LONGITUDINAL CHANGES IN QUALITY OF LIFE AND DISTRESS AMONG CANCER SURVIVORS ENROLLED IN A COMMUNITY SURVIVORSHIP PROGRAM

APPROVED BY SUPERVISORY COMMITTEE

Heidi Hamann, Ph.D.

Bijal Balasubramanian, MBBS, Ph.D.

Michael Businelle, Ph.D.

Laura Howe-Martin, Ph.D.

Jeffrey Kendall, Psy.D.

DEDICATION

In memory of my loving father,

John Earl Funk,

whose perseverance, integrity, and zest for life

taught me to reach for the stars.

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by

RACHEL KATHERINE FUNK

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RACHEL KATHERINE FUNK, Ph.D.

The University of Texas Southwestern Medical Center, 2014

HEIDI A. HAMANN, Ph.D., M.S.

Background: Cancer can be a life-threatening illness with long-term consequences beyond the initial phases of diagnosis and treatment. The post-treatment period presents unique challenges to psychosocial functioning (i.e., psychological distress and quality of life [QOL]), but little is known about the efficacy of psychological and behavioral interventions for cancer survivors, especially in the community setting. *Objective*: This longitudinal study assessed the relationship between participation in a community-based survivorship program and psychosocial functioning among cancer survivors. Aims also addressed how individual characteristics and program participation related to changes in psychosocial functioning over time. *Method*: Participants included 152 cancer survivors receiving psychosocial and behavioral services (e.g.,

exercise, dietary consult, psychological counseling) through the Fort Worth Program for Community Survivorship at the University of Texas Southwestern Moncrief Cancer Institute. Participants completed measures of psychological distress and QOL at enrollment and at 3, 6, and 12 months post-enrollment. Service attendance was recorded throughout the 12-month study period. *Analysis***:** Linear mixed modeling techniques examined changes in psychosocial functioning over time. *Results***:** Significant improvements in both QOL and distress were noted for participants during the 12-month study period. The largest improvements in QOL and distress occurred during the first 3 months and appeared to level out during the last 6 months of program participation. This pattern mirrored participants' attendance in program services, which was highest during the first 3 months of enrollment. Participants with low levels of comorbidity displayed a less pronounced improvement in both psychosocial outcomes over time than those with more comorbid symptoms. Individuals attending exercise and dietary services demonstrated a greater rate of improvement in QOL than those not attending these services. *Discussion***:** Results suggest that the cancer survivorship program was effective in addressing the unmet psychosocial needs of cancer survivors, especially during the first few months of program participation. Uptake of exercise and dietary interventions appeared especially impactful for QOL improvement. Future research should expand assessment of survivorship interventions and utilize non-interventional groups to better understand the specific impact of psychosocial and behavioral survivorship care on psychosocial functioning.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

LIST OF ABBREVIATIONS

ANOVA	Analysis of Variance
BSI	Brief Symptom Inventory
BSI-18	Brief Symptom Inventory 18
CHQ	Confidential Health Questionnaire
CS	Cancer Survivors
EWB	Emotional Well-Being Subscale
FACT-G	Functional Assessment of Cancer Therapy-General
FWB	Functional Well-Being Subscale
IOM	Institute of Medicine
IPAQ	International Physical Activity Questionnaire
JPS	John Peter Smith Hospital
KPS	Karnofsky Performance Status
LMM	Linear Mixed Modeling
MCI	University of Texas Southwestern Moncrief Cancer Institute
NCCN	National Comprehensive Cancer Network
NCCS	National Coalition for Cancer Survivorship
NCI	National Cancer Institute
OCS	Office of Cancer Survivorship
ProComS	Fort Worth Program for Community Survivorship
PWB	Physical Well-Being Subscale
QOL	Quality of Life
SWB	Social/Family Well-Being Subscale

CHAPTER ONE

INTRODUCTION

Statement of the Problem

As the population of cancer survivors (CS) within the United States continues to grow, more attention is being paid to patient functioning and long-term outcomes following the completion of primary treatment. In particular, psychosocial issues like quality of life (QOL) and psychological distress have become common foci for measuring overall well-being of CS. Research has demonstrated that psychological adjustment and QOL of CS generally improve over time and do not significantly differ from population norms four to five years post-treatment (Le Borgne et al., 2013; Rossen, Pedersen, Zachariae, & von der Maase, 2009). However, as many as one-third of CS remain chronically distressed into survivorship or report worse psychosocial functioning post treatment than at diagnosis (Helgeson, Snyder, & Seltman, 2004; Henselmans et al., 2010; Lam et al., 2010). In addition, a substantial minority of CS report notable impairment as a result of cancer treatment in at least one domain of their life, such as emotional, physical, social, sexual and/or occupational well-being (Foster, Wright, Hill, Hopkinson, & Roffe, 2009). Even a slight decline in functioning in these areas can have a significant impact on perceived psychological distress and QOL.

