

THE RELATIONSHIP BETWEEN THE SENSE OF COMMUNITY AND HEALTH-  
RELATED QUALITY OF LIFE OF FEMALE CANCER SURVIVORS

BY

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DISSERTATION

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## ABSTRACT

Currently there are roughly 12 million individuals alive today with a history of cancer (USCS, 2010). Research has shown that cancer and its treatment exact significant psychosocial effects, and that further research on the relationship between the survivor's association with their family, community and larger society and their HRQOL is an important question for study (ACS, 2010; Albrecht & Devlieger, 1999; IOM, 2005; NCI, 2010). Due to the nature of the disease and treatment modalities typically utilized, many cancer survivors report psychosocial and HRQOL effects (Aziz, 2002, 2007; Bloom, 2008). In the case of women who are diagnosed with cancer, research has shown that female survivors report more psychosocial and emotional distress than men (Langeveld, Grootenhuis, Voute, & de Haan, 2004; Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003). Supported by the survivorship literature is the notion that regardless of the cancer type, virtually all individuals experience altered relationships to some extent (Zebrack, Yi, Petersen, & Ganz, 2008). Dependence and/or independence issues, altered and/or reduced support, isolation and loneliness as a result of the sequelae associated with diagnosis and treatment are often reported (Montazeri, 2008; Robb, et al., 2007; Zebrack et al., 2008). As cancer and its treatment often leave its victims highly vulnerable, the sense of community (SOC) one receives from others throughout the continuum of care has been suggested to positively influence their health-related quality of life (HRQOL) (Albrecht & Devlieger, 1999).

As female survivors of cancer are embedded in multiple communities, often within a single day, there is a need to extend current research to better understand how these multiple senses of community may be related to their HRQOL. This has been clearly recognized as an important topic in need of further investigation as both the American Cancer Association [ACS] (2010), National Cancer Institute [NCI] (2005) and the Institute of Medicine [IOM] (2005) have

all called for further investigation into the relationship between cancer survivors' communities of support and their HRQOL.

The purpose of this study was therefore to investigate the relationship that select multiple senses of community have on the health-related quality of life (HRQOL) of adult female cancer survivors. To address this purpose, this study explored adult female cancer survivors' sense of community based on five mutually exclusive community types commonly investigated in the literature (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) and how their sense of community with these community types is related to their HRQOL. More specifically, this study addressed three research questions that investigated the relationship between the SOC and HRQOL of adult female cancer survivors:

Question 1: What is the relationship between SOC and its domains and the HRQOL of women who are cancer survivors?

Question 2: How does the sense of community (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to which a female cancer survivor identifies relate to her HRQOL?

Question 3: How does a female cancer survivor's SOC differentially impact the various components of HRQOL?

Female cancer survivors from a cancer support program based in the Southwestern United States participated in this study. A total of 98 responses from a population of 800 were obtained for data analysis. Multiple Analysis of Covariance (MANCOVA) was used to address the research questions of interest from this purposive sample of female cancer survivors. First, preliminary analyses revealed violations with normality and multicollinearity for the scales that measured respondents' SOC. After attempting several transformation processes for the SOC data, it was determined that a median split would be the most appropriate transformation to correct for issues with assumptions for parametric data analyses. In addition, exploratory factor

analysis revealed that SOC was comprised of a unidimensional solution. As two of the research questions relied on the existence of a multidimensional model of SOC, each of the research questions and associated hypotheses were changed accordingly.

Regarding the relationship between SOC and HRQOL, for these respondents it was found that their Leisure and Work-based SOC was positively related to specific aspects of their HRQOL. With much of the literature finding links between Geographic / Neighborhood community types, this research extended current research and suggested that the relationship between respondents' SOC and HRQOL are not dependent upon the SOC of just one community type, but rather on multiple community types. As this was a purposive biased sample of cancer survivors from a mid-sized Southwestern city in the United States, further research using other samples and methods may provide further insights into this relationship.

For Mom, who for 12 years battled breast cancer and always said her “community” was what made life worth livin’!

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## TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION.....	1
CHAPTER TWO: REVIEW OF THE LITERATURE .....	18
CHAPTER THREE: METHOD .....	41
CHAPTER FOUR: RESULTS .....	58
CHAPTER FIVE: DISCUSSION AND CONCLUSION .....	108
REFERENCES .....	128
APPENDIX A: INITIAL CONTACT E-MAIL .....	143
APPENDIX B: PARTICIPANT CONSENT FORM .....	145
APPENDIX C: QUESTIONNAIRE FOR SURVEY PARTICIPANTS.....	147

## CHAPTER ONE: INTRODUCTION

It has been estimated that one in three Americans will be diagnosed with cancer at some point in their lives, with 65% of them surviving more than five years post-diagnosis (American Cancer Society [ACS], 2010; Helgeson & Tomich, 2005). Representing approximately 4% of the population, the National Cancer Institute [NCI] (2010) reported that as of January 2008 approximately 12 million Americans were currently alive with a history of cancer. Due to the advances in biomedical intervention in the United States, the number of survivors, or those living more than 5 years after their initial diagnosis, has quadrupled since 1971, growing at a rate of 2% per year (Aziz, 2007; Bloom, Peterson, & Kang, 2007; Gotay & Muraoka, 1998; NCI, 2010). At this rate, the NCI estimated that there will be 18.1 million individuals alive in the United States with a history of cancer by the year 2020.

### **Cancer Survivors**

Survivors of cancer occupy a place in American society where they are viewed as neither the well nor the unwell (Frank, 1995). Survivorship is a highly debated topic with many different terms being synonymously employed (Feuerstein, 2007). Definitions of survivorship have traditionally been based on a biomedical approach focused on the formative acute stage of cancer diagnosis, treatment and remission (Aziz, 2002, 2007). However, as more individuals are successfully beating cancer as a result of advances in biomedical interventions, a new definition of what constitutes survivorship has emerged (Aziz, 2002, 2007; Avis & Deimling, 2008). Survivorship currently brings a relatively new way of thinking about cancer outcomes, as there has been a shift from a traditional biomedical treatment-centered approach focusing on remission to a salutogenic patient-centered approach focusing on cancer as it was experienced across the life-course.

A physician and survivor himself, Mullen (1985) identified three different phases of cancer survival: phase one consists of *acute survival* and refers to the diagnosis and treatment of cancer and its side effects; phase two, or *extended survival*, is the period after completion of initial treatment and may be referred to as the period of “watchful waiting”; and phase three, or *permanent survival*, refers to the long-term life beyond cancer (see Table 1). Mullen adopted the term “survival” to be more inclusive of those who not only experienced prolonged life “cancer free,” but it also included those who were experiencing cancer for the first time or continued to live with cancer as a chronic condition. This change in definition and language orientation has been adopted and actively promoted by most cancer organizations including the American Cancer Society and the National Coalition of Cancer Survivors. Although defining cancer survivorship as encompassing the entire cancer continuum from diagnosis until death, it is generally recognized that each stage of the continuum brings with it a different set of challenges and opportunities (Avis & Deimling, 2008).

Survivors comprise a wide and diverse range of individuals representing various diagnoses, treatment exposures, side effects (including physical, psychological, and social), and demographic characteristics, as well as various additional comorbid health conditions (Aziz, 2002, 2007; Bhatia & Robinson, 2008; Bloom, 2008). Diagnosis and treatment modalities for the various cancer types differ with each individual case; however, surgeries, toxic chemotherapy and/or radiation are some of the common invasive approaches used in this battle. Because of these procedures, patients may experience intense physical and psychological side effects including altered gastrointestinal processes, reduced sensitivity to taste and smell, persistent pain, fatigue, depression, and adverse health-related quality of life (HRQOL) effects (Avis & Deimling, 2008).

While each survivor experiences cancer differently, one of the greatest challenges encountered outside of the biomedical realm is the social dysfunction that emerges due to the disease and its treatment (Aziz, 2002, 2007; Bloom, 2008). Research has shown that throughout the cancer continuum, from diagnosis until death, survivors experience extensive social dysfunction, including isolation and loneliness (Albrecht & Devlieger, 1999; Aziz, 2002, 2007; Bloom, 2008; Glover & Parry, 2009; Parry & Glover, 2010). Supported by the survivorship literature is the notion that regardless of the cancer type, virtually all individuals experience altered relationships to some extent (Zebrack, Yi, Petersen, & Ganz, 2008). Dependence and/or independence issues, altered and/or reduced support, and isolation and loneliness as a result of the sequelae associated with diagnosis and treatment are all often reported (Montazeri, 2008; Robb, et al., 2007; Zebrack et al., 2008). As cancer and its treatment often leave its victims highly vulnerable, the support one receives from others throughout the continuum of care has been suggested to influence not only their HRQOL, but potentially their years of survivorship (Albrecht & Devlieger, 1999).

For women, breast cancer is the most commonly diagnosed cancer and the second leading cause of death next to lung cancer in the United States (ACS, 2010; Harper, et al., 2009). Of the 12 million cancer survivors alive today, it is estimated that 2.5 million are breast cancer survivors (ACS, 2010) with an estimated quarter million cases of breast cancer being diagnosed each year for the foreseeable future (ACS, 2010; NCI, 2010). Due to early detection education and mammography programs, most women in the United States are diagnosed in the early stages of the disease, with 96% of those with localized breast cancer and 78% of those with regional breast cancer surviving more than 5 years post-diagnosis (ACS, 2010).

Due to the nature of the disease and treatment modalities typically utilized, many cancer survivors report psychosocial and HRQOL effects (Aziz, 2002, 2007; Bloom, 2008). In the case of women who are diagnosed with cancer, research has shown that female survivors report more psychosocial and emotional distress than men (Langeveld, Grootenhuis, Voute, & de Haan, 2004; Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003). For example, it has been shown that women with breast cancer experience greater psychological distress, sexual issues, identity problems, relationship issues, and financial concerns (Ashing-Giwa, Ganz, & Petersen, 1999; Foster, Wright, Hill, Hopkins, & Roffe, 2009). Additionally, female breast cancer survivors report reduced optimism, increased feelings of vulnerability, and having at least one persistent physical symptom including anemia, fatigue, pain, or sleep disorders, to name a few (Gordon & Simioff, 2010). As women with a history of breast cancer constitute the largest group of cancer survivors, research investigating their needs has been called for in the literature (Carver, Smith, Petronis, & Antoni, 2005, 2006; Montazeri, 2008; Robb, et al., 2007; Thomas-MacLean, 2004).

While social support has been shown to be important for cancer survivors, research has demonstrated it is particularly salient for female cancer survivors (Parry, 2008; Robb, et al., 2007; Thomas-MacLean, 2004). Therefore, cancer survivors' community support networks have garnered increased empirical interest as researchers have begun to explore how and why these networks are related to cancer survivors' HRQOL (cf. Bloom, 2008). Communities of support have been recognized by the National Cancer Institute [NCI] (2005) and the Institute of Medicine [IOM] (2005) as an important component in cancer survivorship and in survivors' HRQOL, however, this research is in its early stages (Aziz, 2002, 2007).

## **Sense of Community and Cancer Survivorship**

The social community is increasingly being recognized as serving a crucial role in the health-related quality of life (HRQOL) of cancer survivors (Albrecht & Devlieger, 1999; Bloom, Peterson, & Kang, 2007; Glover & Parry, 2008; Parry & Glover, 2010). The literature suggests that cancer survivors' participation in, and perception of, their significance in a given community counteracts the feelings of social isolation, loneliness, and social dysfunction that emerge due to the sequelae experienced as a result of their diagnosis and treatment (Albrecht & Devlieger, 1999; Anderson, 2009; McMillan & Chavis, 1986). Thus, it is not surprising to find that community interaction and participation positively influence the HRQOL of cancer survivors (Albrecht & Devlieger, 1999; Aziz, 2007; Bloom, Stewart, Chang, & Banks, 2004). Defining what constitutes "sense of community" has proven to be challenging at best (Sarason, 1974). Sense of community (SOC) as a concept seems to range widely in meaning from those attached to a rural ideal of community (Tonnies, 1988) to those attached to modern day virtual communities that are connected through technology and social media that are perceived to have few specific boundaries (Obst, Zinkiewicz, & Smith, 2002). Whatever SOC may be, most individuals seem to know when they have a SOC and when they do not (Sarason). Yet for survivors of cancer, research has shown that a SOC is heavily impacted and reduced due to the physical, psychological and social effects associated with the diagnosis and treatment of this disease (Aziz, 2002, 2007; Zebrack, et al., 2008).

Sarason wrote further about the concept of community by employing a perceptual lens to understand the construct. He posited that community was really about an individual's perception of their similarity to, and interdependence with, other members. Similar to Sarason, McMillan and Chavis proposed a perceptual/experiential theory of community that they called the Theory

of SOC. They defined it as the ways in which an individual feels towards a community in terms of belonging or mattering to one another, as a feeling that one has the ability to influence / and receive influence from aspects of the community, as a shared faith that their individual and group needs are met, and as a shared emotional connection between members. These researchers proposed a model of SOC that consists of four underlying dimensions: (a) Membership, (b) Influence, (c) Fulfillment of Needs, and (d) a Shared Emotional Connection.

The impact of one's SOC has been suggested by Anderson (2009) to depend largely in part, not on one particular community type with which one may associate, but with the numerous community types with which that individual may interact or participate (Brodsky & Marx, 2001; Dioginni & Lyons, 2010). For example, a cancer survivor may be involved not only with a cancer support community, but also simultaneously with their individual family, neighborhood, church, work, or leisure-related communities. Research also suggests that not all community types have the same outcomes or influence participants in the same way (Peterson, Speer & McMillan, 2009). In their study on multiple psychological senses of community for underserved women involved with a job training and education center in the Eastern United States, Brodsky and Marx (2001) found that these women participated and identified with a number of distinct communities at a given time while at the center. Obst, Zinkiewicz and Smith (2002) found similar findings to that of Brodsky and Marx in their research that explored and contrasted respondents' perceptions of community with two types of community, interest and geographic community types. Participants in their study reported distinct and greater perceptions of community with their science fiction fandom community type when compared to that of their neighborhood community type. With research lacking in the cancer survivor literature on the collective experience of multiple communities to which cancer survivors may belong (Social

Support, Neighborhood, Leisure, Faith, and Work-based community types), and the impact these might have on their HRQOL, research into the relationship between these two constructs is clearly needed (Boadsky & Marx, 2001; Obst & White, 2007; Pretty, Andrewes & Collett, 1994; Royal & Rossi, 1996).

### **Health-Related Quality of Life and Survivorship**

Due to the dramatic increase in the number of survivors living five years post-diagnosis, there has been greater recognition given to the ongoing and emergent sequelae of cancer and its impact on HRQOL (Aziz, 2007; Aziz & Deimling, 2008). HRQOL is a quality of life term that takes into account the impact an illness has on an individual's quality of life. Although HRQOL is suggested in the literature to be a subjective patient-reported outcome (PRO), many of the current instruments used to measure HRQOL for cancer survivors continue to adopt a biomedical clinical-centered approach (Ashing-Giwa & Lim, 2010). Using focus groups and personal interviews of breast cancer patients and survivors, Gotay, Korn, McCabe, Moore and Cheson (1992) developed a patient-centered definition of HRQOL. Based on their research, Gotay et al., proposed HRQOL as consisting of a state of well-being for those with cancer that contains two components: (1) the cancer survivor's ability to perform the tasks of daily living which reflects his or her physical, psychological and social well-being, and (2) the cancer survivor's satisfaction with his or her level of functioning and control of the disease and the associated treatment-related sequelae.

From this definition, a variety of instruments have emerged to measure a cancer patient's HRQOL (Montazeri, 2008). However, many of these instruments have focused primarily on the acute phase of diagnosis and treatment (Avis, 2002; 2007; Avis, Smith, McGraw, Smith, Petronis, & Carver, 2005; Bloom; 2008; Carver, et al., 2006). In an effort to assess the HRQOL

of adult cancer survivors who are more than five years post-diagnosis, Avis et al. (2005) developed and established the psychometric properties of the Quality of Life in Adult Cancer Survivors (QLACS), an instrument designed to assess HRQOL issues relevant to cancer survivors who are 5 years or more post-diagnosis. QLACS consists of five cancer-specific domains (Appearance Concerns, Financial Problems, Distress Over Recurrence, Family-Related Distress, and Benefits of Cancer) and seven more general aspects of health-related quality (Negative Feelings, Positive Feelings, Cognitive Problems, Sexual Problems, Physical Pain, Fatigue, and Social Avoidance). The items were derived from in-depth semi-structured interviews conducted with 58 long-term cancer survivors who identified the domains of most relevance. Results from pilot testing showed the QLACS instrument demonstrated good internal consistency and internal validity, with the instrument shown to be appropriate for comparisons between cancer and non-cancer individuals, as well as for long-term cancer survivors (Avis, et al., 2005; Carver, et al., 2006).

### **Purpose of the Study**

As noted earlier, currently there are roughly 12 million individuals alive today with a history of cancer (USCS, 2010). Research has shown that cancer and its treatment exact significant psychosocial effects, and that further research on the relationship between survivors' associations with the family, community and larger society and their HRQOL is an important question for study (ACS, 2010; Albrecht & Devlieger, 1999; IOM, 2005; NCI, 2010). As survivors of cancer are embedded in multiple communities, often within a single day, there is a need to extend current research to better understand how these multiple senses of community may be related to their HRQOL. This has been clearly recognized as an important topic in need of further investigation as the American Cancer Association [ACS] (2010), National Cancer

Institute [NCI] (2005) and the Institute of Medicine [IOM] (2005) have all called for further investigation into the relationship between cancer survivors' communities of support and their HRQOL.

The purpose of this study was therefore to investigate the impact that select multiple senses of community have on the health-related quality of life (HRQOL) of adult female cancer survivors. To address this purpose, this study explored adult female cancer survivors' sense of community based on five mutually exclusive community types commonly investigated in the literature (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) and how their sense of community with these community types were related to their HRQOL.

### **Research Questions**

The overarching aim of this study was to contribute to an understanding of how female cancer survivor's senses of community might impact their health-related quality of life (HRQOL). The following specific research questions and hypotheses (see Figure 1) guided the methods and analysis:

Question 1: What is the relationship between SOC and its domains and the HRQOL of women who are cancer survivors?

H1a: There will be a positive relationship between overall SOC and HRQOL.

H1b: There will be a positive relationship between the overall Membership domain and HRQOL.

H1c: There will be a positive relationship between the overall Influence domain and HRQOL.

H1d: There will be a positive relationship between the overall Fulfillment of Needs domain and HRQOL.

H1e: There will be a positive relationship between the overall Emotional Connection domain and the HRQOL.

Question 2: How does the sense of community (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to which a female cancer survivor identifies relate to her HRQOL?

H2a: There will be a positive relationship between Social Support SOC and HRQOL.

H2b: There will be a positive relationship between Neighborhood SOC and HRQOL.

H2c: There will be a positive relationship between Leisure SOC and HRQOL.

H2d: There will be a positive relationship between Spiritual\Faith SOC and HRQOL.

H2e: There will be a positive relationship between Work SOC and HRQOL.

Question 3: How does a female cancer survivor's SOC differentially impact the various components of HRQOL?

H3a: There will be a negative relationship between SOCs and the HRQOL cancer-specific Appearance Concerns domain.

H3b: There will be a negative relationship between SOCs and the HRQOL cancer-specific Financial Problems domain.

H3c: There will be a negative relationship between SOCs and the HRQOL cancer-specific Distress Over Recurrence domain.

H3d: There will be a negative relationship between SOCs and the HRQOL cancer-specific Family-Related Distress domain.

H3e: There will be a positive relationship between SOCs and the HRQOL cancer-specific Benefits of Cancer domain.

H3f: There will be a negative relationship between SOCs and the general HRQOL Negative Feelings domain.

H3g: There will be a positive relationship between SOCs and the general HRQOL Positive Feelings domain.

H3h: There will be a negative relationship between SOCs and the general HRQOL Cognitive Problems domain.

H3i: There will be a negative relationship between SOCs and the general HRQOL Sexual Interest domain.

H3j: There will be a negative relationship between SOCs and the general HRQOL Sexual Function domain.

H3k: There will be a negative relationship between SOCs and the general HRQOL Physical Pain domain.

H3l: There will be a negative relationship between SOCs and the general HRQOL Fatigue domain.

H3m: There will be a negative relationship between SOCs and the general HRQOL social avoidance domain.

Figure 1 is a graphical depiction of the research hypotheses put forward for the study.

### **Significance of the Study**

This investigation into the relationship between the SOCs of female cancer survivors and their HRQOL will be of great value to several communities. First, as this was the first investigation into cancer survivors' multiple senses of community and how SOC components may influence HRQOL, this research supported and expanded the current SOC, HRQOL and survivorship literatures. Further, researchers that use the SOC and HRQOL constructs will gain

a better understanding of how multiple senses of community aid in the construction and further development of the quality of life of cancer survivors, as well as the efficacy of various types of community-based interventions.

### **Delimitations**

The following delimited the scope of this study that investigated female cancer survivors' multiple senses of community and the relationship with their HRQOL.

- 1) The study was restricted to a southwestern city in the United States.
- 2) Participant volunteers came from a community-based cancer association.
- 3) Individuals who participated in the study were restricted to females, at least 18 years of age, and who had been diagnosed with cancer.
- 4) Only women who were able to read and understand the English language were able to participate.

### **Limitations**

The following limitations of this research study on the relationship between female cancer survivors' SOCs and their HRQOL are acknowledged:

- 1) The constructs and relationships examined within this study were investigated from data collected on participants and communities that were available in a mid-sized urban city in a southwestern state of the United States. Therefore, any relationships found may not be generalizable to other rural, differently sized, or distantly located geographic areas.
- 2) As participants were restricted to female cancer survivors, findings were not meant to be generalizable to men.

- 3) The data was collected through a convenience sample and therefore may not be representative of the general population of women with a history of cancer.
- 4) As participants responded to a select set of communities (Social Support, Neighborhood, Interest, Faith, and Work-based), this research may not be generalizable to other community types.
- 5) A recall bias may have been present in that female cancer survivors were asked questions about their past experience and they may have been be accurate in their recollection. For example, as respondents were asked to reply to inquiries about multiple different communities, participants may have had difficulty recalling each specific community to which they were a member with a high level of accuracy.
- 6) A social desirability bias may have also been present in that all of the data was based on self-reports by the participants. In effect, participants may have wanted to portray themselves as more active and involved than they really were, however, there were no methods available to validate their responses.
- 7) Limitations with the theory and measurement of SOC have been noted in the literature. Therefore caution must be used when interpreting the findings from this study.

### **Definitions**

As many of the variables are multifaceted, it is helpful to provide definitions to provide a common understanding of the terms utilized in this study. The following definitions are provided to establish the meanings associated with these terms:

- a) *Community of Interest*: the relational or interest-based SOC (i.e., hobby or leisure and recreation-based groups), or that which is concerned with the “quality of character of human relationship, without reference to location” (Gusfield, 1975; p. xvi).

- b) *Neighborhood Community*: the territorial or the geographical notion of SOC (i.e., the neighborhood, town, or city), or the sense of belonging to a particular location.
- c) *Quality of Life (QOL)*: an individual's subjective view of their current physical, psychological and social well-being (Hartl, et al., 2003).
- d) *Health-Related Quality of Life (HRQOL)*: A state of well-being with two components: the ability to perform the tasks of daily living that reflect physical, psychological and social well-being, and the individual's satisfaction with levels of functioning and control of the disease and/or the associated treatment related sequelae (Gotay, et al., 1992).
- e) *Salutogenesis*: An approach to health focusing on factors that support human health and well-being, rather than factors that cause disease.
- f) *Sense of Community (SOC)*: "A feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together" (McMillan & Chavis, 1986, p.9).
- g) *Faith-based Community*: A group/community to which a survivor identifies or associates with which explores and/or attempts to make sense of experience through philosophies and/or practices.
- h) *Support-based Community*: A community that empowers by knowledge, strengthens by action, and sustains the survivor.
- i) *Work-based Community*: A group or community of individuals who share a craft or profession or labor together. It be both "for-pay" and/or "voluntary" in nature (i.e., not for pay).

## **Summary**

Chapter One provided a brief introduction into the current state of research on cancer survivorship with specific emphasis on health-related quality of life and perceived sense of community for specific communities to which the individual belongs. A statement of the problem was provided, the research questions that were addressed, and the hypotheses were delineated. The significance of the study, delimitations and limitations, and definitions of key terms were also included. Chapter Two presents a review of the relevant literature pertaining to the key constructs under study: sense of community (SOC) and cancer survivors' health-related quality of life (HRQOL). Chapter Three presents a description of the research design, sampling plan, data collection, and data analysis procedures propose that were used in this study. Chapter Four presents the results obtained from the data analyses. Chapter Five provides a discussion and conclusion in relation to the findings, relates them to previous studies in the literature, and discusses the potential implications and future directions for this line of inquiry.

Table 1.1

*Phases of Survival (adopted from Mullen, 1985)*

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*Acute Survival*

- Extends from diagnosis to completion of initial treatment
- Dominated by cancer treatment and coping with effects of therapy
- Confronting one's mortality
- Fear and anxiety are constant elements
- Family and community support are important; needs of family often overlooked.

