271-286.

## Appendix A

### Outline of Coping Skills Groups for Cancer Survivors/Co-Survivors

#### ***Session 1: Introduction (BASELINE ASSESSMENT)***

- Informed consent
  - Go through the consent form with the group and explain what we are asking them to do and what they are participating in.
  - Ask if they have any questions and then instruct them to complete the assessment battery.
- Questionnaire battery
  - All questionnaire batteries will have a pre-written subject ID number in the top right hand corner.
  - The questionnaire will be on the same clipboard as the consent form. Collect all clipboards (both consent and assessment battery) together. Make sure to note the name (on the consent form) and the pre-written subject ID number at the end of the group. Once you record this information on the Subject ID log you can separate the two forms.
- Introductions
  - Give a description of the coping Skills groups and what the participants can expect in the next 5 weeks.
    - These groups are based on a positive model of coping that has been developed by researchers at the University of Miami. The

group is meant to provide you with skills to heal in a positive and supportive environment.

- Research has shown that about 35% of cancer survivors and caregivers experience significant distress (Clark, Bostwick, & Rummans, 2003).
  - Distress is defined as “an unpleasant experience of an emotional, physical, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment” (Clark, Bostwick, & Rummans, 2003).
  - Distress exists along a continuum and is a very individual experience.
- Research has also shown that recognizing distress and participating in a group intervention can significantly reduce the feelings and lead to improvements in quality of life.
  - Some studies have shown a decrease in the mortality rates of women with breast cancer who participated in groups aimed at reducing distress (Spiegel, Bloom, & Yalom, 1981). It is not clear why this is and some researchers hypothesize that there may be changes in immune functioning. However, it is important to note that we are not promising changes like this.

- Another study conducted by researchers at Harvard Medical School (Project OMEGA) used a variety of techniques (i.e. goal setting, role playing, relaxation training, etc.) to help participants focus on problem-solving commonly encountered scenarios (Clark, Bostwick, & Rummans, 2003).
- The Coping Skills groups that you are participating in take these techniques a step further and incorporate a set of “indicators for healing” in survivors (or co-survivors) of traumatic illness. These indicators have routinely appeared in multiple studies of traumatic injury (i.e. car accidents, war, etc.), disaster (i.e. 9/11, hurricanes, etc.) and now we are looking at their impact on traumatic illness such as cancer (Burnett & Crosbie-Burnett, 2012).
- Describe APPLES model to all participants
  - Acceptance and Appropriate Grieving for Loss and Reality of Loss
  - Positive Reframing
  - Positive Action
  - Laughter
  - Emotional Support Seeking
  - Stress Tolerance

- Each session of these groups is going to focus on one or two of these indicators. We will use the group time to talk about the meaning of each indicator and how you can successfully incorporate the coping skills into your life.
  - Do an initial check-in with all participants in the group. Ask each person to introduce themselves and say a little about their experience and what prompted them to join the group. Be conscientious about the time and make sure everyone gets a chance to speak.
    - *Tell us a little bit about yourself. What brought you to this group?*
    - *What are you hoping to get out of participating in this group?*
      - For caregivers: make sure to encourage them to talk about themselves and not just the person they are caring for.
- Next session: We will be talking about Acceptance and Appropriate Grieving for Loss and Reality of Loss. We will be acknowledging the changes that cancer has brought to your life, and talking about how to cope with those changes and move forward in life.

