

PSYCHOSOCIAL WELL-BEING AMONG OLDER ADULTS WITH CANCER

By

Kristen R. Admiraal

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Social Work—Doctor of Philosophy

2015

ABSTRACT

PSYCHOSOCIAL WELL-BEING AMONG OLDER ADULTS WITH CANCER

By

Kristen R. Admiraal

Older adults are disproportionately affected by cancer as the majority of new cases and deaths due to cancer are experienced by those older than 65. As the older adult population continues to grow in the United States, it is important to consider the effects of cancer diagnosis and treatment on psychosocial well-being among those in this population, particularly considering which sub-groups may be at greatest risk for deleterious psychosocial outcomes. A sample of 384 adults over the age of 65 who had been diagnosed with cancer in the past five years, with a response rate of 77%, participated in this cross sectional study of psychosocial well-being. The Quality of Life-Cancer Survivors (QOL-CS) scale was used along with socio-demographic variables, such as age, education, and income, and cancer-specific related variables including cancer type, treatment type, and stage at diagnosis. Data were analyzed using multiple regression analysis determining which subgroups were associated with increased psychosocial well-being. Results showed that males reported better psychosocial well-being than females. There was a positive association between education and psychosocial well-being. Having had lung cancer, being diagnosed at a later stage (II, III, or IV), and having been treated with chemotherapy were associated with lower levels of psychosocial well-being. The greatest contributor to psychosocial well-being was physical, or functional, well-being. These results suggest that psychosocial oncologic interventions should be geared towards specific population groups including women and those with lower educational attainment. Further, oncology social

workers need to be attuned to physical well-being and help older adults identify resources to address and cope with the myriad physical issues that accompany a cancer diagnosis.

Keywords: Psychosocial well-being, quality of life, older adults, cancer

Copyright by
KRISTEN R. ADMIRAAL
2015

ACKNOWLEDGMENTS

I would like to express my sincere gratitude to all those who have inspired me, guided me, taught me, and supported me through this journey. I could not have made my way through the doctoral process without my trustworthy and knowledgeable chair, Anne Hughes. Anne, I thank you for being such an amazing mentor, teacher, and friend. You pushed me to apply for fellowships, provided me with research opportunities, and helped me further develop my scholarly writing skills. You provided me with timely advice, much encouragement, and countless jelly beans. I am so thankful to have had you as my advisor in this process.

I also would like to thank my committee members. Thank you Dr. Rena Harold for helping me frame my work sensitively and for your keen editorial eye. Dr. Amanda Woodward, thank you for providing your expertise in quantitative data analysis and for your willingness to review my materials even while you were on sabbatical. Dr. Barbara Given, your expertise in this area of research and your familiarity with the existing literature was such an asset to this study. Thanks also go to my many other mentors along the way, including Barbara Metzger, Frank Boscoe, Mari Brick, and Cheryl Brandsen, who all helped to build my passion for gerontology, cancer care, and research.

This research would not have been possible without generous financial support from the American Cancer Society Doctoral Training Grant in Oncology Social Work and the Michigan Cancer Research Fund. Additionally, thank you to the national office of the American Cancer Society for bringing together experts in oncology social work who helped provide input on my

study and provided me with their research expertise. Thank you to my friends at the Michigan Cancer Research Fund who have been so encouraging and supportive of my research.

My colleagues and students and friends have also been tremendous support systems throughout this process. Thank you to Rachel Venema and Jon Hill for all of your advice on data analysis and methodology. Thank you to Joe Kuilema for great discussions on our car rides to and from Michigan State as well as for being not only a great colleague, but also a great fellow student. Thank you Lissa Schwander for all of your encouragement as I plugged along. Thank you to all my students for asking me about my research and for validating the difficulties of balancing life and school. Thank you to my friends for giving me opportunities to take breaks but also for sparking my competitive nature by constantly asking, “are you almost done yet?”

Much appreciation goes to my family. My parents, Peter and Lois Admiraal, helped me to recognize the value of education. They instilled in me a passion for learning at a young age by reading to me daily, bringing me to fun educational events such as veterinary days at Cornell University, and by challenging me to do complex multiplication problems for fun on Saturday evenings. Their unconditional love and support have propelled me to pursue my educational goals. Thanks also to my sister, Suzanne, who has always served as a great role model, friend, and avid supporter in all that I do and accomplish.

I could not have completed this process without my very best friend and husband, Chris Alford. Throughout the past five years, he always listened to me talk about my research (although sometimes I noticed his eyes glazed over), told me not to quit upon my many threats to do just that, and gave me many hugs when I felt tired or sad or frustrated. He and our son Will also made many sacrifices, particularly on Saturday mornings when I needed quiet time to focus and write. Thanks also to Will who brought smiles to my face and reminded me that there is

much more to life beyond academics. And thank you to our soon-to-be born son, for providing me with a firm deadline and new motivation to finish.

TABLE OF CONTENTS

LIST OF TABLES	xi
LIST OF FIGURES	xii
CHAPTER 1: Background and Theoretical Framework	1
Statement of the Problem.....	1
Previous Research.....	3
Theoretical Framework	5
Models of stress, appraisal, and coping.	5
Stress.	6
Appraisal.	6
Coping.....	7
The life span perspective.	7
Application of theory.	8
CHAPTER 2: Literature Review	11
Psychological Well-being.....	12
Depression, anxiety, and distress.	13
Other indicators of psychological well-being.	17
Summary of psychological well-being.	19
Social Well-being.....	20
Burden on family.	21
Social support.....	23
Financial needs.....	25
Summary of social well-being.	26
Cancer-Specific Variables	27
Stage at diagnosis.....	28
Cancer site.....	29
Time since diagnosis.....	30
Treatment type.	33
Summary of cancer specific variables.	34
Additional Determinants of Well-Being.....	34
Physical well-being.....	35
Age.....	36
Race and ethnicity.....	38
Comorbidities.....	39
Socioeconomic status.....	40
Gender.....	41
Summary of Literature.....	42
Purpose of the Study	46
Research Questions and Hypotheses	48

CHAPTER 3: Methods.....	51
Research Design.....	51
Independent variables.	51
Dependent variables.....	52
Participant Characteristics	52
Sampling Procedure	53
Survey Procedure	53
Sample Size, Power, and Precision.....	54
Measures and Covariates	55
Psychosocial well-being.....	55
Cancer-specific variables.....	56
Socio-demographic variables.....	56
Data Analysis	57
Data cleaning.	57
Bivariate analysis.....	58
Multivariate analysis.....	59
CHAPTER 4: Results	61
Socio-Demographic and Cancer-Related Characteristics.....	61
Bivariate Analysis.....	64
Socio-demographic variables.....	67
Cancer-specific variables.....	68
Physical well-being	69
Multivariate Analysis.....	75
QOL-CS scores.....	75
Model 1: QOL-CS and socio-demographic variables.....	75
Model 2: QOL-CS and cancer-specific predictor variables.....	76
PSWB scores.....	80
Model 1: PSWB and socio-demographic variables.....	80
Model 2: PSWB and cancer-specific predictor variables.....	81
Model 3: PSWB and physical well-being.....	82
CHAPTER 5: Discussion.....	86
Summary of Major Findings	86
Socio-demographic variables.....	86
Cancer-specific variables.....	91
Physical well-being	94
Strengths and Limitations	95
Strengths of this study.....	95
Limitations.....	96
Implications and Future Research Needs.....	97
Clinical implications.....	97
Policy implications.....	99
Theoretical implications.....	100
Future research.....	101
Conclusion	102

APPENDICES.....	104
Appendix A: IRB Approval.....	105
Appendix B: Demographic Profile Data Supplied by the GfK.....	106
Appendix C: Supplemental Variables from GfK.....	110
Appendix D: Final Survey	111
Appendix E: Survey Screen Shots	120
Appendix F: Additional Tables.....	137
REFERENCES.....	140

LIST OF TABLES

<i>Table 1: Personal Characteristics Using Non-Weighted and Weighted Data (N=384).....</i>	<i>62</i>
<i>Table 2: Cancer and Health Characteristics Using Non-Weighted and Weighted Data (N=384)</i>	<i>63</i>
<i>Table 3: Descriptive Statistics of QOL-CS Scores, PSWB Scores, Cancer Variables, and Socio-demographic Variables</i>	<i>64</i>
<i>Table 4: Correlations of QOL-CS scores, PSWB scores, Cancer Variables, and Socio-demographic Variables (N=384)</i>	<i>66</i>
<i>Table 5: Tukey and Tamhane's t2 Post Hoc Results and Effect Size of QOL-CS and PSWB by Socio-Demographic and Cancer Specific Variables.....</i>	<i>71</i>
<i>Table 6: Summary of Hierarchical Regression Analysis for Variables Predicting QOL-CS Scores (N=352).....</i>	<i>78</i>
<i>Table 7: Summary of Hierarchical Regression Analysis for Variables Predicting PSWB Scores (N=352).....</i>	<i>84</i>
<i>Table 8: Demographic Profile Data Supplied by the GfK.....</i>	<i>106</i>
<i>Table 9: Means and Standard Deviations of QOL-CS and PSWB Scores by Socio-demographic and Cancer Specific Variables</i>	<i>137</i>
<i>Table 10: Analysis of Variance for QOL-CS and PSWB Scores</i>	<i>139</i>

LIST OF FIGURES

Figure 1: Proposed Conceptual Model: Antecedents of Overall Quality of Life and Psychosocial Well-being among Older Adults with Cancer 50

Figure 2: IRB Approval..... 105

Figure 3: Final Survey..... 111

Figure 4: Survey Screen Shots 120

CHAPTER 1: Background and Theoretical Framework

Statement of the Problem

The United States is undergoing a demographic shift as the proportion of adults over the age of 65 will grow dramatically in the next 15 years, increasing from 13 percent of the total population in 2010 to nearly 20 percent of the population in 2030 (Federal Interagency Forum on Aging-Related Statistics, 2014). Additionally, subpopulations within will also continue to experience dramatic growth including adults over the age of 85 and racial and ethnic minority populations (2014). Estimates suggest that between 2010 and 2050, the number of adults over the age of 85 will grow from 5.5 million to over 19 million (2014). Between 2010 and 2050, the proportion of those over the age of 65 representing racial minority groups will grow from 14 percent to 24 percent, and the proportion of Hispanic older adults will increase from 7 percent to 20 percent (2014).

Cancer is a major health concern among older adults¹ in the United States. According to the Surveillance, Epidemiology, and End Results (SEER) Program, 53 percent of new cancer cases occur in adults over the age of 65, a cancer incidence rate that is nearly seven times higher than those who are 20 to 44 years of age (Howlader et al., 2013). More strikingly, 69 percent of deaths attributable to cancer occur among those over the age of 65 (2013). Cancer is the leading cause of death among adults between the ages of 60 and 79 and is second only to heart disease among adults 80 years of age and older (R. Siegel, Ma, Zou, & Jemal, 2014). At the same time, five-year survival rates continue to increase. The five-year survival rate following a cancer diagnosis increased from 49 percent between 1975 to 1977 to 68 percent between 2003 and 2009 (2014). While considering the disproportionate burden of cancer on older adults paired with

¹ While the term *older adult* has many different definitions this study will define older adults as 65 and older unless otherwise specified.

increases in survival, it is imperative to understand how diagnosis and subsequent treatments influence psychosocial well-being in this age group. Furthermore, it is imperative to give increased attention to subpopulations within this age group that are growing and may have unique experiences with cancer diagnoses and treatment, including those over the age of 85 and those who represent racial and ethnic minority populations.

Despite the burden of cancer in older adults, this population is largely ignored in all areas of cancer research. Older adults are often under-represented in clinical trials for cancer treatment despite elevated incidence rates in this population (Dale et al., 2012; Given & Given, 2008; Pallis et al., 2010). Several reasons exist for these low participation rates including provider and/or researcher beliefs that older adults cannot handle the toxicity, there are limited expectations for long-term benefits, older adults have different attitudes towards treatment, and psychosocial barriers (Pallis et al., 2010; Repetto et al., 2003). Limited evidence shows that older adults who have been selected carefully have responded well to new treatment options (Given & Given, 2008). As older adults are given more opportunities to participate in cancer research, it is critical to understand how the treatment affects overall psychosocial well-being and quality of life (Dale et al., 2012; Given & Given, 2008). Further, similar to clinical trials, the bulk of psychosocial research related to cancer has been done with the general adult cancer population (18 years of age and older) and little has been done to understand the unique psychosocial needs within the older population.

Cancer diagnosis and treatment have been associated with many changes in psychosocial well-being in areas including marital relationships, intimacy, family functioning, social functioning, and increased depression and anxiety (Gil, Costa, Hilker, & Benito, 2012; Mitschke, 2008). The National Action Plan for Cancer Survivorship (2004) highlights specific

psychological and social issues among those living with cancer including fear, stress, anxiety, coping challenges, helplessness, changes in body-image, difficulties in maintaining social relationships, difficulties interacting with those around them due to changes in self-image, and economic and financial difficulties. Limited studies on psychosocial well-being among older adults suggest that, overall, they tend to have a better adjustment to cancer than younger adults (Costanzo, Ryff, & Singer, 2009; Esbensen, Osterlind, Roer, & Hallberg, 2007; Lev, Paul, & Owen, 1999). This research largely points toward stress, appraisal, and coping models that outline these processes along with the older adults' placement in the life span and subsequent tasks associated with aging. These models suggest that older adults are more likely to seek meaning in their experiences as a developmental task, assisting with their ability to cope and appraise their diagnosis. Further, older adults may have more coping resources than younger adults as a result of more cumulative losses and adjustments as they transitioned to older adulthood, resulting in better overall adjustment when facing a cancer diagnosis and subsequent treatment.

Previous Research

The bulk of the research exploring the relationship between psychosocial well-being and cancer² among older adults has focused on how social and psychological factors influence cancer outcomes including functional status and mortality risk. Well-being is broadly defined as, “the absence of negative conditions and feelings, the result of adjustment and adaptation to a

² The broad term “cancer” in this study will refer to individual cancer experiences particularly as they relate to cancer diagnosis and subsequent treatment, or lack thereof.

hazardous world” (Keyes, 1998, p. 121). Both psychological outcomes, such as distress, anxiety, and depression, and social functioning comprise psychosocial well-being.

Psychosocial well-being can serve as a protective factor for adults with cancer. Previous studies have focused mainly on how social support and social well-being serve as protective factors for those with cancer, resulting in better physical and mental health outcomes. Social support has been tied to lower mortality, higher levels of function, and lower rates of depression and anxiety (Gurung, Taylor, & Seeman, 2003; Robinson & Turner, 2003; Tomaka, Thompson, & Palacios, 2006). Conversely, adults who are more socially isolated have demonstrated greater risk of mortality (Bellury et al., 2011; Esbensen et al., 2007; Extermann & Hurria, 2007; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Similarly, psychological factors contribute to treatment success and disease outcomes. For instance, depression has been associated with issues in symptom management and treatment compliance, longer hospital stays, and increased mortality (McDaniel, Musselman, Porter, Reed, & Nemeroff, 1995; Montazeri, Milroy, Hole, McEwen, & Gillis, 1998; Stommel, Given, & Given, 2002).

Social work practice emphasizes the importance of considering individuals in a holistic manner, seeking to emphasize the importance of not just physical but also psychological and social health (Gitterman & Germain, 2013). However, few studies explore how these areas of psychosocial well-being are affected by cancer, particularly among older adults. While much of the evidence suggests that older adults have a less negative appraisal of their cancer experience and employ more successful coping mechanisms than younger adults, it is imperative that attention be paid to those who are more vulnerable due to their cancer diagnosis. This study will

seek to understand the relationships between cancer and psychosocial well-being among those over the age of 65.

Theoretical Framework

Theoretical models provide a foundational understanding of the relationships between psychosocial well-being and cancer among older adults. Stress, coping, and appraisal models explain how stressful events, such as cancer, affect psychosocial outcomes through one's process of appraisal and coping (Lazarus & Folkman, 1984). Older adults' appraisal and coping mechanisms are largely influenced by their place in the life span, specifically how they attach meaning to events and their ability to face the inevitability of death. Stress, appraisal, and coping models paired with the life span perspective allow us to understand ways in which physical health relates to psychosocial well-being in older adults.

Models of stress, appraisal, and coping.

Models of stress, appraisal, and coping are commonly used to provide a framework for understanding the responses to and psychosocial effects of cancer (K. Siegel, 1990). We can use these frameworks to explore how a life event, such as cancer, causes stress, how the stress is perceived or evaluated, and then works to help us understand how that stress may be alleviated, whether through emotional or problem-solving forms of coping (Siegel, 1990). For instance, the magnitude of stress and strain as it relates to cancer is influenced by several factors including prognosis, treatment outcomes, caregiver burden, and patient distress (Mitschke, 2008). As stressors are identified, coping mechanisms are necessary to mediate the emotional outcome of a stressful event (Lazarus, 1993, 2000). In older adults with cancer, these models also can be used

to understand how the individual attaches meaning to the event of being diagnosed with cancer (Holland et al., 2009).

Stress.

Stress research initially focused on how stressful events affected overall physiological health (Lazarus & Folkman, 1984; Mitschke, 2008; Schulz, 1978). More recent uses of the stress and coping model demonstrate how serious illness affects psychosocial well-being, placing illness as the event or stressor rather than the consequence or outcome (Folkman & Greer, 2000). The model also helps address concerns about how serious illness, like cancer, affects other areas of life, such as social relationships and role functioning, by highlighting the influence of self-efficacy and use of coping processes (2000). This model is particularly useful for older adults who are transitioning to a stage of life where there are many adjustments to changing roles as well as a quest for finding meaning in life events. It allows for better understanding of how older adults may experience, appraise, and cope with stressful situations such as losses in functional abilities, changes in employment status, deaths of peers and significant others, and in facing their own mortality. This will be further explicated in the discussion on the life span perspective.

Appraisal.

The model of stress and coping relies on the processes of appraisal and coping (Lazarus & Folkman, 1984). Cognitive appraisal is the process of evaluating an event in terms of its significance or meaning and how it will affect overall well-being (1984). The appraisal process is dynamic and as individuals experience events, such as cancer diagnosis and treatment, they continually appraise the situation and their ability to respond to the situation (Carver, 2007). One's continual reassessment of their cancer situation alludes to the dynamic, temporal nature of

the appraisal process; as the diagnosis is further away often the appraisal of their cancer experience changes.

Coping.

According to Lazarus and Folkman (1984), the coping process begins after assessing a situation and resources needed to respond to the situation. Coping refers to an individual's efforts to manage constantly changing internal and external demands in relation to an event that was appraised as distressing (Lazarus & Folkman, 1984). This definition is particularly relevant for those diagnosed with cancer as one's experience with cancer is a process with ever changing demands (Deimling, Wagner, et al., 2006). Illness can serve as a barrier to optimal coping; although those who are ill can engage in coping efforts, health facilitates one's ability to cope effectively (Lazarus & Folkman, 1984).

The life span perspective.

As alluded to earlier, older adults' stress, appraisal, and coping to the cancer experience is largely tied to their place in the life cycle. Life span development deals with the interplay between personality development and socialization on personality, specifically highlighting age-related behaviors across the entire life span (Havighurst, 1973). Life span development prescribes developmental tasks to each stage of the life-span, suggesting that individual drives toward growth are combined with the expectations, constraints, and opportunities in their environments (Havighurst, 1973). The life span perspective helps us better understand differences in psychosocial well-being between older and younger adults with cancer, postulating that tasks associated with aging better prepare older adults for adjustment to cancer.

The psychosocial theory, developed by Erikson (1950), utilizes life-span development, postulating that the eighth stage of development, in late adulthood, is characterized by ego

integrity versus despair. Those in this stage often face physical limitations and the inevitability of death, grappling with the inalterability of the past and the unknowingness of the future (Erikson, Erikson, & Kivnick, 1986). Older adults need to reconcile their past and their future in order to achieve a sense of integrity (Erikson et al., 1986). Thus, the major task of older adults is to not only affirm their past and continue to participate in meaningful involvement but also to accept the inevitability of death. In doing so, older adults undergo psychological preparation and planning for their end (Erikson et al., 1986). This results, for those achieving integrity, in an “informed and detached concern with life itself in the face of death itself” (Erikson, 1982, p. 61).

The developmental tasks of later adulthood, according to Erikson, cause individuals to become more inwardly focused (Blank & Bellizzi, 2008). This can lead to more passive coping strategies and a muted reaction to a cancer diagnosis as older adults, particularly among those who fall into the despair category (2008). Older adults with cancer who fall into the despair category may be more likely to experience loneliness, depression, isolation, and psychological distress (Holland et al., 2009). Further, their ability to cope with a cancer diagnosis may be compromised due to lack of personal coping abilities, social supports, and other resources in their environment (2009). Those who fall into the despair category are at high risk for poor psychosocial outcomes.

Application of theory.

The life span perspective, paired with stress, appraisal, and coping models, can explain the variance in outcomes in psychosocial well-being when comparing older and younger cancer survivors. The stress, appraisal, and coping literature refers to how the timing of a stressful event, such as cancer, in the context of the life cycle, or life span, influences how one appraises the event (Lazarus & Folkman, 1984). Events are seen as “on time” or “off time” depending on

when the events are expected in a typical life span (1984). While onset of diseases such as cancer should never be categorized as “on-time”, they may be perceived as more expected as older adults cope with changing health needs and prepare for death as compared to a younger adult (1984). This may, in turn, lead to more positive coping and adaptive strategies among older adults (1984). Research studies have demonstrated that older adults demonstrate more positive reappraisal and more adaptive coping strategies than younger adults, resulting in better psychosocial outcomes (Cohen, Baziliansky, & Beny, 2014). The life span perspective adds to this, as older adults are in the process of attaching meaning to events. How they view or attach meaning to their cancer diagnosis may, in turn, also affect their coping abilities. Reviews of the literature have supported these perspectives, demonstrating that older adults have a more positive appraisal of cancer than younger adults, exhibiting better psychological adjustment and coping to their diagnosis and demonstrating more psychological resilience than younger cancer survivors (Alon, 2011; Blank & Bellizzi, 2008; Cohen et al., 2014; Costanzo et al., 2009; Eton & Lepore, 2002; Jansen, van Weert, van Dulmen, Heeren, & Bensing, 2007; Rowland & Bellizzi, 2014).

However, while chronological age, or life time, is the typical index of change used in life span development, social age and historical age (cohort differences) should also be considered, as demographic changes along with medical advances that have led to increasing life expectancies since the emergence of these theories (Neugarten & Datan, 1973). Gerontological literature continues to define older adulthood as over the age of 65, however, differences within this population particularly as they relate to development must be acknowledged. While ultimately the proposed theories suggest that older adults cope better with cancer, we have a new generation of “older” adults and it is important to understand how variations in socio-

demographic and cancer variables interact with psychosocial well-being following a cancer diagnosis (Institute of Medicine, 2013).

As the older adult population continues to grow in the United States, it is increasingly important to consider the heterogeneity of this population group and begin to have a better understanding of how subgroups within this population seek to make sense of the cancer experience as demonstrated through differences in psychosocial well-being (Institute of Medicine, 2013). This study seeks to understand the heterogeneity of the older adult population as it relates to psychosocial well-being and specific cancer variables. This study will investigate how differences in socio-demographic characteristics such as age, race/ethnicity, education, and income as well as differences in cancer characteristics, such as length of time since diagnosis, stage at diagnosis, and cancer site, may be associated with how older adults appraise and cope with their cancer experience as evidenced by their psychosocial well-being. Stress, coping, and appraisal models paired with a life span perspective provide a framework in which to better understand the differences between these groups.

CHAPTER 2: Literature Review

Psychosocial well-being is broadly defined in cancer research to encompass a number of domains including levels of distress, psychological well-being, social well-being, emotional support, spiritual well-being, informational needs, financial needs, and employment needs (Costanzo et al., 2009; Massie, 2004; Matthews, Baker, & Spillers, 2004; Weiss, Weinberger, Holland, Nelson, & Moadel, 2012). Many terms are used interchangeably in the literature to describe aspects of psychosocial well-being including psychological well-being, distress, social well-being, and quality of life. The lack of consistent conceptual definitions leads to difficulty in summarizing and comparing results. For the current study, these terms will be considered as they relate to the definitions of psychological and social well-being since they are often researched separately or as part of a larger construct such as quality of life. For consistency this review will consider psychological and social well-being separately, acknowledging that both contribute to the overall construct of psychosocial well-being. Thus, for instance, domains of psychological and social well-being within larger studies of quality of life will be considered in understanding psychosocial well-being among older adults with cancer.

This literature review will seek to summarize research relating to psychosocial well-being among older adults with cancer while recognizing lack of consistent measurement and conceptualization in the key areas of well-being. Secondly, the review will seek to understand what is known about the associations between psychosocial well-being and cancer-specific variables such as treatment type, stage at diagnosis, and length since diagnosis as well as demographic variables such as age, gender, and race/ethnicity among older adults with cancer.

The term “older adult” in this review refers to those 65 years of age and older unless otherwise noted. Unless otherwise noted, the samples were drawn from populations in the United States.

A comprehensive search of the literature was conducted to understand psychosocial well-being and quality of life among older adults. Several research databases were used including Web of Science, CINAHL, Sociological Abstracts, and PsycInfo. Search terms included *psychosocial well-being, aging, old, older adult, cancer, quality of life, health-related quality of life, treatment, diagnosis, distress, anxiety, depression, social, and social support* to find pertinent research articles. When relevant articles were identified, references and subsequent studies that cited the articles were reviewed for relevance. Additionally, all issues of *Cancer* (from 2000 to present), the *Journal of Clinical Oncology* (from 2000 and to present), the *Journal of Geriatric Oncology* (from 2010 to present), and the *Journal of Psychosocial Oncology* (from 2000 to present) were reviewed for relevant articles. The search focused on older adults with cancer and areas of psychosocial well-being. In instances when there was little research on older adults specifically, such as psychosocial well-being among various racial and ethnic groups with cancer, the search was then expanded to the general adult population with cancer.