*Extended Survival*

- Beginning to return to normal life after treatment completion
- Period of "watchful waiting" regular follow-up examinations, intermittent therapy as needed, dealing with physical limitations secondary to treatment (e.g., fatigue, hair loss, altered body image, cognitive dysfunction)
- Psychosocial support services important
- Dominated by fear of recurrence

*Permanent Survival*

- Evolves from extended disease-free survival and low likelihood of disease recurrence
- Adjustment to the "new normal"
- Long-term physiological effects of treatment
- Employment and health insurance concerns
- Health promotion strategies

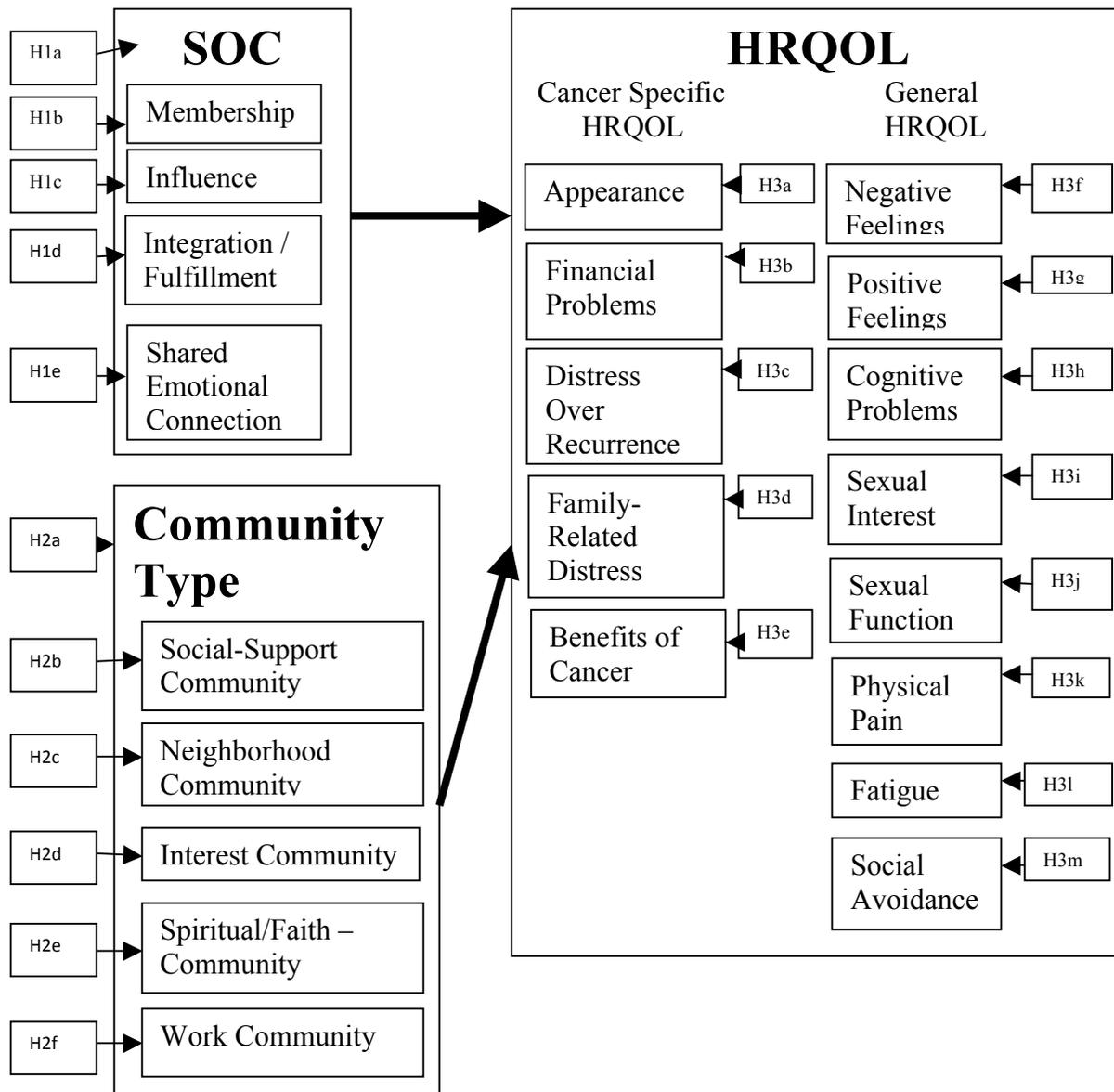


Figure 1. Depiction of the research hypotheses.

## CHAPTER TWO: REVIEW OF THE LITERATURE

### Introduction

Previously, a diagnosis of cancer was considered a living death sentence for many as survival rates were quite low. For example, it is estimated that over 200,000 new cases of breast cancer are diagnosed and approximately 40,000 women die due to complications as a result of this disease each year (NCI, 2010). Due to advances in early detection and potent treatment regimens, over 2.5 million women are alive today with a history of breast cancer (NCI, 2010). Although the overall rate of breast and other cancer diagnoses for women is expected to increase over the next couple of decades, the five year survival rate for those diagnosed with early stage non-metastatic cancer is now greater than 90% (ACS, 2010).

Remission, and ultimately curative treatment, remains the main priority of patients and physicians during the early acute survivor phase (i.e. initial diagnosis and treatment). With many more individuals surviving cancer and its treatment, cancer survivors' long-term health-related quality of life (HRQOL) has emerged as a crucial concern. As such, a substantial body of research exists that has investigated the HRQOL of women diagnosed with cancer during the acute survivor phase (Ferrell, Dow & Grant, 1995; Ganz, 2006; Griggs, et al., 2006; Hartl, et al., 2003; Hegelson & Tomich, 2005; Lipscomb, Gotay, & Snyder, 2007; Loezre, McNees, Powel, Su, & Meneses, 2008; Manne, et al., 2006; Ong, Visser, Lammes, & de Haes, 2000). While each woman's cancer experience differs, several HRQOL issues are common among survivors of this disease. One of the greatest and most common HRQOL challenges reported outside of the biopsychological realm is the social dysfunction that emerges due to the disease and its treatment (Aziz, 2002, 2007; Bloom, 2008; Zebrack, et al., 2008). Supported by the literature that cancer survivors are generally immersed in multiple social groups or "communities" during any given

day (Aziz 2002; 2007; Bloom, 2008; Zebrack, et al., 2008), survivors' perceptions of these multiple communities and the relationship they have to their HRQOL is in need of further investigation.

The purpose of this study was to investigate the relationship between female cancer survivor's multiple senses of community (SOCs) and their HRQOL, with the intention of this specific chapter to review the literature associated with these constructs. Chapter Two is divided into three sections: section one begins with a discussion of the literature regarding HRQOL for adult female cancer survivors, section two presents a discussion of the literature regarding SOCs, and the final section provides a discussion of the literature that relates SOCs to HRQOL.

### **Health-Related Quality of Life (HRQOL)**

Once a cancer patient's clinical goals are achieved (i.e., remission, suppression, or cure), their focus turns from that of survival to survivorship (Zebrack, 2000). With this transition now more commonplace, there has been greater recognition concerning the ongoing and emergent sequelae of cancer long after treatment has ended, especially on the survivor's quality of life (Ashing-Giwa, Ganz, & Petersen, 1999; Aziz, 2002, 2007). As a result, cancer survivors' quality-of-life issues have received substantial attention in the literature over the past 15 years. A recent Web of Science search crossing "cancer" with "quality-of-life" yielded over 30,200 English-language citations, with approximately 80% of these published since the year 2000. Considered a quality of life factor, HRQOL has emerged as a multi-dimensional construct used to broaden the investigation of cancer patients' quality of life (Gotay and Moore, 1992). However, researchers and practitioners alike have been unable to come to a consensus as to an exact definition and domain structure to represent this construct. Two main reasons cited for this difficulty is that various quality-of-life terms have been synonymously used in the published

research to represent this construct (e.g., happiness, health-related quality of life, life satisfaction, mental health, physical health, positive affect and subjective well-being), and, prior to the turn of the century, there was an overreliance on clinical-based assessments that excluded any patient-oriented interpretation of the cancer experience with regard to their quality-of-life (Aziz, 2002, 2007; Ganz, Shag, & Cheng, 1990; Montazeri, 2008).

Prior to the current explosion in cancer-related HRQOL research in the past decade, definitions and measurement of this construct went through a transition from a strictly biomedical clinical-based approach (i.e., auxiliary node status, performance status, receipt of chemo radiotherapy, toxicity ratings, type of surgery, etc) to a patient-reported outcome (PRO) approach (i.e., levels of pain; level of worry about cancer coming back again; feeling treated differently because of changes in appearance due to cancer and/or its treatment, etc) (Ganz, et al., 1990; Montazeri, 2008). As defined by the U.S. Food and Drug Administration (FDA), PROs included any outcomes based on data provided by a research subject without interference from some outside source (i.e., physician, researcher, and care givers) (Lipscomb, Gotay, & Snyder, 2007). Considered more sensitive than clinically-based evaluations, PRO assessments emerged as the predominant approach used in evaluating the impact that cancer and its treatment have had on a patient's HRQOL (Ashing-Giwa, Ganz, & Petersen, 1999).

During this transition between clinical and PRO assessment approaches, HRQOL emerged to broaden the evaluation of cancer to include not only clinical definitions, but also to include the survivor's perception of their quality of life and functioning with the disease (Aaronson, et al., 1993). Through the use of in-depth interviews and focus groups with cancer patients and survivors, Gotay and Moore (1992) put forward a definition and identify basic domains for HRQOL. They conceptualized HRQOL as a state of well-being with two

components: first was the ability to perform the tasks of daily living which reflected physical, psychological and social functioning; and second was a survivor's satisfaction with his/her level of functioning and control of the disease and/or the associated treatment related sequelae. Cella (1995) further added to this discussion by stating that evaluation of a cancer survivor's HRQOL should be explicitly based on the individual's perceptual assessment of the extent to which the disease and its treatment impacts their usual or expected quality of life (i.e., physical, emotional and social well-being) and functional ability.

At the domain level, Gotay and Moore (1992) pointed out that HRQOL consists of a survivor's subjective assessment of three quality of life domains (physical, psychological and social well-being), and the functional assessment of disease control and management. Physical well-being was posited to reflect a survivor's own assessment of his or her ability to provide self-care for those activities that are part of daily living, including dressing, bathing, shopping, and physical activities like walking and climbing stairs. Psychological well-being includes a survivor's own assessment of his or her psychological or emotive feelings, including levels of depression, anxiety, and/or positive affect and optimism. Social well-being includes an assessment of the survivor's participation and level of interaction in social activities like friendships, club activities (if previously undertaken) and other usual or expected social events. Lastly, functional well-being includes a survivor's overall satisfaction with his/her level of functioning and control of the disease and/or the associated treatment-related sequelae (Ashing-Giwa, Ganz, & Petersen, 1998; Gotay and Moore, 1992).

**HRQOL in Adult Cancer Survivors.** Among HRQOL studies with cancer patients, breast cancer has received much attention in the literature. According to Montazeri (2008) there are three reasons for this: first, the numbers of women worldwide being diagnosed with breast

cancer is increasing, with 1.1 million women being diagnosed and 410,000 dying from this disease each year (Stewart & Kleihues, 2003). Second, due to advances in early diagnosis and improvements in biomedical therapies, chances for long-term survival are increasing for all cancer types, thus making the study of HRQOL more central. Lastly, the diagnosis of breast cancer has been shown to heavily impact a women's identity, especially for those who undergo a mastectomy. As cancer is not just a single event but rather is considered by many to be an enduring chronic condition characterized by ongoing uncertainty, breast cancer survivors have been shown to experience altered social roles and identities (i.e., partner, wife, mother, sister, employee(r), religious figure, student, etc), ultimately impacting their short and long-term HRQOL (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Zebrack, 2000).

However, of the HRQOL studies published to date, most have focused on individuals who have been recently diagnosed, with limited use of HRQOL as an outcome variable (Ashing-Giwa, et al., 1998; Mullen, 1985). Of those studies that have used HRQOL in combination with biomedical-based markers, research has shown that greater long-term survivorship-based outcomes were achieved for cancer patients in contrast to solely clinical-based biomedical outcomes (Aziz, 2002, 2007; Bloom, 2008). For example, in an effort to improve survivorship outcomes of the recently diagnosed, Salonen, Lehtinen, Tarkka, Koivisto, and Kaunonen (2010) attempted to further identify factors that might predict negative HRQOL changes within six months of being diagnosed. This six-month longitudinal study involved a sample of 164 recently diagnosed women who were then divided into an intervention ( $n=85$ ) or a waitlist control group ( $n=79$ ). Whereas the waitlist control group only received traditional clinical treatment focused on bio-medical outcomes (i.e., tumor size, chemo radiotherapy effectiveness, remission), the intervention group also received HRQOL-related support and education over the phone for six

months after surgery. The waitlist control group was also evaluated during the same intervals and then once again post-intervention as well. Although the waitlist control group reported significant improvement in their HRQOL six months after receiving the intervention, the researchers found continued differences in HRQOL between these groups, with the waitlist control group experiencing lower HRQOL than the experimental group. Further, several non-clinical factors (i.e., education, employment status, having under-aged children) predicted negative changes in a patient's HRQOL within six months beyond traditional clinical variables (i.e., surgery type, chemo or radiotherapy, etc). By assessing HRQOL throughout the study, the researchers and physicians were able to identify the HRQOL needs of patients, which were then used to further improve the decision making related to the treatment and support needs of each patient.

Of the Breast cancer studies that primarily employed HRQOL as a means to evaluate the effectiveness of different operative techniques (mastectomy versus breast-conservation or intensive versus “wait-and-see” chemo radiotherapy regimens), little focus has been placed on the long-term survivorship implications and/or HRQOL outcomes (Avis, 2002, 2007; Lipscomb, et al, 2007). HRQOL therefore seems to be viewed as little more than an “add on” to the main clinical protocols that have been primarily concerned with the short-term effectiveness of surgical interventions and therapies (Holzner et al., 2001). With breast cancer survivors representing the largest group of cancer survivors, research with this group should therefore not focus solely on the immediate effects of diagnosis and treatment, or remission and survival rates, but also include an emphasis on the long-term levels of effective functioning and subjective well-being, that are key constructs in the discussion of cancer survivors' HRQOL (Avis, et al., 2005; Holzner, et al., 2001; Thomas-McLean, 2004).

In the most recent review of the literature that investigated HRQOL in long-term survivors (5 or more years post diagnosis) of adult onset cancers from 1998 to 2007, Bloom et al. (2007) found 53 studies, of which 20 were based on long-term breast cancer survivors. Although few studies showed a decrease in HRQOL over time, most found that long-term breast cancer survivors reported similar to better overall HRQOL compared to healthy controls. In addition, analyses showed that recurrence and treatment type (i.e., systemic adjuvant therapies like chemotherapy, tamoxifen, or both) had negative effects on long-term HRQOL in cancer survivors. Results from a self-administered HRQOL survey with 278 women (Ashing-Giwa, et al., 1999) showed that, overall, women reported favorable HRQOL with differences being attributable to socioeconomic status and life-burden factors.

Just like their recently diagnosed counterparts, many long-term survivors experience continued and emergent issues related to this disease and its treatment on domain specific HRQOL (Bloom et al., 2007; Montazeri, 2008). For example, 16 of the 20 studies that Bloom et al. (2007) found in their review of long-term cancer survivors discussed a physiological domain HRQOL for cancer survivors. These studies generally found that women who were long-term breast cancer survivors reported lower physical domain HRQOL and lower physical functioning as compared to healthy controls. In addition, it was shown that, for those women who were diagnosed and treated at an older age (age 65 and older), they reported experiencing lower physical domain HRQOL and worse physical functioning (i.e., fatigue, early menopause, and reduced sexual functioning). Similarly, Robb et al. (2007), in their investigation on the impact of breast cancer on the HRQOL of women aged 70 and older, found that when compared to healthy controls these women reported greater physical domain HRQOL decrements, lower psychosocial (i.e., life satisfaction, mastery and spiritual well-being) and functional ability. Results from this

investigation suggested that as cancer survivors age, greater attention must be paid to the physical functionality and other HRQOL specific domains of older long-term cancer survivors even when they may not have obvious cancer-related issues.

In addition to physical symptoms, several studies of women who were long-term cancer survivors found similar levels to healthy controls in regards to overall psychological symptoms (Bloom, et al., 2007; Carver, et al., 2006). Robb et al. (2007) obtained similar results in that older survivors reported no more depression or anxiety symptoms than a comparison group, but they did score lower on measures of positive psychological well-being and had more days with depressed mood and fatigue. Bloom et al.'s (2007) investigation further supported Robb et al., in that being a cancer survivor was a risk factor for lower mental domain HRQOL scores. Post-traumatic stress disorder (PTSD), depression, and being diagnosed at a younger age with cancer were also found to be specific risk factors for poor psychological domain HRQOL (Bloom et al., 2007). However, having fewer chronic conditions, less physical symptoms, greater levels of social support, feelings of personal control over the disease, a life purpose, and being partnered at the time of diagnosis were reported as being protective factors for low scores on the psychological domain of HRQOL (Bloom et al.).

Considered an important area for future research, the social HRQOL domain has received only limited attention. Of the 20 studies Bloom et al. investigated for women who were long-term survivors of breast cancer, 14 addressed social HRQOL domains. However, the main social concern addressed in these studies focused primarily on issues surrounding the lack of interest in, and ability to, relax and enjoy sexual activity. Although sexual activity may be of great concern to some, other social HRQOL concerns including reduced role functioning (i.e., at home, work and during leisure activities) and social identity have been identified as crucial areas in need of

further attention and study. For example, Zebrack (2000) proposed that cancer survivors' social domain beyond sexual functioning needed to be taken into account in order to better understand how this domain impacted their long-term HRQOL. Zebrack posited that we should further expand our understanding of how the experience of cancer, especially for women diagnosed with cancer, impacts a survivor's ability to carry out her social roles and responsibilities, which may ultimately impact her long-term HRQOL.

During acute stages and across the treatment trajectory, many cancer survivors report an increase in social dysfunction and reduced social domain HRQOL (Bloom, 2008). For example, Bloom posited that a possible explanation for this decrease in survivors' social domain HRQOL may include previous illness-imposed restrictions, since many individuals during and long after treatment has ended experienced reduced immunological processes due to radiation and chemotherapy, thereby limiting their ability to participate in social activities (Aziz, 2007). In addition, many cancer survivors have been shown to experience reduced social support over time once treatment has ended and as friends and family return to their daily routine (Schrover, 2004). Likewise, work-related reductions have also been reported, with blue-collar occupations experiencing the greatest difficulty returning to work due to the demands placed on the body for these types of jobs (Satariano & DeLorenze, 1996). However, in a follow-up study of female cancer survivors, Ganz et al. (1998) found that 80% of their sample of disease-free cancer survivors who were employed in white collar occupations were still working after six years.

It has been generally recognized by researchers that the actual and perceived social support received during the acute survival phase is a crucial component that heavily impacts the HRQOL of patients (Aziz, 2002, 2007; Bloom, 2008). Women who are long-term cancer survivors continue to experience and face challenges due to the late effects of treatment,

especially in relation to the social aspect of their quality of life (Bloom, 2002, 2008). Yet much of the current literature and HRQOL measures focus on the physical and psychological aspects with little emphasis on the social domain of HRQOL. As most women interact and associate with multiple social groups and communities and receive ongoing support via many different sources, little research has investigated how these multiple communities relate to their HRQOL.

**Measurement of HRQOL.** Over the past decade researchers have begun to use patient-reported outcomes (PRO) as the central means to assess the HRQOL of cancer patients and survivors. PRO is a term that has been frequently used in the clinical trial literature since the year 2000. It consists of an individual's subjective assessment of his or her own health and well-being without any interpretation of the response by a physician or others (Federal Drug Administration, 2009; Lipscomb, et al., 2007). The FDA has provided three main reasons as to why PROs should be used instead of traditional clinical-based methods. First, only the patient knows some of the effects of the treatment such as pain intensity or relief. Second, a patient provides a unique perspective as to the effectiveness of treatment because many times clinical improvements may not necessarily correspond to the patient's own assessment. Third, formal assessments with a patient versus informal interviews via their provider or a third party are considered more reliable (Lipscomb, et al., 2007).

Additionally, Lipscomb et al. (2007) cited two other sources of evidence as to the importance of using PROs in the decision making process. Anecdotally, the first source occurs whenever a cancer patient's physician asks him/her informal questions regarding how they are feeling, or to what extent they are experiencing pain or fatigue as a result of the cancer and its treatment. Other informal questions they typically ask include the patient's reported ability to participate in activities that they used to, such as work or hobbies, and sources of support for the

patient and a number of other HRQOL-related questions. Second, Lipscomb et al. further posited that several concrete indicators in support of utilizing PROs for assessing cancer's impact have been found via many recent U.S. research and governmental policy-related developments. As discussed earlier, many of the advances and uses of PROs have emerged since the early 2000's, suggesting a growing interest in, and attesting to the importance of, bringing cancer patients' perceptions of the cancer experience to the forefront of research, governmental policy and the individual decision making process.

As the emergent and long-term effects of cancer and its sequelae have garnered much attention as of late, several measures have emerged to evaluate the HRQOL of cancer patients. Moving beyond traditional generic quality of life tools, several cancer-specific HRQOL measures have been developed. These include the Functional Adjustment to Cancer Therapy (FACT; Cella, et al., 1993), European Organization for Research and Treatment of Cancer (EORTC; Borghede & Sullivan, 1996; Osoba, Aaronson, Zee, Sprangers, & te Velde, 1997; Ringdal & Ringdal, 1993), Functional Living Index-Cancer (FLIC; Schipper, Clinch, McMurray, & Levitt, 1984), and Cancer Rehabilitation Evaluation System (CaRES) and its later developed short-form (CaRES-SF; Schag & Heinrich, 1990; Schag, Ganz, & Heinrich, 1991). As most of these instruments were designed to assess cancer patients' HRQOL during the acute survivor phase, one of the most common critiques of these instruments is that they may not be appropriate for assessing HRQOL in long-term cancer survivors that are five years or more post-diagnosis (Avis, Ip, & Foley, 2006; Avis, et al., 2005; Ferrell, Dow, & Grant, 1995; Pearce, Sanson-Fisher, & Campbell, 2008; Zebrack, et al., 2008). For example, concerns about the long-term effects of cancer and its treatment on aspects of social and existential domains continue to arise long after treatments have ended (Albrecht & Devlieger, 1999). Additionally, later effects including

cognitive impairments, fatigue, intimacy issues, pain, and physical decline have also been noted to emerge many years after treatment has ended (Ferrell, et al, 1995). Therefore, it is possible that these issues and others associated with the long-term health and well-being of cancer survivors are potentially missed in general HRQOL instruments (Pearce, et al., 2008; Zebrack, et al., 2008).

Limitations with these measurements aside, the Institute of Medicine, supported by the National Cancer Institute (2010), has identified improvement in the health and QOL of cancer survivors as two of four important areas in need of further research (Hewitt, et al., 2006). To bridge this gap, several new HRQOL tools have recently been developed and found to be valid and reliable instruments for use with long-term cancer survivors (cf. Pearce et al., 2008).

Currently, three PRO-based HRQOL instruments have been specifically designed for use with long-term cancer survivors (cf. Avis et al., 2005). One of the newest measures showing much promise is the Quality of Life in Adult Cancer Survivor Scale (QLACS). QLACS was developed to address the concerns in the literature that current HRQOL tools were not adequate for long-term cancer survivors (Avis et al., 2006). The QLACS is a 47-item instrument consisting of 12 domains (Avis et al., 2005). Five cancer-specific domains measure quality of life issues that are impacted as a result of having cancer, whereas seven generic domains measure quality of life issues that are associated with daily living (Avis et al., 2006). The QLACS has also been shown to be appropriate for comparisons between cancer and non-cancer populations as well as for long-term cancer survivor populations (Avis et al., 2005; Avis et al., 2006; Pearce et al., 2008).

### **Sense of Community (SOC)**

**Definitions and Dimensions.** McMillan and Chavis (1986) reviewed the community literature and put forth a theoretical conceptualization of community called “sense of

community” (SOC). Similar to Sarason, McMillan and Chavis proposed a perceptual/experiential definition of community as “a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together” (p. 9). Suggesting that this theory is equally applicable to both geographic and interest-based communities, SOC consists of four underlying dimensions: (a) Membership, (b) Influence, (c) Fulfillment of Needs, and (d) a Shared Emotional Connection.

*Membership* refers to that feeling or sense of belonging an individual possesses due to their investment in becoming a member of a given community (McMillan & Chavis, 1986). Membership is comprised of five attributes: boundaries, emotional safety, a sense of belonging and identification, personal investment and a common symbol system. These attributes work in concert with one another and contribute to a sense of who is part of a given community and who is not. By providing members with a way to decipher who is and is not a member, boundaries provide members with the structure, emotional safety, and sense of belonging and identification necessary for building group intimacy. Glynn (1981) suggested that the absence of SOC for individuals is indicative of isolation and social dysfunction. Corroborating this notion, Bishop, Chertok, and Jason (1997) found that defining SOC as having a reductive effect on isolation aligns SOC with that of the Membership domain. Further, Bishop et al.’s research with 133 male addicts and alcoholics confirmed these finding that better psychosocial behaviors and use of social resources like material assistance and social support were predictive of greater levels of SOC.

Personal involvement and the investing of one’s self into a given community play a large part in developing the Emotional Connections between members (Bishop & Hoggett, 1986). Without a sense of personal investment in a community, McMillan and Chavis contended that

members will not have a feeling that they have earned their place and as a consequence will find less meaning and less emotional connection. Corroborating this notion, Mullen (1985) suggested that many cancer patients during the acute survival stage commonly experience less personal involvement in the various relationships and groups to which they may associate, resulting in increased isolation and social dysfunction.

Finally, a common symbol system serves as an important boundary for the establishment of a sense of community. Symbols, myths, rituals, holidays and events surround and define membership boundaries. For those who associate with the cancer community, a common symbol for breast cancer survivors is the pink ribbon or the annual cancer 5k walk-for-life events that are generally held each spring and serve as a reminder of the breast cancer community's existence and also who is and is not part of this growing community. As cancer survivors are embedded in multiple communal memberships at a given time, little research has examined how these communities interact to form a tapestry of 'community' that collectively influences survivors' HRQOL. Therefore, this research investigated how simultaneous membership in multiple communities influenced the HRQOL of cancer survivors.