***Session 2: Acceptance and Appropriate Grieving for Loss and Reality of Loss***

- Check-in
  - *How is everyone doing today?*
  - *Any concerns from last week after you left?*

- A diagnosis of cancer leads to some losses or potential losses in your life. It is important to recognize these changes while grieving the loss and accepting the reality of change.
  - Loss of loved ones
  - Loss of valued resources
  - Loss of function/role
  - Recognition of the loss (it will be different than life before cancer)
- The *Tyranny of Positive Thinking* is this idea that you should remain positive and optimistic at all times (Holland & Lewis, 2000). Some people have the belief that if they let their guard down a little and experience the sadness and anger that comes with facing a (*loved one with a*) serious illness, that they are somehow putting themselves or their loved ones at risk. There is an idea that one should keep a “**brave face**” on for the sake of others, and themselves.
  - *What do you think about this? Do you find yourself doing this?*
  - FOR CANCER SURVIVORS: Research has shown that an optimistic attitude may help in tolerating treatments, engaging in healthy behaviors, and even getting yourself to doctor’s appointments. However, the research does not show that ignoring or suppressing negative feelings will keep the cancer at bay (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999).
  - In fact, most research shows the opposite. Those who deny the reality of a situation are more likely to experience depression and anxiety symptoms.

FOR CAREGIVERS: As many as 35% of caregivers report serious symptoms of depression (Pitceathly & Maguire, 2003).

- If you are all willing, I would like to do a brief writing exercise on the topic of accepting and grieving for losses. Hand out clipboards with blank paper on them. Ask participants to think about the following questions and take about 5-10 minutes to write down whatever comes to mind.
  - *How have you experienced loss?*
  - *How have you changed your life in relation to this loss?*
- Group discussion on the writing exercise. Ask a group member to share their thoughts and elicit discussion amongst the group members. The aim is to normalize and accept negative feelings as a way to move on.
  - *What have these changes meant in your life?*
  - *As you move forward in your life, how do you incorporate the changes?*
    - *How have you coped with stress in the past? Do you find yourself doing the same things now or are you doing something different?*
  - *What emotions are attached to these losses? How do you make sense of these feelings?*
- Remember to focus on the positives while acknowledging that there has been a loss (or losses) in life. One must readjust their expectations when faced with information or circumstances that contradict the plans they have made for themselves.

- Next session: We will be talking about Positive Reframing, or simply how to look at life from a different perspective. We will focus on some of the issues that came up today and talk about new ways to tell your story from a positive perspective.

***Session 3: Positive Reframing (3 WEEK ASSESSMENT AFTER SESSION)***

- Check-in
  - *How is everyone doing today? What has been going on for you this week?*
  - *Any concerns from last week after you left?*
- Today we are talking about positive reframing which is quite simply thinking about a new way to tell your story. Last week we acknowledged the losses that one has in relation to cancer. Paying attention to the losses is an important step in allowing you to express your emotions, even if they are negative. However, in an effort to move forward in life, reinterpreting these losses in a way that brings positive thoughts into your life is a useful coping skill.
  - Problems are seen as challenges (*what are different ways to see problems in your life?*)
  - Opportunities for growth (*what positive things have come into your life?*)
  - *How can you tell your story from a new perspective?*
    - When people focus on problems or negative aspects of an experience, these become the dominant themes in their personal narratives (White & Epston, 1990).
    - Meaning making comes from looking at the situation in a new and unique way.
      - *How do you currently see your situation?*



- *What does having this belief do for you? (i.e. secondary gain)*
- *Is there another way you could look at things?*
- *What information are you leaving out of your current perspective?*
  - *Were there ever times when you didn't feel that way?*
  - *Are there other situations in your life where you felt \_\_\_\_\_ and you were able to work through it?*
  - *What aspects of your life are you in control of right now?*
    - *What changes can you make?*
- *If given the chance, what would you do differently with your life?*
  - You are looking to elicit conflicting information to point out that they may not be describing a complete picture (i.e., saying that their life has no hope but also mentioning that their relationship with their spouse is better than it has ever been).
  - Use the other members of the group to help tease out the neglected parts or “unique outcomes” in someone’s personal narrative (i.e., new relationships, repairing old relationships, taking up new activities, reconnecting with old passions, etc.).
    - *“Mr. X, what is Mrs. Y’s story missing?”*

- A lot of cancer survivors struggle with anxiety expressed by loved ones and telling their own story becomes secondary to alleviating the fears of others.
- Next session: We will be talking about Positive Action. We will be talking about how to initiate change in your lives related to the reframed or “positive” version of your story that you spoke about in this session. Encourage the participants to use the time in the next week to think about how they could look at experiences from a new perspective, paying attention to the information that immediately gets left out when they focus on the dominant themes.