Psychological Well-being

Psychological well-being is one aspect of psychosocial well-being and historically, definitions of psychological well-being have focused on either the balance between positive and negative affect or overall life satisfaction (Ryff & Keyes, 1995). Psychological well-being is largely measured in oncology literature through absence of psychological issues. Research studies either elect to develop measures that capture psychological well-being as a whole or focus on one aspect or a combination of aspects of psychological well-being. Of these, the most common domains of psychological well-being explored among adults with cancer encompass

psychological well-being include depression, anxiety, and distress (Ashing-Giwa & Lim, 2010; Bell et al., 2010; Galway et al., 2012; Jarrett et al., 2013; Kenny, Endacott, Botti, & Watts, 2007). Additional domains include uncertainty surrounding the cancer treatment (Schroevers, Helgeson, Sanderman, & Ranchor, 2010), fear of cancer recurrence (Akechi et al., 2012; Blomberg et al., 2009; Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Foley et al., 2006; Stanton, Franco, & Scoggins, 2011), self-control (Bell et al., 2010), self-esteem (Ashing-Giwa & Lim, 2010), and body image (Ashing-Giwa & Lim, 2010). This review will focus on areas of depression, anxiety, distress, uncertainty about the diagnosis, and fear of cancer recurrence as they are the most common measures of psychological well-being among older adults.

Depression, anxiety, and distress.

Cancer diagnosis and treatment may affect psychological well-being in the areas of depression, anxiety, and distress. In reviews of the literature, both Foster, Wright, Hill, Hopkinson, and Roffe (2009) and Jarrett et al. (2013) found that cancer survivors experience rates of depression and anxiety similar to the general population without cancer across a number of studies. However, certain groups were at higher risk for depression and anxiety, including those with cancer who are younger, have a more advanced disease, and have more physical symptoms (2013).

Unlike the general adult population with cancer, there is some indication that older adults with cancer may have poorer psychological outcomes as compared to their peers without cancer (Bell et al., 2010; Deimling, Bowman, et al., 2006; Robb et al., 2007). Differences in psychological well-being have been found when comparing women with and without breast cancer as well as between different age cohorts of women with breast cancer. Bell et al. (2010) compared differences in psychological well-being among different age groups of Australian

women with breast cancer as well as between women with and without breast cancer. The cross-sectional study recruited 1,589 women who were diagnosed with invasive breast cancer within one year using the cancer registry in the state of Victoria, Australia (2010). The women completed a psychological general well-being index which measured anxiety, depression, positive well-being, self-control, general health, and vitality (2010). The results were compared to data gathered from 1,423 women in Victoria who were selected through random telephone screening and had not experienced pregnancy, acute mental illness, acute physical illness, or cancer treatment in the last 3 months (2010). Bell et al. (2010) then analyzed differences between those women with cancer and those without as well as differences between five age groups: women under 40, women 40 to younger than 50, women 50 to younger than 60, women 60 to younger than 70, and women ages 70 and older. While older women with breast cancer exhibited better overall psychological well-being than younger women with breast cancer, differences between older women with and without breast cancer were more pronounced as compared to the differences between younger women with and without breast cancer (2010). Older women with breast cancer had markedly worse overall psychological well-being than those older women in the community based sample (2010).

Robb et al. (2007) conducted a similar study comparing quality of life outcomes for 127 American women over the age of 70 who had been diagnosed with breast cancer in the past year as compared to 87 women over the age of 70 who were enrolled in a longitudinal healthy aging study and had not had a prior diagnosis of breast cancer. The participants completed questionnaires and semi-structured interviews which measured health-related quality of life, fatigue, physical vulnerability, psychological well-being as measured by depression and anxiety, morale, general life satisfaction, sense of mastery, spiritual well-being, and social support (Robb

et al., 2007). Similar to findings from Bell et al. (2010), Robb et al. (2007) found older women with breast cancer had significantly poorer psychological well-being as compared to women of similar age, education, and physical status who did not have cancer. Further, findings suggested that functional decline was the greatest contributor to depression (2007). In a study of coping behaviors among a random sample of 321 adults over the age of 60 who were long-term survivors of cancer, over 5 years since diagnosis, Deimling, Wagner, et al. (2006) found that 24% of study participants met the criteria for clinical depression as outlined by the CES-D as compared to findings in gerontological literature which suggest only 8 to 17% of adults over the age of 65 meet the criteria for clinical depression. Hurria (2009) notes that depression symptoms in older adults often go unnoticed, thus these differences may be even greater.

Anxiety can also be seen in relation to fear around the cancer diagnosis among older adults. Understanding of anxiety is noted as being complex due to its symptoms often being expressed somatically as well as the potential for it to stem from the use of certain medications (Parpa, Tsilika, Gennimata, & Mystakidou, 2015). Current research shows that anxiety in older adults with cancer is largely tied to pain, potential need to move into a long-term care facility, and coping with the inevitability of death (Hanratty et al., 2013; Parpa et al., 2015). Fear of moving into long-term care was associated with loss of independence and anxiety around death among 21 adults over 75 with cancer in the United Kingdom (Hanratty et al., 2013). Themes around death anxiety were also present in a phenomenological study by Esbensen and colleagues (Esbensen, Swane, Hallberg, & Thome, 2008), of 16 older Danish adults newly diagnosed with cancer. These themes included: life and death were suddenly apparent, death was anxiety-causing, and there was an overwhelming desire to remain hopeful (2008). Cancer marked a turning point for participants in this study, raising consciousness of aging and forcing them to

face the inevitability of death. To some, the thought of death produced feelings of despair while others became more hopeful and sought meaning (2008). In interviews with 64 older Swedish adults with cancer over the age of 75, Thome, Dykes, Gunnars, and Hallberg (2003) found that some participants expressed a fear of death yet a desire to die as a means to escape the cancer. Others expressed that the diagnosis of cancer made them suddenly face the imminence of death which caused fear (2003). In the older adult oncology literature, anxiety is largely associated with meaning and existential themes related to the older adult's developmental tasks. The ability to find meaning in their life and cancer experience as well as face eventual death contributed to decreased levels of anxiety.

Distress, or lack thereof, is also a common indicator of psychosocial well-being. Hurria et al. (2009) measured distress among 245 adults over the age of 65 who were receiving cancer treatment through the Memorial Sloan-Kettering Cancer Center. The Distress Thermometer was used to measure distress and findings indicated that 41% of participants demonstrated significant distress. The amount of distress was low compared to previous findings of 42 to 67 percent among cancer patients of all ages showing that older adults with cancer may experience less distress as compared to younger peers (Hurria et al., 2009). These results support the theoretical models, suggesting that older adults may have more positive coping and adaptive strategies which allow them to process their cancer experience differently. However, the results of this study indicated that within this older adult group, certain sub-groups were still identified as more vulnerable to experiencing distress including those who were younger, female, and with poor physical status (Hurria et al., 2009).

As we consider the associations between cancer and psychological well-being, it is important that we further explore how these relate to how an older adult attaches meaning to

their cancer diagnosis and treatment as well as the amount of stress, primarily through physical indicators of disease, their bodies undergo. Considering these studies through an ecological lens highlights the importance of exploring interactions of physical health and psychological well-being.

Other indicators of psychological well-being.

Lack of clarity around the cancer diagnosis, treatment, and survival contributes to negative psychosocial outcomes in the cancer experience. Thome, Esbensen, Dykes, and Hallberg (2004) explored the meaning of cancer in old age through the use of a phenomenological study of 10 Swedish adults between the ages of 75 and 88 who had just completed cancer treatment. The findings from the interviews revealed that those who received vague or conflicting information about their cancer diagnosis and treatment progress felt as if they were low-priority patients because of age and often experienced feelings that health care professionals were abandoning them with their uncertainty (2004). However, those who perceived health care personnel to be supportive and informative felt that their interactions with the professionals provided more ease during the treatment process (2004). These results were consistent with an earlier qualitative study by Thome et al. (2003) of 41 Swedish adults over the age of 75 with cancer. In this study, which explored the experiences of older adults living with cancer, those with a clear understanding of their cancer, primarily based on interactions with health professionals, led to feeling of confidence and control (2003). On the other hand, those with only a diffuse, or insufficient, understanding of their cancer were more likely to lead to feelings of insecurity and lack of control (2003). These studies highlight the importance of

accurate and clear information about the cancer diagnosis in ensuring better psychological outcomes.

Similarly, event uncertainty, in this case the uncertainty of cancer recurrence, is related to poor psychological outcomes (Foster et al., 2009; Thome et al., 2003). Studies of adults with cancer highlight cancer-related health worries including fear of recurrence, concern about symptoms, and emergence of new types of cancer (Akechi et al., 2012; Blomberg et al., 2009; Deimling, Bowman, et al., 2006; Foley et al., 2006; Stanton et al., 2011). These results are mirrored in studies that focus exclusively on older adults with cancer. Stanton et al. (2011) sought to understand physical and psychosocial needs of older adults with cancer as a means to improve case management services for older adults with cancer. They collected 237 surveys from cancer survivors over the age of 50 who attended a survivorship program. The greatest concern among the 117 participants over the age of 65 was the fear of cancer recurrence, with over one-third of respondents indicating that as a concern (2011). Similarly, data from the first wave of a longitudinal study of 321 long-term, older cancer survivors by Deimling, Bowman, et al. (2006) showed that over a third of participants were worried about cancer recurrence, symptoms they were having that may signal the recurrence of cancer, getting another type of cancer, and about the results of future diagnostic tests that may discover cancer. Worries around cancer recurrence and emergence of new cancers led to increased anxiety and depression among older adults with cancer (Deimling, Bowman, et al., 2006). Thome et al. (2003) interviewed 41 Swedish adults over the age of 75 about their experiences with cancer. When exploring the mental experiences of cancer, participants relayed fears about the unpredictable nature of cancer and of not-knowing what the future held in relation to the disease (2003). Fear of cancer

recurrence is particularly troubling when considering psychological well-being as it continues to create anxiety for survivors.

Summary of psychological well-being.

These findings suggest that although older adults with cancer tend to fare better than their younger counterparts, further attention should be given to differences between older adults with cancer and their peers. Understanding of subgroup differences within the older adult population will allow us to identify groups who may be most vulnerable to poorer psychological outcomes and develop targeted interventions. As seen in this review, older adults with cancer have poorer overall psychological well-being as compared to community-based peers. One study even suggested that these results have greater variance when comparing older adults with cancer to community-based peers than younger adults with cancer to their peer groups. Although research studies seem to verify theoretical arguments that older adults will adjust better to cancer diagnosis and treatment than younger adults due to their stage of life development and increased ability to cope, differences between those with and without cancer among the older adult population suggest the need to better understand what population groups within this age range are at greatest risk for detrimental psychological outcomes.

Additionally, many of the studies emphasize the importance of physical indicators of well-being on psychological well-being (Kurtz, Kurtz, Stommel, Given, & Given, 2001; Robb et al., 2007; Thome, Dykes, & Hallberg, 2004). This indicates that different cancer specific variables such as stage at diagnosis, years since cancer diagnosis, type of diagnosis, and types of

treatment received as well as self-reported physical well-being and co-morbidity may also be important to consider as we look to compare those in the 65 and older age group.

Based on these conceptualizations in the current literature, this study will consider psychological well-being broadly by including in a larger scale of psychosocial well-being which includes individual measures of self-perceived coping, life satisfaction, self-efficacy and self-concept, distress and fear around different aspects of cancer (e.g., initial diagnosis, treatment, future tests, and possible recurrence), depression, and anxiety. This approach allows for a more expansive understanding of psychological well-being as compared to studies that focus exclusively on one aspect of psychological well-being such as depression.

Social Well-being

Social well-being, unlike psychological well-being, is less consistently defined. It is broadly defined as “an appraisal of one’s circumstances and functioning in society” (Keyes, 1998, p. 122). Keyes (1998) identifies several dimensions of social well-being including social integration, social acceptance, social contribution, social actualization, and social coherence. These dimensions largely are related to one’s evaluation of their roles and value in society along with their evaluation of the trajectory of society (Keyes, 1998). Social well-being in cancer research is typically defined through the measurement of social needs including stress around family responsibilities and role functioning (Ashing-Giwa & Lim, 2010; Ashing-Giwa et al., 2009; Chase, Watanabe, & Monk, 2010; Jarrett et al., 2013), burden on family (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Esbensen et al., 2008; Foster & Fenlon, 2011; Sarna et al., 2005), social isolation (Esbensen, Oosterlind, & Hallberg, 2004; Foster & Fenlon, 2011), sexual needs (Ashing-Giwa et al., 2009; Hwang, Chang, & Park, 2013; Perz, Ussher, & Gilbert, 2013), perceived and received availability of social support (Chase et al., 2010; Jarrett et al.,

2013; Katz et al., 2003; Reavley, Pallant, & Sali, 2009; Robb et al., 2007; Rose et al., 2008; Schroevers et al., 2010), and financial needs (Esbensen et al., 2007; Thome, Esbensen, et al., 2004). Empirical research investigating the links between cancer and social well-being among older adults has primarily focused on burden on family, social support, and financial needs.

Burden on family.

Research studies have shown that social well-being among older adults with cancer is largely tied to their perceptions on how the disease affects their family (Bowman et al., 2003; Esbensen et al., 2008; Sarna et al., 2005; Thome et al., 2003). In a study assessing public concerns about potential symptoms and issues related to advanced stage cancer Bausewein et al. (2013) found that among the 9,344 respondents over the age of 16 from seven European countries that the fear of being a burden on family was associated with older age. Among 15 Canadian adults between the ages of 42 and 76 with advanced cancer, McPherson, Wilson, and Murray (2007) identified fear of being a burden led to significant distress and respondents attempted to minimize the burden by concealing information, participating in their own care, and making final arrangements. These anticipated fears and attempts to alleviate burden are consistent with actual fears older adults face with a diagnosis of cancer.

Bowman et al. (2003) studied how adults over the age of 60 who had been treated for cancer over five years prior to the study appraised their cancer experience. Face-to-face interviews covering demographics, effects on family, and cancer characteristics were conducted with 321 survivors who had been treated at the Ireland Cancer Center in Cleveland, Ohio (2003). Results showed that greater perceived family distress around the diagnosis and treatment was the strongest correlate of the adult appraising cancer as a stressful life event (2003). Similarly, in a phenomenological study of 16 Danish adults between the ages of 68 and 83, diagnosed with

cancer in the six months prior to the study, Esbensen et al. (2008) found that participants were most concerned about the well-being of family members, attempting to shield children and grandchildren from the illness. Participants in the study were interviewed in a conversational manner, asked to describe what it was like to live with cancer in old age. Maintaining family balance emerged as one of three main themes. In particular, participants were worried about disturbing the family balance and becoming a burden on family, often preventing family from becoming involved in the illness in order to protect them (2008). This stress, in turn, added to the overall burden of their cancer experience by causing them to worry about protecting their loved ones, feeling guilty about being a burden, and feeling frightened about how family would react to the cancer diagnosis (Esbensen et al., 2008). Thome et al. (2003) interviewed 41 Swedish adults over the age of 75 who had been diagnosed with cancer within the past five years. Open-ended questions focused on understanding the cancer disease, its effects on daily life, and treatment experiences (2003). Major themes revolved around living with cancer, understanding of the disease, daily life, and relationships with health care providers. As participants reflected on their life with cancer there were common fears of being a burden to family members or anxiety that they were causing strain on their companions (2003). Participants actively tried to alleviate feelings of burden by avoiding discussion of the cancer in conversations and by getting the household in order as preparation for death (2003).

Desires to reduce feelings of being a burden is mirrored in semi-structured interviews among eight Australian adults over the age of 55 with terminal cancer diagnosis (Aoun, Deas, & Skett, 2015). A theme in these interviews was a reluctance to seek help for fear of being a burden or inconveniencing others and attempted to avoid being a burden by addressing lingering needs such as funeral planning (2015). Similarly, in qualitative interviews with 21 adults in the

United Kingdom over the age of 75 with a diagnosis of cancer Hanratty et al. (2013) identified older adults saw moving in with family members as a last resort due to fear of being a burden or inconvenience.

Regardless of point in the cancer experience, the studies demonstrate the relationship between the older adult's perception of how their family appraises their cancer and their individual appraisal of their cancer experience and, in turn, the level of stress that they experience in relation to the cancer. However, a lack of studies done in the United States among newly diagnosed older adults with cancer leaves a gap in our understanding of the breadth of this issue in the North American context. Further, it is important to see whether these concerns emerge in larger representative samples as well.

Social support.

Social support has implications for psychosocial well-being as well as cancer outcomes for older adults. While older adults may worry about being a burden on family as seen in the previous section, a great deal of support is derived from family and other important relationships in their lives.

Thome, Dykes, Gunnars, and Hallberg (2003) attempted to understand how cancer affected daily life of older adults by conducting open-ended interviews with 41 Swedish individuals over the age of 75 who had been diagnosed with cancer within the five years prior to the study period. The study found that those who felt consolation from their family and other external support, were more likely to feel that they were able to cope with daily life in contrast to those who felt alone (2003).

In a smaller phenomenological study exploring the meaning of living with cancer in older age among ten Swedish adults ages 75 to 88, Thome, Esbensen, et al. (2004) found that family

relationships were credited for helping the participants handle daily life as well as provided the participants with feelings of value and confidence. Esbensen et al. (2007), in a study of 75 Danish adults over the age of 65 with cancer, explored factors contributing to quality of life. This study measured health-related quality of life among participants at the time of diagnosis, at three months post diagnosis, and at six months post diagnosis. Based on changes in quality of life over time, participants were grouped as either “stable QOL” or “deteriorated QOL.” Those in the stable QOL group received significantly more assistance from adult children and grandchildren (2007).

Kurtz, Kurtz, Stommel, Given, and Given (2002) examined the association between social functioning and depression in a larger longitudinal study consisting of four waves over one year, identifying predictors of depression among older adults with colorectal cancer. The study of 158 older adults from the Midwest United States found that increases in social functioning were associated with decreases in depression (2002).

However, in a study of 127 female breast cancer survivors over the age of 70 which explored the role of certain variables in cancer coping, Perkins et al. (2007) found that internal resources of mastery, optimism, and spirituality had stronger positive associations with coping than social support.

Just as social support may serve as protective factors for older adults with cancer, social isolation and lack of support can result in deleterious outcomes. Studies have shown that the oldest subgroups, those over 80 years of age, are at greater risk for deleterious social outcomes as a result of their cancer (Deimling, Wagner, et al., 2006; Esbensen et al., 2004). In a study examining coping among 321 long-term cancer survivors over the age of 60, Deimling, Wagner, et al. (2006) found that the older the survivor, the less likely they were to seek social support as

measured by items from the coping scale developed by Carver, Scheier, and Weintraub (1989). The items on seeking social support included “I talk to someone about how I feel” and “I ask people who have had similar experiences what they did” (Deimling, Wagner, et al., 2006).

Similarly, in a study of 101 older Danish adults newly diagnosed with cancer, participants completed the Interview Schedule for Social Interaction (ISSI), a 13-item scale which asks about the number of people that can be called upon for practical and emotional support (Esbensen et al., 2004). The results of the survey showed that individuals with cancer who were over the age of 80 had poorer social networks, leading to the need for more outside assistance in the form of home health care (2004). These results may be more dramatic as the frailest elderly were not represented in this study (2004). Thome and Hallberg (2004) examined the effects of gender among older adults with cancer. Using a sample of 150 Swedish men and women with cancer over the age of 75 compared to 138 Swedish adults over the age of 75 without cancer, the findings revealed that women with cancer were significantly more vulnerable to loneliness than their male counterparts with cancer or females without cancer (2004). Within this study, women with cancer had poorer social access to family members (2004). These studies emphasize the importance of social support among those with cancer and suggest that the oldest-old may be at the greatest risk for social isolation. Further, there are some indications that older females may be particularly vulnerable when social supports and networks are not accessible. This emphasizes the importance of considering both gender, in terms of changes and roles due to longevity, and age as variables that may affect social well-being.

Financial needs.

There are some indicators that financial distress can lead to lower levels of quality of life among older adults with cancer. In a study of 75 Danish adults over the age of 65 and newly

diagnosed with cancer, lower levels of quality of life was associated with greater financial need (Esbensen et al., 2007). Consistent with these findings, Thome et al. (2004) in a study of 150 Swedish men and women over the age of 75 and who had cancer found, that 22% of the older women perceived their financial situation as bad or very bad as compared to only 1% of the men. These environmental constraints, in the form of financial distress, contributed to lower quality of life among women (2004).

Among 654 adults over the age of 18 diagnosed with breast, prostate, and lung cancer, Sharp, Carsin, and Timmons (2013) found those experiencing financial strain or stress had more adverse outcomes in regards to depression, anxiety, and distress. Cancer can be particularly burdensome for older adults. Using data collected from the National Health Interview Survey between 2006 and 2010, Palmer, Geiger, Lu, Case, and Weaver (2013) found older cancer survivors living in rural areas were also foregoing medical care as compared to urban counterparts. Additionally, needed psychosocial services by cancer survivors may be inaccessible to older cancer survivors due to cost (Weinberger, Bruce, Roth, Breitbart, & Nelson, 2011). Thus, these financial concerns must be understood and addressed as we think about psychosocial interventions, particularly taking into consideration gender and age.

Summary of social well-being.

The majority of studies exploring social well-being among older adults with cancer originated in Scandinavian countries and primarily used qualitative approaches to understanding social well-being. Studies in the United States primarily included older adults who had been cancer survivors for over five years. It is important to take into consideration both the cultural context and the length of time since diagnosis when exploring social well-being. Scandinavian countries have markedly different health care systems than the United States which may cause

differences in outcomes among those with cancer. Length of time since diagnosis is also important to consider as those closer to their diagnosis are more likely to be in active treatment and thus may be experiencing stress and appraising their cancer experience differently than longer term survivors. More research is needed to explore whether findings on family burden, social support, and financial needs, are consistent with older adults in the United States who have been diagnosed within the last five years and using a larger, more representative sample size than those done in the Scandinavian countries. Further, as we compare those within the 65 and older age category, previous literature emphasizes the importance of looking at differences between gender and age groups, as many studies have indicated the increased vulnerability of older women.

As a subset of a larger psychosocial well-being scale, this study conceptualizes social well-being in terms of tangible social concerns that older adults face when diagnosed with cancer and through their cancer journey. These concerns mirror the current literature by addressing perceived burden on family, amount of support, changes in personal relationships, participation in activities at and outside of the home, financial concerns, and isolation due to the illness.

Cancer-Specific Variables

Few studies have been done exploring associations between psychosocial well-being and cancer-specific variables among older adults with cancer. Findings suggest that certain groups may be at greater risk for deleterious psychosocial outcomes including those who have been diagnosed at a more advanced stage, those diagnosed more recently, and those diagnosed with lung cancer (Esbensen et al., 2007; Hopwood & Stephens, 2000; Loerzel, McNees, Powel, Su, & Meneses, 2008; Sarna et al., 2005; Stommel, Kurtz, Kurtz, Given, & Given, 2004; Weitzner, Meyers, Stuebing, & Saleeba, 1997). Results largely show that there is not much variance due to

treatment type. However, it is difficult to measure this variable due to differences in symptom management, time of treatment, and treatment variations (e.g. radiation, targeted cancer therapies, type of chemotherapy used) (Perkins et al., 2007; Stommel et al., 2004). This review will seek to summarize the results that have been found among older adults.

Stage at diagnosis.

Stage of diagnosis can be difficult to capture, particularly when considering multiple cancer sites. Kurtz et al. (2001) addressed this issue by collapsing stage of diagnosis, as determined by the tumor, nodes, and metastasis (TNM) staging system, into early and late stage cancer. Similarly, Simon and Wardle (2008) opted to capture stage of cancer by asking participants to select whether their cancer was “invasive” (lymph node involvement or distant metastases) or “non-invasive.”

While no studies have focused exclusively on associations between stage of cancer and psychosocial well-being among older adults with cancer, studies among the adult cancer population suggest that stage of cancer does influence psychosocial well-being. As may be expected, those diagnosed with more advanced stage cancer generally have poorer psychosocial outcomes. As part of a larger study identifying associations between socioeconomic status and psychosocial well-being among those with cancer, Simon and Wardle (2008) recruited 352 adults between the ages of 29 and 89 with cancer from nine hospitals in the United Kingdom. Those who reported that their cancer had spread to other parts of their body, coded as invasive cancer, reported statistically significant higher rates of depression as measured by the CES and

social difficulties as measured by problems in areas relating to personal care, abilities to do chores, body image, and participation in relationships (2008).

Similarly, in a cross-sectional study of 60 female breast cancer survivors of over five years with a comparison group of 93 low-risk breast cancer screening patients, Weitzner et al. (1997) found that women diagnosed with Stage III breast cancer had higher rates of anxiety than those diagnosed in earlier stages. However, decreases in psychosocial well-being are not exclusive to those with advanced stage cancers. In a cross-sectional study of 217 women who were diagnosed with lung cancer within the last five years, Sarna et al. (2005) found that although the majority of the participants were diagnosed at an early stage (local) over one-third demonstrated depressed mood. Although the study had difficulty recruiting women at more advanced stages of lung cancer those diagnosed at later stages experienced great declines in quality of life (2005). In another study of adults over 18 diagnosed with lung cancer in the United Kingdom, Hopwood and Stephens (2000) found higher rates of lung cancer among those with more advanced stages of disease. This suggests that consideration of how stage of diagnosis interacts with psychosocial well-being can be further explained by concurrently considering other potential contributing factors such as type of cancer.

Cancer site.

Few studies have focused on the associations between cancer sites and psychosocial well-being among older adults. However, the existing studies have shown that older adults with lung cancer are more likely to have poorer psychosocial outcomes as compared to those with breast, colorectal, prostate, or gynecological cancers (Esbensen et al., 2007; Stommel et al., 2004). Using a prospective study design, Esbensen et al. (2007) measured quality of life at diagnosis, 3 months, and 6 months among 75 Danish adults over the age of 65 who had been diagnosed with

breast, colorectal, gynecological, or lung cancer. Due to lowest quality of life scores at baseline and highest attrition rates, those with lung cancer were found to be the most vulnerable (2007). Kurtz et al. (2002) conducted a longitudinal study consisting of 4 waves of data collection tracking study participants in their first year post-diagnosis. Eight hundred and sixty individuals over the age of 65 participated in at least one wave of data collection, completing self-administered measures of depression, physical functioning, and symptom experience (2002). Compared to those with breast, prostate, or colorectal cancer, participants with lung cancer displayed higher depressive somatization and symptomology (2002).

Although studies focusing exclusively on older adults are limited, these studies suggest the importance of considering the cancer site when attempting to understand psychosocial well-being. Several studies explore associations between one cancer site (e.g. lung cancer) and psychosocial well-being and the results are compared to similar studies conducted using a different site. However, there are many limitations to this approach, namely that different methodologies lead to difficulties in making true comparisons between studies. Continued efforts need to be made to compare associations between psychosocial outcomes and multiple cancer sites among older adults. This study will focus on older adults who have been diagnosed with any cancer type in the past five years excluding skin cancer. This will allow for richer data in the exploration of cancer types and the differences in psychosocial well-being as demonstrated by cancer type.