Increased recognition of the persisting challenges faced by patients during the survivorship period has led to an increased demand for methods and programs to address the unmet needs of CS. Psychosocial and behavioral interventions may be particularly important components of survivorship care for the substantial subset of CS who report unmet needs and increased psychological impairment (Harrison et al., 2011). Specific interventions have been identified as having a beneficial impact on adjustment to survivorship, including patient

education, cognitive-behavioral therapy, and exercise (Richardson et al., 2011). More substantially, national organizations, such as the Institute of Medicine (IOM), argue for the establishment of more comprehensive cancer survivorship clinics at the community level to better address the unmet needs of CS (Hewitt, Greenfield, & Stovall, 2005). In general, these survivorship programs or clinics consist of a variety of medical and support services that patients may utilize to varying degrees and frequencies depending on their individual needs. The majority of literature on survivorship programs contains discussions about the best service compilation as well as other practical issues involved in the development and implementation of quality programs for cancer survivorship care (Campbell et al., 2011; Fisher, 2012). Few, if any, studies have looked more directly at the impact of survivorship programs, or the use of concurrent support and/or medical services, on psychosocial functioning among CS.

Research has yet to adequately examine the impact of survivorship programming on patient-reported outcomes. Little is known about the outcome of psychosocial treatments implemented as part of routine programs of survivorship care, especially within survivorship programs that are community-based. Specifically, it is not known how a patient's psychosocial functioning changes during participation in a survivorship program. Similarly, research has not identified the types of routine treatments that have the greatest impact on adjustment to survivorship or the patients who benefit most from community-based psychosocial intervention. Investigation into these unanswered questions may help improve the treatment of the subset of CS experiencing continued distress after treatment as well as offer "implementation-ready" suggestions for improving the outcomes of survivorship care programs. Furthermore, improving the psychological functioning of CS can have a significant impact on health and mortality (Sapolsky, 2004). As such, it is important for cancer survivorship research to focus on patient-

reported psychosocial outcomes of cancer survivorship programming as a means of improving overall health of CS.

CHAPTER TWO

REVIEW OF THE LITERATURE

Overview of Cancer Survivorship

Improvements in the detection and treatment of cancer have led to more individuals living with and surviving the disease. Approximately 68% of cancer patients are expected to survive for at least five years beyond their initial diagnosis (American Cancer Society, 2013), and there has been a significant overall decline in death rates due to cancer over the past twenty years (Jemal et al., 2013). Consistently, the number of CS is expected to grow over the next few years; by 2022 the number of CS in the United States is predicted to increase by over 4 million (de Moor et al., 2013). With such a large expected growth in the number of CS, it has become increasingly relevant to understand the unique needs of CS and to provide ongoing care to meet the needs of this population.

One issue in the area of cancer survivorship research has been the use of a consistent definition of "cancer survivor." In literature to date, the term cancer survivor has been inconsistently applied to individuals at various stages of diagnosis, treatment, and recovery. The trajectory of cancer survivorship can be complex and has been divided into separate, somewhat nebulous, stages of re-entry, short-term survivorship, and long-term survivorship, with the latter category frequently representing those who are at least 5 years beyond diagnosis (e.g., Bloom, Petersen, & Kang, 2007). A recent trend has attempted to simplify the process by more broadly defining CS as anyone living with a cancer diagnosis beginning with the initial diagnosis through to the end of life. This definition is currently supported by numerous national organizations, including the National Coalition for Cancer Survivorship (NCCS), National Comprehensive Cancer Network (NCCN), and the National Cancer Institute's (NCI) Office of Cancer

Survivorship (OCS), all of which focus on promoting improved survivorship care (National Cancer Insititute, 2012; National Comprehensive Cancer Network, 2013b). However this definition of cancer survivorship somewhat neglects the many phases and unique needs that comprise the period following initial diagnosis and treatment. In order to emphasize and better address the growing and understudied unmet needs that occur post-treatment, the Institute of Medicine (IOM) focused its groundbreaking report on cancer survivorship on "survivors of adult cancer during the phase of care that follows primary treatment" (Hewitt et al., 2005). Primary treatment, as mentioned here and throughout this document, is defined as the initial medical therapy(ies), including surgery, radiation, transplant, and chemotherapy, administered to a patient with the intention to cure the disease or significantly reduce tumor size. CS who have completed primary treatment may continue to receive maintenance therapies (e.g., tamoxifen for breast cancer) with the goal of slowing disease progression or reducing the risk of recurrence. It is this group of post-treatment CS that has increasingly become the subjects of cancer care research.

Traditionally, more has been known about the experience of cancer patients at diagnosis and throughout primary treatment, while less attention has been focused on managing the struggles of post-treatment survivors. Cancer patients currently receiving primary treatment typically have a variety of physical and psychosocial services available to them within cancer centers and/or through an established referral system (Deshields, Zebrack, & Kennedy, 2013). Cancer patients are also increasingly monitored on a routine basis for distress and impaired functioning as a result of cancer (Donovan & Jacobsen, 2013; Pirl et al., 2007). However, during the post-treatment period CS generally lose access to the resources available during the primary treatment phase, including regular psychosocial screening and frequent contact with care

providers who would take note of their psychosocial needs. In addition, few, if any, evidence-based services have been available to CS outside of their primary treatment center. Those services that are specifically designed for CS are often inconsistently offered and restricted to larger, comprehensive cancer centers that are more often associated with academic centers rather than community oncology settings (Tesauro, Rowland, & Lustig, 2002). Thus, patients receiving services at the community level generally do not have access to these survivorship-specific services.