***Session 4: Positive Action***

- Check-in
  - *How is everyone doing today? What has been going on for you this week?*
  - *Any concerns from last week after you left?*
- Today we are talking about how to take Positive Action in your life. Up until this point we have spent our time talking about acknowledging the losses and changes in your life. We have also addressed new ways to think about these changes, reframing negatives into positives. Now it is time to focus on initiating these positive changes.
  - Positive action on solvable problems
  - Positive action on rebuilding
  - Positive action on physical and/or occupational recovery
  - Mindfulness (being deliberate about your actions)

- For example, David Spiegel (2009), a prominent physician at Stanford University has a prescription for survivorship he calls RSVP (Eune, 2009). This is pertinent to both survivors and caregivers, as the stress of caregiving can lead to a host of physical and psychological problems in seemingly healthy people.
  - **Recovery**: eat well, get at least 8 hours of sleep, and exercise
  - **Stress Management**: stress is inevitable and good management is necessary. Support groups and peers with similar experiences can be really helpful. “Good survivorship does not require a positive attitude no matter what, but rather realistic optimism—hope for the best but prepare for the worst” (Eune, 2009).
  - **Vigilance**: create a surveillance plan and do not avoid doctor’s appointments (this is pertinent to caregivers as well since they also live with the fear of recurrence)
  - **Prevention**: not necessarily preventing cancer, but other health-related illnesses. According to Spiegel, about 50% of cancer patients survive cancer only to die from something else (i.e. heart disease, diabetes, osteoporosis, etc.). Thus, take an active role in taking care of yourself (Eune, 2009).

- One of the most reported feelings in relation to cancer is the loss of control (i.e. loss of time, loss of security, loss of choices). This can be very distressing to people. In an effort to take charge of your life and initiate positive actions that allow you to feel like you have some control, we are going to do a brief exercise (Appendix C).
  - Exercise: thinking about positive actions in relation to taking charge of situations in your life.
  - Give each participant a clipboard with the Challenging Maladaptive Beliefs form on it. You will explain to them that you would like them to think back in the PAST WEEK to a situation that they found to be distressing. You can share with them the example and ask them to take some time (about 10 minutes) to write their own situation.
    - In the situation row they are to write a brief description of the distressing situation.
    - In the feelings row they are to write down the feelings they had in relation to the situation.
    - In the thoughts and beliefs row they are to write down what they thought or believed was going on in this situation.
    - In the dispute row you want them to challenge their maladaptive thoughts and beliefs and focus on a new way to think about that situation.

- In the positive actions row you want them to write down what they could do to change this situation, take control, and lower the level of distress.
- After the participants are done, ask someone to share what they have written.
  - Use the other group members to help brainstorm other disputing statements and/or positive actions.
    - *Are there other situations in your life where you felt \_\_\_\_\_ and you were able to work through it? What did you do? Could you do something similar to that in this situation?*
    - *Mr. X, what is another way to look at Mrs. Y's situation?*
    - *What other options does she have in this situation?*
    - *How would you handle this situation if it was you faced with this problem?*
- Next session: We will be talking about Laughter and Emotional Support Seeking.  
If you would like to bring in a joke that makes you laugh please feel free to do so.