Time since diagnosis.

Time since diagnosis can also potentially explain variance in psychosocial well-being among older adults with cancer as those closer to diagnosis may experience more anxiety or uncertainty surrounding the diagnosis and treatment. Existing literature suggests adult cancer

survivors may experience initial decreases in psychosocial well-being in the immediate years following diagnosis due to treatment and adjustment to the diagnosis but typically well-being improves among long-term survivors of cancer. In a longitudinal study of quality of life among 75 Danish adults over the age of 65 with cancer, Esbensen et al. (2007) found that while quality of life remained stable for the majority of participants through six months post-diagnosis, 30 percent of the sample experienced diminished quality of life during this time frame. Those with deteriorations in quality of life also reported diminished role and social functioning and had more contact with nursing services, which may suggest greater disease severity among this group (2007).

Stommel et al. (2004) used a 4-wave panel study to understand changes in psychological functioning among 860 adults over the age of 65 with cancer over the first year post-diagnosis. Overall, there were steady declines in depression, with the most significant declines within the first 2 to 3 months following their initial diagnosis (2004). Despite overall declines in depression scores, absence of well-being scores, as measured by a positive affect measure, stayed the same and increased slightly when analyzing over the course of a year since diagnosis (2004). These findings suggest that depression and positive affect may function independently of one another, and while overall depression may decrease following diagnosis, an overall lack of well-being may remain.

Conversely, Loerzel et al. (2008) investigated quality of life outcomes among 50 women over the age of 65 at baseline, 3 months, and 6 months of being diagnosed with early stage (I or II) breast cancer. While findings were not statistically significant, results indicated overall declines in quality of life, specifically in the area of psychological well-being (2008). These studies suggest that within the first year post-diagnosis while some areas of psychosocial well-

being may improve for older adults this is a time where declines in overall well-being may occur, particularly among those with greater disease severity.

However, as the cancer diagnosis becomes further removed some studies have found positive associations between time since diagnosis and psychosocial well-being. As part of a longitudinal study investigating long-term health worries among 321 older, long-term (over 5 years) survivors of cancer, Deimling, Bowman, et al. (2006) found that while fear of cancer recurrence and other health-related worries continued over time, overall most participants did not exhibit poor physical and psychological well-being. Cimprich, Ronis, and Martinez-Ramos (2002) conducted a cross-sectional study investigating the associations between time since diagnosis and quality of life among 105 women, ages 34 to 89, who were at least 5 years past a diagnosis of breast cancer. Although the study was not exclusively composed of older women approximately one-third of the sample participants were over the age of 65. The findings suggested that the farther removed from the cancer diagnosis the women experienced better overall quality of life, psychological well-being, and social well-being (2002). Comparisons between those diagnosed within 5 years and those who are longer-term survivors of cancer suggest that major disruptions in psychosocial well-being occur within the initial years post-diagnosis. It is important to note that while overall psychosocial well-being may stabilize some cancer-specific worries may remain in the long-term.

This study will focus on older adults who have been diagnosed most recently in the past five years to further understand how length since diagnosis affects psychosocial well-being while controlling for other socio-demographic and cancer variables. Since overall well-being may

stabilize over the long-term it is important to capture the areas of need as well as those at highest risk during the time when they are most vulnerable to detrimental psychosocial outcomes.

Treatment type.

The associations between types of cancer treatment and psychosocial wellbeing are challenging to identify due to differences in chemotherapy treatment, symptom management, and treatment timing (Stommel et al., 2004). In the general adult population, there are some mixed reviews with the majority of studies indicating that chemotherapy results in poorer psychosocial well-being among adults with cancer (Fenlon et al., 2013; Hwang et al., 2013; Simon & Wardle, 2008). Other studies demonstrate negative psychosocial outcomes as a result of radiation therapy and surgery (Frumovitz et al., 2005; Simon & Wardle, 2008).

Studies among older adults with cancer have been unable to show any association between treatment type and psychosocial outcomes. In a 4 wave panel study exploring depression among 860 adults 65 years of age and older with breast, colon, lung, or prostate cancer who had participated in at least one wave of data collection, Stommel et al. (2004) were unable to demonstrate an association between chemotherapy and depressive symptoms. These results were echoed by Perkins et al. (2007) in a cross-sectional study investigating associations between well-being and individual differences among 274 older female survivors of breast cancer who had been treated at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Florida. The study found that type of treatment, regardless of surgery type or receipt of chemotherapy, did not play a significant role in life satisfaction or depression outcomes (Perkins et al., 2007).

Since few studies fully consider treatment type as it relates to psychosocial well-being among older adults with cancer it is important to continue to explore relationships between these

two variables. However, as noted earlier, variances in treatment delivery may prevent full understanding of these associations. While noting these differences in treatment, this study will seek to decrease some of those issues by allowing participants to select all types of treatment that have been received and use that data to develop different combinations of treatment (e.g., radiation and surgery versus chemotherapy and surgery). Potentially these groupings may account for some of the variance that is seen in treatment approaches.

Summary of cancer specific variables.

Accurate understanding of how cancer specific variables are associated with psychosocial well-being among cancer survivors is challenging. As noted earlier, differences in severity and time of treatment, lack of knowledge around staging among those with cancer, and difficulties in identifying large enough subsamples to distinguish between cancer types. It is critical to find consistent and reliable measures for these variables while taking into consideration individual differences in cancer experiences.

Additional Determinants of Well-Being

Several other areas and demographic factors contribute to psychosocial well-being among older adults with cancer. Studies have shown that poorer physical well-being, the presence of functional limitations, and the presence of comorbidities all contribute to lower psychosocial well-being (Blank & Bellizzi, 2006, 2008; Kurtz et al., 2001; Robb et al., 2007; Thome, Dykes, et al., 2004). Furthermore, while little research has been done specifically among the aging, there is some evidence indicating that demographic factors within the older adult population such

as age, race and ethnicity, socioeconomic status, and gender may be associated with overall psychosocial well-being.

Physical well-being.

Perceived physical health can also serve as a barrier to optimal psychological and social well-being. Studies among older adults demonstrate losses in functional ability due to cancer leads to poorer psychosocial well-being (Kurtz et al., 2001; Robb et al., 2007). Using data from the first wave of a 4-wave longitudinal study of 420 adults over the age of 65 with breast, colon, lung, or prostate cancer, Kurtz et al. (2001) explored associations between physical functioning and depression. Using the physical functioning subscale from the Medical Outcomes Study 36-item Short Form Health Survey and the Center for Epidemiological Studies Depression Scale, the authors found that decreases in functional ability were associated with higher rates of depression (Kurtz et al., 2001). Similarly, in a cross-sectional study comparing 127 women who had at least one year of breast cancer survivorship and 87 women who had no history of breast cancer, Robb et al. (2007) explored differences in health-related quality of life and other dimensions of well-being. The breast cancer survivors fared significantly worse in health-related quality of life, specifically demonstrating poorer physical functioning, bodily pain, general health perception, and vitality (2007). Limits in ability to complete activities of daily living may lead to further impairments in psychosocial well-being. In a cross-sectional study of 150 Swedish adults ages 75 and older with cancer compared to 138 adults ages 75 and older who had not had cancer, Thome, Dykes, et al. (2004) explored differences in quality of life between these groups. Regardless of cancer diagnosis, the authors found that requiring assistance with activities of daily living is associated with lower quality of life (2004). Using these findings, the authors inferred

that more functional limitations may be seen as a threat to independence and also limit their abilities to carry out activities in other domains of their life (2004).

These studies emphasize the importance of understanding the role of functional decline among older adults with cancer. A better understanding of these functional limitations will assist oncology social workers in developing targeted interventions that prevent declines in other areas of well-being. Further, these studies emphasize the importance of perceived physical well-being in psychosocial well-being as seen earlier in understanding broader contributors to both psychological and social well-being.

Age.

Many studies have found that younger adults tend to have more deleterious psychosocial outcomes in relation to their cancer than older adults (Alon, 2011; Blank & Bellizzi, 2008; Cohen et al., 2014; Costanzo et al., 2009; Eton & Lepore, 2002; Foley et al., 2006; Rose et al., 2008; Sarna et al., 2005). Older cancer patients typically demonstrate less mood and symptom distress as compared to younger counterparts (Cohen et al., 2014; Esbensen et al., 2007; Lev et al., 1999). However, only a few studies consider the differences among age subgroups within the 65 and older age group.

In a cross-sectional study of 150 Swedish adults 75 years of age and older with cancer and a comparison group of adults 75 years of age and over with no history of cancer, drawn from a larger population health study, Thome, Dykes, et al. (2004) looked at differences in quality of life between and within the groups. Participants were split into three age groups: ages 75 to 79, ages 80 to 84, and those over the age of 85. When comparing subpopulations within the older adult population with cancer the oldest age group experienced the greatest decreases in quality of life in relation to their diagnosis with cancer (Thome, Dykes, et al., 2004). However, when

compared to those without cancer, only the youngest age group had significantly different outcomes in quality of life, with those who had cancer demonstrating poorer quality of life outcomes (2004). This suggests that in general the oldest age groups may be at greater risk for functional limitations as a whole and thus may experience overall decreases in quality of life while cancer may be associated with greater declines in quality of life among younger older adults. This is supported by Bowman, Deimling, Smerglia, Sage, and Kahana (2003) who used data drawn from part of a longitudinal study to understand appraisal of the cancer experience among those who had been survivors of cancer for over five years. Face-to-face interviews were conducted with 321 adults 58 years of age and older who had been treated for breast, colorectal, or prostate cancer and had not had active treatment for over five years. The findings showed that older age was associated with a less negative appraisal of cancer (2003). In a study of 321 older Israeli adults over the age of 60 with cancer Cohen (2014) found those 80 and older and those between the ages of 60 and 69 had higher rates of depression and anxiety than those ages 70 to 79. Although age group only accounted for nine percent of the variance in depression and anxiety it still suggests the need to take into account needs specific to subgroups based on age.

These findings are interesting as they suggest that the younger old may have greater declines in quality of life as compared to counterparts who do not have cancer but that the oldest age groups may experience greater declines in quality of life overall. Thus, in a cross-sectional study of older adults with cancer, it is likely that the oldest age groups will have the poorest psychosocial well-being however their well-being may be more generalized than cancer specific. The lower levels of psychosocial well-being at the age extremes (young-old and oldest old) may

prove problematic in regression analyses potentially eliminating linear associations between age and psychosocial well-being.

Race and ethnicity.

Few studies document the differences among different races and ethnicities within the older oncology population and the existing results are mixed (Weiss et al., 2012). Kurtz et al. (2002) explored predictors of depression among 154 adults ages 65 years and older with colorectal using data from a larger 4-wave longitudinal study. African Americans, along with female patients and patients with at least 2 comorbid conditions, were more likely to exhibit depressive symptomology (2002). In contrast, other comparisons between older Whites and African Americans with cancer indicate that there may be a greater sense of resilience among African Americans (Deimling, Wagner, et al., 2006; Nelson, Balk, & Roth, 2010). Deimling, Wagner, et al. (2006) used the first wave of data from a six-wave longitudinal project to explore the relationship between levels of distress and coping among 321 adults ages 58 and older who had survived cancer for over five years. Findings showed that African Americans exhibited less anxiety and overall distress than Whites (2006). Furthermore, race was a significant predictor of cancer-related worries, where African Americans were less likely to have cancer-related worries than Whites (Deimling, Wagner, et al., 2006). Nelson et al. (2010) combined data from 2 separate studies of 723 African American and White men over the age of 18 who had prostate cancer. Although this study was not exclusively focused on older men, the mean ages in the two datasets used were 66 and 71 years of age (2010). Using the Hospital Anxiety and Depression Scale (HADS) and the Distress Thermometer, African American men had higher rates of anxiety in unmatched samples but when matched for education, stage of disease, and age there were no significant differences in distress and fewer African American men met the cut-off for clinical

depression as compared to White men (2010). In a study of 77 African Americans over the age of 50 with cancer, Hamilton et al. (2013) determined that although the rate of depression among participants (12%) was lower than the general population there was increased vulnerability to depression among those who were not involved in religious activities, had lower levels of emotional support, and those who were more collectivist, or concerned about the welfare of others. The authors postulated this concern for others may have been related to not wanting to be a burden to family or friends, causing the older individuals with cancer to share worries, concerns, or information, potentially leading to or enhancing existing depressive symptoms (2012).

Overall, older African American with cancer tend to demonstrate better psychological well-being as measured by distress, anxiety, and depression when controlling for other demographic factors such as socioeconomic status. However, both Deimling, Wagner, et al. (2006) and Nelson et al. (2010) mention the paucity of research comparing ethnic and racial groups, particularly in older subsets of the population, making it difficult to demonstrate consistent results. More studies are needed to further understand these associations as well as explore other areas of psychosocial well-being including cancer related worried and social well-being.

Comorbidities.

A review of the literature found that the presence of non-cancer comorbidities has been linked to depression and other indicators of poor psychological well-being in adults with cancer (Foster et al., 2009). In limited studies among older adults with cancer, the presence of comorbidities has been associated with higher rates of depression and lower levels of well-being. Kurtz et al. (2002) explored predictors of depression among 154 adults ages 65 years and older

with colorectal using data from a larger 4-wave longitudinal study. Participants with 2 or more comorbid conditions were more likely to exhibit depressive symptomology (2002). Although not composed exclusively of older adults, Blank and Bellizzi (2008) explored well-being among cancer survivors using a cross-sectional study of 509 men, ages 47 to 88 years of age, within 8 years of being diagnosed with prostate cancer. Comorbidity was found to be a significant predictor of higher depression scores and poorer well-being (Blank & Bellizzi, 2008). Further compounding the issues, some studies report that cancer survivors report greater numbers of comorbidities than those without cancer (Ogle, Swanson, & Woods, 2000; Santin, Mills, Treanor, & Donnelly, 2012). Higher rates of comorbid conditions among adults with cancer are problematic given the negative association between comorbidities and psychosocial well-being.

Use of a comorbidity measure is preferred over listing the number of co-morbid conditions as an index takes into consideration the severity of the condition and age. Previous assessments of psychosocial well-being among older adults with cancer using strictly the number of co-morbidities may have inaccurate results by not taking these other factors into consideration. This study will match self-report data of comorbid conditions with the Charlson Index, the most commonly used measure to assess comorbidity in individuals with cancer (Lieffers, Baracos, Winget, & Fassbender, 2011). This will allow for a more accurate understanding of the role of comorbidities when assessing psychological well-being.

Socioeconomic status.

While no studies have been done exclusively among older adults with cancer, socioeconomic status and psychosocial well-being appears to be associated among adults with cancer, however, results have been mixed. Simon and Wardle (2008) explored associations between socioeconomic status and psychosocial well-being using a longitudinal study of 352 English

adults with breast, prostate, or colorectal cancer, collecting data at 2 time-points (1-3 months post-diagnosis and 10-13 months post-diagnosis). They found that participants from lower SES backgrounds initially fared worse in depression, anxiety, quality of life, and social difficulties; however, in a 10 month follow-up, these differences were no longer significant (2008). In a cross-sectional study of 560 survivors of cervical cancer identified using the California Cancer Surveillance Program, Ashing-Giwa et al. (2009) sought to better understand cultural and socio-ecological dimensions of health-related quality of life. The results of the study showed that Latina women from lower SES backgrounds experienced the worst quality of life outcomes (2009). The authors postulated that these findings supported previous studies which suggested that resource and economic hardships led to greater burdens in the area of quality of life (2009).

Given the study findings that lower socioeconomic status is associated with poorer psychosocial outcomes, at least at some points in the cancer experience, paired with the increased vulnerability among older adults with poorer finances as seen earlier in the literature review, it is important to explore the associations between socioeconomic status and psychosocial outcomes among older adults. Likely findings among older adults with cancer will be consistent with the adult population, demonstrating that older adults with cancer with a lower socioeconomic status will have poorer psychosocial well-being.

Gender.

Existing literature identifies that older women tend to have poorer psychosocial outcomes in relation to their cancer diagnosis than men (Cohen et al., 2014; Kurtz et al., 2002; Thome & Hallberg, 2004). Cohen et al. (2014) assessed depression and anxiety among 92 individuals with colorectal cancer, half of whom were over the age of 65. They found overall, males had better psychological outcomes than females and those who were older fared better psychologically than

the younger age group (2014). As part of a larger population study, Thome and Hallberg (2004) identified a matched group of 64 Swedish women and 74 Swedish men ages 75 and older who had cancer to explore gender differences in quality of life and social support among older adults with cancer. The study found that women, particularly those who identified increased economic needs, were more likely to experience loneliness and fear than men (2004). These results were particularly pronounced among older women who were facing poorer economic situations (2004). Kurtz et al. (2002) explored predictors of depression among 154 adults ages 65 years and older with colorectal using data from a larger 4-wave longitudinal study. Female patients were more likely to exhibit depressive symptomology than their male counterparts (2002). These studies suggest that older women with cancer are more likely to experience lower levels of psychosocial well-being than their older male counterparts with cancer.

Summary of Literature

The existing literature suggests that, overall, older adults with cancer tend to fare well in terms of psychosocial well-being particularly as compared to younger adults with cancer. However, certain groups seem to be at greater risk for deleterious psychosocial outcomes including those who have been diagnosed with lung cancer, those from a lower socioeconomic status, those with poorer perceived physical well-being, and those who are socially isolated. Further, women are at higher risk for poorer psychosocial outcomes as compared to men. Those who were diagnosed more recently also demonstrated lower levels of psychosocial well-being as compared to longer term survivors.

There are several gaps in the existing literature including few studies of psychosocial well-being among older adults with cancer in the United States, lack of representative samples, failure to adequately investigate within group differences among the aging, and inconsistency

with the definitions of the terms “older adult” and “psychosocial well-being.” In order to best understand how cancer affects psychosocial well-being among older adults, these gaps must be addressed.

Many of the studies that addressed areas of psychological and social well-being were from outside of the United States, primarily Scandinavian countries. While there are most likely overlaps between the populations, Scandinavian countries have different health care delivery systems including how home health care is provided, which could lead to different areas of stress. For instance, according to Maskileyson (2014), older adults in state-based health care systems such as Sweden had significantly better health outcomes than older adults in the United States. As noted earlier, as physical functioning can be linked to psychological and social well-being, different health systems and health outcomes may also result in different psychosocial outcomes. Further, using data from the Survey of Health, Ageing, and Retirement in Europe, Hank (2011) found that over 20% of older Danes met criteria for successful aging as compared to only 10.9% of those in the United States, using similar scoring systems. These differences in overall health and well-being among older adults in Scandinavian countries as compared to the United States, combine with cultural differences in family structure and support may limit our ability to make cross-national comparisons of the effects of cancer on psychosocial well-being.

Additionally, many of the studies used small convenience samples, which resulted in a number of limitations including the possibility of sampling bias (Hurria et al., 2009; Lev et al., 1999; Stanton et al., 2011). Additionally, much of the current research on psychological and social needs of older adults are based on small sample sizes (Dale et al., 2012). Many of the studies reported that their samples over-represented healthier older adults with less severe cancer. Thus, there are limited abilities to generalize and it is likely that psychosocial well-being

was perceived as more positive. Due to these limitations caution must be taken in drawing conclusions from existing literature around psychosocial well-being among older adults with cancer. Dale et al. (2012) contends that larger studies are needed to better understand the interactions between psychological well-being and cancer treatment.

Also, the term “older adult” does not have a consistent definition. While most studies define older adults as over the age of 65, others use the age of 75. This can cause some difficulty in understanding who the subject is that falls into the category of older adult. Previous studies have recommended further breaking down the older age category to recognize differences within this age group (Alon, 2011; Avis & Deimling, 2008). This can be accomplished using standard age ranges of the younger old (ages 65 to 74), the mid-old (ages 75 to 84), and the oldest old (85 years of age and older) (Alon, 2011). Additionally, Galway et al. (2012) emphasize the need to describe results according to gender and age given the existing gender differences found in the literature and the paucity of age-specific studies in the current literature.

Further, the majority of the existing psychosocial research in cancer among older adults uses samples that are white, middle-class individuals, highlighting the need for more research on other ethnic, racial, socioeconomic, and cultural groups (Avis & Deimling, 2008; Cwikel & Behar, 1999; Mitschke, 2008; Weiss et al., 2012). In a review of studies of psychosocial needs among older Black and Hispanic cancer patients, Weiss et al. (2012) only identified one study that examined rates of distress, anxiety, and depression in these groups. Oncology social work occupies a unique niche in psychosocial cancer care as a profession that values cultural diversity and is cognizant of the impact of differences on care and functioning due to religious affiliation, gender or sexual orientation, socioeconomic status, or ethnicity (Raveis, Gardner, Berkman, & Harootyan, 2010). Additionally, past research has largely assumed homogeneity within certain

population groups such as the aging. However, new research is beginning to show within-group heterogeneity (Avis & Deimling, 2008; Esbensen et al., 2004; Thome, Dykes, et al., 2004).

Thus, more emphasis must be placed on identifying within-group differences such as effects of socioeconomic status, race/ethnicity, comorbidities, type of treatment, and cancer type.

Along with issues in sampling, the current research base lacks a consistent definition of psychosocial well-being. Many studies focused primarily on psychological well-being, largely ignoring the social health of individuals. This concern was initially raised by Keyes (1998) who contends that studies of well-being focus on personal functioning and largely ignores the experiences of individuals in the social realm. In order to ensure that findings can be compared across studies, Jarrett et al. (2013) and Galway et al. (2012) suggest using validated measures of psychosocial well-being. Additionally, in order to compare psychosocial well-being across studies, there should be clarity about types of treatment and length of time since diagnosis (2013).

The current study aims to address some of these concerns by employing a stratified sample of adults over the age of 65 who have had cancer within the last five years from a nationally representative panel study. This will help ensure that the results better reflect the heterogeneity of this population in terms of age, race, ethnicity, socioeconomic status, and gender. In order to address the concerns in regards to the definitions of psychosocial well-being, the study will use a validated measure, the Quality of Life-Cancer Survivors (QOL-CS) which was developed specifically for cancer survivors and has undergone extensive psychometric testing. Unlike other more recent measures, the QOL-CS captures social well-being in a way that is more consistent with the domains addressed in the literature. Rather than solely assessing psychological areas as related to social concerns (e.g., measurement of loneliness), the QOL-CS

assesses perceived changes in social domains as a result of the cancer diagnosis including perceived burden on family, financial burden, ability to complete activities at home, and changes in personal relationships. Further, the instrument uses four distinct subscales—physical well-being, psychological well-being, social concerns, and spiritual well-being—to capture quality of life. This allows exploration into psychosocial well-being as a unique construct as well as to further understand the role of perceived physical well-being as that area has been highlighted as a contributor in previous studies.

Purpose of the Study

This study will explore associations between physical well-being, psychological well-being, and social concerns among adults over the age of 65 who have been diagnosed with cancer within the last five years. The Quality of Life Cancer Survivors (QOL-CS) instrument will allow us to better understand within group differences and associations among older adults with cancer in the key areas noted in the literature review. As noted previously, little is known or there are conflicting results in regards to psychosocial well-being as it relates to several demographic and cancer-specific variables. This study will address the gaps in the existing literature by understanding psychosocial well-being among older adults with cancer in the United States using a representative sample that includes diverse populations. As older adults continue to be disproportionately affected by cancer, it is necessary to understand in-group differences among those who are older as well as understand how the burden of cancer is related to psychosocial well-being.

As the demographics of the population over the age of 65 continue to diversify it is important to consider how these changes affect how individuals experience stress related to and appraise and cope with a cancer diagnosis and treatment as seen through their psychosocial well-

being and overall quality of life. Similarly, as these demographic shifts occur, it is also important to consider how our understanding of lifespan theory, as it relates to older adulthood, also may vary. It is important to investigate how chronological and/or other ways to understanding age affects ones psychosocial well-being and ability to attach meaning to cancer diagnosis and treatment.

This study will seek to understand how this within-group heterogeneity affects psychosocial outcomes among older adults with cancer. A cross-sectional study will be used to explore these associations through the distribution of an online survey to a stratified sample drawn from a larger, nationally representative, panel study. The QOL-CS measure will be used, along with demographic and cancer-specific questions, in order to identify associations between psychosocial well-being and specific subgroups within the aging population. This measure not only contains subscales that address psychological well-being and social concerns but also has individual variables within these subscales that address areas that have been found to be of specific importance among older adults with cancer such as family distress and fear of recurrence. Using independent t-tests, ANOVAs, and multiple regression models, the study will analyze variations in psychosocial well-being among these subgroups. Psychosocial well-being will be derived by combining the results of the psychological well-being and social concerns subscales.

The data analysis will seek to understand variations in both the overall scale (QOL-CS) and how socio-demographic and cancer-specific variables interact with the created psychosocial

well-being measure (PSWB). This allows for the isolation of the perceived physical well-being subscale to show how it interacts with the psychosocial domains.

Research Questions and Hypotheses

The main research question will explore the associations between quality of life, psychosocial well-being and cancer diagnosis and treatment among older adults with cancer (Figure 1). Further, subsequent questions will be addressed:

Are within-group socio-demographic differences associated with overall quality of life and psychosocial well-being among older adults with cancer?

Hypothesis 1: Age is positively associated with quality of life and psychosocial well-being.

Hypothesis 2: Males will demonstrate better quality of life and psychosocial well-being than females.

Hypothesis 3: Non-Hispanic Whites will demonstrate poorer quality of life and psychosocial well-being than other racial and ethnic groups.

Hypothesis 4: Annual household income is positively associated with quality of life and psychosocial well-being.

Hypothesis 5: Education is positively associated with overall quality of life and psychosocial well-being.

Hypothesis 6: The co-morbidity index score is negatively associated with overall quality of life and psychosocial well-being.

Are within-group differences in cancer diagnoses and treatment associated with overall quality of life and psychosocial well-being among older adults with cancer?

Hypothesis 7: A diagnosis of lung cancer will demonstrate poorer quality of life and psychological well-being as compared to other types of cancer.

Hypothesis 8: Those treated with chemotherapy will demonstrate poorer quality of life and psychological well-being as compared to other treatment types.