*Influence*, according to McMillan and Chavis (1986), is a bi-directional concept. It refers both to the degree to which members feel that they can influence a sense of community for those to which they belong, and on the other hand, to the perception that the group can exert control over its members. Influence, a second underlying dimension of SOC, is therefore a balance between both individual and group control. In the cancer survivorship context, memberships in various communities are constrained due to the effects of cancer and its treatment (Bloom, 2002; Zebrack, et al., 2008). However, for long-term cancer survivors, the degree to which they influence the various communities SOC to which they belong and how those communities SOC

influence them is relatively unclear. McMillan and Chavis suggested four propositions concerning this influence: first, that members who feel that they are influential to a given community are more attracted to that community; second, that the reverse is equally true in that the more attractive a community, the more likely a member will invest; third, that the need for consensual validation between the individual and the community is due to the competing pressures between conformity and uniformity; and finally, that influence between both the community and the members operate concurrently and are apparent in tightly knit communities. As Influence works in both directions, for cancer survivors this could be a challenge due to the effects of cancer and the associative treatment. However, as some literature on long-term survivors suggests a return to “normal” (Aziz, 2002; Zebrack, et al., 2008), it is still relatively unclear how this domain of SOC may influence survivors’ HRQOL. For this reason, further research is needed, and was one of the purposes of this study.

*Integration and Fulfillment of Needs*, the third SOC dimension, refers to members’ feelings of reinforcement. McMillan and Chavis (1986) posited that reinforcement enables a group to maintain the balance between individual and group relationships as being rewarding for its members. Like Influence, McMillan and Chavis posited four roles for this domain: first, a trait commonly exhibited in strong communities, reinforcement, serves as a primary function of a community; second, the rewards of membership act to reinforce a community and include the status of membership (e.g., prestige of being associated with the cancer cause); third, the success of a community (e.g., successful cancer support groups like Gilda’s Club) gives members a sense of pride in their membership; and fourth, the competence or capabilities of other members (e.g., fundraising more for cancer research than other groups) adds to reinforce the members’ joint commitment and fulfills the needs of a community.

As an organizing principle, McMillan and Chavis (1986) queried that reinforcement may be directionless as many people tend to serve their best interests. To resolve this paradox, the shared values of members were posited as providing a potential unifying directional concept. When members of a community share similar values they then find that their similar needs and goals will be further met if they work together, which ultimately reinforces their joint commitment. With research suggesting that survivors of cancer experience altered relationships to some extent (Zebrack, et al., 2008), little research has investigated how this domain may influence their HRQOL.

*Shared Emotional Connection*, the fourth dimension of SOC, refers to an individual's shared common history with the community in which he or she associates. McMillan and Chavis noted that a shared common history does not mean that group members must have participated together in the past in order to share it. Strong shared emotional connections within the given community provide members with a basis for interaction and a way to positively resolve issues as they arise based on that shared relationship. Further, McMillan and Chavis posited that communities with a high degree of shared emotional connection tend to invest in their members and provide experiences to establish and maintain community. With a central unifying event such as cancer diagnosis and the ensuing treatment, survivors of cancer share a major life event that create bonds regardless of the cancer diagnosis.

Research has shown that most survivors of cancer experience a loss of shared emotional connection due to the isolating effects of cancer and its treatment (Aziz, 2002; Zebrack et al., 2008). Researching Gilda's Club of Toronto, a non-clinical community-based recreation center for cancer survivors, Parry and Glover (2010) found that Gilda's Club provided survivors with an opportunity to form strong emotional connections with other survivors. These connections

positively contributed to participants' survivorship experience and their QOL by providing them with renewed dignity, hope and transcendence.

As members of communities like Gilda's Club invest time and participate in on-going activities and events, McMillan and Chavis posited that more emotional bonds should be established, thus creating greater community spirit. Further, they posited that communities that fostered and honored their members both publicly and privately tended to increase group cohesiveness. However, little research to date has investigated how an individual's membership in multiple different communities influences their HRQOL. As survivors of cancer may belong to many different communities, this research investigated the relationship between the shared emotional connection of belonging to several communities and their HRQOL.

**Measurement of SOC.** McMillan and Chavis (1986) stated that SOC is comprised of the four dimensions of Membership, Influence, Fulfillment of Needs, and Emotional Connection. Further, they posited that each of these dimensions worked in concert with one another to maintain and develop a general sense of community for individuals. Based on McMillan and Chavis' (1986) construct of SOC, the Sense of Community Index (SCI; Chavis, Hogge, McMillan, Wandersman, 1986; see Long & Perkins, 2003) has been the most widely used instrument. Using a Brunswick lens method to determine the shared domains of SOC, Chavis et al., randomly selected 100 SOC profiles from 1200 research participants and had them assessed by 21 expert judges representing four different professions across three urban centers. The results from this measure showed strong reliability and validity for the four-dimensional structure as hypothesized by McMillan and Chavis. From this research, the Sense of Community Index (SCI) was born.

Although the SCI, and the many variations of it (cf. Cantillon, Davidson & Schweitzer, 2003, for a more detailed discussion on variations of the SCI) were intended to measure McMillan and Chavis' (1986) theoretical conceptualization of SOC, several studies have largely failed to replicate and validate the four dimensions found in the Chavis et al. (1986) study (Chipuer & Pretty, 1999; Wombacher, Tagg, Burgi, & MacBryde, 2010). Recently, in an effort to address the shortcomings found throughout the SCI and SOC literatures, Peterson, Speer, and McMillan (2008) put forth a new 8-item Brief Sense of Community Scale (BSCS) that has been shown to be congruent with the four-factor framework of McMillan and Chavis and empirically valid (Wombacher et al., 2010). Investigating a community health promotion initiative in the Midwestern United States, Peterson, et al. surveyed 293 individuals using the newly created BSCS. Results from their study showed that the BSCS demonstrated high reliability in total as well as for each of the four dimensions as hypothesized by McMillan and Chavis (1986), with Cronbach's alpha coefficients ranging from .77 to .92. Results from first-order and second-order confirmatory factor analysis (CFA) showed that not only were the four dimensions represented within the BSCS, but also that they represented one underlying SOC construct (Peterson, et al.; Wombacher, et al.). In addition, after controlling for demographic characteristics, the BSCS correlated as hypothesized with other variables that were measured in the study (i.e., community participation, empowerment, mental health and depression), which was taken to be indicative of the scales convergent and divergent validity. Due to the lack of a valid criterion measure against which to test the BSCS, construct validity has been difficult to establish (N.A. Peterson, personal communication, June 6<sup>th</sup>, 2011; Peterson et al., 2008; Wombach et al., 2010). With acknowledgment of the absence of construct validity, but with the instrument's convergent and divergent validity having been demonstrated, the BSCS was utilized in this study.

## **Sociodemographic Characteristics and Cancer-Specific Variables**

Attempts to explain the influence of individuals' sociodemographic and cancer-specific variables on long-term psychosocial outcomes such as SOC and QOL have resulted in mixed and conflicting findings (Downing, Prakash, Gilthorpe, Mikeljevic, & Forman, 2007). HRQOL researchers in the cancer literature suggested that there was a relationship between a survivor's socioeconomic background, stage of cancer at diagnosis, treatment therapies used, comorbidities, and QOL (Downing et al., 2007; Farrell, Aubry, & Coulombe, 2004). SOC researchers have also agreed that marital status, years with a given community (generally measured as years in the current home), presence of children in the home, education, and socioeconomic status were all equally associated with an individual's SOC (Chavis, et al., 1986; Obst & Tham, 2009; Obst & White, 2007; Peterson, Speer, & McMillan, 2010).

Although many researchers reported positive associations between social status, as defined by education and total household income, and marital status (Bradley, Given, & Roberts, 2002; Gorey et al., 2010), for HRQOL researchers key demographic and cancer-related variables such as age at diagnosis, time since diagnosis, race/ethnicity and gender have been inconsistent predictors of an individual's HRQOL and are therefore in need of further investigation (Ashing-Giwa, Lim & Tang, 2010; Bradley, Given, & Roberts, 2002; Harper, et al., 2009; McDougal & Tsonis, 2009).

Much of the research on the perception of a community's impact on the health and quality of life of its residents has generally focused on the built environment (McMillan & Chavis, 1986; Obst & Tham, 2009). For example, research on the connections between poor health and one's neighborhood environment has been suggested to heavily influence the quality of life of residents (Bowling, Barber, Morris & Ebrahim, 2006; Chaix, 2009). Focusing on the

subjective perceptions of community, Bowling et al. found that one's perception of the neighborhood environment had a strong positive association with both self-rated health and functioning. In addition, Poortinga, Dunstan and Fone (2007) obtained similar findings in that insufficient access to community resources like health care, food and clean water, poor neighborhood quality, disorder in government and services, lack of social cohesion and overall neighborhood deprivation were associated with poor health and quality of life. Overall, one's community from a place-based framework and sense of what it entails has been noted to impact health (Albrecht & Devlieger, 1999). However, little research to date has examined how interest-based communities, and the perception of multiple senses of community, impact the health and QOL of individuals who have experienced cancer.

Although the impact of one's community of place has on health has been established, the collective impact of communities of interest is still relatively unclear (McMillan & Chavis, 1986; Obst & Tham 2009). Bishop and Hoggett (1995) noted that those communities in which individuals participated based on their shared interest provided the opportunity to formulate community and influenced their QOL in four ways: (1) as a vehicle through which social exchange can take place; (2) through opportunities to create a commonly held product; (3) via opportunities for making friends and meeting people; and (4) through opportunities of mutual aid.

Investigating Gilda's Club of Greater Toronto, a non-institutional leisure-based cancer survivor organization, Glover and Parry (2008) suggested that cancer support organizations like Gilda's Club offered therapeutic benefits and opportunities for survivors of cancer to meet and support one another in a non-clinical setting, and to participate in creating programs and events for the Club and each other. These opportunities supplied members and participants in Gilda's

Club with opportunities to exchange mutual aid and build community through the creation of friendships. Glover and Parry further suggested that such friendships helped counteract isolationism by allowing survivors the opportunity to connect socially with others living with cancer. Although not a cancer-specific social support organization, Son, Yarnal, and Kerstetter (2010) obtained similar findings while researching older women's participation in the Red Hat Society® (RHS). Results from their research suggested that participation in interest-based communities like RHS contributed not only to members' health and well-being, but also to the greater community wherein the RHS club was embedded through the club's volunteer efforts. Son et al. contended that these benefits were accomplished by "creating bonding opportunities with other women, giving and receiving social support, providing a sense of community ('sisterhood'), and facilitating opportunities for linking into the larger communities in which they lived" (p.80). These findings corroborated Bishop and Hoggetts' (1995) notion that communities based on enthusiasm or interest, like those found in leisure, do more than provide participants with an opportunity to fill time.

Chavis and Newbrough's (1986) review of the psychosocial literature on community provided further evidence of a connection between SOC and individuals' well-being; particularly via the argument that one's sense of community can directly impact the mental, physical, and social well-being of participants. Bachrach and Zutra (1985) further suggested that within communities in general, as a sense of community increased amongst its members, strategies to change or alter the source of stress increased, leading to an increased sense of well-being. Echoing these sentiments in their study of active older adults, Dionigi and Lyon (2010) found that participants experienced communal benefits on many different levels. Not only did they feel a sense of belonging and emotional connection at the gym and university, but also with the

broader community of “active” older adults. Participants were able to see themselves not just as older adults within the community, but specifically as a part of the community of healthy active older adults. This coincided with what McMillan and Chavis (1986) referred to as the “layering of communities” (p.19) and it may be present throughout the multiple communities in which an individual operates.

As survivors of cancer may experience altered participation and relationships in the groups and communities in which they participate, further research is needed to explore how their sense of these various communities (both geographic and interest-based) influences their HRQOL. The purpose of this study was to examine the relationship between participating in multiple senses of community (SOCs) and the influence these constructs have on the health-related quality of life (HRQOL) of adult women survivors of cancer.

### **Summary**

This chapter first explored and discussed the definitions and literature regarding health-related quality of life (HRQOL) and its evolution from a strictly biomedical construct to a patient reported outcome over the past several decades. Two main components of HRQOL were identified – cancer specific quality of life (C-QOL) and generic quality of life (G-QOL) – and their relationship to survivorship outcomes were discussed. In addition, the impact that psychosocial constructs, including sense of community (SOC) and the relationship with the HRQOL of survivors of cancer were also introduced.

In regards to SOC, McMillan and Chavis’ (1986) theory of a sense of community (SOC) was introduced and suggested to be an important construct for further understanding the ways in which the psychosocial context may influence the HRQOL of cancer survivors. Moreover, it was proposed that as individuals generally belongs and associates with myriad of different

community types over the course of a given day, that a sense of community is comprised of not just one global conceptualization of the construct, but multiple. SOC was therefore proposed to be comprised of four components including membership, influence, needs fulfillment and a shared emotional connection which are independent of one another, but not mutually exclusive.

In the last section, this study recognized the extent literature that suggests that an individuals sociodemographics including gender, marital status, education, and income coupled with their cancer-specific outcomes (age at diagnosis, time since diagnosis, type of cancer, and treatment modalities) have been found to be equally associated with the HRQOL of cancer survivors. These items were used as covariates with in the study as to gain a better assessment of the relationship between a cancer survivor's SOC and HRQOL.

## CHAPTER THREE: METHOD

The overall aim of this study was to examine the relationship between female cancer survivors' sense of community (SOC) and their health-related quality of life (HRQOL). In addition, it was the goal of this research to specifically examine the three research questions about their relationship: 1) how SOC and the construct's individual domains (Membership, Influence, Fulfillment of Needs, and a Shared Emotional Connection) are related to HRQOL; 2) in what ways the unique sense of community types (Support, Neighborhood, Leisure, Faith and Work-based communities) relate to HRQOL; and, 3) the extent to which SOC is related to the specific domains of HRQOL. An online data collection method employing three research instruments was used to gather data from female cancer survivors who were members of the Beat Cancer Boot Camp located in Tucson, Arizona. Presented in this chapter is the description of the sample participants, instrumentation, data collection procedures, and the data analysis strategy for each of the research questions and their associated hypotheses.

### **Participants**

**Population Selection.** The population for this investigation targeted members affiliated with the Beat Cancer Boot Camp, consisting of a mailing list of approximately 800 members. The Beat Cancer Boot Camp is a cancer survivor support program that encourages participants to utilize exercise and camaraderie in an outdoor park setting to help them cope with the effect of the physical, psychological and social effects of their cancer. Beginning in 2001, Anita "Sarge" Kellman began attending and learning how the boot camp philosophy could be used to support cancer survivors throughout their cancer experiences. Infusing the boot camp structure with an exercise regimen based on the United States Navy Seals training program, Sarge developed the Beat Cancer Boot camp to provide an intensive exercise support group for cancer survivors.

Coupled with monthly educational dinners and social activities, including the annual Spring Beat Cancer Boot Camp Obstacle course and weekend retreats to various resorts and area locations, Beat Cancer Boot Camp has been recognized for its innovative approach to supporting cancer survivors wherever they may be found on the cancer continuum.

**Respondent Characteristics.** The sample for this investigation was obtained from participants of the Beat Cancer Boot Camp online mailing list. This list includes individuals who actively or infrequently participate in weekly, monthly and semi-annual events. Those who are not currently active are still considered part of the Beat Cancer Boot Camp sisterhood and remain part of the mailing list. All respondents of this study were invited to complete an online self-administered questionnaire that assessed the constructs under study, as well as to provide some socio-demographic information.

The respondent demographic profile is shown in Table 3.1. On average, respondents were 54 years of age, and over one-half (67.2%) were middle aged or older. This is not surprising given that more than two-thirds of all newly diagnosed cancers occur in patients who are 55 and older (CDC, 2004). Almost three-fourths (74.2%) of respondents identified themselves as married, with the remaining one fourth indicating that they were single, separated, divorced or widowed. Respondents were primarily white (85%), and highly educated with over 70% of the sample having achieved a bachelors degree or higher.

Seventy-five percent of respondents indicated that their annual household income was greater than \$60,000 per year. With the United States average household income from the 2010 national census listed at \$49,445, respondents were clearly above the national average (U.S. Census Bureau, 2011). Given respondents' high level of education and annual household income it was not surprising to find that over 84% of respondents worked at least part – time, with 40.8%

working at least full-time. This is in line with recent studies that have found that cancer survivors do not necessarily differ from non-cancer patients in terms of socioeconomic status including income, household assets, net worth, or the likelihood of being currently employed (c.f., Norredam, Meara, Landrum, Huskamp, & Keating, 2009).

Basic characteristics of respondents' cancer history profile are presented in Table 3.2. As suggested earlier, diagnosis for first time cancer patients has been shown to occur primarily in later life (Avis et al., 2009; CDC, 2004; NCI, 2011; Norredam, et al., 2009). Respondents in this study had an average age of diagnosis in their late forties to early fifties. Although significantly less than the median diagnosis age of 66 years reported by the United States Center for Disease Control's (CDC) Surveillance Epidemiology and End Results (SEER) (Denavas-Walt, Carmen, Bernadette, Proctor, & Smith, 2011), this difference may be due to several factors, including the physical activity nature of Beat Cancer Boot Camp and/or to the lack of older long-term cancer survivors who participated in the questionnaire and/or the Beat Cancer Boot Camp in general. With regard to time since diagnosis, 51% of the sample was considered to be in the acute stages of the cancer continuum (defined as the first five years post diagnosis), whereas 49% were at least 6 years or greater post diagnosis ("long-term" cancer survivors).

The most frequently identified cancer type among respondents (Table 3.2) was that of breast cancer (65.3%), followed by colorectal, melanoma, ovarian, and thyroid (1%). 30% of the respondents failed to identify their cancer type. Of those respondents who reported their cancer type, most indicated having been diagnosed with breast cancer (98%) and most had received invasive surgeries including lumpectomy, and mastectomy (84%). Similar to findings in the literature (CDC, 2004; NCI, 2011; Norredam, et al., 2009), respondents reported complications and or side effects due to invasive therapies, including prolonged chronic pain, fatigue,

neuropathy (nerve damage), Lymphedema (swelling), hair loss, osteoporosis, weight, skin and heart issues.

With an increase in the effectiveness of invasive surgical and chemical therapies for treating cancer, the five-year survival rate for those diagnosed with cancer has risen from below 50% prior to 1975 to greater than 85% in 2003 for the general U.S cancer population (NCI, 2011). For those respondents who reported their time to remission (n = 31) in the present study 21% reported an immediate cure, whereas 51% were told they showed no significant cancer markers between end of treatment and one year post diagnosis, with the remaining 28% reporting their remission dates as greater than one year but less than five years. As only one-third of respondents reported their time to remission, this data may not represent the sample as a whole.

### **Procedures**

Prospective participants were contacted in mid-September 2011 through a direct advertisement from Anita “Sarge” Kellman that explained the purpose of the questionnaire in an e-mail to the Beat Cancer Boot Camp online mailing list (see Appendix B). Further invitations to participate by completing in the self-administered questionnaire were also posted in the monthly Beat Cancer Boot Camp newsletter and website prior to the on-line launch of the survey that was scheduled for October 15<sup>th</sup>, 2011. Surveying of the BCBC membership continued for four weeks from the initial start of the data collection period. Only individuals who were female, at least 18 years of age and older, and had been diagnosed with cancer, were eligible to participate in this study.

For online web-based surveys, Babbie (2008) indicated that the timing of e-mail-based solicitation is an important factor that influences candidates’ willingness to participate. He suggested that sending requests and reminders during the work week between 6 a.m. and 9 a.m.

(excluding Monday) typically produces a greater response rate for web-based surveys. In addition, two weeks after the launch of the survey, Babbie and others recommend sending another invitation to the respective contact list reminding them of the opportunity to participate (Dillman, 2000, 2001). If an interest was shown in the study based on any of the advertisements, participants were then directed to the survey through an external link on the given advertisement through the secure University of Illinois Web Tools survey system. Once connected to the secure online Web Tools survey, respondents were provided with an online cover letter and IRB consent form prior to accessing the questionnaire. Participant consent was obtained from respondents by asking them to type in their initials and click on a submit button. Once consent was obtained, respondents were automatically taken to the questionnaire site. This method was chosen as it allows researchers to conduct their investigations in as efficient a manner as possible, provides a reduction in data entry errors on the part of respondent and researcher, aids in timely turnaround of respondent questionnaires over the duration of the data collection period and, aids in retrieving a higher response rate for organizations that primarily communicate with members through online methods (Dillman, 2000, 2001) such as the Beat Cancer Boot Camp.

In addition, upon successful completion of the questionnaire, participants were eligible to enter their information at the end of the survey into a drawing to win one of several prizes including fifty \$10.00 Amazon gift card (odds of winning are 1 in 12); five of Anita “Sarge” Kellman’s new book, “It’s a Beautiful Day for Boot Camp” (odds of winning are 1 in 60); and, five free Beat Cancer Boot Camp class sessions (odds of winning are 1 in 60). These emails were kept separate from the original surveys by use of a separate form that participants could click on when prompted on the final page of the survey immediately following completion.

## **Instrumentation**

The Beat Cancer Boot Camp Survey (Appendix A) was designed to address the three research questions and hypotheses presented in Chapter One. The complete survey was comprised of four instruments including the Brief Sense of Community Scale (BSCS; Peterson, et al., 2008) repeated for each community type; the Quality of Life in Adult Cancer Survivors Scale (QLACS; Avis, et al., 2005); a form requesting information on demographic characteristics including age, marital status, race, education income, work status, and cancer history; and lastly, an open-ended question that provided respondents with the opportunity to comment on how they felt SOC might have influenced their HRQOL.

**Sense of Community (SOC).** The first part of the survey asked participants to report on five different community types to which they belonged and actively participated during the preceding 12 months. Specifically, the five community types included a Social-Support community, the Neighborhood (Geographic) SOC wherein they resided, a Leisure-based SOC (e.g., walking group or book club), a spiritual or faith-based SOC, and a work-based SOC.

Sample members were asked to complete Peterson et al.'s. (2008) four domain (8-item) Brief Sense of Community Scale (BSCS) by considering each of the five different community types as a single referent point as they responded to each question. Items about participants' SOC included questions that asked respondents if they felt like a member, had a say about what went on, could get what they needed, or felt connected to a given referent community. All items in the BSCS utilized a 7-point Likert scale with anchors of *(1) Strongly disagree and (7) Strongly agree* (see Appendix A.); only positively worded items were used (Peterson et al., 2008; Wombacher et al., 2010). According to Peterson et al. (2008) and Wombacher et al. (2010), the reliability of both the overall scale and individual domains were statistically significant: Cronbach's alpha for the overall BSCS as reported by Peterson et al. was .92 with alpha

coefficients among the individual subscales at .77 and above (.94 for membership, .77 for influence, .86 for needs fulfillment, .87 for emotional connection). Using Confirmatory Factor Analysis (CFA) to establish domain structure, Peterson et al. (2009) surveyed 293 individuals using the newly created BSCS, among other health-related measures. In an attempt to further validate the BSCS, Wombacher et al. (2010) conducted a study with a population comprised of German military personnel. In addition to confirming the results of Peterson et al., results from first-order and second-order factor analyses from both Peterson et al.'s study and Wombacher et al.'s study showed that not only are the four dimensions represented within the BSCS, but they also represent one underlying general SOC construct.

The BSCS has also been shown to be applicable to diverse populations, including American adults. Convergent and divergent validity were established through correlation of this instrument with other assessments of similarly validated constructs including community participation, health and well-being, and depression previously established (Peterson, et al., 2008). According to Peterson, construct validity has been difficult to establish due to the lack of a valid criterion measure against which to test the BSCS (personal communication, June 6<sup>th</sup>, 2011). With acknowledgment of the absence of construct validity, but with the instrument's convergent and divergent validity having been demonstrated, the BSCS was utilized to measure perceptions of community in this study.

**Health-Related Quality of Life (HRQOL).** The second portion of the online survey investigated cancer survivors' HRQOL. The Quality of Life in Adult Cancer Survivors Scale (QLACS) was used to measure respondents' HRQOL (Avis et al., 2005). The QLACS is a 47-item instrument (see Appendix A) consisting of 12 domains (5 cancer-specific and 7 generic QOL domains), with each given a score determined by the mean of the items comprising it.

Cancer-specific domains included Financial Problems resulting from cancer, Distress About Family, Distress About Reoccurrence, Appearance Concerns, and Benefits of Cancer. Questions for the cancer-specific domains asked respondents if, in the past four weeks, they had Money Problems resulting from cancer, were better able to deal with Stress because of cancer, were worried if their Family had cancer-causing genes, felt self-conscious about their Appearance because of cancer, or were worried about their Cancer returning. Generic quality of life domains include Physical Pain, Negative Feelings, Positive Feelings, Cognitive Problems, Sexual Problems, Social Avoidance, and Fatigue (Avis, et al., 2006). Questions for this domain asked respondents if, in the past four weeks, they were bothered by mood swings, enjoyed life, had trouble remembering things, were bothered by pain that prevented participation in activities, or lacked energy.

Internal reliability for each of the 12 domains (Cronbach's alpha coefficient), was .72 or greater. All items in the QLACS were rated on a 7-point Likert scale with anchors of (1) *Never* and (7) *Always*. Greater scores on the QLACS indicated lower (poorer) HRQOL. The QLACS has been shown to be appropriate for comparisons between cancer and non-cancer populations, as well as for long-term cancer survivor populations (Avis, et al., 2005, 2006; Pearce, et al., 2008).