### ***Session 5: Laughter and Emotional Support Seeking***

- Check-in
  - *How is everyone doing today? What has been going on for you this week?*
  - *Any concerns from last week after you left?*

- There are many definitions to humor, such as a stimulus like a movie or comedy show, a mental process such as something you think about, or a response of laughter or smiling (Joshua, Cotroneo, & Clarke, 2005).
  - *What is humor to you?*
  - Invite participants to share some jokes that they have found humorous.
    - *Timothy is in college and he calls home to his younger brother, Jon, and says 'Hey Jon, it is your big brother Timothy. How are you doing?'*
    - *Jon replies 'Oh Timothy [pause], Timothy, I'm sorry but your cat has died.' There is silence on the phone and then a little bit of sobbing.*
    - *Timothy then says 'Jon, don't give me bad news like that. You knew that cat was important to me. You should have said, 'The cat is on the roof and we have been trying desperately to get the cat down but it's scared so we called the fire department.' You leave the conversation like that knowing that I will call back in a few hours to check in. When I call back you should tell me that the cat fell off the roof and it's badly hurt and being rushed to the vet's office and that everyone is really concerned. Then when I call back in a few hours, you then tell me that the cat has died. That way it all comes in steps and it is not such a shock to me.'*
    - *Jon then says, 'Timothy, you are right. I don't know what I was thinking.'*

- *And Timothy replies 'Its okay baby brother, you have a lot to learn. So what else is going on at home?'*
  - *Jon then says 'Mom is on the roof'* (Penson, et al., 2005).
- Cancer survivors have identified humor as helpful in decreasing their anxiety and discomfort related to their illness (Christie & Moore, 2005).
  - Norman Cousins, the former editor of the Saturday Review, reported in his famous book, *Anatomy of an Illness*, that he followed a healthcare regime that involved daily doses of Vitamin C and watching Marx Brothers movies. He reported that ten minutes of real belly laughter gave him two hours of restful and pain-free sleep each night. There is no scientific evidence to support or dispute this claim.
  - Laughter can reduce stress as well as stimulate the circulatory system and the immune system (American Cancer Society, 2010).
- Healthy Humor vs. Unhealthy Humor
  - The key to finding the humor surrounding an illness is TIME.
  - Humor can help us find perspective about a situation when used properly. However, humor is also one of the strongest defense mechanisms. It allows people to face problems while avoiding the negative emotions associated with the situation (Penson, et al., 2005).
    - As discussed in the second session, it is important to allow yourself to feel your emotions, both positive and negative.
  - “People often use humor in an attempt to make themselves more socially acceptable, to identify with other patients, and to distance themselves from

their troubles. ‘Applied’ humor is used by some patients in social settings to challenge assumptions others hold about the disease, and in health settings it is often used to manage feelings, hide embarrassment, reduce tension, share a sense of solidarity with others, or encourage others to examine themselves” (Penson, et al., 2005).

- *When do you use humor in your life?*
- *What does humor give you?*
  - Relaxation
  - Connection to others
  - A chance to disengage from the seriousness of a situation
  - Perspective
- One of the important benefits of humor is the ability to feel connected to others. Humor helps to draw you closer to others that are sharing a similar situation to you. Oftentimes, only those who share the experience are able to find the same humor as you.
  - Emotional support seeking is an important part of the healing process. Being able to connect to others is an indicator of healing and wellness.
    - *How do you recognize when you need emotional support?*
    - *What do you think it says about you if you accept help from others?*
  - Research has shown that survivorship issues are taking a front seat in the fight against cancer (Eune, 2009). It is becoming widely acknowledged that living with cancer requires as much if not more support than being



diagnosed. Support groups are a great way to establish bonds with other cancer survivors/caregivers that can provide a level of comfort and knowledge about moving forward in your life.

- *How do you find emotional support? Who do you talk to?*
- *What are some of the challenges to seeking emotional support?*
  - *How might you work to overcome some of these challenges?*
- Next session: Next week is the final session of the Coping Skills group. We will be talking about Stress Tolerance. We will talk about what stressors are in your life, how to cope with them, and we will provide you with some relaxation and breathing techniques to help you calm yourself when you are feeling stressed.