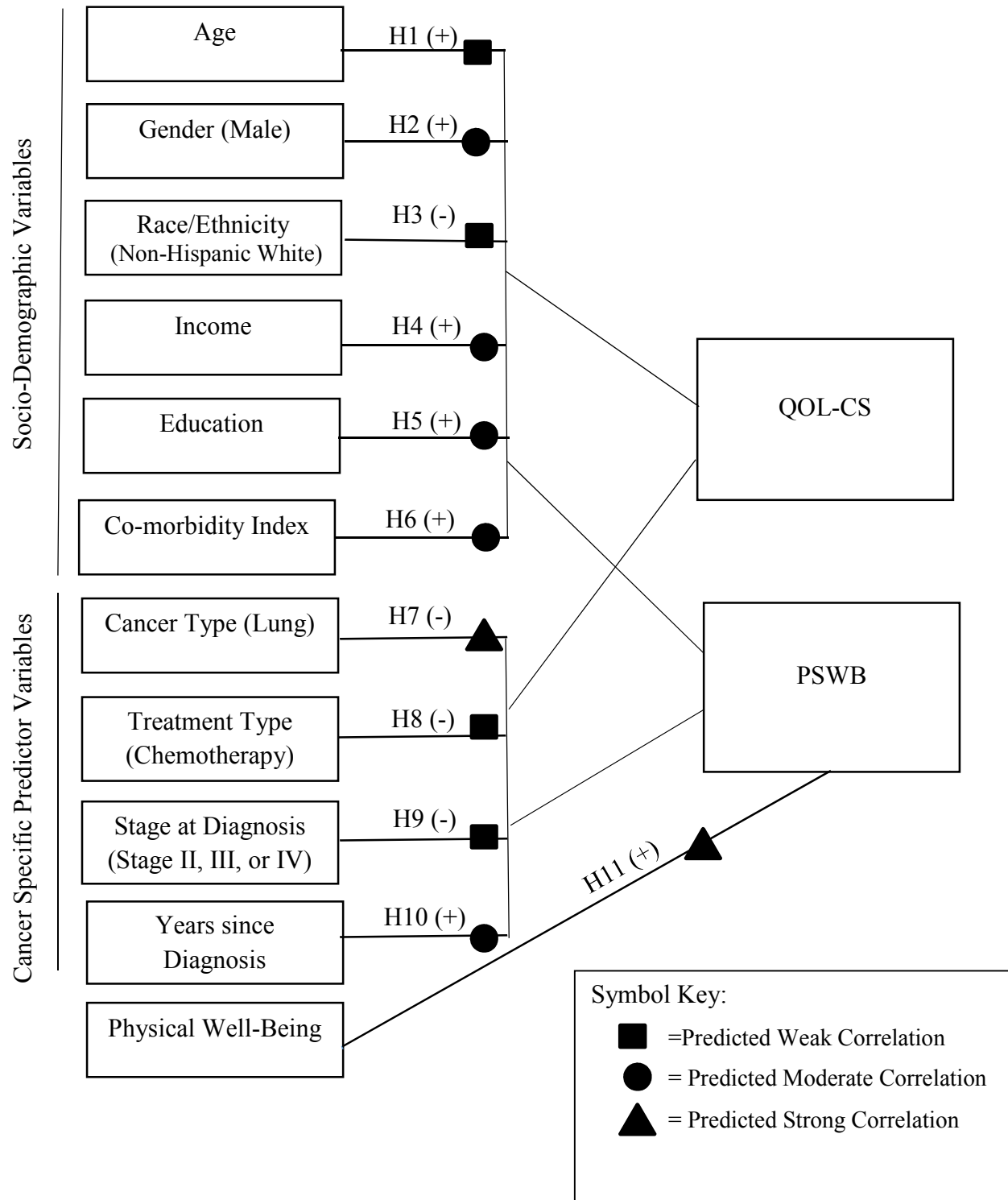
Hypothesis 9: Those diagnosed at a later stage (II, III, or IV) will demonstrate poorer quality of life and psychological well-being as compared to those diagnosed at earlier stages.

Hypothesis 10: Years since diagnosis is positively associated with quality of life and psychosocial well-being.

What role does perceived physical well-being play in psychosocial well-being among older adults with cancer?

Hypothesis 11: Physical well-being is positively associated with psychosocial well-being.

Figure 1: Proposed Conceptual Model: Antecedents of Overall Quality of Life and Psychosocial Well-being among Older Adults with Cancer



CHAPTER 3: Methods

Research Design

This study utilized a cross-sectional design to describe the relationships between cancer diagnosis and treatment variables and psychosocial outcomes. Participation was solicited via an online survey administered through the GfK group. The GfK group designed the online survey using the hard copy developed by the author. The study was approved as an exempt study through the Michigan State University Social Science/Behavioral Education Institutional Review Board (SIRB) (Appendix A).

Independent variables.

Independent variables include self-reported type of cancer, length of time since diagnosis, stage at diagnosis, treatment type, gender, race/ethnicity, income, education, the comorbidity index, and age. Type of cancer, treatment type, gender, race/ethnicity, income and education are coded as dummy variables. Time since diagnosis is reported in years, stage at diagnosis is coded by the self-reported stage and age is reported in years. The age-adjusted co-morbidity index was calculated using the Charlson Comorbidity Index which is based on International Classification of Disease (ICD) codes (Charlson, Pompei, Ales, & MacKenzie, 1987). Self-reported medical conditions and diagnoses, shown in parentheses below, were linked to Charlson comorbidity categories. Each condition/diagnosis was given 1 point unless otherwise noted: myocardial infarction (heart attack), congestive heart failure (heart disease), cerebrovascular disease (stroke), chronic pulmonary disease (asthma or COPD), rheumatologic disease (rheumatoid arthritis), diabetes with chronic complications (diabetes), renal disease (kidney disease), mild liver disease (hepatitis C), and AIDS/HIV (HIV/AIDS, 6 points). Additionally, age was adjusted for decades

over 40, with those ages 60 to 69 given an additional 3 points, 70 to 79 an additional 4 points, 80 to 89 an additional 5 points, and 90 and older an additional 6 points (Fadem, n.d.).

Dependent variables.

The dependent variables are 1) the total score of the QOL-CS and 2) the psychosocial well-being (PSWB) score, which is comprised of the psychological well-being and social concerns subscales of the QOL-CS. The scale consists of 41 items using a 10 point Likert scale. The final scoring for the subscales is based on a scale of 0 (worst outcome) to 10 (best outcome). 27 of the items were reverse-coded. The Cronbach's alpha score for the total score QOL-CS among this sample was .927, indicating a high internal consistency. Additional testing revealed a Cronbach's alpha score of .922 for the psychological well-being subscale and .762 for the social concerns subscale. The two subscales combined, which this study will refer to as the PSWB, had a Cronbach's alpha score of .933. These results were consistent with previous findings from Ferrell, Hassey Dow, and Grant (1995).

Participant Characteristics

A sample of 1282 adults over the age of 65 was drawn from the KnowledgePanel®, an ongoing panel study through the GfK group resulting in a total of 987 completed surveys (see "Sampling Procedure"). Study inclusion criteria included: 1) Be age 65 or older; 2) must have received a cancer diagnosis, not including skin cancer, within the last 5 years as indicated through the annual general population questionnaire; and 3) must read English. Of these, 600 were excluded due to not having been diagnosed with a cancer other than skin in the past five years and an additional 3 participants did not complete the survey instrument. The results reported are derived from final sample of 384 participants.

Sampling Procedure

The sample was drawn from the KnowledgePanel®, a probability sample covering the United States through the GfK Group, formerly known as Knowledge Networks. The panel members were originally recruited using random digit dialing but address-based sampling has been employed since 2009. Using this sampling method, the KnowledgePanel® covers approximately 97 percent of all addresses in the United States. Surveys are conducted online and households are provided with a notebook computer and internet access if needed. Participants in this panel complete an initial profile survey that contains demographic information and this information is updated annually. Efforts are made to limit panel members to four to six surveys per month while still ensuring representative samples.

For this study, GfK drew a random sample of 1,180 of the 1,470 panel participants ages 65 through 85. Additionally, all panel participants over the age of 85 (N=102) were asked to participate in the study. Thus, a total of 1,282 panel participants were sent the survey. Of those, 987 participants responded yielding a response rate of 77%. Of the 987, 39% reported being diagnosed with cancer (other than or in addition to skin) in the last five years resulting in a total analysis sample of 384.

Survey Procedure

The final survey went through two rounds of pre-testing. First, a hard copy and web version of the survey was pre-tested by five social science colleagues to determine which questions may be confusing or problematic. The survey was refined to ask for just the year of diagnosis rather than both the month and year, the cancer specific variables were reordered, and the scale instructions were placed on a separate page to make them more visible. The second round of testing was completed by 20 respondents drawn from the panel with an average

completion time of 20 minutes. Based on their responses, no adjustments were made to the survey following the pre-test. Appendices D and E show the final survey instruments and screen shots of the survey respectively.

Those selected to participate in the survey were notified via e-mail on October 17, 2014, with a link to the survey questionnaire. A standard reminder e-mail was sent to all potential participants after three days. After 6 days in the field, all potential responders received a customized reminder e-mail and, due to the low response rate among adults 85 years and older, non-responders in this age group also received a \$5 incentive to complete the survey. Interactive voice response (IVR) phone calls were also completed with those over the age of 85 between days eight and ten of the survey being in the field. Additionally, all members of the KnowledgePanel® receive modest incentives such as raffles and special sweepstakes which are used to encourage continued panel participation and create member loyalty. The survey closed on October 27, 2014.

Sample Size, Power, and Precision

Sample size was calculated using a 95% confidence level with a confidence interval of 5% resulting in a sample size of 384 (MaCorr, 2014). In a sample of 115 survivors of cancer with an average age of 65, Christy (2010) found mean values of the Quality of Life Cancer Survivors (QOL-CS) instrument domains ranging from 6.96 to 8.14 and accompanying standard deviations ranging from 1.49 to 1.99. These numbers were used to help calculate the known and standard means of the population. Previous research studies indicate that older adult survivors typically fare better than younger adults in the areas of psychological and social well-being. Thus, the expected mean value was increased by 0.25 as the higher the mean on this scale indicates the better the outcome. Using the expected sample size of 384, the power of the two-

tailed test was 0.817 (DSS Research, 2014). Therefore, there is an 85 percent likelihood that the null hypothesis will be correctly rejected when it is false (DSS Research, 2014).

Measures and Covariates

Psychosocial well-being.

The Quality of Life Instrument Cancer Patient/Cancer Survivor (QOL-CS) assesses quality of life in four domains: physical well-being, psychological well-being, social concerns, and spiritual well-being (Ferrell & Grant, n.d.) (Appendix D). It is a 41-item self-report survey that elicits responses using a 0 to 10 Likert scale (Sanson-Fisher, Carey, & Paul, 2009). Scoring ranges from 0 (worst outcome) to 10 (best outcome), with several items requiring reverse scoring due to reverse anchors. The QOL-CS fits well with the theoretical approach as it uses questions on distress, appraisal, coping, and meaning in order to understand psychosocial well-being.

The QOL-CS has undergone extensive psychometric testing, standing up to both measures of reliability and validity using a sample of cancer survivors. Psychometric properties were tested through a mailed survey to the members of the National Coalition for Cancer Survivorship (Ferrell et al., 1995). The final sample consisted of 686 participants; a 57 percent response rate. The mean age was 49.6 years, 81% of the participants were female, and 94% of the sample participants were Caucasian. Two week test-retest reliability for the scale was $r = 0.89$ with subscales ranging from $r = 0.81$ to 0.90 (Ferrell et al., 1995). Internal consistency using Cronbach's α revealed an overall $r = 0.93$ with subscales ranging from $r = 0.71$ to $r = 0.89$. Content validity was assessed through extensive interviews with survivors and quality of life experts. Predictive validity was assessed via step-wise multiple regression which found that seventeen items explained 91 percent of the variance in quality of life. Concurrent validity evaluated the correlations between the QOL-CS and the FACT-G, a validated quality of life

instrument for those with cancer, which revealed an overall correlation of $r = 0.78$. Measures of construct validity were used to further refine the instrument. It is important to note that although the instrument held up quite well to psychometric testing there was little variation in the population in terms of race/ethnicity and it was largely female. Also, no testing has been done on the reliability and validity of this instrument with an exclusively older adult sample.

Although newer quality of life measures have been developed and tested, the QOL-CS was chosen for this study due to its attention to tangible social activities and perceived changes in social functioning rather than measuring psychological responses to social changes due to illness (e.g., perceived loneliness scales to measure isolation). This approach to social well-being allows us to understand perceived changes in ability to participate as a result of illness and treatment.

Cancer-specific variables.

Several variables specific to one's cancer experience were collected in order to best understand differences within the sample. These variables include the types of cancer that have been diagnosed, the year of diagnosis, the stage of diagnosis for their most recent cancer, the types of cancer treatment they have received, the number of recurrences, and the current status of the cancer (e.g., remission, cured). Survey questions were adapted from non-scale questions developed by Dr. Sophia Smith of the Duke School of Nursing (S. K. Smith, 2014).

Socio-demographic variables.

Participant characteristics are drawn from the KnowledgePanel® member profiles which members are required to update annually (Appendix B). All participants in the panel receive an initial demographic survey, which is used to develop a member profile that is then updated annually. Supplemental data was collected from panel participants, which included self-reported

health conditions (Appendix C). The individual demographic and health characteristics were then paired for each participant in this study sample.

Data Analysis

Data cleaning.

Before and following data collection, GfK developed a set of sample-specific weights to allow data adjustment for non-response and non-coverage bias (GfK, 2014). Weighting by GfK occurs in three phases: base weights, panel demographic post-stratification weight, and study-specific post stratification weight. The base weight was initially applied by GfK to offset any deviations from a pure probability sample including undersampling due to telephone numbers unmatched to a valid address and oversampling of certain population groups, census blocks, and regions. The panel post-stratification weight was then applied by GfK prior to the selection of the study and the adjustments are based on the most recent (June 2013) Current Population Survey (CPS) data. To make the sample more reflective of the US population, these weights are applied utilizing post-stratification variables, which include gender, age, race/Hispanic ethnicity, education, census region, household income, home ownership status, metropolitan area, and internet access. Finally, following the data collection, GfK applied study-specific post-stratification weights to account for the sample design and survey non-response. These weights were applied to make the data more reflective of those with cancer over the age of 65. The variables used to weight this data were age (65-69, 70-74, 75-79, 80-84, and 85+), gender, race/ethnicity (White/Non-Hispanic, Black/Non-Hispanic, Hispanic, 2 or more races/Non-Hispanic, and Other/Non-Hispanic), region (Northeast, Midwest, South, West), education (less than high school, high school, some college, and Bachelor's degree or above), and income (under \$25,000, \$25,000-49,999, \$50,000-74,000, and \$75,000 and above). The weights were then

scaled to the sample size of the respondents. Following data cleaning, GfK readjusted the weights to match the final sample.

IBM SPSS Statistics Version 22 was used for data entry and analysis. Prior to data analysis, the data were examined for missing values, outliers, and distributions. First, in order to address missing data within the scale variables, Little's Missing Completely at Random (MCAR) test was used to show that the values were missing at random. The results of the MCAR were not significant, indicating that all of the missing scale variables were missing at random. The expectation-maximization (E-M) imputation algorithm was then used to replace the missing values in the scale. This algorithm employs a process of estimating the missing values using observed data and then repeats the process comparing the observed data and missing values (Lin, 2010). In comparing the E-M imputation algorithm and the Monte Carlo Markov chain (MCMC) method of imputation, Lin (2010) found no significant differences between the two methods for imputing missing values in cross-sectional studies. Missing values in non-scale variables were not replaced but were treated as missing. These missing values occurred primarily in specification of cancer type, stage of diagnosis, and length since diagnosis. This caused the total sample size for the regression models to decrease from $n=384$ to $n=352$. Second, univariate analysis was completed on all variables to determine frequency distribution, measures of central tendency, and to ensure assumptions were met for further data analysis.

Bivariate analysis.

Bivariate analyses were completed with all predictor, control, and dependent variables. Independent t-tests and one-way ANOVA were used to determine whether there were significant differences in means between groups in QOL-CS and PSWB scores. The Levene's test for homogeneity was used to test the assumptions of variance using an alpha level of 0.05. For those

variables that did not meet the assumptions of variance, equal variances were not assumed in the t-test and the Welch test was used for the one-way ANOVA to test equality of means.

Multivariate analysis.

The main analysis employs a regression model to explain variance in psychosocial well-being among older adults with cancer. There are nine main independent variables. Tabachnick and Fidell (2000) suggest a 20:1 ratio of cases to variables in a hierarchical multiple regression. Thus, since the model has eleven main variables, the sample size of 384 is sufficient when using a regression model.

Two sets of hierarchical regression models were used to test the relative contribution of each of the predictor variables while controlling for the effects of other predictor and control variables. The tests for assumptions were met for all of the regression models. The tests for assumption are further discussed in the results.

A hierarchical multiple regression was calculated to predict QOL-CS scores by cancer-specific variables including type of cancer, treatment type, stage at diagnosis, and length since diagnosis. Two models were run; the first model predicted QOL-CS scores based on socio-demographic variables including age, gender, race/ethnicity, income, education, and comorbidity scores and the second model added the cancer-specific variables as the main predictor variables.

A hierarchical multiple regression was then used to predict PSWB scores by cancer-specific variables including type of cancer, treatment type, stage at diagnosis, and length since diagnosis as well as self-reported physical well-being. Three models were run; the first model predicted PSWB scores based on socio-demographic variables including age, gender, race/ethnicity, income, education, and comorbidity. The second model added the cancer-specific

variables as the main predictor variables. The third model added self-reported physical well-being scores.

CHAPTER 4: Results

Socio-Demographic and Cancer-Related Characteristics

The socio-demographic and cancer-related characteristics of the sample participants are provided in Table 1 and Table 2. The majority of the sample participants were male (57%), white, non-Hispanic (88%), and married (68%). While most of the sample participants were ages 65 to 74 (64%), 29% were ages 75 to 84, and an additional 7% were over the age of 85. About a third of the sample participants (34%) had a Bachelor's degree or higher and had an annual household income of over \$75,000. The most commonly reported cancers among participants in this study were prostate (25%), breast (19%), and lung (11%). Approximately a third (31%) of these cancers were diagnosed in stage 1.

Table 1: Personal Characteristics Using Non-Weighted and Weighted Data (N=384)

	Non-weighted		Weighted	
	N	%	N	%
Age				
65-69	140	36.5	109	28.4
70-74	105	27.3	94	24.3
75-79	79	20.6	93	23.7
80-84	34	8.8	42	11.0
85+	26	6.8	49	12.6
Gender				
Female	166	43.2	171	44.5
Male	218	56.8	213	55.5
Race/Ethnicity				
White, Non-Hispanic	336	87.5	307	80.0
Black, Non-Hispanic	20	5.2	41	10.6
Hispanic	18	4.7	19	5.0
Other	10	2.6	17	4.4
Education				
Less than high school	13	3.4	28	7.4
High school	93	24.2	161	41.8
Some college	146	38	89	23.3
Bachelor's degree or higher	132	34.4	106	27.5
Annual Household Income				
Under \$25,000	56	14.6	89	23.3
\$25,000-49,999	120	31.3	126	32.8
\$50,000-74,999	79	20.6	67	17.5
\$75,000-99,999	52	13.5	40	10.5
\$100,000 and higher	77	20.1	61	15.9

Table 2: Cancer and Health Characteristics Using Non-Weighted and Weighted Data (N=384)

	Non-weighted		Weighted	
	N	%	N	%
Type of Cancer				
Bladder	26	6.8	27	7.1
Breast	73	19.0	76	19.7
Colorectal	32	8.3	35	9.0
Leukemia, Lymphoma, or Myeloma	28	7.3	26	6.7
Lung	41	10.7	39	10.2
Prostate	95	24.7	89	23.3
Other	73	19.0	66	17.2
Years Since Diagnosis				
Less than 1	60	15.6	59	15.3
1	86	22.4	83	21.5
2	52	13.5	57	14.9
3	53	13.8	41	10.6
4	70	18.2	74	19.3
5	40	10.4	38	10.0
Missing	23	6.0	32	8.4
Cancer Stage at Diagnosis				
Stage 0	14	3.6	10	2.7
Stage I	118	30.7	114	29.7
Stage II	53	13.8	51	13.2
Stage III	33	8.6	36	9.5
Stage IV	30	7.8	30	7.8
Unknown/Other	136	35.4	143	37.2
Treatment Types				
Surgery only	134	34.9	140	36.4
Surgery and radiation only	39	10.2	41	10.6
Surgery and chemotherapy only	32	8.3	33	8.6
Surgery, chemotherapy, and radiation	21	5.5	21	5.5
Radiation only	43	11.2	40	10.5
Chemotherapy only	26	6.8	25	6.4
Radiation and chemotherapy	14	3.6	15	3.9
Other combination of treatment	42	10.9	36	9.4
No treatment	33	8.6	34	8.7

As seen in Table 3, the average scores for the QOL-CS and PSWB were 324 and 206 respectively, with 451 and 286 as the highest possible scores. The average age of participants was 75 years old. The average physical well-being score was 72 out of a maximum total of 88.

Table 3: Descriptive Statistics of QOL-CS Scores, PSWB Scores, Cancer Variables, and Socio-demographic Variables

Variables	N	Mean	SD	Range	α
QOL-CS	384	324.16	58.86	139-439	0.93
PSWB	384	206.20	45.53	75-279	0.93
Age	384	74.57	6.89	65-93	
Gender ^a	384	0.55	0.50	0-1	
Race/Ethnicity ^b	384	0.80	0.40	0-1	
Income	384	10.96	4.06	1-18	
Education	384	10.06	2.02	1-13	
Co-Morbidity Index	384	5.12	1.50	3-10	
Cancer Type ^c	358	0.11	0.31	0-1	
Treatment Type ^d	384	0.25	0.43	0-1	
Stage at Diagnosis ^e	384	0.30	0.46	0-1	
Years Since Diagnosis	352	2.30	1.66	1-6	
Physical Well-Being	384	71.90	14.27	25-88	0.84

^a Gender: 0=Female, 1=Male.

^b Race/Ethnicity: 0=All other races, ethnicities, 1=White, Non-Hispanic.

^c Cancer Type: 0=All other cancers, 1= Lung Cancer.

^d Treatment type: 0=All treatments except chemotherapy, 1=Chemotherapy.

^e Stage: 0=Stage 0, I, or unknown stage, 1= Stage II, III, or IV.

Bivariate Analysis

Prior to looking at the multivariate analysis, it is useful to examine the bivariate associations between the predictor, control, and dependent variables. A correlation analysis was conducted to determine the strength and significance of relationships among the variables (Table 4). All of the independent variables were significantly correlated with QOL-CS and PSWB with the exception of race/ethnicity and age was not significantly correlated with QOL-CS. All of the

correlations were weak with the exception of physical well-being which was moderately correlated to PSWB. It is important to note that physical well-being and PSWB were not included in the regression analyses for QOL-CS as they comprise three of the subscales of QOL-CS.

Table 4: Correlations of QOL-CS scores, PSWB scores, Cancer Variables, and Socio-demographic Variables (N=384)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. QOL-CS	1												
2. PSWB	^f	1											
3. Years Since Diagnosis	.12*	.14*	1										
4. Cancer Stage ^a	-.23**	-.22**	-.22**	1									
5. Cancer Type ^b	-.33**	-.30**	-.12*	.06	1								
6. Type of Treatment ^c	-.28**	-.26**	-.07	.34**	.24**	1							
7. Physical Well-Being	^f	.65**	.11*	-.22**	-.32**	-.38**	1						
8. Age	.09	.13*	-.02	-.12	.02	-.08	.12*	1					
9. Gender ^d	.15**	.17**	.03	-.09	-.08	-.15**	.20**	.06	1				
10. Race/Ethnicity ^e	-.02	.02	-.05	.02	.10	-.03	.09	.12*	-.06	1			
11. Income	.21**	.20**	-.01	-.07	-.05	-.06	.17**	.05	.22**	.06	1		
12. Education	.20**	.23**	.04	-.05	-.12*	-.05	.19**	.04	.15**	.15**	.47**	1	
13. Comorbid Index	.10**	.08*	.03	-.13**	.06	-.08	.16**	.50**	.00	-.01	-.02	-.02	1

^a Stage: 0=Stage 0, I, or unknown stage, 1= Stage II, III, or IV.

^b Cancer Type: 0=All other cancers, 1= Lung Cancer.

^c Treatment type: 0=All treatments except chemotherapy, 1=Chemotherapy.

^d Gender: 0=Female, 1=Male.

^e Race/Ethnicity: 0=All other races, ethnicities, 1=White, Non-Hispanic.

^f PSWB and physical well-being are subscales of QOL-CS and thus were not part of the final regression models for QOL-CS.

*p<.05. **p<.01.

Socio-demographic variables.

Correlation and simple linear regression analyses were conducted to examine the bivariate relationships between age and QOL-CS, age and PSWB, the co-morbidity index and QOL-CS, and the co-morbidity index and PSWB. While age was significantly correlated to both QOL-CS and PSWB ($r = .091$ and 0.126 , $p < .05$, respectively), it was only significantly associated to PSWB in the regression model ($F(1, 382) = 6.179$, $p < .05$). The results suggest that for every one year in age, the PSWB score increases by 0.83 points. The co-morbidity index was only significantly correlated with QOL-CS ($r = .099$, $p < .05$) and was not significantly associated in the regression model to either QOL-CS or PSWB.

One-way ANOVAs were conducted to determine whether different races/ethnicities, different levels of education and different levels of income were associated with differences in QOL-CS and PSWB scores. No significant main effects were found between race/ethnicity and QOL-CS and PSWB. The one-way ANOVAs for education revealed statistically significant main effects for both QOL-CS scores [$F(3, 380) = 9.16$, $p < 0.000$] and PSWB scores [$F(3, 380) = 10.85$, $p < 0.000$], with effect sizes of $\omega^2 = 0.060$ and $\omega^2 = 0.071$ respectively (Table 5). Post hoc comparisons using Tukey procedures indicated participants with less than a high school education scored significantly lower on the QOL-CS and PSWB than did participants who graduated from high school, participants with some college, and participants with a bachelor's degree or higher (Table 5).

The one-way ANOVA analyses of annual household income and means of QOL-CS [$F(4, 379) = 6.536$, $p < 0.000$] and PSWB [$F(4, 379) = 5.858$, $p < 0.000$] scores revealed statistically significant main effects (Appendix F, Table 10). The ω^2 values equaled 0.055 and 0.048, indicating that approximately 6% and 5% of the variances in the QOL-CS and PSWB scores are

attributable to levels of income respectively. Post hoc comparisons using Tukey procedures indicated that participants with an annual household income of less than \$25,000 scored significantly lower on the QOL-CS and PSWB than did participants who had annual household incomes of \$25,000 to \$49,999, \$75,000 to \$99,999, and \$100,000 and higher (Table 5).