**Respondent Characteristics.** The third section of the online survey requested information about the individual's demographic characteristics, including age, marital status, race, education, income, total hours worked, and cancer history (Appendix A). The sole purpose of collecting demographic characteristics was for descriptive purposes only. There were no hypotheses advanced a priori about any differences that might be detected due to such characteristics.

**Open-Ended Response.** An open-ended question was included to gain further insight from respondents as to how they felt SOC may be related to their HRQOL. The question was phrased as follows:

“Many cancer survivors experience various types of family and community support that have effected them. Please tell us a little bit about how any current groups or communities that you belong to might influence (for better or worse) your health and quality of life as a cancer survivor.”

**Pilot Testing of the Instruments.** As the BSCS was not previously used in populations of women who were cancer survivors prior to this study, this questionnaire as well as the QLACS, was pilot tested on a small group (n = 10) of BCBC members who were cancer survivors. The pilot testing was conducted for several reasons: 1) to determine if the survey instructions were clear and easy to follow; 2) to determine if the online survey completion time presented a burden to participants; and, 3) to examine the clarity and readability of the individual items for respondents.

Responses from the pilot testing revealed that instructions for the survey were not completely clear, and clarification was added to the BSCS and QLACS scales. Owing to the difficulty in differentiating between SOC community types and the length of the HRQOL section, community types and HRQOL domains of general and cancer – specific quality of life were placed on separate pages in an attempt to reduce information overload on a single page. Pictures were also placed on each page of the online questionnaire to make taking the survey a more pleasurable experience. Following these minimal changes, the survey was considered to be in its final form and comprised the version to which sample participants were asked to respond.

**Response Rate.** As the survey sample size was not reached after the two and three week mark, an additional round of sampling advertisements were sent out to the Beat Cancer Boot Camp (BCBC) mailing list during the final week of the sampling period in an attempt to garner additional respondents. With an estimated mailing list of approximately 800 individuals, 100 online surveys were returned during the survey period, which resulted in a response rate of approximately 12.50%. Two surveys could not be used due to a complete lack of data, therefore, 98 useable surveys resulted in a final 12.25% response rate. A non-response check was not performed for this exploratory study as respondents were completely anonymous and would have violated the IRB procedures.

## **Data Analysis**

### **Preliminary Analyses**

For the purpose of analyzing the data from the online self-administered survey, all data were coded, keyed, and analyzed using the Statistic Package for the Social Sciences (SPSS Version 17.0 for Windows). Once data entry was completed, data was checked for errors and cleaned by performing frequency checks for each variable. The data set was also checked for outliers and to gain an initial picture of the data.

Since this was a purposive sample that was also limited in size, it was deemed necessary to check for violation of underlying assumptions before statistical tests could be employed to test the study's hypotheses. The Kolmogorov-Smirnov (K-S) test was performed in order to test the normality of the data.

Scales for each of the main instruments were computed using the procedures outlined by their authors in the literature. Domains of interest for SOC came from the Brief Sense of Community Scale (BSCS) and HRQOL domains of interest came from the Quality of Life in

Adult Cancer Survivors (QLACS). For both SOC and HRQOL, the average of scores for the required items for grand and domain levels were calculated. Respondents' demographic characteristics were computed with a select number used as covariates in the statistical analysis for each hypothesis as outlined in Chapter One.

In addition to testing for violations of underlying assumptions which could compromise parametric statistical tests, it was also deemed necessary to be sure that the two scales were consistent with prior tests of their validity and reliability. Principal components analyses (PCA) and internal consistency reliability (Chronbach's Alpha Coefficients) were utilized for this purpose for the BSCS (SOC) and the QLACS (HRQOL) (Field, 2009). As a validation technique, PCA with varimax rotation was used to reduce the factor loadings for each of the scales and their domain structures to determine that the scales and their domains could be utilized with this biased sample. Field (2009) suggested that for Cronbach's alphas with values greater than .70 are considered to be satisfactory in scale reliability.

### **Method of Analysis for Research Question One and Hypotheses 1a – 1e**

Question 1: What is the relationship between SOC and its domains and the HRQOL of women who are cancer survivors?

This research question explored the relationship between female cancer survivors' SOC and its specific domains (Membership, Influence, Needs Fulfillment, Emotional Connection) and that of HRQOL. To test these research hypotheses (H1a – H1e), SOC scores were combined across community types (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to create a composite mean score. Next, composite mean scores for each of the specific domains of SOC (Membership, Influence, Integration, Fulfillment of Needs, Shared

Emotional Connection) were computed across the community types. A higher SOC scores indicated a greater sense of community.

HRQOL was similarly computed by finding the mean of the scores across all items to create a grand HRQOL score. As HRQOL consists of two subscales, general quality of life (G-QOL) and cancer-specific quality of life (C-RQOL) a mean for each subscale was calculated by taking the average of the specific items as outlined by the authors in the literature to compute each of these two subscale scores. A greater HRQOL score was interpreted as indicative of a lower (poorer) HRQOL for the respondent.

Once values for SOC and HRQOL were computed as indicated, these variables were entered into a hierarchical linear regression with two blocks. With the grand HRQOL mean and G-QOL and C-RQOL subscales mean scores as separate outcome variables depending on the research question and hypothesis of interest, block one consisted of the demographic information (level of education, survivor group, work level, and marital status) and block two(s) consisted of the scale score or domain scores, according to the hypothesis being tested.

### **Method of Analysis for Research Question Two and Hypotheses 2a-2e**

Question 2: How does the sense of community (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to which a female cancer survivor identifies relate to her HRQOL?

This research question explored how SOC for each of the five selected community types (Social Support, Neighborhood, Leisure, Faith and Work-based community types) might differentially relate to female cancer survivors' HRQOL. To analyze Research Question Two and its associated hypotheses (H2a – H2f), SOC scores were computed using the means for each community type (Social Support, Neighborhood, Leisure, Faith, Work-based). HRQOL, and the

subscales of G-QOL and C-RQOL, were also computed using the means of scores for each, as was done previously for the first research question.

Outcome and predictor variables were entered into two hierarchical regression analyses. Block one consisted of the demographic information (level of education, survivor group, work level, and marital status); block two consisted of the mean scores for the five community types. The first regression analysis used G-QOL as the criterion variable, while the second used the C-QOL data.

### **Method of Analysis for Research Question Three and Hypotheses 3a-3m**

Question 3: How does a female cancer survivor's SOC differentially impact the various components of HRQOL?

The aim of question three and its associated hypotheses was to determine how SOC was related to the specific domains of HRQOL. In essence, this question asks, "Is there a difference at the domain level?" To analyze this question and its associated hypotheses (H3a – H3m) multiple hierarchical linear regression analyses were conducted. For each HRQOL subscale (i.e., G-QOL and C-QOL), the mean across individual items was computed for each of the 13 original domains (Negative Feelings, Positive Feelings, Cognitive Problems, Sexual Interest, Physical Pain, Fatigue, Social Avoidance, Sexual Interest, Sexual Issues, Appearance Concerns, Financial Problems, Distress-Recurrence, Family-Related Distress, and Benefits of Cancer). In all regression analyses, the first block consisted of the demographic information (level of education, survivor group, work level, and marital status), and, block two consisted of the grand mean for all SOC scores across all community types (Social Support, Neighborhood, Leisure, Faith and Work-based). To further explore of any relationships that might be found, regression analyses were then conducted separately on each of the individual SOC domains for each individual

community type (i.e., Social Support – Membership, Social Support – Influence, Social Support – Integration, Social Support – Shared Emotional Connection). These comprised the second block in the second hierarchical analysis. In the analyses, higher scores were interpreted as indicative of greater community type/domain outcomes.

### **Open-ended Research Question**

An open-ended question was used to provide additional insight into how respondents felt that a SOC relates to their HRQOL. The qualitative data received from participants was to be transcribed and placed into themes using content analysis. However, as respondents generally declined to reply to this final question on the survey (n = 13 received), this data was not interpreted.

Table 3.1

*Demographic Profile of Respondents*

Characteristics	Frequency	Percent
<b>Age (Mode = 50 – 59 Yrs.)</b>		
30 – 39	8	9.6
40 – 49	17	20.5
50 – 59	31	37.3
60 – 69	24	28.9
70 +	3	3.6
Total	83	100
<b>Marital Status (Mode = Married)</b>		
Single (Never Mar.)	2	2.1
Married	72	74.2
Partner	6	6.2
Separated	13	13.4
Divorced	2	2.1
Widowed	2	2.1
Total	97	100
<b>Race (Mode = White)</b>		
American Indian or Alaskan Native	0	0
African American or Black	1	1.0
Asian	3	3.1
Hispanic or Latino	8	8.2
Native Hawaiian or Pacific Islander	1	1.0
White or Caucasian	84	85.7
Other	1	1.0
Total	98	100
<b>Education (Mode = Bachelors degree)</b>		
Less than High School Diploma/GED	1	1.0
High School Diploma or GED	6	6.1
Some College	11	11.2
Associate Degree	8	8.2
Bachelor Degree	37	37.8
Master Degree	25	25.5
Doctorate / Medical / Law	7	7.1
Technical Degree	2	2.0
Other	1	1.0
Total	98	100
<b>Income (Mode = \$100,000 - \$249,000)</b>		
Under \$10,000	2	2.2
\$10,000 - \$29,000	3	3.3
\$30,000 - \$59,000	18	19.6

Table 3.1 (cont.)		
\$60,000 - \$99,000	26	28.3
\$100,000 - \$249,000	39	42.4
\$250,000	4	4.3
Total	92	100
<b>Employed Hours / Week (Mode = Working part-time)</b>		
Working Full-Time	40	40.8
Working Part-Time	43	43.9
Retired	8	8.2
Unemployed	4	4.1
Disabled	3	3.1
Total	99	100

Table 3.2		
<i>Cancer-History Profile of Respondents</i>		
Item	Frequency	Percent
<b>Age at Diagnosis (Mode = 40 -49 yrs.)</b>		
20-29	4	5.3
30 – 39	5	6.6
40 – 49	30	39.5
50 – 59	29	38.2
60 +	8	10.5
Total	76	100
<b>Survivorship (Mode = 0 – 5 yrs.)</b>		
0 – 5 years	39	51
6 + years	37	49
Total	76	100
<b>Type of Cancer (Mode = Breast cancers)</b>		
Breast	64	65.3
Colorectal	1	1.0
Melanoma	1	1.0
Ovarian	1	1.0
Thyroid	1	1.0
Other / N/a	30	30.6
Total	98	100
<b>Surgeries (Mode = Mastectomy)</b>		
Mastectomy	34	54.8
Lumpectomy	18	29.0
Hysterectomy	7	11.3
Other	3	4.8
Total	62	100
<b>Additional Health Issues Due to Cancer (Mode = Chronic pain)</b>		
Chronic Pain	11	35.5

Table 3.2 (cont.)		
Fatigue	7	22.6
Hair Loss	4	12.9
Heart –Related Issues	2	6.5
Lymphedema	5	16.1
Memory Loss	5	16.1
Neuropathy	6	19.3
Osteoporosis	5	16.1
Skin Issues	3	9.7
Weight Gain	3	9.7
Total	31	100
<b>Remission (Mode = 13 months or more)</b>		
Immediately	7	21.2
0 – 3 months	6	18.2
4 – 6 months	5	15.2
7 – 12 months	6	18.2
13 months or greater	9	27.3
Total	33	100

## CHAPTER FOUR: RESULTS

This chapter presents in two sections the findings from the analysis of the research questions and associated hypotheses as outlined in chapter three. The first section provides the results of the preliminary analysis for the Brief Sense of Community Scale (BSCS) and the Quality of Life in Adult Cancer Survivors (QLACS), the three research questions and associated hypotheses. The second section of this chapter provides the results of the analyses that investigated the research hypotheses exploring relationships between sense of community (SOC) and health-related quality of life (HRQOL) of female cancer survivors.

### **Preliminary Analyses**

The BSCS and the QLACS represent two multi-scaled instruments that assessed respondents' SOC and HRQOL, respectively. However, prior to addressing the three research questions, tests of assumptions underlying the use of the proposed parametric statistics for these two scales were conducted. In addition, analyses to insure that these instruments yielded the same factor structure with this biased sample as produced by the authors of the scales was undertaken. Once the scales were found to function as intended with the sample in this study, and the data was shown to comply with the assumptions underlying the use of the intended analyses, hypothesis testing could commence.

### **Brief Sense of Community Scale (BSCS)**

#### **Tests of underlying assumptions to enable the use of parametric statistics.**

Descriptive statistics for each of the four SOC domains and five community types are presented in table 4.1. Higher scores from the BSCS indicated greater domain specific responses and greater SOC responses for the given community type. All items from the BSCS were rated on a 7-point Likert scale with anchors of *(1) Strongly Disagree and (7) Strongly Agree*. For each of

the underlying SOC domains, responses were generally elevated towards higher scores, where Influence scored lowest ( $M = 5.18$ ;  $SD = 1.11$ ) while Membership scored highest ( $M = 5.57$ ;  $SD = 1.24$ ). However, when examining the skewness and kurtosis of each of these SOC variables, it was found that these values were not completely within a tolerable range for assuming a normal distribution. Examination of the histograms for each of the General SOC domains and community types further revealed the elevated levels of skew and kurtosis. To further assess whether or not the levels of skew and kurtosis violated normality, the Kolmogorov-Smirnov (K-S) test was performed for each SOC domain and community type (see Table 4.2). What is clear from the K-S test is that the scores as measured by the BSCS strongly departed from a normal distribution (all  $p < .000$ ).

Proceeding to conduct the regression analyses with the dramatic deviation from normality of the SOC variables posed concerns. In addition, examination of the correlation matrix for the SOC domains (see Table 4.3) and community types (see Table 4.4), indicated highly significant positive correlations among all of the SOC domains and all but one of the community types (Social Support and Neighborhood). These high intercorrelations raised serious issues related to multicollinearity which is highly problematic for regression analysis as it produces untrustworthy  $b$ -values and limits the size of  $R$  and therefore the regression model's ability to predict the outcome variable of interest (Field, 2009).

In an effort to account for the violations of normality and issues with multicollinearity presented by and among the SOC variables, several variable transformations were attempted including recomputation of the variables, examining the data for outliers, attempting transformations of the data, utilizing factor scores, factor analysis, and, finally as a last resort, the creation of groups through a median split procedure (high versus low SOC). In terms of

recomputation of the variables, the syntax for each of the variables were analyzed and checked to make sure they were computed correctly. This process confirmed that each of the items and variables of interest for SOC were computed properly and therefore deemed not to be the source of the problems. When looking at outliers it was determined that several respondents' individual scores were potentially outliers and might be a contributing factor to the violation of normality. Although these specific outliers were initially removed, violations of normality remained and therefore these outliers were kept as part of the data for analysis.

**Replication of the SOC domains.** In an attempt to find another way of controlling for the high correlation between the variables, as multicollinearity was shown to be an issue with the SOC domain and community type variables, factor analysis was used to remedy this issue as it combines items together that are correlated into factors, and then uses the relative factor scores in subsequent analysis (Field, 2009). Hence, factor analytics was performed on the SOC items.

Principal Component Analysis (PCA) with orthogonal (Varimax) rotation on the 40-item (5 community types by 8 items) Likert scale questions for all SOC domains was performed. To perform PCA the common rule is to have approximately 10 – 15 participants per variable for this type of factor analysis (Comrey & Lee, 1992; Field, 2009; Tabachnick & Fidell, 2007).

However, as the sample size for this data set was relatively small ( $N < 100$ ), the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO) was also assessed to determine if PCA was possible for the data gathered by the BSCS for the SOC domains. The KMO test is an alternative test of sampling adequacy for performing factor analysis with small sample sizes (Field, 2009). The KMO is defined as the ratio of the squared correlations to the squared partial correlations between variables and varies between 0 and 1. Scores with a value closer to 0 indicate that factor analysis is inappropriate due to the sum of partial correlations being large and diffuse when

compared to the sum of squared correlations. Scores closer to 1 inform the researcher that the patterns of correlations are relatively compact and should yield distinct and reliable factors. Field (2009) recommends that values below 0.5 are not acceptable; values between 0.5 and 0.7 are average at best; values between 0.7 and 0.8 are good; values between 0.8 and 0.9 are great; and values greater than 0.9 are superior (Hutcheson & Sofroniou, 1999; Kaiser, 1974).

A Principal Component Analysis (PCA) with orthogonal (Varimax) rotation was therefore conducted on the 40 items for both the four Generic SOC domains and for the five community types. In regards to the four Generic SOC domains, each domain required a separate PCA to be performed. As for the Membership domain (Social Support Membership + Neighborhood Membership + Leisure Membership + Faith Membership + Work Membership), the KMO measure (see Table 4.5) verified the sampling adequacy for the analysis of the SOC domain Membership,  $KMO = .75$ , which was above the accepted limit of .5 (Field, 2009). In addition, Bartlett's Test of Sphericity ( $\chi^2 (45) = 421.62, p < .000$ ), indicated that the correlations between items were sufficiently large for the requirements of PCA. An initial factor analysis was conducted to obtain eigenvalues for the SOC Membership domain data, and resulted in three components that had eigenvalues over Kaiser's criterion of 1, with a total explained variance of 79.0%. With the 10 membership items resulting in a three component solution rather than a single one, it was determined that membership for each of the community types was not equivalent and therefore a general SOC Membership score was deemed to be ineffectual. Findings from the additional PCA tests for each of the remaining General SOC domain scores (e.g., Influence, Needs Fulfillment, and Emotional Connection) were equally compromised due to each having multiple component solutions (see table 4.6 – 4.9). Based on the results of the PCA for the SOC Generic domains, use of these variables as outlined in Chapter Three were

deemed inappropriate thereby rendering analysis of the hypotheses related to research Question One to be uninterpretable (e.g., Hypotheses H1a – H1e).

As the PCA for the individual SOC domains were all unsuccessful, PCA for each of the five community types was analyzed to see if a unidimensional model for each would result. Initially when all five community types (e.g., Social Support, Neighborhood, Leisure, Faith and Work – based communities) were entered into the analysis, a factor solution did not emerge. After investigating the computation of the community type to check for errors it was determined that the issue might lie with the number of responses for each of the five community types. As the Faith-based community type ( $n = 47$ ) lacked a significant number of responses, it was determined that removal of this variable and its items could provide an adequate solution.

A Principal Components Analysis (PCA) was conducted on the remaining 32-items with orthogonal rotation (Varimax). The KMO measure verified that there was sampling adequacy for the analysis,  $KMO = .819$ , and all KMO values for individual community types were  $> .88$  (see Table 4.5), which was well above the accepted limit of  $.5$  (Field, 2009). In addition, Bartlett's Test of Sphericity, ( $\chi^2 (496) = 3834.13, p < .000$ ), indicated that the correlations between items were sufficiently large to conduct PCA. An initial analysis was then conducted to obtain eigenvalues for each component in the data. Four components had eigenvalues over Kaiser's criterion of 1 and in combination explained 82.31% of the variance. Given the sample size, KMO, Bartlett's adequacy, and Kaiser's criterion on four components, the number of components that were retained in the final analysis was four. Table 4.10 shows the factor loadings for each item within the four community types after rotation. Inspection of the items that clustered on the same components suggested that factor 1 represented a sense of community for Work, factor 2 was a sense of community for Social Support, factor 3 was a sense of

community for Leisure, and factor 4 was a sense of community for Neighborhood. As a sense of community for Faith-based communities lacked a sufficient number of responses and was therefore removed from the PCA, the Faith-based community type was removed from further analyses. With regard to the internal consistency reliability of the four factors, Social Support, Neighborhood, Leisure and Work-based community types all had high reliabilities, with Cronbach's  $\alpha > .94$  (see Table 4.10). As the reliability score for each of the community types was very high (ranging from  $\alpha = .94$  to  $.97$ ), this served as further evidence that the items for each of these factors worked together and measured one of the four unique community types.

Composite scores for each of the four SOC community types (Social Support, Neighborhood, Leisure and Work) are presented in table 4.11. As demonstrated by this table, problems with normality, skew, and kurtosis were still prevalent.

To further assess whether the data for SOC violated normality, the Kolmogorov-Smirnov (K-S) test was performed on the newly created community type rotated factor scores (see Table 4.12). What was clear from these and past K-S tests that had been performed was that these four SOC community type factor scores violated the test of normality, thus indicating that they were also non-normal and that a different transformation strategy would be necessary. From the PCA and reliability analyses, it was discovered that the four-domain factor solution of the BSCS, as outlined by Peterson et al. (2008), was non-existent based on the data in this study. Therefore, any analysis of hypotheses that included these domains could not be performed (e.g., Hypotheses H1a – H1e). What did emerge from this preliminary analysis was a four-factor solution showing the community types (e.g., Social Support, Neighborhood, Leisure, and Work-based communities). As the community types were found to be non-normal and in violation of the assumptions for parametric statistics, the SOC data were transformed using several procedures

and re-tested. Since none of these transformations yielded a normal distribution, these data were grouped using a median split process.

As an adequate method for correcting issues when normality was not achieved through the above processes (recompilation of variables, reexamining data for outliers, looking to past research, exploratory factor analysis), it was determined that splitting each of the four remaining community types into groups based on their respective median split would provide an adequate and useable solution. Based on the median calculated individually for each community type, two groups were then created for each community type representing those below and above the median. However, the difference between low and high community types was troubling given that those scores which were in the Low (below the median) category showed a high degree of variability (e.g., 1 = 0 – 49 in the case of Social Support community type), whereas those scores that were found in the High (above the median) category (e.g., ranging from 50 to 60) were much less variable. Table 4.13 shows the median and resultant Low and High groups for each of community types.

### **Quality of Life in Adult Cancer Survivors (QLACS)**

**Tests of underlying assumptions to enable for the use of parametric statistics.** The Quality of Life in Adult Cancer Survivors scale (QLACS) is a 47-item instrument consisting of two different subscales, Generic and Cancer-Specific Quality of Life (G-QOL and C-QOL respectively). Items in the two separate scales, Generic (seven domains) and Cancer Quality of Life (five domains), were measured on a seven-point Likert-type scale (1 = “Never” through 7 = “Always”) with higher scores representing lower HRQOL. Table 4.14 shows the mean and standard deviation for each of the two composite scales (G-QOL & C-QOL) and their underlying domains. For each of the underlying QLACS domains, responses tended to be clustered towards

the lower end of the distribution of possible scores (1 to 7), indicating that respondents reported their HRQOL to be above average (total  $M = 3.49$ ;  $SD = 0.76$ ). This was largely the case for the domains comprising G-QOL for total G-QOL ( $M = 3.41$ ;  $SD = 0.75$ ), whereas respondents' C-QOL tended to be closer to the average or above (total C-QOL,  $M = 3.69$ ;  $SD = 1.26$ ). Domain mean values for C-QOL were more in the above average range (indicating lower QOL) except for that of the "Positive Feelings" ( $M = 5.58$ ;  $SD = 1.20$ ) and "Benefits of Cancer" ( $M = 4.83$ ;  $SD = 1.44$ ) domains, which were below average (indicating higher QOL) for this data set.

The bivariate correlations between domains for the G-QOL and C-QOL are presented in Tables 4.14 and 4.15, respectively. Correlations among the Generic QOL domains suggested that the domains were moderately correlated, ranging from  $-.51$  to  $.64$ . The bivariate correlations for the C-QOL domains (see Table 4.15) revealed that the domains were also moderately correlated with each other (ranging from  $+.08$  -  $+.61$ ). With regard to the test of normality, initial assessment of the skewness and kurtosis for each of the domains suggested that they were within a tolerable range. Further, examining the histograms and plots for each of the items revealed that G-QOL and C - QOL values were normal. To further assess whether the data from the QLACS violated the normality assumption, the Kolmogorov-Smirnov (K-S) test was performed for each domain (see Tables 4.16 and 4.17). Results of the K-S test showed that G-QOL and C-QOL total domain scores were non-significant indicating that these composite variables could be considered to be normally distributed. When K-S tests were conducted within the individual domains (see Table 4.17), however, a different result emerged, as all domains items except three (Fatigue, Distress Recurrence, Benefits), were found to violate the test of normality.

**Replication of the HRQOL subscales and individual domains.** Factor analysis was conducted to verify the domain structure because of the purposive sample participating in this

study. A PCA with orthogonal (Varimax) rotation was conducted on the 28 QLAC item responses constituting the G-QOL subscale. As this was a data set that was limited in size, the KMO-test was first performed to determine the sampling adequacy. The KMO measure verified that sampling was adequate for the PCA, where  $KMO = .815$  ('great' according to Field, 2009). In addition, Bartlett's Test of Sphericity ( $\chi^2 (378) = 1763.06, p < .000$ ) indicated that the correlations between items were sufficiently large to be able to conduct the PCA. Results of the PCA yielded six components with eigenvalues greater than Kaiser's criterion of 1, and cumulatively explained 70.14% of the total variance. Given the sample size, KMO, Bartlett's adequacy, and Kaiser's criterion for size of eigenvalues, the number of factors that were retained in the final analysis was six. Table 4.18 shows the factor loadings after rotation. Although Avis et al. (2005) found seven component factors, the Beat Cancer Boot Camp data produced only six. Inspection of the items that loaded on the same factor suggested that factor 1 represented a Generic QOL domain relating to "Energy / Fatigue;" factor 2 was a domain for "Pain;" factor 3 was for "Social Avoidance;" factor 4 was for "Positive Feelings;" factor 5 was for "Sexual Limitations;" and factor 6 was a G-QOL domain for "Negative Feelings." The six Generic Quality of Life factors that were obtained were each tested for internal consistency reliability, and all had high reliabilities (Cronbach's  $\alpha > .82$ ; see Table 4.18). This confirmed the item placement for each obtained factor from the PCA.