***Session 6: Stress Tolerance (6 WEEK ASSESSMENT AFTER SESSION)***

- Check-in
  - *How is everyone doing today? What has been going on for you this week?*
  - *Any concerns from last week after you left?*
- Stress is simply defined as anything that causes you to adapt to a situation. Some stresses can be seen as positives and other stresses can be seen as negatives. This negative stress, or distress, is what we aim to reduce or eliminate in our life.
  - *What do you find distressing in your life right now?*
  - *How do you usually handle life's stresses?*
- There is significant research that shows that stress can have a negative impact on your physical health. Stress is associated with hypertension, heart attacks, anxiety

disorders, depression, and weakened immune systems to name a few (Lepore & Coyne, 2006; Schmitz & Crystal, 2000).

- When stressed, your body responds in a programmed fashion of alertness.
- Glands in your brain and on your kidneys release many hormones such as cortisol and epinephrine to gear your body up for whatever situation has alerted you.
- Once your body initiates the stress response, your body must adapt to the extra hormones in the bloodstream, and eventually your body will return to a level of homeostasis, or balance.
- However, chronic stress can cause your body to be on a chronic level of alert, flooding the bloodstream with cortisol and epinephrine. After awhile your body can no longer handle this prolonged stage of alert and your body becomes exhausted.
- It is during this stage of exhaustion that we are most susceptible to getting sick as our immune systems are weakened.
  - Chronic stress can be caused by many different things and research has shown that the specific situation is not as important as your interpretation of the situation (Lepore & Coyne, 2006). Thus, what is stressful to one person may not be stressful to another person. It is important for you to recognize what causes you stress as you are working to make positive changes in your life.
- There are many techniques one can use to relax and help to alleviate some of the distress they are feeling.

- Today we are going to teach you two techniques that you can practice on your own and use when you are feeling stressed and overwhelmed (Caldwell, 2009; Fahey, Insel, & Roth, 2005; Smith, 1999).
  - Diaphragmatic (or deep) breathing
  - Progressive Muscle Relaxation
- DIAPHRAGMATIC BREATHING (Caldwell, 2009)
  - (turn down the lights in the room)
  - *This deep breathing exercise will help you achieve a state of calmness and relaxation. As we begin, take one hand and place it on your stomach right over your belly button. Take your other hand and place it on your chest, just above your breastbone. Now, for a moment take a few deep breaths as you normally would. As you're doing this, notice which hand is moving more than the other. Once you have learned the proper technique of deep breathing you will be able to feel your abdomen and then your lungs fill with air as one hand rises, and then the other.*
  - *Now, in order to begin settle comfortably into your chair. Close your eyes, and pay attention as you take a few normal breaths. (PAUSE).*
  - *When we start the deep breathing exercise, imagine as you're breathing in that the air is traveling in through your nose, down into your stomach filling your abdomen, causing that hand on your stomach to rise. Then, continue breathing in filling your lungs with air, causing the hand on your chest to rise. We'll then hold that full breath for a moment, and then the exhalation will be very slow at the same pace we did our inhalation.*

- *Let's begin. Breathe in slowly through your nose. Keep pulling air in down into your stomach... feeling your stomach rise... keep bringing that air in as your lungs fill with air. When you have taken in all the air that you can, hold that breath... hold it... and now very slowly exhale that breath through your nose allowing your lungs to collapse as they empty, and then your stomach to sink as you use your stomach muscles to squeeze all of that air out of your stomach. Good.*
- *Let's try that one more time. This time, as you're taking the breath in, imagine all of your muscles filling with air and expanding. And then, as we exhale that breath imagine all of your muscles slowly relaxing, leaving you feeling very relaxed and heavy in your chair.*
- *Let's begin. Breathe in slowly through your nose... imagine that air going down into your stomach... filling your stomach with air. Once your stomach fills, keep breathing in... filling your lungs... keep breathing in until you can't take in any more air. Hold that breath... and now slowly exhale that breath, allowing your lungs to empty... and then allowing your abdomen to sink inward.*
- *Now, take a moment to notice how different your body is already feeling. Notice how much warmer your muscles are feeling, how much more relaxed and heavy you feel against the surfaces of your chair.*
- *For this next breath, I want you to continue with the abdomen and then the lungs. However, this time we are going to learn to pace our breath. So, as we breathe inward, we are going to breathe inward to a count of 10. Then*