An independent samples t-test was used to determine if there were differences in mean scores on the QOL-CS and PSWB scales between genders. Males had higher mean QOL-CS scores ($t=-3.05$, $p<0.001$) and lower mean PSWB scores ($t=-3.40$, $p<0.001$) than women.

Cancer-specific variables.

One-way ANOVA was used to determine differences in mean scores in QOL-CS and PSWB among different cancer types, stages at diagnosis, and years since diagnosis. The one-way ANOVA comparing different cancer types revealed statistically significant main effects for both QOL-CS scores [*Welch's* $F(6,114.98)=6.04$, $p<0.000$] and PSWB scores [*Welch's* $F(6,115.88)=5.21$, $p<0.000$], with effect sizes of estimated $\omega^2=0.078$ and estimated $\omega^2=0.066$ respectively (Appendix F, Table 10). Post hoc comparisons using Tamhane's t^2 procedures indicated participants with lung cancer scored significantly lower on the PSWB than did participants diagnosed with any other cancer and on the QOL-CS for all cancers except leukemia, lymphoma, and myeloma (Table 5).

There were statistically significant main effects when comparing mean QOL-CS [*Welch's* $F(5, 65.66)=5.046$, $p<0.05$] and PSWB [*Welch's* $F(5, 66.05)=4.490$, $p<0.05$] scores among participants diagnosed at different stages (Appendix F, Table 10). The estimated effect sizes using the Welch F-statistic are $\omega^2=0.050$ (QOL-CS) and $\omega^2=0.043$, indicating that approximately 5% of the variance in the QOL-CS and approximately 4% of variance in PSWB are attributable to stage of diagnosis. Post hoc comparisons using Tamhane's t^2 procedures

indicated participants diagnosed at stage IV scored significantly lower on the QOL-CS and PSWB than did participants diagnosed at stage I or at an unknown stage (Table 5).

The number of years since diagnosis and QOL-CS [*Welch's F*(5, 144.16)=4.292, $p<0.05$] and PSWB [*F*(5,346)=4.024, $p<0.001$] scores also resulted in statistically significant main effects. The effect sizes are $\omega^2=0.045$ (est. using Welch's F-statistic) for QOL-CS and $\omega^2=0.041$ for PSWB, indicating that approximately 5% of the variance in QOL-CS and 4% of the variance in the PSWB are attributable to length since diagnosis. Post hoc comparisons using Tamhane's T2 indicated that participants diagnosed with cancer 2 years ago scored significantly higher on the QOL-CS scale than did participants diagnosed in the past year and 1 year ago. Post hoc comparisons using Tukey procedures indicated that participants diagnosed with cancer in the past year scored significantly lower on the PSWB score than did participants who had been diagnosed 2 years ago, 3 years ago, and 4 years ago.

An independent samples t-test was used to determine if there were differences in mean scores on the QOL-CS and PSWB scales between those who had been treated with chemotherapy and those who had not been treated with chemotherapy. Participants who underwent chemotherapy had lower mean QOL-CS scores ($t=5.34$, $p<0.001$) and lower mean PSWB scores ($t=4.99$, $p<0.001$) than those who did not have chemotherapy treatment.

Physical well-being.

Correlation and simple linear regression analyses were conducted to examine the bivariate relationships between physical well-being and PSWB. Physical well-being was significantly correlated to PSWB ($r = .645$, $p<.05$) and demonstrated a positive significant association with PSWB in the regression analysis [*F*(1, 382)=271.92, $p<.05$]. The results

suggest that for every one unit increase in self-reported physical well-being, the PSWB score increases by 2 points.

Table 5: Tukey and Tamhane's t2 Post Hoc Results and Effect Size of QOL-CS and PSWB by Socio-Demographic and Cancer Specific Variables

QOL-CS									
Mean Differences ($\bar{X}_l - \bar{X}_k$) (Effect size is indicated in parentheses)									
Variable	Group	Mean	1.	2.	3.	4.	5.	6.	7.
Education									
QOL-CS	1. Less than High School	274.76	0.00						
	2. High School	325.28	50.53** (0.89)	0.00					
	3. Some College	321.86	47.10** (0.83)	-3.43	0.00				
	4. Bachelor's Degree or Higher	337.69	62.94** (1.10)	12.41	15.84	0.00			
PSWB	1. Less than High School	164.91	0.00						
	2. High School	205.26	40.35** (0.92)	0.00					
	3. Some College	207.55	42.65** (0.97)	2.29	0.00				
	4. Bachelor's Degree or Higher	217.62	52.72** (1.20)	12.37	10.07	0.00			
Income									
QOL-CS	1. Less than \$25,000	301.07	0.00						
	2. \$25,000 to \$49,999	329.91	28.84** (0.50)	0.00					

Table 5 (cont'd)

	3. \$50,000 to \$74,999	318.20	17.14	-11.71	0.00				
	4. \$75,000 to \$99,999	346.20	45.14** (0.79)	16.29	28.00	0.00			
	5. \$100,000 and Higher	338.07	37.01** (0.65)	8.16	19.87	-8.13	0.00		
PSWB	1. Less than \$25,000	189.70	0.00						
	2. \$25,000 to \$49,999	210.57	20.88** (0.47)	0.00					
	3. \$50,000 to \$74,999	200.86	11.16	-9.71	0.00				
	4. \$75,000 to \$99,999	223.29	33.59** (0.76)	12.71	22.43	0.00			
	5. \$100,000 and Higher	215.93	26.24** (0.59)	5.36	15.08	-7.35	0.00		
Cancer Type ^a									
QOL-CS	1. Bladder	345.31	0.00						
	2. Breast	332.84	-12.48	0					
	3. Colorectal	318.84	-26.48	-14.00	0				
	4. Lung	268.68	-76.64* (0.48)	-64.16* (0.40)	-50.16* (0.31)	0			
	5. Prostate	336.35	-8.97	3.51	17.51	67.67* (0.42)	0		
	6. Leukemia, lymphoma, or myeloma	320.25	-25.06	-12.59	1.42	51.58	-16.10	0	
	7. Other	323.72	-21.59	-9.12	4.89	55.04* (0.34)	-12.63	-3.47	0
PSWB	1. Bladder	221.67	0.00						

Table 5 (cont'd)

	2. Breast	211.67	-9.99	0					
	3. Colorectal	201.71	-19.96	-9.97	0				
	4. Lung	166.3	-55.37* (0.48)	-45.38* (0.39)	-35.41	0			
	5. Prostate	215.45	-6.22	3.78	13.74	49.15* (0.43)	0		
	6. Leukemia, lymphoma, or myeloma	203.68	-17.99	-7.99	1.97	37.38	-11.77	0	
	7. Other	205.3	-16.37	-6.37	3.59	39.00* (0.34)	-10.15	1.62	0
Stage at Diagnosis ^a									
QOL-CS	1. Stage 0	350.42	0						
	2. Stage I	328.41	-22.01	0					
	3. Stage II	308.2	-42.23	-20.21	0				
	4. Stage III	308.86	-41.56	-19.55	0.66	0			
	5. Stage IV	291.46	-58.97	-36.95* (0.29)	-16.74	-17.40			
	6. Unknown/Other	335.25	-15.18	6.84	27.05	26.39	43.79* (0.35)	0	
PSWB	1. Stage 0	217.22	0						
	2. Stage I	207.09	-10.13	0					
	3. Stage II	193.98	-23.25	-13.11	0				
	4. Stage III	193.12	-24.10	-13.97	-0.86	0			
	5. Stage IV	184.39	-32.83	-22.70	-9.59	-8.73	0		

Table 5 (cont'd)

	6. Unknown/Other	216.91	-0.31	9.82	22.93* (0.24)	23.79	32.52* (0.34)	0
Years since Diagnosis								
QOL-CS ^a	1. Less than 1 year	299.00	0.00					
	2. 1 year	318.65	19.65	0.00				
	3. 2 years	345.59	46.59** (0.80)	26.93* (0.46)	0.00			
	4. 3 years	330.01	31.01	11.36	-15.57	0.00		
	5. 4 years	330.31	31.31	11.66	-15.27	.301	0.00	
	6. 5 years	319.86	20.86	1.20	-25.73	-10.16	-10.46	0.00
PSWB	1. Less than 1 year	185.61	0.00					
	2. 1 year	202.05	16.44	0.00				
	3. 2 years	219.19	33.58** (0.74)	17.14	0.00			
	4. 3 years	212.45	26.84* (0.60)	10.40	-6.74	0.00		
	5. 4 years	212.57	26.96* (0.60)	10.52	-6.61	.124	0.00	
	6. 5 years	202.70	17.09	.644	-16.49	-9.75	-9.88	0.00

^aTamhane's t2 was used for post-hoc analysis as the assumption for equality of variance was not met.

*p<.05; **p<.01

Multivariate Analysis

QOL-CS scores.

Hierarchical multiple regression was used to predict QOL-CS scores by cancer-specific variables including type of cancer, treatment type, stage at diagnosis, and length since diagnosis. Two models were run; the first model predicted QOL-CS scores based on socio-demographic variables including age, gender, race/ethnicity, income, education, and comorbidity scores and the second model added the cancer-specific variables as the main predictor variables.

The models were first tested for assumptions and adequately met. Multicollinearity was not a concern in either model as all of the VIF values were below 10 (Range: 1.03 to 2.98) and the tolerance values were all greater than 0.1 (Range: 0.288 to 0.968). The histogram of standardized residuals indicated that the data contains approximately normally distributed errors, as did the normal P-P plot of standardized residuals. The scatterplot of standardized predicted values confirmed that assumptions of homoscedasticity and linearity were met in these models.

Model 1: QOL-CS and socio-demographic variables.

Model 1 attempted to predict QOL-CS scores by socio-demographic characteristics of the participants including age, gender, race/ethnicity, income, education, and their comorbidity index. Age, gender, Hispanic in comparison to White non-Hispanic, income, education, and comorbidity index all had statistically significant yet weak ($0.09 \leq r \leq 0.17$) zero-order correlations with QOL-CS (Table 4). However, only gender and education had significant partial effects in the full model (see Table 6). The model was able to account for 10% of the variance in QOL-CS, ($F(9,342) = 4.181, p < .000$), with an R^2 of .099 and an adjusted R^2 of .075.

Results from Model 1 support some of the main hypotheses outlined in the conceptual model. QOL-CS scores for men ($M=332.27, S.D. =56.90$), as predicted, were statistically higher

than those for women ($M=314.04$; $S.D. =59.87$). Education was related to QOL-CS, showing that for each unit increase in educational level, QOL-CS scores increased by 5 points.

Model 2: QOL-CS and cancer-specific predictor variables.

Model 2 examined the predictive values of cancer-specific variables including cancer type, treatment type, stage at diagnosis, and years since diagnosis, while controlling for socio-demographic variables outlined in Model 1. Cancer-specific predictor variables of bladder cancer or prostate cancer in comparison to lung cancer, no chemotherapy as compared to chemotherapy, unknown stage of diagnosis in comparison to diagnosis at stages II, III, and IV, and years since diagnosis all had significant ($p<0.05$) but weak ($0.11 \leq r \leq 0.29$) zero-order correlations with QOL-CS. However, in the full model significant partial effects were found for education, all types of cancer (bladder; breast; colorectal; leukemia, lymphoma and myeloma; prostate, and other identified cancers) in comparison to lung cancer, no chemotherapy in comparison to chemotherapy, and unknown stage at diagnosis and diagnosis at stage 0 or I as compared to stage II, III, and IV. This model accounted for 26% of the variance in QOL-CS, ($F(19,332) = 6.247$, $p<.000$), with an R^2 of .263 and an adjusted R^2 of .221. Thus, the cancer-specific variables in model 2 accounted for an incremental 16% (F Change (10,331) = 7.402, $p<.000$) of the variance in QOL-CS scores above and beyond the variance accounted for by socio-demographic variables.

As hypothesized, participants with lung cancer ($M = 268.68$; $S.D. = 70.03$) scored significantly lower on quality of life than participants reporting diagnosis with any other form of cancer. Type of treatment was also found to be statistically significant as those having undergone chemotherapy had lower QOL-CS scores ($M = 296.09$; $S.D. = 64.11$) than those who were not treated with chemotherapy ($M = 333.17$; $S.D. = 54.19$). As hypothesized, those who

were diagnosed at later stages of cancer had statistically significant lower QOL-CS scores ($M = 304.14$; $S.D. = 61.07$) than those who had been diagnosed at stages 0 or I ($M = 330.23$; $S.D. = 57.42$) or were unaware of their stage of diagnosis ($M = 335.25$; $S.D. = 54.38$).

After adding the cancer-specific predictor variables only education continued to be a significant predictor of QOL-CS. In this final model, gender was no longer a statistically significant indicator of QOL-CS scores.

Table 6: Summary of Hierarchical Regression Analysis for Variables Predicting QOL-CS Scores (N=352)

Variable	Model 1				Model 2			
	<i>B</i>	<i>SE B</i>	β	t	<i>B</i>	<i>SE B</i>	β	t
Age	0.26	0.53	0.03	0.49	-0.27	0.51	-0.03	-0.53
Gender ^a	13.16	6.37	0.11*	2.07	9.68	8.62	0.08	1.12
Race/Ethnicity ^b								
Black, Non-Hispanic	11.63	9.81	0.06	1.19	6.24	9.26	0.03	0.67
Hispanic	-15.28	13.64	-0.06	-1.12	-23.09	12.94	-0.09	-1.78
2 or More Races, Non-Hispanic	-15.98	24.41	-0.03	-0.66	-23.03	23.13	-0.05	-1.00
Race other than White or Black, Non-Hispanic	31.81	21.86	0.08	1.46	38.23	20.34	0.09	1.88
Income	1.37	0.87	0.09	1.57	1.36	0.82	0.09	1.67
Education	4.75	1.76	0.16**	2.71	3.54	1.64	0.12*	2.16
Co-morbidity Index	3.68	2.34	0.10	1.58	4.19	2.22	0.11	1.89
Type of Cancer ^c								
Bladder					64.29	13.98	0.29**	4.60
Breast					53.57	11.80	0.37**	4.54
Colon/Rectal					54.58	12.72	0.27**	4.29
Prostate					40.12	12.12	0.29**	3.31
Leukemia, Lymphoma, Myeloma					50.08	13.86	0.22**	3.61

Table 6 (cont'd)

Other Type of Cancer (e.g. Kidney, Uterine)	41.86	11.31	0.27**	3.70
Treatment Type	22.11	7.94	0.16**	2.78
Stage at Diagnosis ^d				
Stage 0 or I	17.93	7.79	0.14*	2.30
Unknown Stage	25.87	7.75	0.21**	3.34
Years since Diagnosis	1.43	1.80	0.04	0.79
R^2	0.099		0.263	
Adjusted R^2	0.075		0.221	
F for change in R^2	4.181**		7.402**	

^a Gender: 0=Female, 1=Male.

^b Race/Ethnicity: Race/ethnicity was represented as four dummy variables with Non-Hispanic White serving as the reference group.

^c Type of cancer: Type of cancer was represented as seven dummy variables with lung cancer serving as the reference group.

^d Stage at diagnosis was represented as two dummy variables with those diagnosed at stages II, III, or IV serving as the reference group.

* $p < 0.05$. ** $p < 0.01$.

PSWB scores.

Hierarchical multiple regression was used to predict PSWB scores by cancer-specific variables including type of cancer, treatment type, stage at diagnosis, and length since diagnosis as well as self-reported physical well-being. Three models were run; the first model predicted PSWB scores based on socio-demographic variables including age, gender, race/ethnicity, income, education, and comorbidity. The second model added the cancer-specific variables as the main predictor variables. The third model added self-reported physical well-being scores.

The models were first tested for assumptions and were sufficiently met. Multicollinearity was not a concern in these models as all of the VIF values were below 10 (Range: 1.03 to 2.49) and the tolerance values were all greater than 0.1 (Range: 0.279 to 0.974). The histogram of standardized residuals indicated that the data contains approximately normally distributed errors, as did the normal P-P plot of standardized residuals. The scatterplot of standardized predicted values confirmed that assumptions of homoscedasticity and linearity were met in these models.

Model 1: PSWB and socio-demographic variables.

Model 1 predicted PSWB scores by socio-demographic characteristics of the participants including age, gender, race/ethnicity, income, education, and their comorbidity index. Age, gender, Hispanic in comparison to White non-Hispanic, income, and education all had significant ($p < 0.05$) yet weak ($-0.096 \leq r \leq 0.247$) zero-order correlations with PSWB. However, only gender and education had significant ($p < 0.05$) partial effects in the full model (see Table 7). The model was able to account for 11% of the variance in PSWB, ($F(9,342) = 4.583, p < .000$), with an R^2 of .108 and an adjusted R^2 of .084.

Results from Model 1 support some of the main hypotheses outlined in the conceptual model. PSWB scores for men ($M=213.18, S.D. = 43.78$), as predicted, were statistically higher

than those for women ($M=197.50$; $S.D. =46.30$). Education was positively statistically significantly related to PSWB, showing that for every increase in educational level, PSWB scores increased by 4 points.

Model 2: PSWB and cancer-specific predictor variables.

Regression coefficients are presented in Table 7. Model 2 examined the predictive values of cancer-specific variables while controlling for socio-demographic variables outlined in Model 1. Cancer-specific predictor variables of bladder cancer or prostate cancer in comparison to lung cancer, no chemotherapy as compared to chemotherapy, unknown stage in comparison to diagnosis at stages II, III, and IV, and years since diagnosis all had significant ($p<0.05$) yet weak ($0.106 \leq r \leq 0.271$) zero-order correlations with PSWB. Gender, Hispanic in comparison to White non-Hispanic, income, education, and comorbidity index all had significant ($p<0.05$) zero-order correlations with PSWB. However, within the full model gender, education, all types of cancer in comparison to lung cancer, no chemotherapy in comparison to chemotherapy, and stages 0 and I and unknown stage at diagnosis as compared to stage II, III, and IV had significant ($p<0.05$) partial effects in the full model.

The model was able to account for 26% of the variance in PSWB, ($F(19,332) = 6.007$, $p<.000$), with an R^2 of .256 and an adjusted R^2 of .213. Thus, the cancer-specific variables in model 2 accounted for an incremental 15% of the variance in PSWB scores above and beyond the variance accounted for by socio-demographic variables with an F-change of 6.611 ($p < .000$) from model 1.

Results from Model 2 partially support the hypotheses. As hypothesized, participants with lung cancer scored statistically significantly lower on PSWB than participants reporting diagnosis with any other form of cancer. Type of treatment was also found to be statistically

significant as those having undergone chemotherapy had lower PSWB scores than those who were not treated with chemotherapy. As hypothesized, those who were diagnosed at later stages of cancer had statistically significant lower PSWB scores than those who were diagnosed at an earlier stage or unaware of their stage of diagnosis.

After adding the cancer-specific predictor variables only education continued to be significant predictor of PSWB. In this model, gender was no longer a statistically significant indicator of PSWB scores.

Model 3: PSWB and physical well-being.

Model 3 examined the predictive values of physical well-being while controlling for socio-demographic and cancer specific variables as outlined in models 1 and 2. Physical well-being had a strong ($r = 0.653$) statistically significant ($p < 0.05$) zero-order correlation with PSWB. Within the full model, along with physical well-being, non-Hispanic race other than Black or White as compared to White, education, a cancer other than those specified (bladder, breast, prostate, colorectal, leukemia, lymphoma, myeloma) as compared to lung, and unknown stage at diagnosis as compared to stage II, III, and IV had significant ($p < 0.05$) partial effects in the full model.

The model was able to account for 49% of the variance in PSWB, ($F(20,331) = 15.811$, $p < .000$), with an R^2 of .489 and an adjusted R^2 of .458. Thus, the addition of physical well-being in model 3 accounted for an additional 23% of the variance in PSWB scores above and beyond the variance accounted for by socio-demographic and cancer-specific variables with an F -change of 150.618 ($p < .000$).

Results from Model 3 supported the hypothesis that physical well-being is positively associated with PSWB. When controlling for socio-demographic and cancer specific variables,

for every one unit increase of physical well-being there is a 1.87 increase in PSWB scores ($p < 0.01$). After adding physical well-being, education, those reporting an “other” type of cancer compared to lung, and unknown stage at diagnosis as compared to stages II, III, and IV continued to be significant predictors of PSWB. Additionally, those who were non-Hispanic and didn’t identify their race as White or Black had significantly higher PSWB scores as compared to those who identified as White. In this model, most cancer types (bladder, breast, colorectal, prostate, leukemia/lymphoma/myeloma) compared to lung, no chemotherapy compared to chemotherapy, and stages 0 and I as compared to stages II, III, and IV, were no longer a statistically significant indicators of PSWB scores.

Table 7: Summary of Hierarchical Regression Analysis for Variables Predicting PSWB Scores (N=352)

Variable	Model 1				Model 2				Model 3			
	<i>B</i>	<i>SE B</i>	β	t	<i>B</i>	<i>SE B</i>	β	t	<i>B</i>	<i>SE B</i>	β	t
Age	0.52	0.40	0.08	1.29	0.11	0.40	0.02	0.28	0.29	0.33	0.04	0.88
Gender ^a	11.37	4.91	0.12*	2.32	9.27	6.71	0.10	1.38	-0.65	5.63	-0.01	-0.12
Race/Ethnicity ^b												
Black, Non-Hispanic	1.99	7.55	0.01	0.26	-2.55	7.20	-0.02	-0.35	0.74	5.98	0.01	0.12
Hispanic	-11.88	10.50	-0.06	-1.13	-18.15	10.06	-0.09	-1.80	-12.57	8.37	-0.06	-1.50
2 or More Races, Non-Hispanic	-23.52	18.79	-0.07	-1.25	-28.35	17.98	-0.08	-1.58	-9.33	15.01	-0.03	-0.62
Race other than White or												
Black, Non-Hispanic	24.94	16.83	0.08	1.48	29.63	15.81	0.09	1.87	36.62	13.14	0.11**	2.79
Income	0.65	0.67	0.06	0.96	0.63	0.63	0.06	0.99	0.21	0.53	0.02	0.40
Education	4.47	1.35	0.20**	3.31	3.65	1.27	0.16**	2.87	2.16	1.06	0.09*	2.03
Co-morbidity Index	1.74	1.80	0.06	0.97	1.83	1.73	0.06	1.06	-1.60	1.46	-0.05	-1.09
Type of Cancer ^c												
Bladder					43.28	10.87	0.25**	3.98	13.66	9.34	0.08	1.46
Breast					38.52	9.17	0.34**	4.20	10.28	7.96	0.09	1.29
Colon/Rectal					37.56	9.89	0.24**	3.80	14.61	8.42	0.10	1.74
Prostate					26.90	9.43	0.25**	2.85	9.87	7.95	0.09	1.24

Table 7 (cont'd)

Leukemia, Lymphoma,								
Myeloma	33.92	10.78	0.19**	3.15	9.96	9.16	0.06	1.09
Other Type of Cancer (e.g.								
Kidney, Uterine)	31.06	8.79	0.26**	3.53	19.28	7.36	0.16**	2.62
Treatment Type	15.12	6.18	0.14*	2.45	1.31	5.25	0.01	0.25
Stage at Diagnosis ^d								
Stage 0 or I	11.31	6.05	0.12*	1.87	4.78	5.05	0.05	0.95
Unknown Stage	21.47	6.03	0.22**	3.56	16.08	5.02	0.17**	3.20
Years since Diagnosis	1.93	1.40	0.07	1.38	1.60	1.16	0.06	1.37
Physical Well-Being					1.87	0.15	0.58**	12.27
R^2	0.108		0.256				0.489	
Adjusted R^2	0.084		0.213				0.458	
F for change in R^2	4.583**		6.611**				150.618**	

^a Gender: 0=Female, 1=Male.

^b Race/Ethnicity: Race/ethnicity was represented as four dummy variables with Non-Hispanic White serving as the reference group.

^c Type of cancer: Type of cancer was represented as seven dummy variables with lung cancer serving as the reference group.

^d Stage at diagnosis was represented as two dummy variables with those diagnosed at stages II, III, or IV serving as the reference group.

* $p < 0.05$. ** $p < 0.01$.

CHAPTER 5: Discussion

This study explored the associations between socio-demographic variables, cancer-specific variables, quality of life, and psychosocial well-being among older adults with cancer. Findings support the hypotheses in the original model although the strength of these associations are weaker than findings in previous literature suggest. Additionally, the results confirm the importance of assessing physical well-being when considering overall psychosocial well-being. This study helps us better understand how differences in gender, education, cancer type, treatment type, stage, and physical well-being among the older adult population with cancer may influence their ability to cope and adjust as demonstrated through their overall psychosocial well-being and quality of life. These findings will allow us to further target social work interventions and policy to meet the needs of the most vulnerable groups within this growing population group.

Summary of Major Findings

Socio-demographic variables

The results indicate that while socio-demographic variables are associated with quality of life and psychosocial well-being, the strength and significance of these associations may not be as pronounced as suggested in previous research findings. The socio-demographic variables only accounted for 10 percent and 11 percent of the variance in QOL-CS and PSWB scores, respectively. While the majority of the socio-demographic variables demonstrated significant correlations with the QOL-CS and PSWB, the significance was no longer evident in the subsequent regression models. Gender was significantly associated with both PSWB and QOL-CS when controlling for other socio-demographic variables, demonstrating that older women with cancer report poorer quality of life and psychosocial outcomes than older men with cancer.

Education was a significant predictor of QOL-CS and PSWB in all regression models demonstrating that higher educational levels were associated with better quality of life and psychosocial well-being reports.

Consistent with previous findings, women with cancer in this study reported poorer psychosocial outcomes than men with cancer (Kurtz et al., 2002; Linden, Vodermaier, MacKenzie, & Greig, 2012; Thome & Hallberg, 2004). Linden et al. (2012) assessed 10,153 individuals diagnosed with cancer between 2004 and 2009 using the Psychosocial Screen for Cancer questionnaire. In this study, women demonstrated significantly higher rates of depression and anxiety than men, among some cancer types prevalence rates were two to three times higher than men. This is mirrored in the older adult population, with studies emphasizing the importance of addressing social isolation, social interactions, and expression of feelings among older women in order to combat poorer psychological and social outcomes (Kurtz et al., 2002; Thome & Hallberg, 2004). The findings of this study, along with previous studies, indicate that women are at higher risk for deleterious outcomes and emphasize the importance of assessing the specific psychosocial needs of women. Further, previous studies show a need for interventions to the most vulnerable women, specifically those who are socially isolated due to circumstances not personal preferences. Interventions should be designed to help alleviate undesired isolation among women with cancer, which, in turn, will promote better overall psychosocial well-being.