For the C-QOL subscale, a PCA with orthogonal (Varimax) rotation was conducted on QLAC responses from the 19 items intended to comprise this subscale. First, the KMO measure verified the sampling adequacy to conduct PCA with  $KMO = .769$  ('good' according to Field, 2009). In addition, Bartlett's Test of Sphericity ( $\chi^2 (171) = 1000.33, p < .000$ ) indicated that the correlations between items were sufficiently large to conduct PCA. The initial PCA yielded five

factors with eigenvalues over Kaiser's criterion of 1, and in combination they explained 78.58% of the variance. This five-factor solution was similar to that of Avis et al. (2005). Table 4.19 shows the factor loadings after rotation for each of the items. Inspection of the items that loaded on each factor suggested that factor 1 represented a C-QOL domain titled "Financial," factor 2 was "Appearance," factor 3 was "Distress-Recurrences," factor 4 was "Distress-Family," and factor 5 was "Benefits." All five Cancer-Specific QOL factors produced Cronbach's  $\alpha > .83$ , indicating a high level of internal consistency reliability (see Table 4.19).

In sum, the preliminary analyses provided information about the instruments measuring respondents' sense of community (SOC) and health-related quality of life (HRQOL). Respondents showed that they had high levels of SOC and moderate levels of HRQOL. When investigating the data for the measurement of SOC and HRQOL, issues with normality and multicollinearity were present. With regard to SOC, the data showed elevated levels of skewness and kurtosis indicating potential problems with normality. As the SOC items were highly correlated, issues with multicollinearity were problematic for the purpose of performing hierarchical linear regression. In an attempt to provide a solution for these issues, the researcher attempted to transform the specific SOC variables using a square root transformation, inverse transformation, and an inverse transformation coupled with a square root transformation, all which proved to be ineffectual. PCA with orthogonal (Varimax) rotation was conducted to both confirm and, if needed, identify the underlying factor structure for this data set. What emerged from the PCA of SOC for this data were four single factor community type solutions and not the four domain specific items (Membership, Influence, Needs Fulfillment, Emotional Connection) outlined by Peterson et al. (2008). As factor scores used from the PCA were found to be in

violation of normality as well, a median split was selected as the best procedure for converting the SOC data into a useable format.

With regard to the measurement of HRQOL (QLACS), the two subscales (Generic-QOL and Cancer-QOL) were both found to be normal, thus allowing for their use with parametric statistics. Factorial solutions from PCA with orthogonal (varimax) rotation for the G-QOL and C-QOL subscales were similar to those found by Avis et al. (2005), with the only exception being that the factor solution for G-QOL was comprised of six factors instead of the seven outlined by Avis et al. The C-QOL factor solution was replicated exactly as it was found in the Avis et al. study.

To conclude, results from the preliminary analyses found problems with normality, multicollinearity, and the resultant factor structure of the SOC variables. As a result of these issues, a different method employing multiple analysis of covariance (MANCOVA) for analyzing each of the hypotheses for the research questions as outlined in Chapter Three is presented in the Hypothesis Testing section below.

### **Hypothesis Testing**

Given the violations of the underlying assumptions associated with the items that comprised the measure of SOC, a different method for analyzing data addressing each of the three research questions and associated hypotheses was required compared to original intentions. The next section is organized by research question, and presents any revisions to the proposed statistical analysis, as well as the findings resulting from those analyses.

#### **Research Question One and Hypotheses 1a – 1e**

The purpose of Research Question One was to examine the relationship between SOC and the health-related quality of life (HRQOL) of women who are cancer survivors. The following specific research questions and hypotheses were presented in Chapter One:

Question 1: What is the relationship between SOC and its domains and the HRQOL of women who are cancer survivors?

H1a: There will be a positive relationship between overall SOC the greater the overall HRQOL.

H1b: There will be a positive relationship between the overall membership domain and HRQOL.

H1c: There will be a positive relationship between the overall influence domain and HRQOL.

H1d: There will be a positive relationship between the overall integration\fulfillment of needs domain and HRQOL.

H1e: There will be a positive relationship between the overall shared emotional connection domain and the HRQOL.

Given the results from the preliminary analysis, specifically the PCA that failed to replicate the factor solution, it was determined that the domain specific factor structure as outlined by Peterson and colleagues (2008) did not exist for this data set. Therefore, the analysis for testing hypotheses for research question one could not be performed due to the lack of the specific SOC domain structure from this data set.

### **Research Question Two and Hypotheses 2a – 2e**

Research Question Two represented an extension of the first research question but explored the relationships between the specific community types (Social Support, Neighborhood, Leisure, Faith, and Work-based) and the HRQOL of female cancer survivors.

Question 2: How does the sense of community (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to which a female cancer survivor identifies relate to her HRQOL?

H2a: There will be a positive relationship between those who identify with Social Support community and their HRQOL.

H2b: There will be a positive relationship between those who identify with the Neighborhood-based community and their HRQOL.

H2c: There will be a positive relationship between those who identify with a Leisure-based community and their HRQOL.

H2d: There will be a positive relationship between those who identify with spiritual\Faith-based community and their HRQOL.

H2e: There will be a positive relationship between those who identify with a Work-based community and their HRQOL.

Hierarchical linear regression was initially proposed as the method for testing these hypotheses. However, as the measure for SOC community types was found to be non-normal and demonstrated issues with multicollinearity for each community type, and this problem could not be adequately resolved by a transformation process, a median split was computed, resulting in two groups for each of the SOC community types. Data analyses was changed to conduct four multivariate analysis of covariance (MANCOVA) tests to examine differences between groups (created by median splits) for each of the SOC community types (e.g., Social Support, Neighborhood, Leisure, Work-based) in their HRQOL scores. As the Spiritual/Faith-based community type had an insufficient number of responses and was not part of the final PCA solution from the preliminary analysis, this community type and its associated hypothesis (H2d) was not considered further. Education and survivor group were selected as the primary covariates

of interests given that they were the only two variables that consistently significantly influenced the relationship between HRQOL and SOC during preliminary analyses with this sample.

Before testing the hypotheses, exploration into the appropriate use of MANCOVA and its underlying assumptions was conducted. Four tests of assumptions were: 1) the test of independence of observations, 2) that the data be randomly sampled from the population of interest and measured at the interval level, 3) that of multivariate normality, and 4) that the covariance matrices be homogeneous. Regarding the independence of observations, each respondent replied to the measures independently and therefore the assumption of independence was not violated. The absence of random sampling will be listed as a limitation for the study. With regard to multivariate normality, the K-S test performed earlier was nonsignificant (see Table 4.12) and demonstrated that neither subscale (G-QOL and C-QOL) violated the assumption of normality. As for homogeneity of variance, Table 4.19 presents the findings from Box's Test of the assumptions of equality of covariance matrices. This statistic tested the null hypothesis that the variance-covariance matrices were the same in both groups comprising the independent variable. If all matrices were equal, the assumption of homogeneity would be met as indicated by a nonsignificant finding for Box's Test. For these data, three of the four community types were nonsignificant ( $p > .08$ ), indicating that the covariance matrices were generally equal and that the assumption of homogeneity was therefore tenable. Although Box's Test on the Work based community type was significant, Levene's Test of Equality of Variances was found to be nonsignificant for both G-QOL and C-QOL, indicating that Work-based outcomes did not violate the homogeneity criterion.

Having met most of the tests of assumptions in order to conduct MANCOVA, the following presents the results of this data analysis for each of the hypotheses derived from Research Question Two.

**H2a: There will be a relationship between those who identify with Social Support community type and their HRQOL**

Table 4.21 presents the findings from the multivariate tests conducted to determine the viability of hypothesis 2a. Findings suggested that there was not a significant difference in HRQOL subscales between cancer survivors who are above and below the median on Social Support community type,  $F(2, 69) = .12, p < .05$ . The MANCOVA also revealed that the education covariate approached significance ( $V = .069, F(2, 69) = 1.97, p < .15$ ). There was also no significant relationship between the covariates of education and survivorship group and the HRQOL subscales.

**H2b: There will be a positive relationship between those who identify with the neighborhood-based community type and their HRQOL**

Table 4.22 presents the findings from the multivariate test between the High and Low Neighborhood community type and the two HRQOL subscales. Similar to Social Support, there was not a significant difference between cancer survivors who are High and Low in Neighborhood community SOC and their HRQOL,  $F(2, 69) = .202, p < .818$ . There was not a significant relationship with any of the covariates of interest and that of the two HRQOL subscales.

**H2c: There will be a positive relationship between those who identify with a Leisure-based community type and their HRQOL**

Table 4.23 presents the findings from the MANCOVA for Leisure community type SOC and HRQOL. As with the two preceding community types, there was not a significant

multivariate relationship between cancer survivors' Leisure-based SOC and their HRQOL ( $F(2, 67) = .138, p < .87$ ). Again, there was not a significant relationship between the covariates and the HRQOL subscales.

**H2d: There will be a positive relationship between those who identify with the Spiritual\Faith-Based community type and their HRQOL**

Results for hypothesis H2d were unattainable due to the lack of responses for the Faith-based community type.

**H2e: There Will Be a Positive Relationship Between Those Who Identify With a Work-Based Community type and Their HRQOL**

Table 4.24 presents the findings from the multivariate test between the Work-based community type SOC groups and respondents' HRQOL subscales. The results indicated that there was not a significant difference between the Work-based SOC and their HRQOL scores ( $F(2, 62) = .912, p < .41$ ). The covariates of interest were also nonsignificant.

In sum, results of the multivariate analyses for the hypotheses associated with Research Question Two did not deter a significant relationship between the SOC for the four community types and HRQOL subscales. The following presents the findings for Research Question Three and its associated Hypotheses.

**Research Question Three and Hypotheses 3a – 3m**

Question three represents an extension of the first two research questions by examining the relationship between SOC and the underlying HRQOL subscale domains (G-QOL – Energy, Pain, Social Avoidance, Positive Feelings, Sexual Limitations, Negative Feelings; C-QOL – Appearance Concerns, Financial Problems, Distress Recurrence, Family-Related Distress, Benefits of Cancer). Following the previous analysis for Research Question Two, the SOC

scores based on the median splits were employed to test the relationship between SOC and the HRQOL subscale domains as outlined below.

Question 3: How does a female cancer survivor's SOC differentially impact the various components of HRQOL?

H3a: There will be a negative relationship between SOC and the Appearance Concerns domain

H3b: There will be a negative relationship between SOC and the Financial Problems domain

H3c: There will be a negative relationship between SOC and the Distress-Recurrence domain

H3d: There will be a negative relationship between SOC and the Distress-Family domain

H3e: There will be a positive relationship between SOC and the Benefits of Cancer domain.

H3f: There will be a negative relationship between SOC and the Negative Feelings domain

H3g: There will be a positive relationship between SOC and the Positive Feelings domain

H3h: There will be a negative relationship between SOC and the Sexual Limitations domain

H3i: There will be a negative relationship between SOC and the Physical Pain domain

H3j: There will be a negative relationship between SOC and the Energy / Fatigue domain

H3k: There will be a negative relationship between SOC and the Social Avoidance domain

Research Question Three examined how SOC might be related to the individual domains that comprised the HRQOL subscales. However, as the measure for SOC community types was

found to be non-normal and demonstrated issues with multicollinearity for each community type, and this problem could not be adequately resolved by a transformation process, a median split was computed, resulting in two groups for each of the SOC community types. Data analyses was changed to conduct a total of eight multivariate analysis of covariance (MANCOVA) tests to examine differences between groups (created by median splits) for each of the SOC community types (e.g., Social Support, Neighborhood, Leisure, Work-based) on their HRQOL subscale domains (G-QOL and C-QOL). As the Spiritual/Faith-based community type had an insufficient number of responses and was not part of the final PCA solution from the preliminary analysis, this community type was not considered further. Education and survivor group were again selected as the primary covariates given that they were the only two demographic variables that consistently and significantly influenced the relationship between HRQOL and SOC during preliminary analyses for the sample.

Before testing the hypotheses, exploration into the appropriate use of MANCOVA and its underlying assumptions was conducted. The same four tests of the underlying assumptions were performed: 1) the test of independence of observations, 2) that the data were randomly sampled from the population of interest and measured at the interval level, 3) that of multivariate normality, and 4) that the covariance matrices were homogeneous. Regarding the independence of observations, each respondent replied to this data set independently and therefore the assumption of independence was not violated. The absence of random sampling however was not met and will be listed as a limitation for the study.

With regard to multivariate normality, the descriptive statistics for each of the HRQOL subscale domains indicated possible violations of normality given the level of skew and kurtosis (see Table 4.25). To further assess this violation of normality, the K-S test was performed. Table

4.26 presents the results from this test and demonstrated that several violations of normality existed. In an effort to correct for these violations of normality, several transformations of the data were attempted including square root, reciprocal and log transformations on each of the 47 – items that comprised the HRQOL subscales. Once the item transformations were completed for each item, each of the individual HRQOL domains were then recalculated. Table 4.26 presents the K-S test of normality with the square root transformation and demonstrates that the issues with normality for the individual domains were still present ( $p < .05$ ) except for that of Energy ( $p = .09$ ), Sexual Limitations ( $p = .064$ ), Appearance Concerns ( $p = .08$ ), and Distress Recurrence ( $p = .200$ ). As a square root transformation was then shown to be largely ineffectual, a log transformation process was then performed on the HRQOL subscale domains following a similar pattern as outlined above with the square root transformation process.

Table 4.28 presents the K-S test of normality for the HRQOL domains based on the use of a log transformation. According to Field (2009), a log transformation is also recommended as a method for reducing positive skew within a data set. Of the 11 HRQOL domains, only five benefited from the log transformation: Energy ( $p > .05$ ), Social Avoidance ( $p > .05$ ), Sexual Limitations ( $p > .05$ ), Negative Feelings ( $p > .05$ ), and Appearance Concerns ( $p > .05$ ). As a log transformation process was sufficient for only 5 of the total 11 HRQOL domains, a final transformation using a reciprocal process was conducted to see if this type of data transformation could produce further corrections beyond that of a log-based transformation.

Table 4.29 presents the results of the reciprocal transformation process that was conducted on the HRQOL subscale domains. As a reciprocal transformation reverses the scores (e.g. big scores become small and small scores become big), the highest score (7 out of a possible 1 – 7 Likert-type scale) was entered into the equation so that the reciprocal scores would

not be reversed (e.g.  $1 / (7 - X_i)$ ). Results from this K-S test suggested that the reciprocal transformation was also, ineffectual as each of the HRQOL subscales demonstrated highly significant K-S test values ( $p \leq .31$ ; see Table 4.27).

Field (2009) argued that the payoff for normalizing data through one of the above transformations was not worth the effort as they generally produced insufficient increases in normality (p.155; Glass, Peckham, and Sander, 1972). Field and others have also argued that the *F*-test as found in MANCOVA is a robust test that should be accurate even when a violation of normality exists (Glass, Peckham, and Sander (1972). Further, preliminary analyses of the relationships between SOC and HRQOL subscale domains using the Log-based transformation produced results that violated multivariate homogeneity. Therefore, the obtained HRQOL subscale domain scores as generated by the factor analysis provided earlier were used for the purpose of addressing the hypotheses from Research Question Three (H3a – H3k). The violation of the normality assumption was noted as a limitation of this study. With regard to the test of homogeneity of variance, Table 4.30 and Table 4.31 present the findings from Box's Test of the assumptions of equality of covariance matrices for the community types on both G-QOL and C-QOL domains values, respectively. This statistic tests the null hypothesis that the variance-covariance matrices were the same in both High and Low groups of the independent variables. If all matrices were equal, the assumption of homogeneity was met as indicated by a non-significant finding for Box's Test. For these data, the tests of homogeneity of variance were nonsignificant ( $p > .087$ ), indicating that the covariance matrices were generally equal and that the assumption of homogeneity was tenable.

Having met most of the tests of assumptions to conduct MANCOVA, the following presents the results of this data analysis for each of the hypotheses for Research Question Three,

with Cancer-Specific Quality of Life domains being presented first, followed by that of the Generic-Quality of Life domain results.

### **Cancer-Specific QOL Domains**

The following presents the findings from the MANCOVA regarding the relationship between SOC and Cancer-Specific Quality of Life (C-QOL) domains (Appearance Concerns, Financial Problems, Distress-Recurrence, Family-Related Distress, Benefits of Cancer).

**H3a: There Will be a Negative Relationship between SOC and the Appearance Due to Cancer domain**

**H3b: There Will Be a Negative Relationship between SOC and the Financial Problems Due to Cancer Domain**

**H3c: There Will Be a Negative Relationship between SOC and the Distress Over Recurrence of Cancer Domain**

**H3d: There Will Be a Negative Relationship between SOC and the Family-Related Distress of Cancer Domain**

**H3e: There Will Be a Positive Relationship between SOC and the Benefits of Cancer Domain**

**Social Support SOC.** There was not a significant difference between High and Low groups in Social Support SOC and the C-QOL domains of Appearance Concern, Financial Problems, Distress – Recurrence, Family-Related Distress, and Benefits of Cancer ( $F(5,67) = .52, p > .05$ ), nor was there a relationship found with either of the covariates ( $p > .10$ ; see Table 4.32).

**Neighborhood SOC.** There was not a significant difference between the groups for Neighborhood SOC and the C-QOL domains of Appearance Concern, Financial Problems,

Distress – Recurrence, Family-Related Distress, and Benefits of Cancer ( $F(5,67) = .22, p > .05$ ), nor was a relationship found with either of the covariates ( $p > .10$ ; see Table 4.33).

**Leisure SOC.** There was no significant difference between High and Low Leisure SOC groups and the C-QOL domains of Appearance Concern, Financial Problems, Distress – Recurrence, Family-Related Distress, and Benefits of Cancer ( $F(5,63) = 1.74, p > .05$ ). The covariates were also found to be nonsignificant ( $p > .10$ ; see Table 4.34).

**Work SOC.** There was not a significant difference between High and Low Work SOC groups and the C-QOL domains of Appearance Concern, Financial Problems, Distress – Recurrence, Family-Related Distress, and Benefits of Cancer ( $F(5,59) = .02, p > .05$ ). The covariates were also found to be nonsignificant ( $p > .10$ ; see Table 4.35).

In sum, none of the four community types or any of the covariates showed a relationship with any of the C-QOL domains.

### **Generic-Quality of Life Domains**

**H3f: There Will Be a Positive Relationship Between SOC and the Generic HRQOL Negative Feelings Domain**

**H3g: There will be a Positive Relationship between SOC and the Generic HRQOL Positive Feelings Domain**

**H3h: There Will Be a Positive Relationship Between SOC and the Generic HRQOL Sexual Limitations Domain**

**H3i: There Will Be a Positive Relationship Between SOC and the Generic HRQOL Physical Pain Domain**

**H3j: There Will Be a Positive Relationship Between SOC and the Generic HRQOL Energy / Fatigue Domain**

### **H3k: There Will Be a Positive Relationship Between SOC and the Generic HRQOL Social Avoidance Domain**

The following presents the findings of the MANCOVA for the Generic-Quality of Life (G-QOL) subscale domains (Negative Feelings, Positive Feelings, Sexual Limitations, Physical Pain, Energy / Fatigue, Social Avoidance).

**Social Support SOC.** There was no significant difference between High and Low Social Support SOC groups and the C-QOL domains of Negative Feelings, Positive Feelings, Sexual Limitations, Physical Pain, Energy / Fatigue, Social Avoidance ( $F(5,86) = 1.04, p > .05$ ), nor was there a significant relationship with either of the covariates ( $p > .10$ ; see Table 4.32).

**Neighborhood SOC.** There was not a significant difference between Neighborhood SOC High and Low groups and the G-QOL domains of Negative Feelings, Positive Feelings, Sexual Limitations, Physical Pain, Energy / Fatigue, Social Avoidance ( $F(5,87) = .859, p > .05$ ), nor any significant relationship with for any of the covariates ( $p > .10$ ; see Table 4.33).

**Leisure SOC.** There was a significant difference between the High and Low Leisure SOC and the G-QOL domains of Negative Feelings, Positive Feelings, Sexual Limitations, Physical Pain, Energy / Fatigue, Social Avoidance ( $F(5,61) = .132, p = .04$ ). Univariate test results showed that difference between Leisure-based SOC groups had a significant relationship with the G-QOL specific domains of Energy Fatigue ( $F(1,85) = 3.56, p = .06$ ), Positive Feelings ( $F(1,85) = 4.30, p = .04$ ), and Social Avoidance ( $F(1,85) = 4.31, p = .04$ ). These findings suggested that for those respondents who had higher Leisure based SOC, they had less Energy Fatigue, less Social Avoidance and greater Positive Feelings. The covariates were found to be nonsignificant ( $p > .10$ ; see Table 4.34).

**Work SOC.** There was a significant difference obtained between High and Low Work based SOC groups and the G-QOL domains of Negative Feelings, Positive Feelings, Sexual Limitations, Physical Pain, Energy / Fatigue, Social Avoidance ( $F(5,78) = 2.29, p = .05$ ). Univariate test results showed that Work-based SOC groups differed for the G-QOL specific domain of Positive Feelings ( $F(1,82) = 9.97, p = .002$ ), with the High group having more positive feelings than the low Work based group in SOC. The covariates were also found to be nonsignificant ( $p > .10$ ; see Table 4.35).

In sum, a significant relationship between SOC and G-QOL domains was found for the Leisure and Work-Based SOC community types.

Table 4.1				
<i>Descriptive Statistics for the SOC Domains and Community types (N = 98)</i>				
Domains	<i>M(SD)</i>	Skewness	Kurtosis	Sig.
Membership	5.57(1.24)	-2.29	5.37	0.81
Influence	5.18(1.11)	-1.59	3.13	0.77
Needs Fulfillment	5.22(1.17)	-1.66	3.26	0.76
Emotional Connection	5.34(1.22)	-1.73	3.15	0.83
Domains	<i>M(SD)</i>	Skewness	Kurtosis	Sig.
Social Support	5.83 (1.53)	-1.91	3.06	0.97
Neighborhood	4.16 (1.38)	-.21	-.23	0.94
Leisure	5.75 (1.51)	-1.80	3.23	0.98
Faith	5.71 (1.61)	-1.59	2.00	0.97
Work	5.36 (1.60)	-1.14	.70	0.97

Table 4.2			
<i>Test of Normality for SOC Variables</i>			
	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Membership	0.20	97	.000
Influence	0.19	97	.000
Needs Fulfillment	0.16	97	.000
Emotional Connection	0.16	97	.000
Social Support	0.22	96	.000
Neighborhood	0.13	97	.000
Leisure	0.20	90	.000
Faith	0.21	92	.000
Work	0.15	87	.000

Table 4.3				
<i>Inter-Item Correlation Matrix of the Four SOC domains</i>				
	Membership	Influence	Needs Fulfillment	Emotional Connection
Membership	1			
Influence	0.85**	1		
Needs Fulfillment	0.91**	0.88**	1	
Emotional Connection	0.92**	0.89**	0.94**	1

Note. \*\* p < .01

Table 4.4					
<i>Inter-Item Correlation Matrix of the Five Community Types</i>					
	Social Support	Neighborhood	Leisure	Faith	Work
Social Support	1				
Neighborhood	0.19	1			
Leisure	0.70**	0.38**	1		
Faith	0.64**	0.47**	0.88**	1	
Work	0.46**	0.26*	0.57**	0.65**	1

Note. \* p < .05; \*\* p < .01

Table 4.5		
<i>SOC Domains KMO measure for Sampling Adequacy</i>		
Domain	KMO statistic	Value
Membership	0.75	Good
Influence	0.75	Good
Needs Fulfillment	0.72	Good
Emotional Connection	0.73	Good
Community type		
Social Support Community	0.91	Superior
Neighborhood Community	0.88	Great
Leisure Community	0.90	Superior
Faith Community	0.92	Superior
Work Community	0.91	Superior

Table 4.6			
<i>PCA with Orthogonal (Varimax) Rotation for Membership Domain</i>			
Component	Factor		
	1	2	3
Support Membership 1	.176	<b>.944</b>	.047
Support Membership 2	.140	<b>.917</b>	.108
Neigh. Membership 1	.139	.181	<b>.881</b>
Neigh. Membership 2	.138	.093	<b>.882</b>
Leisure Membership 1	.456	<b>.675</b>	.281
Leisure Membership 2	.540	<b>.640</b>	.308
Faith Membership 1	<b>.665</b>	.160	.430
Faith Membership 2	<b>.694</b>	.092	.477
Work Membership 1	<b>.838</b>	.224	.066
Work Membership 2	<b>.843</b>	.313	-.019
Eigenvalues	5.22	1.55	1.14
Percentage of total variance	52.15	15.45	11.43
Cronbach's $\alpha$	--	--	--
Number of test measures	6	2	2

Table 4.7

*PCA with Orthogonal (Varimax) Rotation for Interest Domain*

Component	Factor		
	1	2	3
Social Support Influence 1	-.048	<b>.882</b>	.057
Social Support Influence 2	.311	<b>.839</b>	-.094
Neighborhood Influence 1	.085	-.020	<b>.847</b>
Neighborhood Influence 2	.032	.101	<b>.866</b>
Leisure Influence 1	.493	<b>.536</b>	.394
Leisure Influence 2	<b>.506</b>	.549	.383
Faith Influence 1	<b>.826</b>	.027	.016
Faith Influence 2	<b>.745</b>	-.039	.375
Work Influence 1	<b>.788</b>	.294	.018
Work Influence 2	<b>.809</b>	.265	-.027
Eigenvalues	4.62	1.60	1.25
Percentage of total variance	46.17	16.00	12.48
Cronbach's $\alpha$	--	--	--
Number of test measures	5	3	2