*we'll hold our breath for a count of 2. And then we'll slowly exhale that breath to a count of 10. Don't forget to use your hands as a gauge of how you're filling your stomach and your lungs with air.*

- *So take a few normal breaths. And, let's begin.*
- *Breathe in slowly through your nose... 2... 3... 4... 5... 6... 7... 8... 9... 10. Hold that breath... and now slowly exhale that breath through your nose... 3... 4... 5... 6... 7... 8... 9... 10. And, one more time. Breathe in slowly through your nose... 2... 3... 4... 5... 6... 7... 8... 9... 10. Hold that breath... and now slowly exhale that breath through your nose... 3... 4... 5... 6... 7... 8... 9... and 10.*
- *This is a simple technique that you can use any time that you feel yourself becoming anxious or stressed.*
- PROGRESSIVE MUSCLE RELAXATION (Inner Health Studio, 2009)
  - *Progressive muscle relaxation exercises are relaxation techniques that involve progressively tensing and then relaxing muscles or muscle groups. By tightening a muscle and then releasing, you can feel the difference between being tense and relaxed. Actively engaging in progressive muscle relaxation exercises effectively loosens and relaxes the muscles.*
  - *Make sure not to do any movements that cause pain. If any of these exercises causes discomfort, ease up or stop to ensure that you do not cause muscle cramping or injury.*

- *Begin by finding a comfortable position. You can change positions any time during the progressive muscle relaxation exercises to make yourself more comfortable as needed.*
- *The first progressive muscle relaxation exercise is breathing. Breathe in forcefully and deeply, and hold this breath. Hold it...hold it... and now release. Let all the air go out slowly, and release all the tension.*
- *Take another deep breath in. Hold it.... and then exhale slowly, allowing the tension to leave your body with the air.*
- *Now breathe even more slowly and gently... breathe in....hold....out..... breathe in...hold...out...*
- *Continue to breathe slowly and gently. Allow your breathing to relax you.*
- *The next progressive muscle relaxation exercise focuses on relaxing the muscles of your body.*
- *Start with the large muscles of your legs. Tighten all of the muscles of your legs. Tense the muscles further. Hold onto this tension. Feel how tight and tensed the muscles in your legs are right now. Squeeze the muscles harder, tighter... Continue to hold this tension. Feel the muscles wanting to give up this tension. Hold it for a few moments more.... and now relax. Let all the tension go. Feel the muscles in your legs going limp, loose, and relaxed. Notice how relaxed the muscles feel now. Feel the difference between tension and relaxation. Enjoy the pleasant feeling of relaxation in your legs.*

- *Now focus on the muscles in your arms. Tighten your shoulders, upper arms, lower arms, and hands. Squeeze your hands into tight fists. Tense the muscles in your arms and hands as tightly as you can. Squeeze harder.... harder..... hold the tension in your arms, shoulders, and hands. Feel the tension in these muscles. Hold it for a few moments more.... and now release. Let the muscles of your shoulders, arms, and hands relax and go limp. Feel the relaxation as your shoulders lower into a comfortable position and your hands relax at your sides. Allow the muscles in your arms to relax completely.*
- *Focus again on your breathing. Slow, even, regular breaths. Breathe in relaxation.... and breathe out tension..... in relaxation....and out tension.... Continue to breathe slowly and rhythmically.*
- *Now focus on the muscles of your buttocks. Tighten these muscles as much as you can. Hold this tension..... and then release. Relax your muscles.*
- *Tighten the muscles of your back now. Feel your back tightening, pulling your shoulders back and tensing the muscles along your spine. Arch your back slightly as you tighten these muscles. Hold.... and relax. Let all the tension go. Feel your back comfortably relaxing into a good and healthy posture.*
- *Turn your attention now to the muscles of your chest and stomach. Tighten and tense these muscles. Tighten them further...hold this tension.... and release. Relax the muscles of your trunk.*