This study identified that educational level is significantly positively associated with both QOL-CS and PSWB. Although the correlations were fairly weak, this supports previous research, which suggest that lower educational levels are associated with poorer quality of life outcomes among cancer survivors (Ashing-Giwa, Ganz, & Petersen, 1999; Bellizzi et al., 2012;

Mehnert & Koch, 2008). These differences in well-being may be partially attributed to patient-provider communication and lack of understanding of the disease process. In a study of 114 women with breast cancer, Matsuyama et al. (2011) found that those with lower educational attainment reported more information needs about their diagnosis, prognosis, treatment, psychosocial and emotional concerns. However, this may be compounded by decreased communication with provider. In a study of 405 newly diagnosed women with breast cancer, Simonoff, Graham, and Gordon (2006) found that women who were older and less educated were less likely to ask additional questions and be asked additional questions by providers. Lower educational levels are also related to lower rates of health literacy. In a study of 3,260 Medicare enrollees between June and December 1997, Gazmararian et al. (1999) found that 34% of English-speaking and 54% of Spanish speaking participants had marginal or low health literacy. The ability for older cancer patients to understand and communicate diagnoses has been linked to increased self-efficacy which, in turn, is associated with lower levels of depression and better psychosocial adjustment post-diagnosis (Amalraj, Starkweather, Nguyen, & Naeim, 2009). Our findings demonstrating associations between lower education and lower psychosocial well-being may be linked to lower health literacy rates. This emphasizes the importance of providing understandable communication of diagnoses and treatment to older adults with cancer so they feel equipped to make health care decisions. Oncology social workers can play a role in assessing health literacy of older adult patients and using those assessments to provide clear explanations in regards to cancer diagnosis and treatment.

Race/ethnicity was not significantly correlated with either QOL-CS nor PSWB however when controlling for other socio-demographic variables, cancer specific variables, and physical well-being, those who did identify as a race/ethnicity other than Hispanic, White, or Black

demonstrated better psychosocial outcomes than Whites. Although overall race/ethnicity was not significant in predicting QOL-CS or PSWB, the findings of this study were consistent with previous studies showing Blacks had better psychosocial outcomes and Hispanics had poorer psychosocial outcomes as compared to those who were White (Ashing-Giwa et al., 2009; Deimling, Bowman, et al., 2006; Kurtz et al., 2002; Nelson et al., 2010; Stommel et al., 2004). Janz et al. (2009) suggests that Hispanics/Latinos may be more vulnerable to poorer psychosocial outcomes following a cancer diagnosis due to lack of culturally appropriate services and those with the lowest levels of acculturation were the most vulnerable. Similarly, in a study of breast cancer survivors of all ages, Giedzinska, Meyerowitz, Ganz, and Rowland (2004) found that Latina women had the poorest psychosocial outcomes. Further, African American women, compared to other racial and ethnic groups, had the best psychosocial outcomes despite the most physical symptoms, which the results of the study suggested may be due to stronger social networks, attributing more meaning to their diagnosis, and the fewest changes in sexual functioning (Giedzinska et al., 2004). Better understanding levels of acculturation and meaning may better inform these racial and ethnic differences among older adults as well.

This study used weighted data which closely represented the racial and ethnic profiles of those over the age of 65 in the United States with a slight over-representation of non-Hispanic African American/Black and non-Hispanic other, and a slight under-representation of those who identified as Hispanic. United States Census data from 2008 indicated that of those over the age of 65, approximately 80% identified as non-Hispanic White, 8.2% African American/Black, 6.8% Hispanic, and 4.4% as other (United States Administration on Aging, 2015). Although the data were representative, the sample sizes within subgroups were small. This continued challenge further emphasizes the need to oversample older adults with cancer who are racial

and/or ethnic minorities so we can have a clearer understanding of their specific needs. Further, qualitative studies may further inform our understanding of why psychosocial outcomes vary.

Contrary to initial hypotheses, age was not significantly associated with psychosocial well-being among older adults with cancer. This could be due to a variety of factors including heterogeneity of population in other areas or vulnerability at opposite ends of the older adult population. Previous studies of older adults in general have shown that the oldest-old are the most likely to feel socially disconnected and lonely, often due to functional limitations and multiple losses (Ailshire & Crimmins, 2011; Fees, Martin, & Poon, 1999; Martin et al., 2006). Thus, while the younger old (ages 65 to 74) may experience more distress as a result of a cancer diagnosis and treatment as suggested in the stress, coping, and appraisal models; the oldest-old (ages 85 and older) may have begun their cancer experience at a lower psychosocial baseline due to other factors related to aging.

There were also no significant associations between income and psychosocial well-being in this study. In a study of older adults in England, Grundy and Holt (2001) noted the difficulty in using income as a measure of socioeconomic status among older adults due to problems with reverse causation. Unlike education, which is typically fixed at a younger age, upon entering older adulthood income usually varies due to retirement and receipt of government assistance (both in-kind and direct) resulting in measurement challenges (2001). These compounding factors in measuring household income potentially contributed to the lack of significant relationships between income and psychosocial well-being in this study.

Finally, no significant associations were found between the co-morbidity index and psychosocial well-being. Developing an accurate measure of co-morbidity proved challenging in this study as it relied on pre-collected data which did not include all possible co-morbidities

listed in the Charlson Index and included no indicators of the severity of the co-morbidities. Thus, the accuracy of this measure may have been compromised due to inadequate data collection. However, given the strong associations between physical well-being and psychosocial well-being there are indications that poorer baseline abilities in physical functioning as a result of comorbidities may contribute to poorer psychosocial outcomes as a result of a cancer diagnosis and subsequent treatment. This is mirrored in a study of older adults with cancer conducted by Hewitt, Rowland, and Yancik (2003), showing that those individuals with comorbid conditions experienced poor health and disabilities, including mental health difficulties, five to ten times more than expected. Although the results of this present study were not significant they indicated that as one's score on the comorbidity index increased, indicated more comorbidities and/or increased age, one's self-reported psychosocial well-being and quality of life scores also improved. The only exception was when physical well-being was taken into account. As these results are contrary to existing research, future research will need to use consistent co-morbidity measures to more accurately understand the role of comorbidities in psychosocial well-being and quality of life.

Cancer-specific variables.

The results largely supported the initial hypotheses in relation to cancer-specific variables with the exception of years since diagnosis. These variations due to differences in cancer diagnosis and treatment as they affect psychosocial well-being allow us to better structure our intervention approaches as well as determine who may be in most need of targeted interventions and therapy.

Consistent with previous studies, those participants with lung cancer experienced much lower levels of psychosocial well-being and quality of life than those who reported other forms

of cancer. When adding cancer-specific variables to the regression model, findings indicate that QOL-CS and PSWB scores among older adults with cancer ranged from 40 and 27 points higher among those with prostate cancer to 64 and 43 points higher among those with bladder cancer when compared to those participants with lung cancer respectively. This may be largely connected to the effects of a lung cancer diagnosis and treatment on overall physical functioning as compared to other cancer sites. Kurtz et al. (2002) suggest that those with lung cancer demonstrate the greatest declines in function as compared to breast cancer due to the more debilitating nature of the treatment as well as lower levels of pre-diagnosis functioning. The results of this study partially confirm these findings as when physical well-being was added to the PSWB regression model, only those diagnosed with less common types of cancer (e.g., kidney, uterine, and pancreas) continued to have significantly higher scores than lung. This shows that those with lung cancer may experience lower levels of physical well-being thus affecting other areas of well-being including psychological and social well-being.

Findings also suggested that older adults treated with chemotherapy were at risk for poorer self-reported psychosocial well-being. This study was able to show a significant, albeit small, associations between receipt of chemotherapy and psychosocial well-being among older adults with cancer unlike Stommel et al. (2004) and Perkins et al. (2007) who attempted to show associations between chemotherapy and depressive symptoms in similar populations. Although this study attempted to understand these differences more comprehensively by controlling for factors such as co-morbidities, cancer site, stage of diagnosis, and years since diagnosis other factors need to be taken into consideration such as when the treatment occurred in relation to the diagnosis, length of treatment, and dosing levels. As treatment options are presented to older

adults, the deleterious potential psychosocial outcomes associated with chemotherapy should be articulated in order to ensure fully informed decision-making.

As with previous studies, collecting accurate data regarding stage at diagnosis was difficult to obtain. Over a third of participants reported that they did not know their stage at diagnosis or reported other stages. These responses varied from stage 6 to being rushed immediately into surgery to saying that their doctor never told them their stage. Despite difficulties in measurement, those diagnosed in stages II, III, and IV did have significantly worse quality of life and psychosocial well-being than those in diagnosed in stages 0 and I and in unknown stages when controlling for socio-demographic variables although the effect sizes were small as demonstrated by the standardized beta values. Previous findings have demonstrated that more advanced stages at diagnosis are associated with poorer psychological outcomes (i.e., depression and anxiety) however these negative outcomes are more pronounced in younger adults (Vodermaier, Linden, MacKenzie, Greig, & Marshall, 2011). The findings suggest the importance of providing accurate staging information to older adults with cancer as many indicated that the stage of their cancer was never communicated. Further, it highlights the need to acknowledge the effects of stage on psychosocial well-being, tailoring interventions to meet the needs of those diagnosed at later stages.

Length since diagnosis, measured in years, did not yield significant findings in this study. Findings suggested a very slight but non-significant positive association between years since diagnosis and PSWB and QOL-CS. Previous studies have been able to show some declines in areas of psychosocial well-being in the first year post-diagnosis with increasing psychosocial well-being as the diagnosis became further removed (Cimprich et al., 2002; Deimling, Bowman, et al., 2006; Stommel et al., 2004). Since length since diagnosis was calculated based on year of

diagnosis, imprecision in measurements may have contributed to lack of significant findings. Similarly, previous studies accounted for individual variability and utilized longitudinal studies to better understand the effects of length since diagnosis.

Physical well-being.

Physical well-being accounted for the majority of the variance in the PSWB scores, emphasizing the importance of self-perceived health when working with older adults who have who have had cancer within the five years. The effects of cancer on physical, or functional well-being, as demonstrated in health-related quality of life scales has been well-documented (Reeve et al., 2009; A. W. Smith et al., 2008). Kurtz et al. (2001) found that poorer pre-diagnosis physical functioning was associated with higher levels of post-diagnosis depressive symptomology among older adults with cancer. A qualitative study by Esbensen et al. (2008) suggests that poorer physical functioning among older adults with cancer leads to more dependence on others resulting in them feeling like a burden on those around them. Further, participants indicated that the cancer diagnosis resulted in decreased self-efficacy and feelings of control and increased consciousness about death and dying (2008). Kurtz et al. (2001) posits that the interplay between physical functioning and depression can also be attributed to these changing social relationships as well as decreased self-esteem. The previous research all align with the results of our current study which showed that physical well-being was the strongest

correlate of psychosocial well-being. As the single-most important indicator of psychosocial well-being, it is imperative that changes in physical functioning are assessed and addressed.

Strengths and Limitations

Strengths of this study.

Strengths of the present study include the representativeness of the sample, the selection of the sampling frame, the use of a broad set of both socio-demographic and cancer-specific variables, and the use of a well-known and well-validated psychosocial instrument. Through the use of an existing panel study, this study was able to collect original data using a nationally representative sample, which allows the results to be generalizable to the population. Unlike many previous studies, the sample was not drawn from cancer centers or cancer registries. This may have allowed participants to think about their experiences with cancer without associating the questions with the setting of their diagnosis and treatment, possibly resulting in more honest responses. Further, due to the nature of the panel and commitment of the panel participants, this study yielded an extremely high response rate of 77%. This, along with the sampling design, decreases the potential for sampling bias.

The study also included a broad spectrum of socio-demographic and cancer variables allowing for a more comprehensive understanding of the factors associated with psychosocial well-being and quality of life among older adults with cancer. This approach allows for us to grasp differences among specific subgroups while having the ability to control for a number of other factors that can play into psychosocial well-being. Use of the pre-existing, nationally representative panel for collecting social science data is a new approach and seeks to identify innovative ways to better understand the populations we serve. Coupled with the use of a standardized and psychometrically tested instrument, the QOL-CS, the results of this study can

be compared to other studies in the field. This study is important as it is comprehensive in nature, collecting data on many demographic characteristics including purposefully seeking out groups that have been largely neglected in previous studies including the oldest-old (85 years of age and older) and those who identify as non-White.

Limitations.

The study has several limitations based on study design and sample. While the QOL-CS is a well-validated instrument, previous critiques of the instrument discuss issues in the directionality of some of the items as well as the attempt to measure multiple constructs within each subscale (Avis et al., 2005; Azuero, Su, McNees, & Meneses, 2013). While this instrument provides breadth in terms of understanding psychosocial well-being it is somewhat lacking in depth. Therefore, as we identify vulnerable populations it is important to delve more to understand their specific needs in this area. Furthermore, the QOL-CS and the other questionnaire responses were all based on self-report which may bias the study results. While self-report allows us to capture one's perceived needs it may lead to inaccuracies. A combination of self-reported data along with cross-referenced cancer surveillance data would be beneficial for future research. This approach would also address the issues of cancer type, stage, cancer recurrence, and how recently the diagnosis occurred. Participants were asked to list the cancer diagnoses, excluding skin cancer, they had had in the past 5 years and their year of diagnosis. The results used the most recent diagnosis to determine cancer type and years since diagnosis. This may have led to some error in determining primary cancer site as well as the extent to which cancer has affected the well-being of participants. Further, over a third of individuals were unable to report their stage at diagnosis. Of those, only 1 respondent (0.3%) did not respond to the question and the additional 142 (36.9%) stated that they did not know their

stage at diagnosis. Additional feedback included responses that they were never told the stage, their doctor didn't know their stage, stage 6 (this was a man with prostate cancer so likely this referred to the Gleason score), or that their cancer was early or moderate or metastasized. Lack of awareness around cancer stage limits our ability to fully understand the implications of stage and psychosocial well-being.

Since the sample was drawn from community-dwelling older adults there may be over-representation of healthier and younger older adults. More emphasis needs to be placed on understanding the psychosocial needs of those adults over the age of 85 who have had cancer and expanding sampling frames to include some levels of continuing care communities may add depth to our understanding. Also, while representative, this sample lacked the number of participants needed to make meaningful conclusions about the association of race/ethnicity with psychosocial well-being among older adults with cancer. Oversampling will be necessary in order to understand the unique needs of specific racial and ethnic subgroups. Finally, the cross sectional study design only allows us to understand associations and not directionality between well-being and cancer treatment and diagnosis. Further, we are only surveying participants following a cancer diagnosis and thus are unable to measure their psychosocial well-being prior to their experience with cancer. An understanding of psychosocial well-being prior to diagnosis may shed light on why certain demographic factors were not significant, particularly chronological age.

Implications and Future Research Needs

Clinical implications.

While socio-demographic and cancer variables provide some explanation for overall well-being among older adults with cancer, physical well-being is the strongest predictor of

psychosocial well-being in this population. Thus, it is imperative that comprehensive geriatric assessments (CGA) are utilized to assess functional status, comorbid conditions, cognitive abilities, nutrition, psychological well-being and social needs among older adults with cancer (Extermann & Hurria, 2007; Given & Given, 2009). As part of a multidisciplinary team, clinical social workers can be instrumental in assessing psychological and social concerns as well as using the CGA as a means of understanding the overarching needs of the individual (Bellury et al., 2011; Massie, 2004). Standardized use of CGAs can also better inform treatment decisions for older adults by showing their potential effects on overall quality of life and psychosocial well-being.

Clinical social work interventions should also seek to address areas of physical well-being, along with specific socio-demographic and cancer-specific needs, by providing education on the impacts of the disease, referrals to appropriate resources such as in-home services, and serving as cancer care navigators (Massie, 2004). The current study further articulates the need for psychosocial interventions to be tailored to specific needs, taking into consideration how individual characteristics influence perceived quality of life and psycho-social well-being. Given the significant relationship between education and psychosocial well-being, it is imperative oncology social workers help patients, particularly those with less education, understand their diagnosis and treatment as well as raise awareness about stage at diagnosis and other information about their cancer site. As discussed by Amalraj et al. (2009), greater understanding of the diagnosis, such as stage, may lead to greater self-efficacy and in turn positively affect psychological well-being. Clinical oncologists can serve as educators and navigators with older

adults in regards to their experiences with a cancer diagnosis and treatment providing a greater understanding and sense of control around the cancer experience.

Policy implications.

As we continue to recognize the complex interactions between physical, cognitive, psychological, and social functioning among older adults with cancer, it is critical that we advocate for standardized use of comprehensive geriatric assessments. Although the National Comprehensive Cancer Network Guidelines for Senior Adults Oncology guidelines include CGA, it is still not used consistently in practice (Bellury et al., 2011; Hurria, 2009; White & Cohen, 2008). The need for increased use of CGAs among older adult cancer patients, particularly in relation to clinical trial enrollment, was also highlighted in the Institute of Medicine's 2013 report *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* and is one of many areas that the American Society of Clinical Oncology (ASCO) is highlighting in its increased efforts in addressing geriatric oncology (Institute of Medicine, 2013; Klapper, 2013).

Additionally, oncology social workers need to continue to forge multidisciplinary partnerships to ensure that the unique needs among older adults with cancer are met. As growing emphasis is placed on geriatric oncology and on cancer treatment options and outcomes, it is imperative that social workers give voice to the psychosocial needs and desires of older adults with cancer. Critical roles for oncology social workers emerge as organizations like ASCO begin to integrate more geriatric oncology into their educational modules, academic journals, and research, particularly as they begin to recognize the importance of the effects of treatment on incidence of depression and other psychological distress as well as the importance of social support. Further, as ASCO and similar organizations recognize that treatment goals may differ

from younger patients in terms of more focus on independence and functioning rather than cure, social work professionals can help develop tools for clinicians to better understand these desires.

As policy statements and reports from the NCCN, IOM, and ASCO begin to recognize more fully the interplay between changes in physical health, specifically as a result of cancer diagnosis and treatment, and psychosocial well-being, oncology social workers have unique skillsets to help assess and address these complex bio-psycho-social-spiritual interactions. Oncology social workers should be actively participating in and formulating these larger policy documents as they relate to overall well-being as part of larger multi-disciplinary teams.

Theoretical implications.

The findings suggest implications for the use and application of stress, appraisal, and coping models as well as the life span perspective. Specific socio-demographic and cancer-specific variables are associated with increased stress and more negative appraisal of the cancer diagnosis and treatment, as demonstrated in significantly lower psychosocial well-being and quality of life scores. The appraisal process, as the models suggests, is dynamic and is very much attached to individual characteristics. While the results were unable to show any significant differences in terms of age and psychosocial well-being, the life span perspective may help us to identify older adults who may be experiencing despair and difficulty making sense or deriving purpose from their current life events, specifically their cancer diagnosis and treatment. Further, there are limitations in thinking about one's adjustment to aging and cancer using a dichotomous framework. In light of a cancer diagnosis and subsequent treatment, older adults often experience both hope and despair (Hughes, Closs, & Clark, 2009). While many older

adults are at peace with death itself, they are fearful about the process of dying including the prospect of increased symptoms and dependence on others (2009).

Within the present study, although more variation was expected in psychosocial outcomes as a result of generational and cohort differences within the older adult age group of 65 and older, these results support the importance of taking into account the heterogeneity of the population. This may be particularly relevant to the life span perspective as different subpopulations may attribute meaning to their cancer diagnosis and treatment in a variety of ways. It is also important to recognize the potential for seemingly contradictory responses which include both aspects of integrity and despair. This may lead to different understandings of how meaning is derived and applied in this population. Despite the limitations in these theoretical approaches, they provide a context for this study, showing that, based on their appraisal of the disease, certain subpopulations among the aging population may be less resilient psychosocially and may be in greater need of social work interventions.

Future research.

This study sought to explore the heterogeneity of quality of life and psychosocial well-being outcomes among particular subgroups of older adults with cancer. Future research in this area can add richness to these findings by comparing older adults with and without cancer along with comparing older adults with cancer to younger adults with cancer. While some similar studies have been done, future research would need to maintain a wide net of data collection, ensuring that multiple cancer types, stages, treatment types, and socio-demographic subgroups were represented. This would begin to further inform our understanding of what factors influence psychosocial well-being, particularly, how much can be attributed to cancer. Another research opportunity is seeking to better understand the needs of older adults with cancer who

are the most socially isolated and the oldest-old as these are difficult, yet important subgroups to address. As we seek to understand the needs of the most vulnerable, perhaps future research needs to extend to older adults with cancer who are living in long-term care facilities as this is a relatively unstudied population.

Conclusion

This study helps complement previous studies by providing a more comprehensive understanding of the psychosocial associations among older adults with cancer which can be paired with the growing literature base on health-related and functional aspects of quality of life in this population.

Results from this study will contribute to the gerontologic oncology research in several ways. First, it gives us a more in-depth look at particular subgroups within the aging population, providing a better picture of how psychosocial well-being is associated with particular socio-demographic and cancer specific variables among older adults with cancer. Second, it helps us to continue to recognize the complex interactions between psychosocial and perceived physical well-being beyond simply reporting co-morbidities. Third, this study introduces the use of alternate means of identifying and surveying older adults. Using participants in a pre-existing panel helps ensure participant commitment. Further, conducting a cancer survey from a non-health care setting may ensure more honest results as participants are not re-experiencing stress by receiving communications from health care providers. This methodology also allows for representative sampling unlike many other previous studies that have relied on convenience samples.

As we continue to experience a demographic shift in the United States with our ever-growing older adult population, it is important to continue to tailor our oncology social work

interventions to specific needs among subpopulations within this extremely heterogeneous age group. This study demonstrates many groups that are at-risk for poorer psychosocial well-being following cancer diagnosis and treatment including women, those who are less educated, those diagnosed at later stages, those with lung cancer, and those who have poorer self-reported physical well-being. Continued research needs to go into understanding subpopulations who are growing rapidly yet are under-researched including those over the age of 85, those who are no longer community dwelling, and those who represent racial and/or ethnic minorities. The results of this study highlight the importance of understanding the unique needs of subgroups within the older adult population as it results to psychosocial well-being and developing appropriate social work interventions and policies to ensure that these needs are being addressed.

APPENDICES

Appendix A: IRB Approval

Figure 2: IRB Approval

MICHIGAN STATE UNIVERSITY

September 9, 2014

Anne Hughes
Email: hughesa@msu.edu

Re: Request for Determination of Human Subject Research

Dear Dr. Hughes:

It has been determined that the activity described in the application request entitled "Psychosocial well-being among older adults with cancer" submitted 9-2-14 does not meet the definition of

☐ "research" as defined by the DHHS.

☒ "human subjects" as defined by the DHHS.

Human Subject

For DHHS, "human subject" means "a living individual about whom an investigator (whether professional or student) conducting research obtains: (1) Data through intervention or interaction with the individual, or (2) Identifiable private information." [45 CFR 46.102(f)].

After reviewing the information you have provided, it has been determined that:

☐ Living individuals are not involved

☒ The activity is not "about" the living individual

☐ Will not obtain data through interaction or intervention or private identifiable information

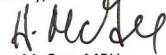
Based upon the information submitted in your application, you will obtain de-identified data with no personal identifying information. Ultimately, your research is a study of the utilizing data with no personal identifiers.

Hence, your activity does not involve human subjects.

Therefore, the federal regulations for the protection of human subjects would not apply to your project and you do not need MSU IRB approval to proceed. However, please note that while MSU IRB approval is not required, other federal, state, or local regulations or requirements or ethical or professional standards may still be applicable based on your activity.

If any of these circumstances may change, please contact the IRB as your activity may involve human subjects and require IRB approval. If you have any further questions, please contact the MSU IRB office at 517-355-2180.

Sincerely,



Harry McGee, MPH

Chair, Social Science Behavioral/Education Institution Review Board (SIRB) Human Research Protection Program



Office of Regulatory
Affairs
Human Research
Protection Programs

Biomedical & Health
Institutional Review
Board (BIRB)

Community Research
Institutional Review
Board (CIRB)

Social Science
Behavioral/Education
Institutional Review
Board (SIRB)

Olds Hall
408 West Circle Drive
Room 207
East Lansing, MI 48824
(517) 355-2180
Fax: (517) 432-4503
Email: irb@msu.edu

MSU is an affirmative-action,
equal-opportunity employer.

Appendix B: Demographic Profile Data Supplied by the GfK

Table 8: Demographic Profile Data Supplied by the GfK

Variable	Values
Age	Actual age in years
Education (14 categories)	1 = No formal education
	2 = 1st, 2nd, 3rd, or 4th grade
	3 = 5th or 6th grade
	4 = 7th or 8th grade
	5 = 9th grade
	6 = 10th grade
	7 = 11th grade
	8 = 12th grade NO DIPLOMA
	9 = HIGH SCHOOL GRADUATE - high school DIPLOMA or the equivalent GED)
	10 = Some college, no degree
	11 = Associate degree
	12 = Bachelors degree
	13 = Masters degree
	14 = Professional or Doctorate degree

Table 8 (cont'd)

	1 = Less than HS
Education (4 categories)	2 = HS
	3 = Some college
	4 = Bachelors degree or higher
	1 = White, Non-Hispanic
Race/Ethnicity	2 = Black, Non-Hispanic
	3 = Other, Non-Hispanic
	4 = Hispanic
	5 = 2+ races, Non-Hispanic
Gender	1 = Male
	2 = Female
Household Head	0 = No
	1 = Yes
Household Size (from Recruitment)	Total number of members in household
	1 = A one-family house detached from any other house
Housing Type	2 = A one-family house attached to one or more houses
	3 = A building with 2 or more apartments
	4 = A mobile home
	5 = Boat, RV, van, etc.