Table 4.8

*PCA with Orthogonal (Varimax) Rotation for Needs Domain*

Component	Factor		
	1	2	3
Social Support Needs 1	.12	<b>.942</b>	-.003
Social Support Needs 2	.114	<b>.925</b>	.038
Neighborhood Needs 1	.094	.111	<b>.900</b>
Neighborhood Needs 2	.107	.079	<b>.926</b>
Leisure Needs 1	.357	<b>.738</b>	.196
Leisure Needs 2	.461	<b>.689</b>	.231
Faith Needs 1	<b>.785</b>	.137	.298
Faith Needs 2	<b>.734</b>	.122	.373
Work Needs 1	<b>.839</b>	.272	-.062
Work Needs 2	<b>.840</b>	.213	-.078
Eigenvalues	5.08	1.69	1.33
Percentage of total variance	50.83	16.89	13.25
Cronbach's $\alpha$	--	--	--
Number of test measures	4	4	2

Table 4.9

*PCA with Orthogonal (Varimax) Rotation for Emotional Connection Domain*

Component	Factor		
	1	2	3
Social Support Emotional Connection 1	<b>.936</b>	.052	-.008
Social Support Emotional Connection 2	<b>.948</b>	.106	.021
Neighborhood Emotional Connection 1	.081	.068	<b>.915</b>
Neighborhood Emotional Connection 2	.113	.161	<b>.868</b>
Leisure Emotional Connection 1	<b>.771</b>	.341	.309
Leisure Emotional Connection 2	<b>.703</b>	.490	.288
Faith Emotional Connect. 1	.134	<b>.682</b>	.492
Faith Emotional Connect. 2	.123	<b>.653</b>	.620
Table 4.9 (cont.)			
Work Emotional Connection 1	.164	<b>.891</b>	.081
Work Emotional Connection 2	.226	<b>.905</b>	.043
Eigenvalues	5.07	1.95	1.27
Percentage of total variance	50.77	19.51	12.74
Cronbach's $\alpha$	--	--	--
Number of test measures	4	4	2

Table 4.10

*PCA with Orthogonal (Varimax) Rotation for the Community types*

SOC Item	Factor			
	1	2	3	4
Support1_3	.199	<b>.862</b>	.330	.031
Support2_4	.219	<b>.755</b>	.348	.138
Support3_5	.156	<b>.749</b>	.101	.036
Support4_6	.382	<b>.787</b>	.285	-.009
Support5_7	.179	<b>.894</b>	.298	.064
Support6_8	.154	<b>.898</b>	.315	.088
Support7_9	.149	<b>.903</b>	.300	.048
Support8_10	.154	<b>.857</b>	.379	.054
Neighborhood1_11	.054	.012	.140	<b>.878</b>
Neighborhood2_12	-.049	.014	.099	<b>.838</b>
Neighborhood3_13	.158	.198	.140	<b>.788</b>
Neighborhood4_14	.033	.045	.131	<b>.878</b>
Neighborhood5_15	.161	.026	.108	<b>.925</b>
Neighborhood6_16	.163	.091	.088	<b>.869</b>
Neighborhood7_17	-.015	-.027	.234	<b>.636</b>
Neighborhood8_18	.279	.081	.031	<b>.795</b>
Leisure1_20	.279	.397	<b>.748</b>	.174
Leisure2_21	.215	.352	<b>.829</b>	.134
Leisure3_22	.227	.341	<b>.799</b>	.210
Leisure4_23	.354	.424	<b>.765</b>	.224
Leisure5_24	.289	.329	<b>.796</b>	.160
Leisure6_25	.239	.261	<b>.819</b>	.165
Leisure7_26	.262	.397	<b>.800</b>	.223
Leisure8_27	.344	.361	<b>.765</b>	.213
Work1_38	<b>.849</b>	.239	.200	.123
Work2_39	<b>.830</b>	.292	.247	.051
Work3_40	<b>.820</b>	.125	.257	.118
Work4_41	<b>.875</b>	.138	.207	.163
Work5_42	<b>.867</b>	.159	.260	.068
Work6_43	<b>.844</b>	.185	.142	.109
Work7_43	<b>.931</b>	.143	.152	.100
Work8_45	<b>.884</b>	.191	.213	.078
Eigenvalue	15.72	5.03	3.75	1.84
Percentage of total variance	49.12	15.72	11.71	5.76
Cronbach's $\alpha$	0.97	0.97	0.97	0.94
Number of test items	8	8	8	8

Table 4.11

*Descriptive Statistics for SOC Community type Factor Scores (n =75)*

	No. Items	M(SD)	Skewness	Kurtosis	Alpha
Social Support	8	.01 (1.02)	-1.16	3.40	0.97
Neighborhood	8	-.06 (1.01)	-.28	-.12	0.94
Leisure	8	-.002 (1.00)	-.50	-.58	0.98
Work	8	-.11 (1.0)	-.32	-1.16	0.97

Table 4.12

*Test of Normality for SOC Community types*

	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Social Support	0.22	96	.000
Neighborhood	0.13	97	.000
Leisure	0.20	90	.000
Faith	0.21	92	.000
Work	0.15	87	.000

Table 4.13

*SOC Median Split*

Construct	Median (SD)	Below	Above
Social Support	50.00 (12.29)	0 - 49	50 +
Neighborhood	35.00 (10.96)	0 - 34	35 +
Leisure	49.00 (11.96)	0 - 48	49 +
Faith	48.00 (13.19)	0 - 47	48 +
Work	46.00 (12.69)	0 - 45	46 +

Table 4.14

*Generic QOL Correlations (n = 97)*

Domains	Neg. Feel	Positive Feel	Cog. Prob.	Sexual Interest.	Phys. Pain	Energy Fatigue	Sex. Ftn.
Generic QOL							
Negative Feelings							
Positive Feelings	-.42**						
Cognitive Feelings	.64**	-.18					
Sexual Interest	.29**	-.28**	.17				
Physical Pain	.46**	-.28**	.41**	.36**			
Energy/Fatigue	.63**	-.37**	.60**	.28**	.68**		
Sexual Function	.35**	-.25*	.24*	.60**	.38**	.45**	
Social Avoidance	.47**	-.51**	.31**	.25*	.40**	.40**	.16

Table 4.15

*Cancer-Specific QOL Correlations (n = 77)*

	Appearance Concerns	Financial Problems	Distress Recurrence	Distress -Family
Appearance Concerns				
Financial Problems	.44**			
Distress Recurrence	.59**	.38**		
Distress Family	.42**	.37**	.61**	
Benefits	.21	.08	.32**	.40**

Table 4.16

*QLACS Descriptive Statistics and Tests of Normality*

	No. Items	<i>M</i> ( <i>SD</i> )	Skewness	Kurtosis
HRQOL	47	3.49(0.76)	.217	-.683
Generic QOL	28	3.41(0.75)	.316	-.850
Cancer QOL	19	3.69(1.26)	.245	-.174
Generic QOL				
Negative Feelings	4	3.03(1.07)	.488	-.436
Positive Feelings	4	5.58(1.20)	-.824	.448
Cognitive Problems	4	3.12(4.56)	.707	-.255
Sexual Interest	2	3.33(1.73)	.475	-.722
Physical Pain	4	2.88(1.68)	.713	-.659
Fatigue	4	3.23(1.33)	.513	-.012
Social Avoidance	4	2.22(1.17)	1.38	2.36
Sexual Function	2	2.91(1.68)	.875	-.118
Cancer-Specific QOL				
Appearance Concerns	4	3.13(1.68)	.407	-.895
Financial Problems	4	2.96(1.97)	.661	-.825
Distress Recurrence	4	3.85(1.86)	.175	-1.05
Family-Related Distress	3	3.59(1.98)	.205	-1.29
Benefits of Cancer	4	4.83(1.44)	-.638	.188

Table 4.17

*HRQOL Test of Normality*

	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
HRQOL	.058	98	.200
Generic QOL	.074	97	.200
Cancer QOL	.076	77	.200
Generic QOL			
Negative Feelings	.127	96	.001
Positive Feelings	.129	96	.000
Cognitive Problems	.165	96	.000
Sexual Interest	.117	95	.003
Physical Pain	.149	96	.000
Fatigue	.082	96	.111
Social Avoidance	.159	96	.000
Sexual Function	.170	96	.000
Cancer-Specific QOL			
Appearance Concerns	.132	76	.002
Financial Problems	.165	76	.000
Distress Recurrence	.086	76	.200
Family-Related Distress	.131	76	.003
Benefits of Cancer	.100	76	.060

Table 4.18

*PCA with Orthogonal (Varimax) Rotation for the 28 Generic QOL items*

Generic QOL Item	Factor					
	1	2	3	4	5	6
Energy 1	-.350	-.364	-.326	<b>.610</b>	-.081	.026
Activity 2	<b>.657</b>	.097	.102	-.029	-.134	.367
Attention 3	<b>.704</b>	.004	.225	-.147	.045	.467
Remember 4	<b>.689</b>	.176	.039	.009	.096	.521
Fatigued 5	<b>.743</b>	.253	.129	-.160	.067	.029
Happy 6	-.018	-.143	-.103	<b>.818</b>	-.170	-.066
Blue 7	<b>.684</b>	.104	.179	-.199	.133	-.055
Life 8	-.190	.038	-.398	<b>.797</b>	-.098	.048
Worried 9	.297	-.059	-.120	-.137	.015	<b>.700</b>
Ftn Sex	.397	.160	-.039	-.159	<b>.758</b>	-.021
Energy 11	<b>.601</b>	.464	.026	-.017	.157	.134
Disat. Sex 12	.113	.070	-.063	-.139	<b>.706</b>	-.010
Pain 13	.402	<b>.718</b>	.005	-.143	.177	.090
Tired 14	<b>.571</b>	.516	-.073	-.034	.261	.207
New Relat. 15	-.057	.513	<b>.562</b>	.008	-.056	-.061
LackedSx 16	-.216	.231	.042	.019	<b>.813</b>	.245
MoodPain 17	.094	<b>.880</b>	.110	-.143	.107	.231
Social 18	.237	.161	<b>.805</b>	-.196	.031	.138
Mood 19	.419	.268	<b>.516</b>	-.395	.156	.068
Avoid 20	.256	.346	<b>.712</b>	-.341	.067	-.017
Aches 21	.223	<b>.758</b>	.157	-.039	.245	.102
Outlook 22	-.101	-.078	-.567	<b>.670</b>	-.121	.050
Forget 23	.265	.244	.134	.126	.196	<b>.655</b>
Anxious 24	-.006	.343	.137	-.083	.039	<b>.756</b>
Newppl 25	.009	-.052	<b>.840</b>	-.254	.051	.101
Avoidsx 26	.092	.036	.399	.157	<b>.764</b>	.051
Painsocial 27	.187	<b>.756</b>	.241	-.254	.000	.136
Content 28	-.052	-.096	-.065	.637	-.041	-.103
Eigenvalue	9.66	3.44	2.27	1.94	1.46	1.17
Percentage of total variance	34.51	12.28	8.11	6.93	5.24	4.17
Cronbach's $\alpha$	.87	.90	.84	.85	.82	.70
Number of factor items	7	4	5	5	4	3

Table 4.19

*PCA with Orthogonal (Varimax) Rotation for the 19 Cancer-Related QOL Items*

Component	Factor				
	1	2	3	4	5
ApprecLife 29	.241	-.107	-.003	.081	<b>.828</b>
Financial 30	<b>.922</b>	.233	.123	.020	.079
Getcancer 31	.120	.177	.212	<b>.883</b>	.090
Cope 32	-.116	.211	-.113	.484	<b>.656</b>
Self Cons 33	.086	<b>.825</b>	.064	.165	.117
Genes 34	.090	.073	.278	<b>.822</b>	.264
Unattract 35	.188	<b>.812</b>	.260	.163	.096
Dying 36	.024	.398	<b>.650</b>	.423	.073
Insurance 37	<b>.689</b>	-.140	.051	.360	-.002
Hairloss 38	.106	<b>.679</b>	.216	.045	.074
Back 39	.122	.076	<b>.832</b>	.294	.105
Important 40	-.034	.100	.246	.080	<b>.861</b>
Stress 41	-.110	.283	.210	.112	<b>.788</b>
Tests 42	.275	.201	.353	<b>.684</b>	.130
Money 43	<b>.935</b>	.192	.084	.076	-.052
Appearance 44	.535	<b>.627</b>	.159	.057	.106
Lossincome 45	<b>.903</b>	.234	.153	.035	-.001
Canceragain 46	.178	.225	<b>.839</b>	.107	.258
Preoccupied 47	.198	.500	<b>.687</b>	.221	-.013
Eigenvalues	7.30	3.01	1.88	1.64	1.09
Percentage of total variance	38.43	15.86	9.90	8.62	5.76
Cronbach's $\alpha$	.92	.80	.90	.87	.83
Number of test measures	4	4	4	3	4

Table 4.20

*Box's Test of Equality of Covariance Matrices*

	Box's M	Sig.
Social Support	1.74	.638
Neighborhood	.76	.865
Leisure	7.14	.075
Work	9.08	.032

Table 4.21

*Social Support and HRQOL Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.434	26.444	2	69	.000
Wilks' Lambda	.566	26.444	2	69	.000
Hotelling's Trace	.766	26.444	2	69	.000
Roy's Largest Root	.766	26.444	2	69	.000
Social Support SOC-Group					
Pillais's Trace	.003	.118	2	69	.889
Wilks' Lambda	.997	.118	2	69	.889
Hotelling's Trace	.003	.118	2	69	.889
Roy's Largest Root	.003	.118	2	69	.889
Education Level Covariate					
Pillais's Trace	.054	1.965	2	69	.148
Wilks' Lambda	.946	1.965	2	69	.148
Hotelling's Trace	.057	1.965	2	69	.148
Roy's Largest Root	.057	1.965	2	69	.148
Survivor Group Covariate					
Pillais's Trace	.042	1.495	2	69	.232
Wilks' Lambda	.958	1.495	2	69	.232
Hotelling's Trace	.043	1.495	2	69	.232
Roy's Largest Root	.043	1.495	2	69	.232

Table 4.22

*Neighborhood and HRQOL Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.425	25.15	2	69	.000
Wilks' Lambda	.575	25.15	2	69	.000
Hotelling's Trace	.740	25.15	2	69	.000
Roy's Largest Root	.740	25.15	2	69	.000
Neighborhood SOC-Group					
Pillais's Trace	.006	.202	2	69	.818
Wilks' Lambda	.994	.202	2	69	.818
Hotelling's Trace	.006	.202	2	69	.818
Roy's Largest Root	.006	.202	2	69	.818
Education Level Covariate					
Pillais's Trace	.051	1.865	2	69	.163
Wilks' Lambda	.949	1.865	2	69	.163
Hotelling's Trace	.054	1.865	2	69	.163
Roy's Largest Root	.054	1.865	2	69	.163
Survivor Group Covariate					
Pillais's Trace	.038	1.371	2	69	.261
Wilks' Lambda	.962	1.371	2	69	.261
Hotelling's Trace	.040	1.371	2	69	.261
Roy's Largest Root	.040	1.371	2	69	.261

Table 4.23

*Leisure and HRQOL Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.704	79.506	2	67	.000
Wilks' Lambda	.296	79.506	2	67	.000
Hotelling's Trace	2.373	79.506	2	67	.000
Roy's Largest Root	2.373	79.506	2	67	.000
Leisure SOC-Group					
Pillais's Trace	.004	.138	2	67	.871
Wilks' Lambda	.996	.138	2	67	.871
Hotelling's Trace	.004	.138	2	67	.871
Roy's Largest Root	.004	.138	2	67	.871
Education Level Covariate					
Pillais's Trace	.068	2.433	2	67	.095
Wilks' Lambda	.932	2.433	2	67	.095
Hotelling's Trace	.073	2.433	2	67	.095
Roy's Largest Root	.073	2.433	2	67	.095
Survivor Group Covariate					
Pillais's Trace	.033	1.153	2	67	.322
Wilks' Lambda	.967	1.153	2	67	.322
Hotelling's Trace	.034	1.153	2	67	.322
Roy's Largest Root	.034	1.153	2	67	.322

Table 4.24

*Work SOC and HRQOL Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.445	27.847	2	62	.000
Wilks' Lambda	.555	27.847	2	62	.000
Hotelling's Trace	.802	27.847	2	62	.000
Roy's Largest Root	.802	27.847	2	62	.000
Work SOC-Group					
Pillais's Trace	.029	.912	2	62	.407
Wilks' Lambda	.971	.912	2	62	.407
Hotelling's Trace	.029	.912	2	62	.407
Roy's Largest Root	.029	.912	2	62	.407
Education Level Covariate					
Pillais's Trace	.058	1.898	2	62	.158
Wilks' Lambda	.942	1.898	2	62	.158
Hotelling's Trace	.061	1.898	2	62	.158
Roy's Largest Root	.061	1.898	2	62	.158
Survivor Group Covariate					
Pillais's Trace	.048	1.554	2	62	.220
Wilks' Lambda	.952	1.554	2	62	.220
Hotelling's Trace	.050	1.554	2	62	.220
Roy's Largest Root	.050	1.554	2	62	.220

Table 4.25				
<i>Descriptive Statistics for Generic QOL Domains</i>				
	No. Items	M(SD)	Skewness	Kurtosis
Generic QOL				
Positive Feelings	5	5.52(1.17)	-1.02	.631
Negative Feelings	3	3.29(1.36)	.532	-.772
Energy / Fatigue	7	3.21(1.31)	.560	-.161
Pain	4	2.87(1.67)	.729	-.638
Social Avoidance	5	2.31(1.16)	1.341	2.381
Sexual Issues	4	3.14(1.51)	.572	.485
	No. Items	M(SD)	Skewness	Kurtosis
Cancer-Related				
Appearance	4	3.15 (1.67)	.389	-.892
Financial Problems	4	2.95 (1.96)	.669	-.792
Distress-Recurrence	4	4.85 (1.45)	-.641	.167
Distress-Family	3	3.58 (1.97)	.217	-1.266
Benefits of Cancer	4	3.87 (1.85)	.150	-1.055

Table 4.26			
<i>HRQOL Sub Scale Test of Normality</i>			
	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Generic QOL			
Energy	.090	97	.053
Pain	.152	97	.000
Social Avoidance	.152	97	.000
Positive Feelings	.159	97	.000
Sexual Limitations	.096	97	.028
Negative Feelings	.151	97	.000
Cancer-Specific QOL			
Appearance Concerns	.130	77	.003
Financial Problems	.161	77	.000
Distress Recurrence	.083	77	.200
Family-Related Distress	.127	77	.004
Benefits of Cancer	.098	77	.063

Table 4.27			
<i>HRQOL Sub Scale Domains Square Root Transformation Test of Normality</i>			
	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Generic QOL			
Sqrt Energy	.083	97	.094
Sqrt Pain	.124	97	.001
Sqrt Social Avoidance	.106	97	.009
Sqrt Positive Feelings	.173	97	.000
Sqrt Sexual Limitations	.088	97	.064
Sqrt Negative Feelings	.103	97	.012
Cancer-Specific QOL			
Sqrt Appearance Concerns	.095	77	.083
Sqrt Financial Problems	.156	77	.000
Sqrt Distress Recurrence	.080	77	.200
Sqrt Family-Related Distress	.104	77	.039
Sqrt Benefits of Cancer	.112	77	.018

Table 4.28			
<i>HRQOL Sub Scale Domains Log Transformation Test of Normality</i>			
	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Generic QOL			
log Energy	.060	97	.200
log Pain	.100	97	.018
log Social Avoidance	.088	97	.062
log Positive Feelings	.184	97	.000
log Sexual Limitations	.055	97	.200
log Negative Feelings	.074	97	.200
Cancer-Specific QOL			
log Appearance Concerns	.095	77	.084
log Financial Problems	.109	77	.024
log Distress Recurrence	.115	77	.013
log Family-Related Distress	.110	77	.000
log Benefits of Cancer	.166	77	.023

Table 4.29			
<i>HRQOL Sub Scale Domains Reciprocal Transformation Test of Normality</i>			
	Kolmogorov-Smirnov (K-S)		
	Statistic	df	Sig.
Generic QOL			
Reciprocal Energy	.162	97	.000
Reciprocal Pain	.225	97	.000
Reciprocal Social Avoidance	.241	97	.000
Reciprocal Positive Feelings	.177	97	.000
Reciprocal Sexual Limitations	.217	97	.000
Reciprocal Negative Feelings	.234	97	.000
Cancer-Specific QOL			
Reciprocal Appearance Concerns	.177	77	.000
Reciprocal Financial Problems	.250	73	.000
Reciprocal Distress Recurrence	.165	70	.000
Reciprocal Family-Related Distress	.195	71	.000
Reciprocal Benefits of Cancer	.111	71	.031

Table 4.30		
<i>Box's Test of Equality of Covariance Matrices - G-QOL Sub Scale Domains</i>		
Community Type	Box's M	Sig.
Social Support	16.66	.403
Neighborhood	23.74	.098
Leisure	24.33	.087
Work	22.90	.123

Table 4.31		
<i>Box's Test of Equality of Covariance Matrices - C-QOL Sub Scale Domains</i>		
Community Type	Box's M	Sig.
Social Support	12.10	.737
Neighborhood	16.58	.424
Leisure	10.81	.821
Work	10.13	.861

Table 4.32

*Social Support Community Type SOC and C-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.305	5.87	5	67	.000
Wilks' Lambda	.695	5.87	5	67	.000
Hotelling's Trace	.438	5.87	5	67	.000
Roy's Largest Root	.438	5.87	5	67	.000
Social Support SOC					
Pillais's Trace	.037	.515	5	67	.764
Wilks' Lambda	.963	.515	5	67	.764
Hotelling's Trace	.038	.515	5	67	.764
Roy's Largest Root	.038	.515	5	67	.764
Education Level Covariate					
Pillais's Trace	.047	.655	5	67	.658
Wilks' Lambda	.953	.655	5	67	.658
Hotelling's Trace	.049	.655	5	67	.658
Roy's Largest Root	.049	.655	5	67	.658
Survivor Group Covariate					
Pillais's Trace	.051	.724	5	67	.607
Wilks' Lambda	.949	.724	5	67	.607
Hotelling's Trace	.054	.724	5	67	.607
Roy's Largest Root	.054	.724	5	67	.607

Table 4.33

*Neighborhood Community Type SOC and C-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.298	5.693	5	67	.000
Wilks' Lambda	.702	5.693	5	67	.000
Hotelling's Trace	.425	5.693	5	67	.000
Roy's Largest Root	.425	5.693	5	67	.000
Neighborhood SOC					
Pillais's Trace	.016	.215	5	67	.955
Wilks' Lambda	.984	.215	5	67	.955
Hotelling's Trace	.016	.215	5	67	.955
Roy's Largest Root	.016	.215	5	67	.955
Education Level Covariate					
Pillais's Trace	.033	.461	5	67	.804
Wilks' Lambda	.967	.461	5	67	.804
Hotelling's Trace	.034	.461	5	67	.804
Roy's Largest Root	.034	.461	5	67	.804
Survivor Group Covariate					
Pillais's Trace	.044	.622	5	67	.684
Wilks' Lambda	.956	.622	5	67	.684
Hotelling's Trace	.046	.622	5	67	.684
Roy's Largest Root	.046	.622	5	67	.684

Table 4.34

*Leisure Community Type SOC and C-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.303	5.476	5	63	.000
Wilks' Lambda	.697	5.476	5	63	.000
Hotelling's Trace	.435	5.476	5	63	.000
Roy's Largest Root	.435	5.476	5	63	.000
Leisure SOC					
Pillais's Trace	.122	1.744	5	63	.138
Wilks' Lambda	.878	1.744	5	63	.138
Hotelling's Trace	.138	1.744	5	63	.138
Roy's Largest Root	.138	1.744	5	63	.138
Education Level Covariate					
Pillais's Trace	.057	.760	5	63	.582
Wilks' Lambda	.943	.760	5	63	.582
Hotelling's Trace	.060	.760	5	63	.582
Roy's Largest Root	.060	.760	5	63	.582
Survivor Group Covariate					
Pillais's Trace	.079	1.075	5	63	.383
Wilks' Lambda	.921	1.075	5	63	.383
Hotelling's Trace	.085	1.075	5	63	.383
Roy's Largest Root	.085	1.075	5	63	.383

Table 4.35

*Work Community Type SOC and C-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.329	5.792	5	59	.000
Wilks' Lambda	.671	5.792	5	59	.000
Hotelling's Trace	.491	5.792	5	59	.000
Roy's Largest Root	.491	5.792	5	59	.000
Work SOC					
Pillais's Trace	.023	.278	5	59	.923
Wilks' Lambda	.977	.278	5	59	.923
Hotelling's Trace	.024	.278	5	59	.923
Roy's Largest Root	.024	.278	5	59	.923
Education Level Covariate					
Pillais's Trace	.036	.441	5	59	.818
Wilks' Lambda	.964	.441	5	59	.818
Hotelling's Trace	.037	.441	5	59	.818
Roy's Largest Root	.037	.441	5	59	.818
Survivor Group Covariate					
Pillais's Trace	.079	.802	5	59	.553
Wilks' Lambda	.922	.802	5	59	.553
Hotelling's Trace	.083	.802	5	59	.553
Roy's Largest Root	.064	.802	5	59	.553