- *Finally, tighten the muscles of your face. Scrunch your eyes shut tightly, wrinkle your nose, and tighten your cheeks and chin. Hold this tension in your face.... and relax. Release all the tension. Feel how relaxed your face is.*
- *Notice all of the muscles in your body.... notice how relaxed your muscles feel. Allow any last bits of tension to drain away. Enjoy the relaxation you are experiencing. Notice your calm breathing.... your relaxed muscles.... Enjoy the relaxation for a few moments....*
- *When you are ready to return to your usual level of alertness and awareness, slowly begin to re-awaken your body. Wiggle your toes and fingers. Swing your arms gently. Shrug your shoulders. Stretch if you like.*
- *You may now end this progressive muscle relaxation exercise feeling calm and refreshed.*
- Check in with the group to see how they feel. Allow the group members to ask questions about the exercise.



## Appendix B

### COPING SKILLS GROUPS FOR CANCER SURVIVORS AND CAREGIVERS Groups begin Wednesday, April 7<sup>th</sup> at 6:30pm!

Coping with a serious illness can be a highly stressful experience, not only for the survivor, but also for their friends, family members, and caretakers. Research has shown that membership in a coping skills group may be beneficial for those who are dealing with the stresses of a chronic illness.

Beginning on April 7th, Cancer Support Community Greater Miami (*formerly The Wellness Community*) will begin offering separate coping skills groups for cancer survivors and co-survivors (family members, friends, and/or caretakers). These groups will meet independently once a week for 90 minutes each session (6:30pm-8:00pm). The groups will last for 6 weeks.

Group sessions will focus on the identification of signs of healing in relation to cancer. Indicators of healing include:

- Acceptance and appropriate grieving for the loss
- Positive reframing
- Positive action
- Laughter
- Emotional support seeking
- Stress tolerance

Group members will be provided educational information about coping with cancer, as a survivor and as a co-survivor. In addition, groups will utilize discussion, peer support, relaxation techniques, and problem solving skills to work towards healing in a supportive and healthy environment.

These groups are part of a research project in conjunction with the University of Miami. If you would like to participate we ask that you fill out a few brief questionnaires throughout the course of the sessions.

If you have any questions or are interested in participating in these groups, please contact Erin Schweers Cornelius at 617-501-6135 or [e.schweers@umiami.edu](mailto:e.schweers@umiami.edu). Space is limited so please sign up today!

## Appendix C

<b>Challenging Maladaptive Beliefs (example)</b>	
<b>Situation</b>	Having to keep asking Anne (my friend) to do things for me that I used to be able to do myself.
<b>Feelings</b>	Guilt and despair
<b>Thoughts and Beliefs</b>	She must be burdened by my frequent requests. She's probably sick of me constantly asking for favors. I should be totally self-sufficient. I should never ask people to do things for me. By asking for help, I am being a burden to my friend.
<b>Dispute</b>	I prefer to be self-sufficient, and I usually am, but I don't have to always be completely self-sufficient. It's OK to ask for help when I need it. I have no reason to believe that Anne feels burdened by my request for help. She appears always happy to help. People often enjoy feeling that they can help others. I would not mind if someone asked me for help; I have no reason to presume that Anne doesn't feel the same way.
<b>Positive Actions</b>	I will tell Anne that I feel bad about asking her for help, and ask her how she feels. I'll reassure her that if it's not convenient for her to help out, I completely understand.