Table 8 (cont'd)

HH Income (profile and imputed)	1 = Less than \$5,000; 2 = \$5,000 to \$7,499
	3 = \$7,500 to \$9,999; 4 = "\$10,000 to \$12,499
	5 = \$12,500 to \$14,999; 6 = "\$15,000 to \$19,999
	7 = \$20,000 to \$24,999; 8 = \$25,000 to \$29,999
	9 = \$30,000 to \$34,999; 10 = \$35,000 to \$39,999
	11 = \$40,000 to \$49,999; 12 = \$50,000 to \$59,999
	13 = \$60,000 to \$74,999; 14 = \$75,000 to \$84,999
	15 = \$85,000 to \$99,999; 16 = \$100,000 to \$124,999
	17 = \$125,000 to \$149,999; 18 = \$150,000 to \$174,999
	19 = \$175,000 or more
Marital Status	1 = Married
	2 = Widowed
	3 = Divorced
	4 = Separated
	5 = Never married
	6 = Living with partner
MSA Status	0 = Non-Metro
	1 = Metro (as defined US OMB Core-Based Statistical Area)
Internet access	0 = No
	1 = Yes

Table 8 (cont'd)

Ownership Status of Living Quarters	1 = Owned or being bought by you or someone in your household
	2 = Rented for cash
	3 = Occupied without payment of cash rent
Region 4 (U.S. Census)	1 = Northeast
	2 = Midwest
	3 = South
	4 = West

Appendix C: Supplemental Variables from GfK

Q19. Have YOU been diagnosed by a physician or other qualified medical professional with any of the following medical conditions?

Acid reflux disease

ADHD or ADD

Anxiety disorder

Asthma, chronic bronchitis, or COPD

Atrial fibrillation/Afib

Bipolar Disorder

Cancer (any type except skin cancer)

Chronic pain (such as low back pain, neck pain, or fibromyalgia)

Cystic Fibrosis

Depression

Diabetes

Epilepsy

Eye disease (other than poor vision)

Gout

Heart attack

Heart disease

Hepatitis C

High blood pressure

High cholesterol

HIV/AIDS

Kidney disease

Menopause

Mood disorder

Multiple sclerosis

Osteoarthritis, joint pain or inflammation

Osteoporosis or osteopenia

Perimenopause/Initial signs of menopause

Psoriasis

Rheumatoid arthritis

Seasonal allergies

Schizoaffective Disorder

Schizophrenia

Skin cancer

Sleep disorders such as sleep apnea or insomnia

Stroke

Other mental health condition not included above

Something else not previously listed

None of these

Appendix D: Final Survey

Figure 3: Final Survey

Psychosocial Well-being among Older Adults with a History of Cancer
September, 2014
- Study Details -

Note: This page may be removed when the questionnaire is sent to the client. However, it must exist in the version sent to OSD.

SNO	19092 Pretest/19093 Main
Survey Name	Psychosocial Well-being among Older Adults with Cancer Pretest
Client Name	Calvin College
G&A WBS	TBD
Project Director Name	Faulkner
Team/Area Name	G&A

Samvar (Include name, type and response values. "None" means none. Blank means standard demos. This must match SurveyMan.)	
Sample specs	
Timing Template Required (y/n)	Enabled by default
Multi-Media	

Important: Do not change Question numbers after Version 1; to add a new question, use alpha characters (e.g., 3a, 3b, 3c.) Changing question numbers will cause delays and potentially errors in the program.

Psychosocial Well-being among Older Adults with Cancer
September, 2014
- Questionnaire -

[DISPLAY]

Please answer the following questions about your experience with cancer.

[SP]

[PROMPT ONCE]

QS1. Has your diagnosis of cancer occurred in the last 5 years?

Yes 1
No 2
I have never had cancer 3

[TERMINATE IF QS1 NE 1]

[IF QS1 = 1]

Figure 3 (cont'd)

[PROMPT ONCE]

[GRID, MP]

[PLEASE CREATE DROPDOWN MENUS FOR EACH DATE, RANGE 2014 2009]

Q1. What type/types of cancer have you been diagnosed with? *Please select **all that apply to you**.* If the type of cancer you had is not listed please indicate what type you had and the date you were diagnosed in the "Other" section.

Note: Please enter the year of diagnosis and the type of cancer.

Bladder	Year of diagnosis: [YYYY]
Breast	Year of diagnosis: [YYYY]
Colon or Rectal	Year of diagnosis: [YYYY]
Lung	Year of diagnosis: [YYYY]
Pancreatic	Year of diagnosis: [YYYY]
Prostate	Year of diagnosis: [YYYY]
Other (please specify) [TEXTBOX]	Year of diagnosis: [YYYY]
Other (please specify) [TEXTBOX]	Year of diagnosis: [YYYY]
Other (please specify) [TEXTBOX]	Year of diagnosis: [YYYY]

[DISPLAY]

For the items 2 through 5, please answer regarding your most recent experience with cancer.

[SP]

Q4. When you were first diagnosed, what were you told was your initial stage of disease?

- Stage I 1
- Stage II 2
- Stage III 3
- Stage IV 4
- Other (please specify) [TEXTBOX] ... 5
- I don't know 6

[MP]

Q5. What type of cancer treatment did you receive?

- a. I have not received treatment for cancer
- b. Surgery
- c. Chemotherapy
- d. Radiation therapy
- e. Bone marrow or stem cell transplant
- f. Biologic therapy (e.g., Rituxan, Interferon)
- g. Other (please specify) [TEXTBOX]

[SP]

Q2. Are you currently in remission or cured of your cancer?

- Yes 1
- No 2
- Don't know 3

[SP]

Figure 3 (cont'd)

Q3. How many times has your cancer recurred?

I have never had a recurrence 1
 My cancer has never been in
 remission 2
 My cancer recurred about [NUMBER
 BOX, RANGE 1-100] time(s) 3

Quality of Life Scale/CANCER PATIENT/CANCER SURVIVOR

[DISPLAY]

[GRID, SP ACROSS, MP DOWN]

We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**.

Physical Well Being

Please select the number from 0 - 10 that best describe your experiences:

To what extent are the following a problem for you:

	No Problem										Severe Problem
	0	1	2	3	4	5	6	7	8	9	10
1. Fatigue											
2. Appetite changes											
3. Aches or pain											
4. Sleep changes											
5. Constipation											
6. Menstrual changes or fertility											
7. Nausea											

[NEW SCREEN]

[GRID, SP]

Q8. Please rate your overall **physical health** on a scale from 0 to 10 with "0" meaning "Extremely Poor" and "10" meaning "Excellent":

Extremely Poor										Excellent
0	1	2	3	4	5	6	7	8	9	10

Figure 3 (cont'd)

[DISPLAY ON A NEW SCREEN]

[PLEASE DISPLAY Q9-Q11 ON ONE SCREEN]

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q9. How difficult is it for you to **cope** today as a result of your disease and treatment?

Not at all difficult										Very difficult
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q10. How good is your **quality of life**?

Extremely Poor										Excellent
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q11. How much **happiness** do you feel?

None at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[PLEASE DISPLAY Q12-Q14 ON ONE SCREEN]

[GRID, SP]

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

Q12. Do you feel like you are **in control** of things in your life?

Not at all										Completely
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q13. How **satisfying** is your life?

Not at all										Completely
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q14. How is your present ability to **concentrate or to remember** things?

Extremely Poor										Excellent
0	1	2	3	4	5	6	7	8	9	10

[PLEASE DISPLAY Q15-Q17 ON ONE SCREEN]

[GRID, SP]

Figure 3 (cont'd)

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

Q15. How **useful** do you feel?

Not at all										Extremely
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q16. Has your illness or treatment caused changes in your **appearance**?

Not at all										Extremely
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q17. Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

Not at all										Extremely
0	1	2	3	4	5	6	7	8	9	10

[DISPLAY ON A NEW SCREEN]

[GRID, SP ACROSS, MP DOWN]

How distressing were the following aspects of your illness and treatment?

Please select the number from 0 - 10 that best describe your experiences:

	Not at all distressing										Very distressing
Q18. Initial diagnosis	0	1	2	3	4	5	6	7	8	9	10
Q19. Cancer treatments (i.e. chemotherapy, radiation, or surgery)											
Q20. Time since my treatment was completed											

[DISPLAY ON A NEW SCREEN; PLEASE DISPLAY Q21 AND Q22 ON THE SAME PAGE]

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q21. How much **anxiety** do you have?

None at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

Figure 3 (cont'd)

[GRID, SP]

Q22. How much **depression** do you have?

None at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[DISPLAY ON A NEW SCREEN]

[GRID, SP ACROSS, MP DOWN]

To what extent are you fearful of:

	No Fear										Extreme Fear
	0	1	2	3	4	5	6	7	8	9	10
23. Future diagnostic tests											
24. A second cancer											
25. Recurrence of your cancer											
26. Spreading (metastasis) of your cancer											

[DISPLAY ON A NEW SCREEN, PLEASE DISPLAY Q27, Q28, Q29 AND Q30 ON THE SAME PAGE]

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q27. How distressing has illness been for your **family**?

Not at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q28. Is the amount of **support** you receive from others sufficient to meet your needs?

Not at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Figure 3 (cont'd)

Q29. Is your continuing health care interfering with your **personal relationships**?

Not at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q30. Is your **sexuality** impacted by your illness?

Not at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[DISPLAY, PLEASE SHOW Q31 AND Q32 ON THE SAME PAGE]

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q31. To what degree has your illness and treatment interfered with your **employment**?

No problem										Severe problem
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q32. To what degree has your illness and treatment interfered with your **activities at home**?

No problem										Severe problem
0	1	2	3	4	5	6	7	8	9	10

[DISPLAY, PLEASE SHOW Q33 AND Q34 ON THE SAME PAGE]

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q33. How much **isolation** do you feel is caused by your illness or treatment?

None										A great deal
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q34. How much **financial burden** have you incurred as a result of your illness and treatment?

None										A great deal
0	1	2	3	4	5	6	7	8	9	10

Figure 3 (cont'd)

[DISPLAY ON A NEW SCREEN, PLEASE SHOW Q35, Q36, Q37 ON ONE PAGE]

Spiritual Well Being

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q35. How important to you is your participation in **religious activities** such as praying, going to church?

Not at all important										Very important
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q36. How important to you are other **spiritual activities** such as meditation?

Not at all important										Very important
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q37. How much has your **spiritual life** changed as a result of cancer diagnosis?

Less important										More important
0	1	2	3	4	5	6	7	8	9	10

[DISPLAY, PLEASE SHOW Q38, Q39, Q40 AND Q41 ON SAME PAGE]

Spiritual Well Being

Please select the number from 0 - 10 that best describe your experiences:

[GRID, SP]

Q38. How much **uncertainty** do you feel about your future?

Not at all uncertain										Very uncertain
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q39. To what extent has your illness made **positive changes** in your life?

None at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

Figure 3 (cont'd)

[GRID, SP]

Q40. Do you sense a **purpose/mission** for your life or a reason for being alive?

None at all										A great deal
0	1	2	3	4	5	6	7	8	9	10

[GRID, SP]

Q41. How **hopeful** do you feel?

Not at all hopeful										Very hopeful
0	1	2	3	4	5	6	7	8	9	10

[GFK CLOSING]

Appendix E: Survey Screen Shots

Figure 4: Survey Screen Shots

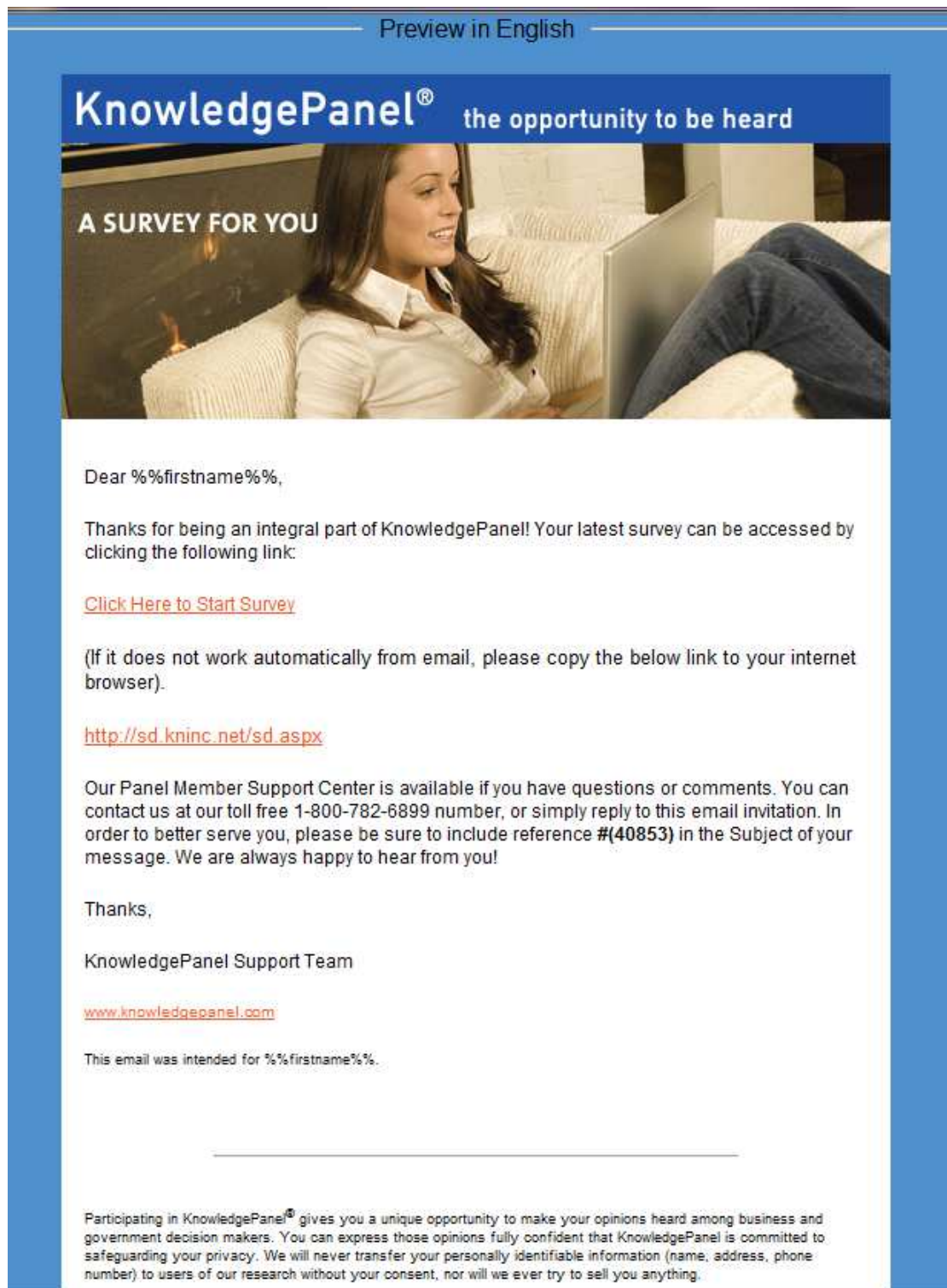


Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Please answer the following questions about your experience with cancer.

Next

© 2015 GfK - All rights reserved.

Need help?

Next

© 2015 GfK - All rights reserved.

Need help?

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

For the items 2 through 5, please answer regarding your most recent experience with cancer.

Next

© 2015 GfK - All rights reserved.

Need help?

When you were first diagnosed, what were you told was your initial stage of disease?

Select one answer only

☐ Stage I

☐ Stage II

☐ Stage III

☐ Stage IV

☐ Other (please specify)

☐ I don't know

Next

© 2015 GfK - All rights reserved.

Need help?

What type of cancer treatment did you receive?

Select all answers that apply

☐ I have not received treatment for cancer

☐ Surgery

☐ Chemotherapy

☐ Radiation therapy

☐ Bone marrow or stem cell transplant

☐ Biologic therapy (e.g., Rituxan, Interferon)

☐ Other (please specify)

Next

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Are you currently in remission or cured of your cancer?

Select one answer only

☐ Yes

☐ No

☐ Don't know

Next

© 2015 GfK - All rights reserved.

Need help?

How many times has your cancer recurred?

Select one answer only

☐ I have never had a recurrence

☐ My cancer has never been in remission

☐ My cancer recurred about time(s)

Next

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.
Need help?

We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**.

Physical Well Being

Please select the number from 0 - 10 that best describe your experiences:

To what extent are the following a problem for you:

Select one answer from each row in the grid

	No Problem 0	1	2	3	4	5	6	7	8	9	Severe Problem 10
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appetite changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aches or pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Constipation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Menstrual changes or fertility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

© 2015 GfK - All rights reserved.
Need help?

Please rate your overall **physical health** on a scale from 0 to 10 with "0" meaning "Extremely Poor" and "10" meaning "Excellent":

Select one answer only

Extremely Poor 0	1	2	3	4	5	6	7	8	9	Excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

How difficult is it for you to **cope** today as a result of your disease and treatment?

Select one answer only

Not at all difficult 0	1	2	3	4	5	6	7	8	9	Very difficult 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How good is your **quality of life**?

Select one answer only

Extremely Poor 0	1	2	3	4	5	6	7	8	9	Excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much **happiness** do you feel?

Select one answer only

None at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

Do you feel like you are **in control** of things in your life?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How **satisfying** is your life?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How is your present ability to **concentrate or to remember** things?

Select one answer only

Extremely Poor 0	1	2	3	4	5	6	7	8	9	Excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Psychological Well Being

Please select the number from 0 - 10 that best describe your experiences:

How **useful** do you feel?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	Extremely 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Has your illness or treatment caused changes in your **appearance**?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	Extremely 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	Extremely 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

How distressing were the following aspects of your illness and treatment?

Please select the number from 0 - 10 that best describe your experiences:

Select one answer from each row in the grid

	Not at all distressing 0	1	2	3	4	5	6	7	8	9	Very distressing 10
Initial diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer treatments (i.e. chemotherapy, radiation, or surgery)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time since my treatment was completed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

Please select the number from 0 - 10 that best describe your experiences:

How much **anxiety** do you have?

Select one answer only

None at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much **depression** do you have?

Select one answer only

None at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

To what extent are you fearful of:

Select one answer from each row in the grid

	No Fear 0	1	2	3	4	5	6	7	8	9	Extreme Fear 10
Future diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A second cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recurrence of your cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spreading (metastasis) of your cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

© 2018 GRIK - All rights reserved.

Need help?

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

How distressing has illness been for your family?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is the amount of support you receive from others sufficient to meet your needs?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is your continuing health care interfering with your personal relationships?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is your sexuality impacted by your illness?

Select one answer only

Not at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

To what degree has your illness and treatment interfered with your **employment**?

Select one answer only

No problem 0	1	2	3	4	5	6	7	8	9	Severe problem 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what degree has your illness and treatment interfered with your **activities at home**?

Select one answer only

No problem 0	1	2	3	4	5	6	7	8	9	Severe problem 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

Social Concerns

Please select the number from 0 - 10 that best describe your experiences:

How much **isolation** do you feel is caused by your illness or treatment?

Select one answer only

None 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much **financial burden** have you incurred as a result of your illness and treatment?

Select one answer only

None 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

Spiritual Well Being

Please select the number from 0 - 10 that best describe your experiences:

How important to you is your participation in **religious activities** such as praying, going to church?

Select one answer only

Not at all important 0	1	2	3	4	5	6	7	8	9	Very important 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How important to you are other **spiritual activities** such as meditation?

Select one answer only

Not at all important 0	1	2	3	4	5	6	7	8	9	Very important 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much has your **spiritual life** changed as a result of cancer diagnosis?

Select one answer only

Less important 0	1	2	3	4	5	6	7	8	9	More important 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 4 (cont'd)

© 2018 GSK - All rights reserved.

Need help?

Spiritual Well Being

Please select the number from 0 - 10 that best describe your experiences:

How much uncertainty do you feel about your future?

Select one answer only:

Not at all uncertain 0	1	2	3	4	5	6	7	8	9	Very uncertain 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what extent has your illness made positive changes in your life?

Select one answer only:

None at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you sense a purpose/mission for your life or a reason for being alive?

Select one answer only:

None at all 0	1	2	3	4	5	6	7	8	9	A great deal 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How hopeful do you feel?

Select one answer only:

Not at all hopeful 0	1	2	3	4	5	6	7	8	9	Very hopeful 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next

Figure 4 (cont'd)

© 2015 GfK - All rights reserved.

Need help?

Thinking about this topic, do you have any comments you would like to share?

Any comments welcome!

Next

© 2015 GfK - All rights reserved.

Need help?

Thank you for completing this survey. We have successfully received your responses.

Appendix F: Additional Tables

Table 9: Means and Standard Deviations of QOL-CS and PSWB Scores by Socio-demographic and Cancer Specific Variables

<i>Variable</i>	<i>n</i>	QOL-CS		PSWB	
		<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>
Gender					
Male	213	332.27	56.90	213.18	43.78
Female	171	314.04	59.87	197.50	46.30
Education					
Less than High School	28	274.76	57.26	164.91	44.87
High School	161	325.28	58.18	205.26	45.23
Some College	89	321.86	59.37	207.55	47.02
Bachelor's Degree or Higher	106	337.69	53.19	217.62	38.41
Total	384	324.16	58.86	206.20	45.53
Income					
Less than \$25,000	89	301.07	50.34	189.70	41.93
\$25,000 to \$49,999	126	329.91	57.36	210.57	43.67
\$50,000 to \$74,999	67	318.20	63.71	200.86	51.55
\$75,000 to \$99,999	40	346.20	56.91	223.29	44.65
\$100,000 and Higher	61	338.07	59.16	215.93	40.75
Total	384	324.16	58.86	206.20	45.53
Cancer Type					
Bladder	27	345.31	44.40	221.67	29.77
Breast	76	332.84	51.84	211.67	39.14
Colon/Rectal	35	318.84	60.91	201.71	51.64
Lung	39	268.68	70.03	166.30	55.83
Leukemia, lymphoma, myeloma	26	320.25	62.92	215.45	38.30
Prostate	89	336.35	47.39	203.68	49.18
Other	66	323.72	59.99	205.30	45.00
Total	358	323.71	59.13	205.71	45.75
Treatment Type					
Chemotherapy	97	295.33	63.56	185.48	48.72

Table 9 (cont'd)

No Chemotherapy	287	333.83	53.96	213.16	42.27
Stage at Diagnosis					
Stage 0	10	350.42	56.00	217.22	37.41
Stage I	114	328.41	57.44	207.09	45.03
Stage II	51	308.20	60.75	193.98	46.34
Stage III	36	308.86	68.66	193.12	52.98
Stage IV	30	291.46	51.21	184.39	43.67
Unknown/Other	143	335.25	54.38	216.91	41.58
Total	384	324.16	58.86	206.20	45.53
Years since Diagnosis					
Less than 1 year	59	299.00	66.97	185.61	53.21
1 year	83	318.65	59.29	202.05	44.98
2 years	57	345.59	46.78	219.19	37.62
3 years	41	330.01	57.17	212.45	45.74
4 years	74	330.31	58.67	212.57	42.10
5 years	38	319.86	56.40	202.70	46.37
Total	352	323.64	59.46	205.57	46.00

Table 10: Analysis of Variance for QOL-CS and PSWB Scores

	QOL-CS					PSWB				
	SS	df	MS	F	p	SS	Df	MS	F	p
Education										
Between Groups	89500.25	3	29833.41	9.16	.000	62626.07	3	20875.36	10.85	.000
Within Groups	1237601.35	380	3256.846			731361.44	380	1924.64		
Total	1327101.60	383				793987.50	383			
Income										
Between Groups	85635.78	4	21408.95	6.536	.000	46231.62	4	11557.91	5.858	.000
Within Groups	12414465.82	379	3275.64			747755.88	379	1972.97		
Total	1327101.60	383				793987.50	383			
Cancer Type ^a	<i>Welch's F</i>	<i>df1</i>	<i>df2</i>		<i>p</i>	<i>Welch's F</i>	<i>df1</i>	<i>df2</i>		<i>p</i>
Welch	5.704	6	114.48		.000	4.906	6	115.42		.000
Stage at Diagnosis ^a	<i>Welch's F</i>	<i>df1</i>	<i>df2</i>		<i>p</i>	<i>Welch's F</i>	<i>df1</i>	<i>df2</i>		<i>p</i>
Welch	5.046	5	65.66		.001	4.490	5	66.05		.001
Years Since Diagnosis ^a	<i>Welch's F</i>	<i>df1</i>	<i>df2</i>		<i>p</i>					
Between Groups	4.292	5	144.16		.001	40896.30	5	8179.260	4.024	.001
Within Groups						701264.79	345	2032.65		
Total						742161.09	350			

^aWhen homogeneity of variance could not be assumed, Welch's test of robust equality of means was used.

REFERENCES

REFERENCES

- Ailshire, J. A., & Crimmins, E. M. (2011). Psychosocial factors associated with longevity in the United States: Age differences between the old and oldest-old in the health and retirement study. *Journal of Aging Research, 2011*.
- Akechi, T., Okuyama, T., Uchida, M., Nakaguchi, T., Ito, Y., Yamashita, H., . . . Wada, M. (2012). Perceived needs, psychological distress and quality of life of elderly cancer patients. *Japanese Journal of Clinical Oncology, 42*(8), 704-710.
- Alon, S. (2011). Psychosocial challenges of elderly patients coping with cancer. *Journal of Pediatric Hematology Oncology, 33*(Supplement 2), S112-S114.
- Amalraj, S., Starkweather, C., Nguyen, C., & Naeim, A. (2009). Health literacy, communication, and treatment decision-making in older cancer patients. *Oncology, 23*(4), 369-375.
- Aoun, S., Deas, K., & Skett, K. (2015). Older people living alone at home with terminal cancer. *European Journal of Cancer Care, 24*(1), 1-10.
- Ashing-Giwa, K. T., & Lim, J. W. (2010). Exploring the association between functional strain and emotional well-being among a population-based sample of breast cancer survivors. *Psycho-Oncology, 19*(2), 150-159. doi: 10.1002/pon.1517
- Ashing-Giwa, K. T., Tejero, J. S., Kim, J., Padilla, G. V., Kagawa-Singer, M., Tucker, M. B., & Lim, J. W. (2009). Cervical cancer survivorship in a population based sample. *Gynecologic Oncology, 112*(2), 358-364. doi: 10.1016/j.ygyno.2008.11.002
- Ashing-Giwa, K., Ganz, P. A., & Petersen, L. (1999). Quality of life of African-American and white long term breast carcinoma survivors. *Cancer, 85*(2), 418-426.
- Avis, N. E., & Deimling, G. T. (2008). Cancer survivorship and aging. *Cancer Supplement, 113*(12), 3519-3529.
- Avis, N. E., Smith, K. W., McGraw, S., Smith, R. G., Petronis, V. M., & Carver, C. S. (2005). Assessing quality of life in adult cancer survivors (QLACS). *Quality of Life Research, 14*(4), 1007-1023.
- Azuero, A., Su, X., McNees, P., & Meneses, K. (2013). A revision of the quality of life breast cancer survivors (QOL-BCS) instrument. *Research in Nursing & Health, 36*(4), 423-434.
- Bausewein, C., Calanzani, N., Daveson, B. A., Simon, S. T., Ferreira, P. L., Higginson, I. J., . . . Toscani, F. (2013). 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. *BMC Cancer, 13*(1), 105.