Table 4.36

*Social Support Community Type SOC and G-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.589	24.682	5	86	.000
Wilks' Lambda	.411	24.682	5	86	.000
Hotelling's Trace	1.435	24.682	5	86	.000
Roy's Largest Root	1.435	24.682	5	86	.000
Social Support SOC					
Pillais's Trace	.097	1.042	5	86	.112
Wilks' Lambda	.903	1.042	5	86	.112
Hotelling's Trace	.108	1.042	5	86	.112
Roy's Largest Root	.108	1.042	5	86	.112
Education Level Covariate					
Pillais's Trace	.057	1.380	5	86	.399
Wilks' Lambda	.943	1.380	5	86	.399
Hotelling's Trace	.061	1.380	5	86	.399
Roy's Largest Root	.061	1.380	5	86	.399
Survivor Group Covariate					
Pillais's Trace	.074	1.257	5	86	.240
Wilks' Lambda	.926	1.247	5	86	.240
Hotelling's Trace	.080	1.237	5	86	.240
Roy's Largest Root	.080	1.688	5	86	.240

Table 4.37

*Neighborhood Community Type SOC and G-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.587	24.685	5	87	.000
Wilks' Lambda	.413	24.685	5	87	.000
Hotelling's Trace	1.419	24.685	5	87	.000
Roy's Largest Root	1.419	24.685	5	87	.000
Neighborhood SOC					
Pillais's Trace	.047	.859	5	87	.512
Wilks' Lambda	.953	.859	5	87	.512
Hotelling's Trace	.049	.859	5	87	.512
Roy's Largest Root	.049	.859	5	87	.512
Education Level Covariate					
Pillais's Trace	.046	.843	5	87	.523
Wilks' Lambda	.954	.843	5	87	.523
Hotelling's Trace	.048	.843	5	87	.523
Roy's Largest Root	.048	.843	5	87	.523
Survivor Group Covariate					
Pillais's Trace	.055	1.012	5	87	.416
Wilks' Lambda	.945	1.012	5	87	.416
Hotelling's Trace	.058	1.012	5	87	.416
Roy's Largest Root	.058	1.012	5	87	.416

Table 4.38

*Leisure Community Type SOC and G-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.582	22.551	5	81	.000
Wilks' Lambda	.418	22.551	5	81	.000
Hotelling's Trace	1.392	22.551	5	81	.000
Roy's Largest Root	1.382	22.551	5	81	.000
Leisure SOC					
Pillais's Trace	.132	2.461	5	81	.040
Wilks' Lambda	.868	2.461	5	81	.040
Hotelling's Trace	.152	2.461	5	81	.040
Roy's Largest Root	.152	2.461	5	81	.040
Education Level Covariate					
Pillais's Trace	.056	.960	5	81	.447
Wilks' Lambda	.944	.960	5	81	.447
Hotelling's Trace	.059	.960	5	81	.447
Roy's Largest Root	.059	.960	5	81	.447
Survivor Group Covariate					
Pillais's Trace	.074	1.302	5	81	.271
Wilks' Lambda	.926	1.302	5	81	.271
Hotelling's Trace	.080	1.302	5	81	.271
Roy's Largest Root	.080	1.302	5	81	.271

Table 4.39

*Work Community Type SOC and G-QOL Domains Multivariate Test*

Effect	Value	F	Hyp. df	Error df	Sig.
Intercept					
Pillais's Trace	.575	21.096	5	78	.000
Wilks' Lambda	.425	21.096	5	78	.000
Hotelling's Trace	1.352	21.096	5	78	.000
Roy's Largest Root	1.352	21.096	5	78	.000
Social Support SOC					
Pillais's Trace	.128	2.288	5	78	.054
Wilks' Lambda	.872	2.288	5	78	.054
Hotelling's Trace	.147	2.288	5	78	.054
Roy's Largest Root	.147	2.288	5	78	.054
Education Level Covariate					
Pillais's Trace	.076	1.282	5	78	.280
Wilks' Lambda	.924	1.282	5	78	.280
Hotelling's Trace	.082	1.282	5	78	.280
Roy's Largest Root	.082	1.282	5	78	.280
Survivor Group Covariate					
Pillais's Trace	.099	1.709	5	78	.142
Wilks' Lambda	.901	1.709	5	78	.142
Hotelling's Trace	.110	1.709	5	78	.142
Roy's Largest Root	.110	1.709	5	78	.142

## **CHAPTER FIVE: DISCUSSION AND CONCLUSION**

Chapter five presents the discussion and concluding remarks regarding the findings from this study about the relationship between adult female cancer survivors' sense of community (SOC) and their health-related quality of life (HRQOL). This chapter begins with a brief summary of the research questions under investigation, then discusses the results of the study integrating them with extant research, and follow up with future avenues of research. The Chapter concludes with the implications, limitations and conclusions of the study.

The purpose of this study was to investigate the relationship that select multiple senses of community have with the health-related quality of life (HRQOL) of adult female cancer survivors. To address this purpose, this study explored adult female cancer survivors' sense of community (SOC) based on five mutually exclusive community types commonly investigated in the literature (Social Support, Neighborhood, Leisure, Faith, and Work-based community types), and how SOC with these community types relates to survivors' HRQOL. More specifically, this study addressed the following three research questions related to the relationship between SOC and HRQOL:

Question 1: What is the relationship between SOC and its domains and the HRQOL of women who are cancer survivors?

Question 2: How does the sense of community (Social Support, Neighborhood, Leisure, Faith, and Work-based community types) to which a female cancer survivor identifies relate to her HRQOL?

Question 3: How does a female cancer survivor's SOC differentially impact the various components of HRQOL?

### **Preliminary Findings**

Prior to addressing the research questions, it was necessary to first demonstrate that the properties of the instruments used to measure the constructs of this study (dimensions of SOC

and subscales and domains of HRQOL) could be replicated with this unique sample. To accomplish this, preliminary analyses were conducted on the two major instruments that were utilized in the study: The Brief Sense of Community Scale (BSCS) employed to measure SOC, and the Quality of life in Adult Cancer Survivors (QLACS) as an assessment of HRQOL.

**The Brief Sense of Community Scale (BSCS).** Prior to utilizing this measure of SOC, analyses examined whether or not the four-factor solution as outlined by McMillan and Chavis (1986), and represented in the BSCS as developed by Peterson et al. (2008), could be reproduced with members of the select sample of cancer survivors participating in this study. Initial analyses examined the factor structure of the BSCS in and across the five mutually exclusive community types (Social Support, Neighborhood, Leisure, Faith, and Work-based community types).

Overall, the findings from this study indicated that the items developed to measure SOC in the BSCS did not replicate the SOC domains as outlined by McMillan and Chavis (1986), that the proposed community types were exclusive and varied according to the community type, and that the BSCS could provide a foundation for developing a cancer survivor-specific SOC scale that could be consistent with the model outlined by McMillan and Chavis (1986).

Factor analytic efforts to assess the model structure of the SOC items indicated that the four-factor model as outlined by McMillan and Chavis (1986) was not obtained with the sample participants in the study. With only four of the five community types entered into the model for analysis (the Faith-based community type lacked a sufficiently large number of responses), the original four-factor solution was not obtained, as an aggregate or for each community type, but rather four unique uni-dimensional solutions for each of the respective community types obtained. These findings indicated that the specific domains of SOC across the four community

types did not reflect the four underlying theoretical dimensions as outlined by McMillan and Chavis.

The findings regarding the BSCS and its inability to accurately assess the SOC domains of interest across varied community types, and corroborated Chipuer and Pretty's (1999) findings suggesting that SOC instruments have difficulty validly assessing the rich nature of the SOC domains as originally outlined (Chipuer & Pretty, 1999; Long & Perkins, 2003; McMillan & Chavis, 1986; Peterson, et al., 2008). As the BSCS consists of two items for each of the four domains of the SOC theory and is apparent that this small number of items is insufficient to accurately assess these four complex underlying domains. While the ease and efficiency of the BSCS for survey research administration is undeniable, the findings from this study corroborated past research that current instruments developed to assess the underlying nature of SOC (as outlined by McMillan and Chavis) are inadequate. In addition, as a validated independent criterion measure of SOC to compare to the BSCS was unavailable (Peterson, et al.), whether or not the BSCS measures SOC could not be ascertained. Chipuer and Pretty (1999), Long and Perkins (2003), and Obst and White (2005) have recommended using instruments similar to that of the BSCS, including the Sense of Community Index (SCI; Perkins, et al., 1990), as a uni-dimensional assessment. These researchers posit that much of the failure to generate a valid multidimensional measure is attributable to measurement weakness and not to that of theoretical shortcomings (Peterson, et al., 2008; Proescholdbell, et al., 2006; Wombacher, et al., 2010). However, it is clear from this and previous research that an adequate comprehensive quantitative assessment of SOC has yet to be fully developed.

As outlined earlier, the BSCS was developed for use with adults in a setting without consideration of their current health status or past health-based experiences. Hence, an

instrument that is sensitive to the altered state of SOC for cancer survivors is needed. In addition, efforts to assess a cancer survivor's multiple senses of community should employ research using a multiple methods approach which could then yield insights for the further refinement of SOC theory and the development of instruments that are sensitive to those who experience life altering health-based diseases like cancer.

**The Quality of Life in Adult Cancer Survivors Scale (QLACS).** As previously mentioned, the QLACS was recently developed to assess the HRQOL of long-term cancer survivors from a diverse sample of respondents with various cancer types, socioeconomic backgrounds, and gender (Avis, et al., 2005). It is partitioned into two sub-scales – one relating to survivors' generic quality of life (G-QOL) with domains of Negative Feelings, Positive Feelings, Cognitive Problems, Sexual Problems, Physical Pain, Fatigue, and Social Avoidance; and one relating specifically to the cancer sequelae (C-QOL) with domains of Appearance Concerns, Financial Problems, Distress over Recurrence, Family-Related Distress, and Benefits of Cancer). Overall, findings from the data indicated that factor solutions were considered interpretable for each of the subscales' underlying domains, but with some exceptions for the G-QOL subscale. The items comprising the G-QOL subscale were found to load on only six factors instead of the seven originally proposed. In terms of the component loadings for the G-QOL subscale, seven of the 28 items loaded on factors other than those as originally obtained by Avis and colleagues (2005).

For the C-QOL subscale, the component structure was equivalent to that of Avis et al. (2005) with the 19 items that comprise the C-QOL subscale loading on the same five domains obtained by Avis et al. As the QLACS is a relatively new HRQOL instrument, this is one of the first studies to independently analyze and replicate its component structure. Overall, these

finding indicate that items on the QLACS provide a basis for further research measuring a cancer survivor's HRQOL. As this data set consisted of a sample that was highly educated, wealthy, White, and who self-selected to participate in a physically active cancer support group, these results need to be further tested with different samples. Overall, these findings suggest that items on the QLACS can be adapted to provide a place from which to start and examine survivor's HRQOL.

**Research Question One: Sense of Community and Health-Related Quality of Life.**

With this study unable to reconfirm the SOC measurement that was utilized either across or within community types, the first research question and associated hypotheses (H1a – H1e) were not possible to empirically test. H1a hypothesized that there would be a positive relationship between of SOC across community types and the HRQOL of cancer survivors. As a general SOC score across community types was found to be unattainable, this suggests that SOC might be unique to each community type in the study (Chipuer & Pretty, 1999; Perkins and Long, 2003; Peterson, et al., 2008). Anderson's (2009) assertion that the impact of an individual's SOC depends largely, not with one particular community type with which she may associate, but rather with the combined community types in which that individual may participate was supported by the results of this study (Broadsky & Marx, 2001; Dioginni & Lyons, 2010). However, this is a tentative conclusion given that a convincing argument could not be made that the instrument that was utilized did in fact measure SOC. Further research that employed a multiple methods approach may yield further insights into how the quality and quantity of the multiple senses of community that a cancer survivor experiences is related to their HRQOL are warranted.

The remaining hypotheses from the first research question were also not directly tenable because they related to (H1b – H1e) each of the four domains which were not obtained from the BSCS data with this sample. As posited earlier, the individual domains of SOC (i.e., Membership, Influence, Fulfillment of Needs, and Emotional Connection; as defined by McMillan and Chavis, 1986) are thick with rich description and detail. As the BSCS consists of only four domains, each assessed by only two items, the ability of the BSCS to capture this depth of description, especially considering the altered nature of cancer survivors' social relationship (Avis & Deimling, 2008, Bloom, 2002, 2008) is questionable. In addition, as this study's sample was derived from a non-random purposive sample, results should be considered with caution. It is highly possible that findings regarding the BSCS and the QLACS, and hypotheses about the interrelationships of their underlying dimensions, subscales, and domains, are due to the nature of biases among respondents including high levels of education, high socioeconomic standing, marital status, gender, and lack of diverse racial identity.

**Future Research.** Although research question one and its associated hypotheses were not directly addressed due to the failure to replicate the properties of the BSCS, this does not mean that the study of SOC is an unimportant area for continued investigation. As sense of community has been an active topic for research since it was first introduced by Sarason (1974), further investigation using this construct has been called for (cf., Puddifoot, 1995). Researcher(s) have proposed several unique variations on how to measure SOC for their particular studies with most being determined statistically through factor analysis but with little attention paid to the rationale behind initial item generation and inclusion (c.f., Proescholdbell, Rossa, & Nemeroff, 2006). McMillan and Chavis (1986) were the first to postulate a four-domain theory of SOC that was based on a review of the available SOC literature, group cohesion literature, and their own factor

analytic empirical work. In addition, other research methods, including extensive and probing qualitative inquiry, might be used to gain a better understanding of how multiple senses of community are experienced by cancer survivors wherever they are found along the cancer continuum.

### **Research Question Two: Community Types and Health-Related Quality of Life.**

Research Question Two represented an extension of the first research question between the specific community types (Social Support, Neighborhood, Leisure, Faith, and Work-based) and the HRQOL of female cancer survivors. Results from the analyses of Question Two found no significant relationships between these constructs. The lack of a relationship between any of the community type SOC and their HRQOL was somewhat surprising, given the extant literature. To date, much of the research on the perception of a sense of community's impact on the health and quality of life of individuals has generally focused on the built environment (McMillan & Chavis, 1986; Obst & Tham, 2009). For example, research on the connections between poor health and one's neighborhood environment has been suggested to heavily influence the quality of life of residents (Bowling, Barber, Morris & Ebrahim, 2006; Chaix, 2009). Focusing on the subjective perceptions of community, Bowling et al. found that one's perception of the neighborhood environment had a strong positive association with both their self-rated health and functioning. In addition, Poortinga, Dunstan and Fone (2007) obtained similar findings, reporting that insufficient access to community resources like health care, food and clean water, poor neighborhood quality, disorder in government and services, lack of social cohesion and overall neighborhood deprivation were associated with the poor health and quality of life. Overall, one's community from a place-based framework and sense of what it entails has been noted to impact health (Albrecht & Devlieger, 1999).

With much of the SOC studies focusing on the connection between geographic / neighborhood-based SOC, little research has investigated the relationship between interests or relationship based SOC and HRQOL. Of those that do exist, research has shown that a stronger positive relationship generally exists between respondents' interest-based SOC and their quality of life when compared with respondents' geographically based SOC (Obst & Tham, 2009; Obst & White, 2007). Obst, Zinkiewicz and Smith (2002) explored and contrasted respondents' perceptions of community with two types of community, interest and geographic community types. Results found distinct and greater perceptions of community with their leisure SOC when compared to that of their neighborhood SOC.

The literature has also shown a stronger relationship for that of Faith-based SOC when compared with that of respondent's neighborhood/geographic neighborhood. Obst and Tham (2009) compared the difference between churchgoers' SOC and their neighborhood SOC on their health and quality of life found that the church-based SOC had a statistically stronger positive influence on the QOL of respondents compared to that of respondents' Neighborhood based SOC. Work-based investigations have revealed similar findings as well (Hughey, Peterson, Lowe, & Oprescu, 2007; Klein & D'Aunno, 1986; Pretty & McCarthy, 1991;

Of particular note is the non-significant finding between respondent's Social Support-based SOC and that of HRQOL, especially considering the extent literature on social support theory, research and practice (c.f., Glanz, Rimer, & Lewis, 2002). The influence that social relationships, especially those developed through a negative life event such as cancer, has received great interest among health educators, researchers, and practitioners. Although not explicitly the purpose of this dissertation, according to House (1981), social support theory and research investigates the functional aspect of social relationships which can be broken down into

four broad based behaviors: emotional support, instrumental support, informational support, and appraisal support. Berkman and Glass (2000) posit that supportive communities like the Beat Cancer Boot Camp help to provide the basic needs of people through companionship (emotional support), intimacy (instrumental support), a sense of belonging (appraisal support), providing information about cancer (informational support) and reassurance of one's worth (appraisal support). These supportive relationships are then thought to further enhance individual's well-being and health (Avis, et al., 2005). In addition, it has been well established that the perception of support one receives is strongly linked to individual's health and well-being (Wethington & Kessler, 1986). As Social Support SOC attempted to tap into the perceptual aspects of this community type and its influence on respondents HRQOL, the non-significant finding suggest that further research into this community type SOC from a cancer survivor's perspective is necessary. In addition, future research investigating cancer survivors Social Support SOC should reference social support theory and concepts to gain a better understanding of how this community types SOC influences their HRQOL.

**Future Research.** To further assess the relationship between a Leisure-based sense of community and the HRQOL of cancer survivors, research employing multiple methods may prove to be productive. If a sense of community is indeed comprised of the four specific domains as originally promulgated that are full of rich description and detail, it would be valuable to further investigate the ways in which each of these domains contribute to a sense of community for survivors of cancer. In addition, as this and other research has shown that survivors of cancer experience a sense of community across different community types in potentially different and unique ways, further investigation into the varied nature of the sense of community across

community types is strongly warranted and best accomplished using multiple methods, including qualitative-based research strategies.

**Research Question Three: Sense of Community and the Domains with Health-Related Quality of Life.** The findings revealed that, after controlling for educational attainment and time since diagnosis (survivorship), the Leisure and Work-based SOC were significantly related to the HRQOL subscale G-QOL's domains of interest. With regard to the Leisure-based SOC, analysis further revealed that Leisure SOC was related to greater levels of Positive Feelings, and lower levels of Energy Fatigue and Social Avoidance. Bishop and Hodgett (1986) posited that involvement and investing of one's self into a given community based on leisure interests plays a large part in developing the emotional connections between members that buoy them up through difficult times. Mullen (1985) also posited that many cancer survivors, during treatment and throughout the cancer continuum, commonly experience less personal involvement in the various social relationships and with their individual community-based groups than they may have associated with previous to being diagnosed with cancer. In their investigation into communities based on recreational interest, Bishop and Hoggett also noted that leisure based communities provide the opportunity to formulate community and influence QOL in four ways: (1) as a vehicle through which social exchange can take place; (2) through opportunities to create a commonly held product (i.e., friendship); (3) via opportunities for making friends and meet people; and (4) through opportunities of mutual aid. As this study found a significant relationship between survivors' G-QOL domains and their Leisure-based SOC, it would suggest that respondents felt they were more a part of this community type (i.e., Membership), felt that they had a greater ability to influence and be influenced (i.e., Influence), had a greater sense of reinforcement (i.e., Fulfillment of Needs), and had a greater shared history and/or relationship

(Shared Emotional Connection) with this type of community. This then would lead to greater opportunities for social exchange to take place, for opportunities for developing and maintaining friendships and to provide aid when needed. However, as preliminary findings did not confirm the four-factor model, the above interpretation can only be regarded as speculative.

Other leisure researchers using primarily qualitative methods of inquiry have also found similar findings between cancer support communities that are leisure-based and relationships with HRQOL. Investigating Gilda's Club in Toronto, Glover and Parry (2008) found that organizations like this offered therapeutic benefits and opportunities for survivors of cancer to meet and support one another in a non-clinical, social environment. Gilda's Club provides members and participants of the Club with what Bishop and Hodgett have termed as "mutual aid." Mutual aid is a concept wherein individuals are able to assist one another in a reciprocal exchange of resources (including friendship) and other services for the benefit of each other and/or the larger group. Glover and Parry further argued that friendships based on mutual aid and that are created through a common leisure-based interest help to counteract the effects of social isolationism. Son, Yarnal, and Kerstetter (2010) obtained similar findings in their research on older women's participation in the Red Hat Society® (RHS). Results from their study suggested that participation in an interest-based community such as RHS contributed significantly to members' health and well-being. Son et al. further argued that these benefits were accomplished by "creating bonding opportunities with other women, giving and receiving social support, providing a [sense of community], and facilitating opportunities for linking into the larger communities in which they lived" (p.80). In essence, communities that are based on recreational interest ("Leisure-based") do more than provide participants with an opportunity to fill discretionary time.

Research has shown that depressive symptoms among the medically ill are highly prevalent especially during the initial phase of diagnosis and treatment, with recent investigations finding longer-lasting implications (Bloom, 2002, 2008; Katon & Sullivan, 1990). Schrover, Sanderman, van Sonderen and Ranchor (2000) acknowledged that “the recognition and treatment of depressive symptoms in cancer patients is crucial, because depressive symptoms may adversely affect survival, the length of stay, compliance with treatment, the ability to care for oneself, and quality of life” (p.1015). Depressive symptoms can impact the outcomes of treatments (Schnur, David, Kangas, Green, Bovbjerg, & Montgomery, 2009) future quality of life (Stone, Murphy, Matar & Almerie, 2008), activities of daily living (Kurland, Gill, Patrick, Larson & Phelan, 2006) and positive and affect states (Kelsey, DeVellis, Begum, Belton, Hooten, & Campbell, 2006). The benefits of reducing the impact of depressive symptoms that a cancer diagnosis and the associated treatment produce have been well established (Schroevers, et al., 2001; Stone, Murphy, Matar & Almerie, 2008). Planning and offering assistance for “psychological morbidity, distress and adverse quality of life for patients [is as crucial] throughout the disease course” as the biological treatments (Kang, Chung, Kim, Choi, Ahn, Jeung, and Namkoong, 2008).

Although a significant relationship between Leisure SOC and Negative Feelings was not found, the relationship between leisure’s impact on positive and negative affect has been researched in the leisure and the stress-coping literature (Glover & Parry, 2008; Kleiber, Hutchinson, & Williams, 2002). Leisure has traditionally been viewed as a buffer between negative life events and one’s health and psychological well-being (Iwasaki, & Smale, 1998). Kleiber, Hutchinson, and Williams suggest leisure as a resource in transcending negative life events and proposed four methods whereby this may be accomplished. First, leisure activities

may buffer the impact of negative life event through a process of distractions. Second, this process of distraction provided an opportunity for generating optimism. Leisure activities may also provide the opportunity and space necessary for hope and optimism to grow. Third, the pursuit of outside activities may also help with the reconstruction of a life story that is continuous with the past. Fourth, leisure activities can be used as vehicles for personal transformation.

Parry's (2008) qualitative based inquiry into Dragon Boat Racing (DBR) found that the participants described DBR as contributing to their social, emotional, physical, spiritual, and mental health. DBR, is an intense physically active team paddling sport competition for cancer survivors with teams of 22 individuals who paddled a dragon boat watercraft through a designated open-water course. Through the demands of long training sessions and racing events, DBR has been shown to impact these women's health, fitness and HRQOL. Through direct contact with other individual DBR participants who had cancer, physicians interviewed from Parry's research noted that DBR provided them with access to solidarity and provided positive emotional benefits that have been shown to improve treatment outcomes and HRQOL, fulfilling all of Kleiber and colleagues' (2002) four ways in which participation in leisure based activities enable individuals to transcend negative life events like cancer. In terms of less physically active activities, Reynolds and Prior (2006, 2008) found that engaging in visual art-making in the everyday life of cancer patients helped to support, maintain and reconstruct their personal identities. They further suggested that leisure activities can be a powerful way to help maintain a familiar, positive identity throughout the cancer experience, and provide a resource for coping.

In regards to the results for respondent's Work-based SOC, as most participants reported working at least part-time with more than half of those numbers employed full-time, results

found that their Work-based SOC was significantly related to their Positive Feelings. Montazeri (2008), in his meta-analysis of the QOL literature, found that a diagnosis of cancer, especially for women who experienced mastectomy due to breast cancer, heavily impacted their identity and life role. As cancer is not just a single event, but rather considered by many to be an enduring chronic condition characterized by ongoing uncertainty, cancer survivors have been shown to experience altered social roles and identities (e.g., partner, wife, mother, sister, employee(r), religious figure, student, etc.), ultimately impacting their HRQOL (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Zebrack, 2000).

Based on the findings from this research, the varied nature of multiple senses of community need to be considered when assessing the relationship between a cancer survivor's SOC and HRQOL as not each community type SOC may influence their HRQOL in the same manner or to the same extent, especially on the HRQOL subscale domain level. These results add to the HRQOL literature that when investigating the relationship between this construct and various psychosocial contexts, the multiple and varied nature of the communal SOC context as perceived by the individual needs to be strongly considered.

**Future Research.** Future research between domain level HRQOL will therefore need to take into account not only how a SOC may influence the HRQOL of cancer survivors, but also the underlying domains that comprise each construct. As these findings suggest, more than one community type was related to the domains of Positive and Negative Feelings domains. Further investigation to understand how multiple senses of community are related to the positive and negative affect of cancer survivors is clearly warranted.

## **Additional Findings**

Although used as covariates for the analysis of this study, education and survivor group continually demonstrated a significant relationship with the HRQOL subscales and domains. Of particular note was the inverted U-shaped relationship between education and HRQOL outcome measures. In essence, those respondents who were least educated (less than a bachelors degree) and those who were highly educated (masters level graduate degree or greater) had lower HRQOL than those who had only a bachelor's degree. These findings support past research indicating that higher levels of education are related to greater levels of HRQOL (c.f. Ashing-Giwa, & Lim, 2009). However, the finding that those with the greatest levels of education were related to lower HRQOL is unique to this study. Caution should be taken when interpreting these findings given that research has found that individuals who belong to a cancer survivor group have been shown to differ from the population of cancer survivors as a whole (Avis et al., 2005). In their review of the cancer support literature from 1980 forward, Grande, Myers, and Sutton (2006) found that cancer support group participants were predominantly female, younger, and enjoyed a greater socioeconomical status compared to nonparticipants. Future research should therefore further investigate those who do not belong to a cancer support group, are less educated, and represent a diversity of socioeconomically groups. In addition, future research should include different cancer types as specific cancer types may have different SOC and HRQOL outcomes.

## **Implications**

This study contends put forth the contention that multiple senses of community (SOC) will influence the health-related quality of life (HRQOL) of cancer survivors. As the concept of

SOC has received little attention from health and quality of life scholars, this relationship has not yet been empirically investigated in detail. In general, the results of this study suggested that a cancer survivor's multiple SOC might be related to her HRQOL. Also, it was found that individual community types are differentially related to the specific domains of HRQOL. Thus, this study provided a basis for the further empirical study of the relationship between SOC and HRQOL. Further, it provided new ways of thinking about SOC and about how it can be applied to those who experience life-changing health events, such as cancer. Moreover, the study contributed to the advancement of knowledge regarding SOC by demonstrating some unique findings that question the existing literature surrounding the theory and measurement of SOC.

The importance of examining the multiple senses of community that a cancer survivor's repertoire of community types holds needs to be re-emphasized. This study is unique in independently examining the validity and component structure of the Brief Sense of Community Scale (BSCS). As a four-component solution for the BSCS was unable to be replicated as originally outlined by McMillan and Chavis (1986), this study suggests that the BSCS can only be used as a uni-dimensional tool when measuring multiple SOCs, at least with populations of this type. Further, future studies should employ multiple methods of data collection, including an emphasis on qualitative methods, to better inform the researcher regarding how survivors perceive SOC is related to their HRQOL. As past qualitative research has found relationships between an individual's SOC and other health-related constructs including depression, this method in particular may impart further insights into the relationship between SOC and HRQOL than when quantitative measures are utilized alone.

This study also found that the Leisure and Work based SOC was significantly related to the generic quality of life (G-QOL) of the female cancer survivors. This suggests that for these

respondents, the SOC from communities of interest, like those found in and through leisure and work, provides survivors with a potential barrier from their negative life experiences and also provide an avenue for the development and maintenance of mutual aid and their HRQOL. For these cancer survivors, this suggests that practitioners, physicians, and policy makers should encourage cancer survivors to be involved with leisure and work based communities of interest. Further investigations into specific communities of interest like those associated with leisure are needed.

As this study emphasized the importance of multiple senses of community for the health-related quality of life for adult female cancer survivors, the implications focus primarily on the ways to increase their HRQOL through SOC. Improvements in these cancer survivors' HRQOL can be achieved by the cooperative efforts of survivors' leisure, work and neighborhood-based community types.

### **Limitations**

The general purpose of this study was to investigate the relationship between the multiple senses of community and the HRQOL of cancer survivors. As just reviewed, probable relationships between Neighborhood, Leisure, and Work-based community types and certain aspects of HRQOL were shown. However, these relationships are in need of further replication. As this study was able to find possible relationships between survivors' multiple senses of community and their HRQOL subscale and HRQOL domains, it contributed to the knowledge and advancement of both SOC and HRQOL literatures. However, this study also had several limitations.

First, this study only surveyed participants of a physically active cancer support program from a single geographical location in the Southwestern United States. As research has found,

cancer support group participants are different from those who do not participate in cancer support groups, random sampling and diversification is required for future studies that investigate the relationship between SOC and HRQOL. In addition, as this sample was a purposive sample, findings from this research are not generalizable to other cancer support groups or to other adult female cancer survivors. By including a more diverse and random sample of cancer survivors who are not involved with a cancer support program, further investigation of the interrelationships and assessments of SOC and HRQOL, across and with community types, would be greatly improved.

Second, following recommendations from the SOC literature, this study only investigated the positive aspects of survivors' SOC. As not all communities provide a positive experience, the negative aspects of community on a cancer survivor's HRQOL also needs to be considered as research has shown that not all community types provide positive experiences (Bloom, 2002, 2008). Thus, for future studies and to better understand the relationship between survivors' multiple senses of community and their HRQOL, it would be informative to investigate the negative aspects that certain communities may exert on the HRQOL of cancer survivors.

Third, this investigation used a self-report online survey to collect data from respondents who participated in the Beat Cancer Boot Camp. This method was initially selected as it has been suggested to provide lower data gathering cost, potentially access to a larger sampling frame, reduce researcher bias as the survey is taken at the respondent's leisure and, potentially, a reduction in issues with data entry common with paper and pencil methods (Babbie, 2008). In addition, all communication with the BCBC membership in regards to this study were through online means including the BCBC website, online blogs, and newsletters. Although many efforts were made to achieve a high response rate through various online advertisement and incentives,

this study was unable to achieve a relatively large number of respondents given the estimated number of individuals on the Beat Cancer Boot Camp communication and membership roles. Only online methods were used to make the BCBC membership aware of the survey and this was likely the contributing reason behind the low response rate for this study. In addition, it was also thought that the timing of the survey (late October – mid November) and the researcher's lack of a direct relationship with BCBC members as a further explanation for the lack of response. Given these identified issues associated with the poor response rate for this study, future studies of survivors multiple senses of community should provide multiple options for the promotion of the study and collection of data, including mail-drop, in-person interviews, and alternative online methods.

Fourth, issues with the data regarding violations of assumptions required for some statistical tests need to be mentioned. Although significant steps were taken to correct for violations of normality, multicollinearity, homogeneity of variance, and others, not all of these issues were completely resolvable given conventional methods. Therefore, future studies with a larger, more diverse, and randomly chosen sample may produce data that do not violate the underlying assumptions of statistical tests.

Lastly, this study's quantitative approach must be regarded as a limitation. As many cancer survivors' social relations suffer greatly due to this disease and its associated sequelae, further inquiry using qualitative data collection methods and analysis may yield insights that are not possible with the use of a quantitative approach. Also, as the underlying domain structure of SOC has been suggested to be comprised of rich description and detail, a qualitative approach should allow for introspection that a quantitative method could only approach limitedly. Therefore, for future research, it is suggested that a qualitative study be conducted that allows for

survivors of cancer to express their understanding of a sense of community given their experience with cancer. Once completed, it may be possible to further understand the relationship between cancer survivors' SOC and HRQOL, and isolate or contextualize the most relevant variables as theory and further research progress.

## **Conclusions**

In conclusion, the importance of the overarching question regarding the relationship between cancer survivors' SOC and HRQOL is still important. As SOC and its underlying domain structure are highly subjective with multiple and diverse meanings depending on the community type under study, future research with a SOC instrument that is more germane and specific to cancer survivors may yield further insights. Thus, the general inability to draw empirical findings from this study strongly necessitates that further research into the relationship between SOC and HRQOL using multiple methods including qualitative data gathering techniques. Further use of multiple methods for collecting data will also allow for understanding of SOC from the voices of those who have been diagnosed with cancer. This study should be regarded as providing the grounds for investigating and understanding the relationship between individuals' multiple senses of community and their HRQOL and provide future directions for investigating this relationship in the leisure field.

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## APPENDIX A: INITIAL CONTACT E-MAIL

UNIVERSITY OF ILLINOIS  
Department of Recreation, Sport and Tourism

Long-Term Survivor Survey

Dear Long-Term Survivor,

We would like to invite you to participate in a study questionnaire that investigates the relationship between the social groups/communities that you may belong to and your health and quality of life as a long-term cancer survivor. This questionnaire will take you approximately 20 minutes to complete and asks you about five groups that you may belong to, your perceptions about those groups, and your current health and quality of life as you perceive it.

There are a three potential ways in which you may benefit from participation in this research project. First, participants often enjoy sharing their experiences and benefit from reflecting on their experience as long-term cancer survivors. Second, once you complete this survey, you will have the option to provide your name and e-mail address to receive a summary of results. Third, upon completion of the survey, you will be given a list of links to several online resources for long-term cancer survivors.

In addition, upon successful completion of the questionnaire, you will be eligible to enter into a drawing to win a one of several prizes including: one of twenty five \$25.00 Amazon gift card (odds of winning are 1 in 12), one of five Anita “Sarge” Kellman’s new book, “It’s a Beautiful Day for Boot Camp (odds of winning are 1 in 60), and one of five Beat Cancer Boot Camp class sessions (odds of winning are 1 in 60).

Your participation in this study is completely voluntary and you have the right to withdraw at any point. There are no right or wrong answers to this survey and only your personal opinions will be considered. You will remain completely anonymous as your answers will be kept strictly confidential and will be used only as combined in a group format – there will be no way in which you could be individually identified. Identifying information is removed at time of completion of the questionnaire.

It should only take you about 20 – 30 minutes to complete the online survey. Please carefully read the directions at the beginning of each part, and answer all of the questions as accurately as possible. Your prompt response and completion of the survey are important and will be greatly appreciated.

Thank you so much for agreeing to spend a few minutes on this survey to learn more about how to help cancer survivors. Please feel free to contact either of us if you have any questions. This project has been approved by the University Institutional Review Board and you may contact them at (217) 333-2670 or by e-mail ([irb@illinois.edu](mailto:irb@illinois.edu)) as well.

Project Investigator: Lynn Barnett-Morris PhD, Associate Professor

Phone: (217) 333-4410  
e-mail: [lynnbm@illinois.edu](mailto:lynnbm@illinois.edu)

Investigator: Jesse J Jones, M.S., PhD Candidate  
Phone: 217-244-1528  
e-mail: [jjjones4@illinois.edu](mailto:jjjones4@illinois.edu)

If you would like to participate, please click on the link below.

“CLICK THIS LINK”

## **APPENDIX B: PARTICIPANT CONSENT FORM**

### **The Long-Term Survivor's Project Participant Consent Form**

#### **Who is conducting this research study?**

Jesse J Jones, a doctoral candidate in the Department of Recreation, Sport and Tourism at the University of Illinois at Urbana-Champaign is conducting this research project under the direction of Dr. Lynn Barnett-Morris. This project is part of Jesse's dissertation research.

#### **What is the purpose of this study?**

The purpose of this study is to gain further insight into the relationships between the social groups/communities of women who are long-term breast cancer survivors and their health and quality of life. We hope to learn more about how a survivor's social network (if any) may aid their health and quality of life.

#### **What will I experience as a research participant?**

You will be asked to fill out a survey that asks you to identify several different social groups/communities that you may be participating in currently. We are also interested in knowing about individuals who may not be currently participating in any groups or communities. Your responses to the survey will be collected through an established online survey company (SurveyMonkey.com ®) and should take approximately 20 – 30 minutes to complete.

In addition, participants often enjoy sharing their experiences and benefit from reflecting on their experience as long-term cancer survivors. You also may experience personal satisfaction from knowing that your responses represent thousands of other long-term survivors and that future researchers, educators and especially other women who are breast cancer survivors, at any stage of the cancer survivor continuum, may gain insight from your experiences.

#### **What will happen to the surveys?**

The surveys will be downloaded onto a University of Illinois at Urbana-Champaign computer system with all identifying information removed from the surveys to maintain anonymity. The surveys will be archived on a secure computer server along with all other information from this project. All information you provide will be kept private and confidential. Only statistical information, with identifying information completely removed, will be shared with others on the research team.

#### **How will this information be used?**

After the completion of this study, the information will be summarized and the knowledge we gain from this research will allow us to offer recommendations to enhance, support and inform current policies, research, and educational practices regarding the relationship between the social groups/communities of survivors and their health and quality of life. In addition, project reports and presentations will benefit from this research and will not include any identifying information.

#### **Are there any risks involved in participating in this project?**

Participation in this study involves minimal risks comparable to those you experience in your everyday life. There are no known physical or emotional risks involved in this study. At the conclusion of your participation in this survey, several links to resources will be made available to you. Your choice to participate or refrain from participation is entirely up to you. No one, except for the researchers, will have access to your individual responses, nor will anyone have information that can identify you as all identifying information is separated from responses. Your participation is completely voluntary and you may terminate your participation at any time without consequences.

**CONTACT INFORMATION:** If at any time you have questions about The Survivors Project, please feel free to contact Mr. Jesse Jones at [jjjones4@illinois.edu](mailto:jjjones4@illinois.edu) or by phone at 217-244-1528 or Dr. Lynn Barnett-Morris, Jesse’s adviser, at [lynnbm@illinois.edu](mailto:lynnbm@illinois.edu) or by phone at 217-333-4410. You can also contact the Institutional Review Board at the University of Illinois at Urbana-Champaign by e-mail at [irb@illinois.edu](mailto:irb@illinois.edu) or by phone at (217) 333-2670; identify yourself as a participant in The Survivor Project. If you live outside the study area, you may call collect.

(print)

I, (name): \_\_\_\_\_, hereby agree to my participation and as a volunteer in a research study under the supervision of Dr. Lynn Barnett-Morris at the University of Illinois.

I am 18 years of age or older and of legal age to provide informed consent for research.

                      
(Please initial)

This investigation and my part in it has been defined and fully explained to me by Mr. Jesse J. Jones. I fully understand this explanation. I have also been given the opportunity to ask questions and these have been answered to my satisfaction. I have been given a copy of this consent form for my records.

I have read the content of this form and understand that (a) I am under no obligation to participate in the study; (b) all information gathered about me will remain confidential with respect to my identity and will be used for research purposes only and that my identity will remain anonymous. I understand that I am free to withdraw consent and terminate my participation at any time. To agree to the above and wish to continue onto the survey, please click the “I agree” button provided below. If you do not agree and do not wish to participate, please click the “I do not agree” button and you will be directed away from the survey.

“I agree”

“I do not agree”

## **APPENDIX C: QUESTIONNAIRE FOR SURVEY PARTICIPANTS**

Survivorship, Community, Health and Quality of Life: A Questionnaire

Conducted by

Jesse J Jones  
PhD Candidate  
The University of Illinois at Urbana-Champaign  
Department of Recreation, Sport and Tourism  
Leisure, Health and Wellness Lab

## YOUR NEIGHBORHOOD COMMUNITY

The following are some questions about the NEIGHBORHOOD where you live. As you read the following set of statements, please reflect on your home neighborhood as you answer these questions.

Please select the most applicable response about your home neighborhood community.

	Strongly Disagree			Neutral			Strongly Agree
Q1. My neighborhood helps me fulfill my needs	1	2	3	4	5	6	7
Q2. I feel like a member of my neighborhood	1	2	3	4	5	6	7
Q3. I have a good bond with others in my neighborhood	1	2	3	4	5	6	7
Q4. I have a say about what goes on in my neighborhood	1	2	3	4	5	6	7
Q5. I belong in my neighborhood	1	2	3	4	5	6	7
Q6. I can get what I need in my neighborhood	1	2	3	4	5	6	7
Q7. People in my neighborhood are good at influencing each other	1	2	3	4	5	6	7
Q8. I feel connected to my neighborhood	1	2	3	4	5	6	7

## YOUR PERSONAL INTEREST GROUP

The following are some questions about a group in which you may have a personal interest (for example, a book club, morning walking group, etc). Participation in this group is usually done during your free time and any number of other people may be interested. If you have several to which you belong, please select the one that you feel closest to. Please tell us what type of group you are involved in:

\_\_\_\_\_.

If you do not belong to a personal interest group please check the box

Then go to the next page.

As you read the statements below, please respond to them in relation to the group you just named.

Please reply by selecting the most applicable response about this group.

	Strongly Disagree			Neutral				Strongly Agree
Q1. I feel like a member of this group.	1	2	3	4	5	6	7	
Q2. People in this group are good at influencing each other.	1	2	3	4	5	6	7	
Q3. I have a say about what goes on in this group.	1	2	3	4	5	6	7	
Q4. I belong in this group.	1	2	3	4	5	6	7	
Q5. I can get what I need in this group.	1	2	3	4	5	6	7	
Q6. I have a good bond with others in this group.	1	2	3	4	5	6	7	
Q7. I feel connected to this group.	1	2	3	4	5	6	7	
Q8. This group helps me fulfill my needs.	1	2	3	4	5	6	7	

## YOUR SPIRITUAL OR FAITH-BASED GROUP

The following are some questions about a SPIRITUAL or FAITH-BASED GROUP to which you may belong. If you belong to multiple spiritual or faith-based groups, please select the one that you feel closest to.

As you read over these statements, please reflect on this SPIRITUAL or FAITH-BASED GROUP as you answer these questions.

Please reply to the following statements by selecting the most applicable response about your spiritual or faith-based group.

If you do not belong to a spiritual or faith-based community please check this box:

Then go to the next page.

	Strongly Disagree		Neutral				Strongly Agree
Q1. I have a say about what goes on in this group.	1	2	3	4	5	6	7
Q2. I belong in this group.	1	2	3	4	5	6	7
Q3. I can get what I need in this group.	1	2	3	4	5	6	7
Q4. People in this group are good at influencing each other.	1	2	3	4	5	6	7
Q5. I feel connected to this group.	1	2	3	4	5	6	7
Q6. This group helps me fulfill my needs.	1	2	3	4	5	6	7
Q7. I feel like a member of this group.	1	2	3	4	5	6	7
Q8. I have a good bond with others in this group.	1	2	3	4	5	6	7

## YOUR SOCIAL SUPPORT GROUP

The following are some statements about a SOCIAL SUPPORT group to which you may belong. If you have multiple social support groups, please select one that you feel the closest to.

As you proceed over the next set of statements, please reflect on this SOCIAL SUPPORT group as you respond to these statements.

If you would like to share with us your social support community name or type please feel free to do so:

Social Support Community Name: \_\_\_\_\_

If you do not belong to a SOCIAL SUPPORT group please check this box:

Then go to the next page.

Please reply to the following statements by selecting the most applicable response about your social support group.

	Strongly Disagree		Neutral			Strongly Agree	
	1	2	3	4	5	6	7
Q1. I have a good bond with others in this group.	1	2	3	4	5	6	7
Q2. I can get what I need in this group.	1	2	3	4	5	6	7
Q3. I belong in this group.	1	2	3	4	5	6	7
Q4. People in this group are good at influencing each other.	1	2	3	4	5	6	7
Q5. This group helps me fulfill my needs.	1	2	3	4	5	6	7
Q6. I have a say about what goes on in this group.	1	2	3	4	5	6	7
Q7. I feel connected to this group.	1	2	3	4	5	6	7
Q8. I feel like a member of this group.	1	2	3	4	5	6	7

**YOUR WORK OR VOLUNTEER-BASED GROUP.**

The following are some questions about a **WORK OR VOLUNTEER-BASED** group that you may belong to (for example: employment, self-employment, PTA, Relay for Life, or other volunteer organizations). Some individuals belong to several of these groups than the ones we have asked you about. Please select the one you are feeling the closest to.

If you would like to share with us your social support community name or type please feel free to do so:

Work or Volunteer-Based group Name: \_\_\_\_\_

If you do not belong to a **WORK OR VOLUNTEER** group please check this box:

Then go to the next page.

Please reply to the following statements by selecting the most applicable response about your social support group.

	Strongly Disagree				Neutral				Strongly Agree
Q1. I feel like a member of this group.	1	2	3	4	5	6	7		
Q2. I have a good bond with others in this group.	1	2	3	4	5	6	7		
Q3. I have a say about what goes on in this group.	1	2	3	4	5	6	7		
Q4. This group helps me fulfill my needs.	1	2	3	4	5	6	7		
Q5. I can get what I need in this group.	1	2	3	4	5	6	7		
Q6. People in this group are good at influencing each other.	1	2	3	4	5	6	7		
Q7. I feel connected to this group.	1	2	3	4	5	6	7		
Q6. I belong in this group.	1	2	3	4	5	6	7		

### About Your Health and Quality of Life.

We'd like to ask you about some things that can affect the health and quality of people's lives. Some of these statements may sound similar, but please be sure to answer each one. Answer each one using the scale below that ranges from "never" to "always". Please indicate how often each of these statements has been true for you in the past four weeks.

*1 = Never 2 = Seldom 3 = Sometimes 4 = About as Often as Not  
5 = Frequently 6 = Very Often 7 = Always*

#### In the past 4 weeks ...

	Never		As often As Not			Always	
	1	2	3	4	5	6	7
1. You had the energy to do the things you wanted to do.	1	2	3	4	5	6	7
2. You had difficulty doing activities that require concentrating.	1	2	3	4	5	6	7
3. You were bothered by having a short attention span.	1	2	3	4	5	6	7
4. You had trouble remembering things.	1	2	3	4	5	6	7
5. You felt fatigued.	1	2	3	4	5	6	7
6. You felt happy.	1	2	3	4	5	6	7
7. You felt blue or depressed.	1	2	3	4	5	6	7
8. You enjoyed life.	1	2	3	4	5	6	7
9. You worried about little things.	1	2	3	4	5	6	7
10. You were bothered by being unable to function sexually.	1	2	3	4	5	6	7
11. You didn't have energy to do the things you wanted to do.	1	2	3	4	5	6	7
12. You were dissatisfied with your sex life.	1	2	3	4	5	6	7
13. You were bothered by pain that kept you from doing the things you wanted to do.	1	2	3	4	5	6	7

*1 = Never 2 = Seldom 3 = Sometimes 4 = About as Often as Not  
5 = Frequently 6 = Very Often 7 = Always*

<b>In the past 4 weeks ...</b>	Never		As often As Not			Always	
14. You felt tired a lot.	1	2	3	4	5	6	7
15. You were reluctant to start new relationships.	1	2	3	4	5	6	7
16. You lacked interest in sex.	1	2	3	4	5	6	7
17. Your mood was disrupted by pain or its treatment.	1	2	3	4	5	6	7
18. You avoided social gatherings.	1	2	3	4	5	6	7
19. You were bothered by mood swings.	1	2	3	4	5	6	7
20. You avoided your friends.	1	2	3	4	5	6	7
21. You had aches or pains.	1	2	3	4	5	6	7
22. You had a positive outlook on life.	1	2	3	4	5	6	7
23. You were bothered by forgetting what you started to do.	1	2	3	4	5	6	7
24. You felt anxious.	1	2	3	4	5	6	7
25. You were reluctant to meet new people.	1	2	3	4	5	6	7
26. You avoided sexual activity.	1	2	3	4	5	6	7
27. Pain or its treatment interfered with your social activities.	1	2	3	4	5	6	7
28. You were content with your life.	1	2	3	4	5	6	7

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

*1 = Never 2 = Seldom 3 = Sometimes 4 = About as Often as Not  
5 = Frequently 6 = Very Often 7 = Always*

<b>In the past 4 weeks ...</b>	Never		As often as not			Always	
29. You appreciated life more because of having had cancer.	1	2	3	4	5	6	7
30. You had financial problems because of the cost of cancer surgery or treatment.	1	2	3	4	5	6	7
31. You worried that your family members were at risk of getting cancer.	1	2	3	4	5	6	7
32. You realized that having had cancer helps you cope better with problems now.	1	2	3	4	5	6	7
33. You were self-conscious about the way you look because of your cancer or its treatment.	1	2	3	4	5	6	7
34. You worried about whether your family members might have cancer-causing genes.	1	2	3	4	5	6	7
35. You felt unattractive because of your cancer or its treatment.	1	2	3	4	5	6	7
36. You worried about dying from cancer.	1	2	3	4	5	6	7
37. You had problems with insurance because of cancer.	1	2	3	4	5	6	7
38. You were bothered by hair loss from cancer treatment.	1	2	3	4	5	6	7
39. You worried about cancer coming back.	1	2	3	4	5	6	7

*1 = Never 2 = Seldom 3 = Sometimes 4 = About as Often as Not  
5 = Frequently 6 = Very Often 7 = Always*

**In the past 4 weeks ...**

	Never		As often As Not			Always	
40. You felt that cancer helped you to recognize what is important in life.	1	2	3	4	5	6	7
41. You felt better able to deal with stress because of having had cancer.	1	2	3	4	5	6	7
42. You worried about whether your family members should have genetic tests for cancer.	1	2	3	4	5	6	7
43. You had money problems that arose because you had cancer.	1	2	3	4	5	6	7
44. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	1	2	3	4	5	6	7
45. You had financial problems due to a loss of income as a result of cancer.	1	2	3	4	5	6	7
46. Whenever you felt a pain, you worried that it might be cancer again.	1	2	3	4	5	6	7
47. You were preoccupied with concerns about cancer.	1	2	3	4	5	6	7

### A Few Questions about You

How older are you? \_\_\_\_\_ years old.

What is your current marital status?

- Single (never married)
- Married
- Partnered or significant other
- Separated
- Divorced
- Widowed
- Other: \_\_\_\_\_.

Please indicate the highest level of education you have completed:

- Less than high school degree
- High school diploma or GED
- Some college
- Associated degree
- Bachelors degree
- Master degree
- Doctorate, medical, or legal, degree
- Other: \_\_\_\_\_.

What is your gross annual household income (before taxes)?  
(select one):

- Under \$10,000
- \$10,000 to \$29,999
- \$30,000 to \$59,999
- \$60,000 to \$99,999
- \$100,000 to \$249,999
- \$250,000 and above

Please indicate the number of hours you work on average per week (whether for gainful employment or voluntary in nature): \_\_\_\_\_ hours/wk

Many cancer survivors experience various types of family and community support that have affected them. Please tell us a little bit about how any current groups or communities that you belong to might influence (for better or worse) your health and quality of life as a long-term breast cancer survivor.

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Thank you for taking time to participate in this study!

Please click on the “next” button below if you would like to receive a summary of results and to be included in a raffle. The information you enter will be stored separately from your responses to the survey, thus preserving your anonymity.

“Next”

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Please provide your name and e-mail address that will be used to send the summary of results and to enter you into the drawing for an Apple iPad.

Your Name: \_\_\_\_\_.

Your Email: \_\_\_\_\_.