- Bell, R. J., Lijovic, M., La China, M., Schwarz, M., Fradkin, P., Bradbury, J., & Davis, S. R. (2010). Psychological well-being in a cohort of women with invasive breast cancer nearly 2 years after diagnosis. *Supportive Care in Cancer*, 18(8), 921-929. doi: 10.1007/s00520-009-0726-z
- Bellizzi, K. M., Aziz, N. M., Rowland, J. H., Weaver, K. E., Arora, N. K., Hamilton, A. S., . . . Keel, G. (2012). Double jeopardy? Age, race, and HRQOL in older adults with cancer. *Journal of Cancer Epidemiology*, 2012.
- Bellury, L. M., Ellington, L., Beck, S. L., Stein, K., Pett, M., & Clark, J. (2011). Elderly cancer survivorship: An integrative review and conceptual framework. *European Journal of Oncology Nursing*, 15, 233-242.
- Blank, T. O., & Bellizzi, K. M. (2006). After prostate cancer: Predictors of well-being among long-term prostate cancer survivors. *Cancer*, 106(10), 2128-2135.
- Blank, T. O., & Bellizzi, K. M. (2008). A gerontologic perspective on cancer and aging. *Cancer*, 112(11), 2569-2576.
- Blomberg, B. B., Alvarez, J. P., Diaz, A., Romero, M. G., Lechner, S. C., Carver, C. S., . . . Antoni, M. H. (2009). Psychosocial adaptation and cellular immunity in breast cancer patients in the weeks after surgery: An exploratory study. *Journal of Psychosomatic Research*, 67(5), 369-376. doi: 10.1016/j.jpsychores.2009.05.016
- Bowman, K. F., Deimling, G. T., Smerglia, V., Sage, P., & Kahana, B. (2003). Appraisal of the cancer experience by older long-term survivors. *Psycho-Oncology*, 12, 226-238.
- Carver, C. S., Scheier, M., & Weintraub, J. (1989). Assessing coping strategies: A theoretically-based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Charlson, Mary E, Pompei, Peter, Ales, Kathy L, & MacKenzie, C Ronald. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases*, 40(5), 373-383.
- Chase, D. M., Watanabe, T., & Monk, B. J. (2010). Assessment and significance of quality of life in women with gynecologic cancer. *Future Oncology*, 6(8), 1279-1287. doi: 10.2217/fon.10.96
- Christy, S. M. (2010). *Quality of life differences among long-term cancer survivors based upon cancer type and number of treatment types*. (Master of Arts in Counseling), Ball State University, Muncie, IN.
- Cimprich, B., Ronis, D. L., & Martinez-Ramos, G. (2002). Age at diagnosis and quality of life in breast cancer survivors. *Cancer Practice*, 10(2), 85-93.

- Cohen, M. (2014). Depression, anxiety, and somatic symptoms in older cancer patients: a comparison across age groups. *Psycho-Oncology*, 23(2), 151-157.
- Cohen, M., Baziliansky, S., & Beny, A. (2014). The association of resilience and age in individuals with colorectal cancer: An exploratory cross-sectional study. *Journal of Geriatric Oncology*, 5(1), 33-39.
- Costanzo, E. S., Ryff, C. D., & Singer, B. H. (2009). Psychosocial adjustment among cancer survivors: Findings from a national survey of health and well-being. *Health Psychology*, 28(2), 147-156.
- Cwikel, J. G., & Behar, L. C. (1999). Organizing social work services with adult cancer patients. *Social Work in Health Care*, 28(3), 55-76.
- Dale, W., Mohile, S. G., Eldadah, B. A., Trimble, E. L., Schilsky, R. L., Cohen, H. J., . . . Hurria, A. (2012). Biological, clinical, and psychosocial correlates at the interface of cancer and aging research. *Journal of the National Cancer Institute*, 104(8), 581-589.
- Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology*, 15, 306-320.
- Deimling, G. T., Wagner, L. J., Bowman, K. F., Sterns, S., Kercher, K., & Kahana, B. (2006). Coping among older-adult, long-term cancer survivors. *Psycho-Oncology*, 15, 143-159.
- DSS Research. (2014). Statistical power calculator.
- Erikson, E. H. (1950). *Childhood and Society*. London: Vintage Books.
- Erikson, E. H. (1982). *The Life Cycle Completed: A Review*. New York: W.W. Norton and Company.
- Erikson, E. H., Erikson, J. M., & Kivnick, H. Q. (1986). *Vital Involvement in Old Age*. New York: W.W. Norton and Company.
- Esbensen, B. A., Oosterlind, K., & Hallberg, I. R. (2004). Quality of life of elderly persons with newly diagnosed cancer. *European Journal of Cancer Care*, 13(5), 443-453.
- Esbensen, B. A., Osterlind, K., Roer, O., & Hallberg, I. R. (2007). Quality of life of elderly persons with cancer: A 6-month follow-up. *Scandinavian Journal of Caring Sciences*, 21, 178-190.
- Esbensen, B. A., Swane, C. E., Hallberg, I. R., & Thome, B. (2008). Being given a cancer diagnosis in old age: A phenomenological study. *International Journal of Nursing Studies*, 45, 393-405.

- Eton, D. T., & Lepore, S. J. (2002). Prostate cancer and health-related quality of life: A review of the literature. *Psycho-Oncology*, *11*, 307-326.
- Extermann, M., & Hurria, A. (2007). Comprehensive geriatric assessment for older patients with cancer. *Journal of Clinical Oncology*, *25*(14), 1824-1831.
- Fadem, S. Z. (n.d.). Charlson comorbidity scoring system. from http://touchcalc.com/calculators/cci_js
- Federal Interagency Forum on Aging-Related Statistics. (2014). Population. from http://www.agingstats.gov/main_site/data/2012_documents/population.aspx
- Fees, B. S., Martin, P., & Poon, L. W. (1999). A model of loneliness in older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *54*(4), P231-P239.
- Fenlon, D., Frankland, J., Foster, C. L., Brooks, C., Coleman, P., Payne, S., . . . Addington-Hall, J. M. (2013). Living into old age with the consequences of breast cancer. *European Journal of Oncology Nursing*, *17*(3), 311-316. doi: 10.1016/j.ejon.2012.08.004
- Ferrell, B. R., Hassey Dow, K., & Grant, M. (1995). Measurement in the quality of life in cancer survivors. *Quality of Life Research*, *4*, 523-531.
- Foley, K. L., Farmer, D. F., Petronis, V. M., Smith, R. G., McGraw, S., Smith, K. , . . . Avis, N. . (2006). A qualitative exploration of the cancer experience among long-term survivors: Comparisons by cancer type, ethnicity, gender, and age. *Psycho-Oncology*, *15*, 248-258.
- Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British Journal of Cancer*, *105*, S21-S28. doi: 10.1038/bjc.2011.419
- Foster, C., Wright, D., Hill, H., Hopkinson, J., & Roffe, L. (2009). Psychosocial implications of living 5 years or more following a cancer diagnosis: A systematic review of the research evidence. *European Journal of Cancer*, *18*, 223-247.
- Frumovitz, M., Sun, C. C., Schover, L. R., Munsell, M. F., Jhingran, A., Wharton, J. T., . . . Bodurka, D. C. (2005). Quality of life and sexual functioning in cervical cancer survivors. *Journal of Clinical Oncology*, *23*, 7428-7436.
- Galway, K., Black, A., Cantwell, M., Cardwell, C. R., Mills, M., & Donnelly, M. (2012). Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients. *Cochrane Database of Systematic Reviews*(11). doi: 10.1002/14651858.CD007064.pub2
- Gazmararian, J. A., Baker, D. W., Williams, M. V., Parker, R. M., Scott, T. L., Green, D. C., . . . Koplan, J. P. (1999). Health literacy among Medicare enrollees in a managed care organization. *Journal of the American Medical Association*, *281*(6), 545-551.

- Giedzinska, A. S., Meyerowitz, B.E., Ganz, P.A., & Rowland, J.H. (2004). Health-related quality of life in a multiethnic sample of breast cancer survivors. *Annals of Behavioral Medicine*, 28(1), 39-51.
- Gil, F., Costa, G., Hilker, I., & Benito, L. (2012). First anxiety, afterwards depression: Psychological distress in cancer patients at diagnosis and after medical treatment. *Stress and Health*, 28, 362-367.
- Gitterman, A., & Germain, C. B. (2013). *The life model of social work practice: Advances in theory and practice*: Columbia University Press.
- Given, B., & Given, C. W. (2008). Older adults and cancer treatment. *Cancer*, 113(12), 3505-3511.
- Given, B., & Given, C. W. (2009). Cancer treatment in older adults: Implications for psychosocial research. *Journal of the American Geriatric Society*, 57, S283-S285.
- Grundy, Emily, & Holt, Gemma. (2001). The socioeconomic status of older adults: How should we measure it in studies of health inequalities? *Journal of Epidemiology and Community health*, 55(12), 895-904.
- Gurung, R. A. R., Taylor, S. E., & Seeman, T. E. (2003). Accounting for changes in social support among married older adults: Insights from the MacArthur Studies of Successful Aging. *Psychology and Aging*, 18(3), 487-496.
- Hamilton, J. B., Deal, A. M., Moore, A. D., Best, N. C., Galbraith, K. V., & Muss, H. B. (2013). Psychosocial predictors of depression among older African American patients with cancer. *Oncology Nursing Forum*, 40(4), 394-402.
- Hank, Karsten. (2011). How “successful” do older Europeans age? Findings from SHARE. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66(2), 230-236.
- Hanratty, B., Addington-Hall, J., Arthur, A., Cooper, L., Grande, G., Payne, S., & Seymour, J. (2013). What is different about living alone with cancer in older age? A qualitative study of experiences and preferences for care. *BMC Family Practice*, 14(1), 22.
- Havighurst, R. J. (1973). History of developmental psychology: Socialization and personality development through the life span. In P. B. Baltes & K. W. Schaie (Eds.), *Life-Span Developmental Psychology: Personality and Socialization*. New York: Academic Press.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(1), M82-M91.

- Holland, J. C., Poppito, S., Nelson, C., Weiss, T., Greenstein, M., Martin, A., . . . Roth, A. (2009). Reappraisal in the eighth life cycle stage: A theoretical psychoeducational intervention in elderly patients with cancer. *Palliative and Supportive Care*, 7, 271-279.
- Hopwood, P., & Stephens, R. J. (2000). Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data. *Journal of Clinical Oncology*, 18(4), 893-893.
- Howlader, N., Noone, A. M., Krapcho, M., Garshell, J., Neyman, N., Altekruse, S. F., . . . Cronin, K. A. . (2013). SEER Cancer Statistics Review, 1975-2010
http://seer.cancer.gov/csr/1975_2010/
- Hughes, N., Closs, S. J., & Clark, D. (2009). Experiencing cancer in old age: a qualitative systematic review. *Qualitative Health Research*, 19(8), 1139-1153.
- Hurria, A. (2009). Geriatric assessment in oncology practice. *Journal of the American Geriatric Society*, 57, S246-S249.
- Hurria, A., Li, D., Hansen, K., Patil, S., Gupta, R., Nelson, C., . . . Kelly, E. (2009). Distress in older patients with cancer. *Journal of Clinical Oncology*, 27(26), 4346-4351.
- Hwang, S. Y., Chang, S. J., & Park, B. W. (2013). Does Chemotherapy Really Affect the Quality of Life of Women with Breast Cancer? *Journal of Breast Cancer*, 16(2), 229-235. doi: 10.4048/jbc.2013.16.2.229
- Institute of Medicine. (2013). Delivering high-quality cancer care: Charting a new course for a system in crisis Washington, DC: The National Academies Press.
- Jansen, J., van Weert, J. C. M., van Dulmen, S., Heeren, T., & Bensing, J. (2007). Patient education about treatment in cancer care: An overview of the literature on older patients' needs. *Cancer Nursing*, 30(4), 251-260.
- Janz, N. K., Mujahid, M. S., Hawley, S. T., Griggs, J. J., Alderman, A., Hamilton, A.S., . . . Katz, S. J. (2009). Racial/ethnic differences in quality of life after diagnosis of breast cancer. *Journal of Cancer Survivorship*, 3(4), 212-222.
- Jarrett, N., Scott, I., Addington-Hall, J., Amir, Z., Brearley, S., Hodges, L., . . . Foster, C. (2013). Informing future research priorities into the psychological and social problems faced by cancer survivors: A rapid review and synthesis of the literature. *European Journal of Oncology Nursing*, 17(5), 510-520. doi: 10.1016/j.ejon.2013.03.003
- Katz, M. R., Irish, J. C., Devins, G. M., Psych, C., Rodin, G. M., & Gullane, P. J. (2003). Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support. *Head and Neck-Journal for the Sciences and Specialties of the Head and Neck*, 25(2), 103-112. doi: 10.1002/hed.10174

- Kenny, A., Endacott, R., Botti, M., & Watts, R. (2007). Emotional toil: psychosocial care in rural settings for patients with cancer. *Journal of Advanced Nursing*, 60(6), 663-672. doi: 10.1111/j.1365-2648.2007.04453.x
- Keyes, C. L. M. (1998). Social well-being. *Social Psychology Quarterly*, 61(2), 121-140.
- Klapper, S. (2013, December 23). Focus on geriatric oncology: ASCO prepares for an aging nation. *ASCO Connection*.
- Kroenke, C. H., Kubzansky, L. D., Schernhammer, E. S., Holmes, M. D., & Kawachi, I. (2006). Social networks, social support, and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, 24(7), 1105-1111.
- Kurtz, M. E., Kurtz, J. C., Stommel, M., Given, C. W., & Given, B. (2001). Physical functioning and depression among older persons with cancer. *Cancer Practice*, 9(1), 11-18.
- Kurtz, M. E., Kurtz, J. C., Stommel, M., Given, C. W., & Given, B. . (2002). Predictors of depressive symptomatology of geriatric patients with colorectal cancer: A longitudinal view. *Supportive Care in Cancer*, 10, 494-501.
- Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55, 234-247.
- Lazarus, R. S. (2000). Toward better research on stress and coping. *American Psychologist*, 55(6), 665-673.
- Lazarus, R. S., & Folkman, S. . (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Lev, E. L., Paul, D., & Owen, S. V. (1999). Age, self-efficacy, and change in patients' adjustment to cancer. *Cancer Practice*, 7(4), 170-176.
- Lieffers, J. R., Baracos, V. E., Winget, M., & Fassbender, K. (2011). A comparison of the Charlson and Elixhauser comorbidity measures to predict colorectal cancer survival using administrative health data. *Cancer* 117, 1957-1965.
- Lin, T. H. (2010). A comparison of multiple imputation with EM algorithm and MCMC method for quality of life missing data. *Quality and Quantity*, 44, 277-287.
- Linden, W., Vodermaier, A., MacKenzie, R., & Greig, D. (2012). Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. *Journal of Affective Disorders*, 141(2-3), 343-351.
- Loerzel, V. W., McNees, P., Powel, L. L., Su, X., & Meneses, K. (2008). Quality of life in older women with early-stage breast cancer in the first year of survivorship. *Oncology Nursing Forum*, 35(6), 924-932.

MaCorr. (2014). Sample Size Calculator.

Martin, P., da Rosa, G., Siegler, I. C., Davey, A., MacDonald, M., Poon, L.W., & Georgia Centenarian Study. (2006). Personality and longevity: Findings from the Georgia Centenarian Study. *Age*, 28(4), 343-352.

Maskileyson, Dina. (2014). Healthcare system and the wealth–health gradient: A comparative study of older populations in six countries. *Social Science & Medicine*, 119, 18-26.

Massie, D. K. (2004). Psychosocial issues for the elderly with cancer: The role of social work. *Topics in Geriatric Rehabilitation*, 20(2), 114-119.

Matsuyamaa, R. K., Wilson-Genderson, M., Kuhn, L., Moghanakic, D., Vachhanid, H., & Paasche-Orlowe, M. (2011). Education level, not health literacy, associated with information needs for patients with cancer. *Patient Education and Counseling*, 85(3), e229-e236.

Matthews, B. A., Baker, F., & Spillers, R. L. (2004). Oncology professionals and patient requests for cancer support services. *Supportive Care in Cancer*, 12, 731-738.

McDaniel, J. S., Musselman, D. L., Porter, M. R., Reed, D. A., & Nemeroff, C. B. (1995). Depression in patients with cancer: Diagnosis, biology, and treatment. *Archives of General Psychiatry*, 52, 89-99.

McPherson, C. J., Wilson, K. G., & Murray, M. Ann. (2007). Feeling like a burden: Exploring the perspectives of patients at the end of life. *Social Science & Medicine*, 64(2), 417-427.

Mehnert, A., & Koch, U. (2008). Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research*, 64, 383-391.

Mitschke, D. (2008). Cancer in the family: Review of the psychosocial perspectives of patients and family members. *Journal of Family Social Work*, 11(2), 166-184.

Montazeri, A., Milroy, R., Hole, D., McEwen, J., & Gillis, C. R. (1998). Anxiety and depression in patients with lung cancer before and after diagnosis: Findings from a population in Glasgow, Scotland. *Journal of Epidemiology and Community Health*, 52, 203-204.

National Comprehensive Cancer Network. (2012). NCCN clinical practice guidelines in oncology: Senior adult oncology (Version 1.2013 ed.). Fort Washington, Pennsylvania: National Comprehensive Cancer Network.

Nelson, C. J., Balk, E. M., & Roth, A. J. (2010). Distress, anxiety, depression, and emotional well-being in African-American men with prostate cancer. *Psycho-Oncology*, 19, 1052-1060.

- Neugarten, B. L., & Datan, N. (1973). Sociological perspectives on the life cycle. In P. B. Baltes & K. W. Schaie (Eds.), *Life-Span Developmental Psychology: Personality and Socialization*. New York: Academic Press.
- Ogle, K. S., Swanson, G. M., & Woods, N. (2000). Cancer and comorbidity. *Cancer*, 88, 653-663.
- Pallis, A. G., Fortpied, C., Wedding, U., Van Nes, M. C., Penninckx, B., Ring, A., . . . Wildiers, H. (2010). EORTC elderly task force position paper: Approach to the older cancer patient. *European Journal of Cancer*, 46, 1502-1513.
- Palmer, N. R. A., Geiger, A. M., Lu, L., Case, L. D., & Weaver, K. E. (2013). Impact of rural residence on forgoing healthcare after cancer because of cost. *Cancer Epidemiology Biomarkers & Prevention*, 22(10), 1668-1676.
- Parpa, E., Tsilika, E., Gennimata, V., & Mystakidou, K. (2015). Elderly cancer patients' psychopathology: A systematic review: Aging and mental health. *Archives of Gerontology and Geriatrics*, 60(1), 9-15.
- Perkins, E. A., Small, B. J., Balducci, L., Extermann, M., Robb, C., & Haley, W. E. (2007). Individual differences in well-being in older breast cancer survivors. *Critical Reviews in Oncology/Hematology*, 62, 74-83.
- Perz, J., Ussher, J. M., & Gilbert, E. (2013). Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *Bmc Cancer*, 13. doi: 10.1186/1471-2407-13-270
- Raveis, V.H., Gardner, D.S., Berkman, B., & Harootyan, L. (2010). Linking the NIH strategic plan to the research agenda for social workers in health and aging. *Journal of Gerontological Social Work*, 53(1), 77-93.
- Reavley, N., Pallant, J. F., & Sali, A. (2009). Evaluation of the Effects of a Psychosocial Intervention on Mood, Coping, and Quality Of Life in Cancer Patients. *Integrative Cancer Therapies*, 8(1), 47-55. doi: 10.1177/1534735408329411
- Reeve, B. B., Potosky, A. L., Smith, A. W., Han, P. K., Hays, R. D., Davis, W. W., . . . Clauser, S. B. (2009). Impact of cancer on health-related quality of life of older Americans. *Journal of the National Cancer Institute*, 101(12), 860-868.
- Repetto, L., Venturino, A., Fratino, L., Serraino, D., Troisi, G., Gianni, W., & Pietropaolo, M. (2003). Geriatric oncology: A clinical approach to the older patient with cancer. *European Journal of Cancer*, 39, 870-880.
- Robb, C., Haley, W. E., Alducci, L. B., Extermann, M., Perkins, E. A., Small, B. J., & Mortimer, J. (2007). Impact of breast cancer survivorship on quality of life in older women. *Critical Reviews in Oncology Hematology*, 62(1), 84-91. doi: 10.1016/j.critrevonc.2006.11.003

- Robinson, J. D., & Turner, J. (2003). Impersonal, interpersonal, and hyperpersonal social support: Cancer and older adults. *Health Communication, 15*(2), 227-234.
- Rose, J. H., O'Toole, E. E., Einstadter, D., Love, T. E., Shenko, C. A., & Dawson, N. V. (2008). Patient Age, Well-Being, Perspectives, and Care Practices in the Early Treatment Phase for Late-Stage Cancer. *Journals of Gerontology Series a-Biological Sciences and Medical Sciences, 63*(9), 960-968.
- Rowland, J. H., & Bellizzi, K. M. (2014). Cancer survivorship issues: life after treatment and implications for an aging population. *Journal of Clinical Oncology, 32*(24), 2662-2668.
- Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology, 69*(4), 719-727.
- Sanson-Fisher, R., Carey, M., & Paul, C. (2009). Measuring the unmet needs of those with cancer: A critical overview *Cancer Forum* (33 ed., Vol. 3).
- Santin, O., Mills, M., Treanor, C., & Donnelly, M. (2012). A comparative analysis of the health and well-being of cancer survivors to the general population. *Supportive Care in Cancer, 20*(10), 2545-2552. doi: 10.1007/s00520-011-1372-9
- Sarna, L., Brown, J. K., Cooley, M. E., Williams, R. D., Chernecky, C., Padilla, G., & Danao, L. L. (2005). Quality of life and meaning of illness of women With lung cancer. *Oncology Nursing Forum, 32*(1), E9-E19.
- Schroevers, M. J., Helgeson, V. S., Sanderman, R., & Ranchor, A. V. (2010). Type of social support matters for prediction of posttraumatic growth among cancer survivors. *Psycho-Oncology, 19*(1), 46-53. doi: 10.1002/pon.1501
- Sharp, L., Carsin, A., & Timmons, A. (2013). Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer. *Psycho-Oncology, 22*(4), 745-755.
- Siegel, K. (1990). Psychosocial oncology research. *Social Work in Health Care, 15*(1), 21-43.
- Siegel, R., Ma, J., Zou, Z., & Jemal, A. (2014). Cancer statistics, 2014. *CA: A Cancer Journal for Clinicians, 64*, 9-29.
- Simon, A. E., & Wardle, J. (2008). Socioeconomic disparities in psychosocial wellbeing in cancer patients. *European Journal of Cancer, 44*(4), 572-578. doi: 10.1016/j.ejca.2007.12.013
- Simonoff, L. A., Graham, G. C., & Gordon, N. H. (2006). Cancer communication patterns and the influence of patient characteristics: Disparities in information-giving and affective behaviors. *Patient Education and Counseling, 62*(3), 355-360.

- Smith, A. W., Reeve, B. B., Bellizzi, K. M., Harlan, L. C., Klabunde, C. N., Amsellem, M., . . . Hays, R. D. (2008). Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financing Review*, 29(4), 41.
- Smith, S. K. (2014, June 10, 2014).
- Stanton, M., Franco, G., & Scoggins, R. (2011). Case management needs of older and elderly cancer survivors. *Professional Case Management*, 17(2), 61-69.
- Stommel, M., Given, B. A., & Given, C. W. (2002). Depression and functional status as predictors of death among cancer patients. *Cancer*, 94, 2719-2727.
- Stommel, M., Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2004). A longitudinal analysis of the course of depressive symptomatology in geriatric patients with cancer of the breast, colon, lung, or prostate. *Health Psychology*, 23(6), 564-573.
- Tabachnick, B. G., & Fidell, L. S. (2000). *Using Multivariate Statistics* (4th ed.). New York: Allyn & Bacon.
- Thome, B., Dykes, A., Gunnars, B., & Hallberg, I. R. (2003). The experiences of older people living with cancer. *Cancer Nursing*, 26(2), 85-96.
- Thome, B., Dykes, A., & Hallberg, I. R. (2004). Quality of life in old people with and without cancer. *Quality of Life Research*, 13(6), 1067-1080.
- Thome, B., Esbensen, B. A., Dykes, A., & Hallberg, I. R. (2004). The meaning of having to live with cancer in old age. *European Journal of Cancer Care*, 13, 399-408.
- Thome, B., & Hallberg, I. R. (2004). Quality of life in older people with cancer: A gender perspective. *European Journal of Cancer Care*, 13, 454-463.
- Tomaka, J., Thompson, S., & Palacios, R. (2006). The relation of social isolation, loneliness, and social support to disease outcomes among the elderly. *Journal of Aging and Health*, 18, 359-384.
- United States Administration on Aging. (2015). Number of persons 65+ by race and Hispanic origin by state, 2008. from www.aol.acl.gov/Aging_Statistics/minority_aging/DOCS/Table11_Num_Persons_65_by_Race_Hispanic_2008.xls
- Vodermaier, A., Linden, W., MacKenzie, R., Greig, D., & Marshall, C. (2011). Disease stage predicts post-diagnosis anxiety and depression only in some types of cancer. *British Journal of Cancer*, 105(12), 1814-1817.

- Weinberger, Mark I, Bruce, Martha L, Roth, Andrew J, Breitbart, William, & Nelson, Christian J. (2011). Depression and barriers to mental health care in older cancer patients. *International journal of geriatric psychiatry*, 26(1), 21-26.
- Weiss, T., Weinberger, M. I., Holland, J., Nelson, C., & Moadel, A. (2012). Falling through the cracks: A review of psychological distress and psychosocial service needs in older Black and Hispanic patients with cancer. *Journal of Geriatric Oncology*, 3, 163-173.
- Weitzner, M. A., Meyers, C. A., Stuebing, K. K., & Saleeba, A. K. (1997). Relationship between quality of life and mood in long-term survivors of breast cancer treated with mastectomy. *Supportive Care in Cancer*, 5, 241-248.
- White, H. K., & Cohen, H. J. (2008). The older cancer patient. *Nursing Clinics of North America*, 43(2), 307-322.