The substantial medical and psychological impacts of cancer have been recognized for decades, but cancer survivorship represents a separate and equally rich phase of the cancer experience. The report issued in 2005 by the IOM sparked an increased national interest in cancer survivorship and provided a basis for survivorship research and care (Hewitt et al., 2005). Up to this time, local and national CS organizations (e.g., NCCS, NCI OCS) were active, but this unified focus on survivorship was still missing. To address these gaps, the 2005 IOM report provided a comprehensive characterization of the long-lasting effects of cancer treatment on an individual's physical and emotional health. This report reviewed research demonstrating the pervasive negative effects of cancer treatment on patients' bodily tissues and organ systems, psychological symptoms, spiritual well-being, and social functioning. The report further emphasized the far-reaching effects of cancer treatment by differentiating between late-term and long-term effects in an effort to contrast those complications that manifest months to years after completion of treatment with those that persist from active treatment onwards.

More specifically, the IOM report highlighted the ways in which late- and long-term effects can erode quality of life (QOL) for CS. The combination of traditional interventions, including chemotherapy, radiation, surgery, and hormone therapy, are associated with pervasive

side effects, including neuropathy, impaired sexual functioning, and cardiac toxicity that can continue into the survivorship period (Loescher, Welch-McCaffrey, Leigh, Hoffman, & Meyskens, 1989). These side effects may not only serve as reminders of the cancer experience but also increase the burden placed on CS (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). In addition, the time and financial resources required to complete treatment and appropriate follow-up care may threaten patients' futures by impacting their employment, economic security, familial obligations, social interactions, and even their insurance coverage (Crist, 2013; Tunceli, Short, Moran, & Tunceli, 2009; Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989). Emotionally, the phase of survivorship is also distinct; CS struggle to come to terms with finding meaning or purpose after such a life-altering experience, grapple with a decreased sense of control, face the increased health concerns and worries that accompany follow-up care, and must reestablish a sense of normalcy (Costanzo et al., 2007; Gall & Cornblat, 2002; Stein, Syrjala, & Andrykowski, 2008). Furthermore, cancer patients typically do not experience cancer alone, and the effects of the illness trajectory go beyond the individual patient to affect family, friends, and even the larger society through productivity loss and economic burden (Northouse, Williams, Given, & McCorkle, 2012; Skalla, Smith, Li, & Gates, 2013; Wan et al., 2013). These consequences of cancer and treatment highlighted in the 2005 IOM report have been aptly termed "the price of survival" (Ganz, 2002), and they have helped to direct research and policy makers to better understand cancer survivorship. In particular, research has begun to focus on the psychosocial functioning of CS, especially the constructs of psychological distress and QOL.

Psychosocial Functioning and Unmet Needs of Cancer Survivors

As the population of CS within the United States continues to grow, more attention is being paid to their QOL and long-term psychosocial outcomes. Overall, research findings have

demonstrated that although the majority of CS do well, a substantial minority have unmet psychosocial and behavioral needs. Research from aggregated samples of CS show that psychological adjustment and QOL generally improve over time and do not significantly differ from population norms 4 to 5 years post-treatment (Le Borgne et al., 2013; Rossen et al., 2009). Indeed, a large meta-analysis examining psychological and psychiatric problems in cancer patients 3 to 6 months post diagnosis revealed no significant differences in psychological distress and anxiety between cancer patients and the general population (van't Spikjker, Trijsburg, & Duivenvoorden, 1997), and CS appear to function as well as their peers in other domains such as social connectedness, spirituality, and personal growth (Costanzo, Ryff, & Singer, 2009). Some CS even report growth or improvement in key aspects of their lives as a result of cancer (Bower et al., 2005; Stewart, Wong, Duff, Melancon, & Cheung, 2001). However, other research has identified ongoing issues during the survivorship phase, especially in regards to psychological functioning (Baker, Denniston, Smith, & West, 2005; Foster et al., 2009; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Hoffman, McCarthy, Recklitis, & Ng, 2009). For instance, Costanzo and colleagues (2009) found that CS reported poor psychological functioning in a variety of domains compared with an age-, gender-, and education-matched sample without a history of cancer.

Depression, in particular, may be related to poor psychological functioning among those who have experienced cancer. While individuals with cancer do not on average report more psychological distress than healthy counterparts, they frequently experience depression and depressive symptoms (Massie, 2004). Even as the severity of depressive symptoms decline during the first year following diagnosis, CS do not appear to recover their sense of well-being (Stommel, Kurtz, Kurtz, Given, & Given, 2004). Indeed the IOM cites that CS may experience

an emergence or exacerbation of psychological disorders as a result of cancer or treatment and generally experience worry, fear of the future or death, difficulty sleeping, and trouble concentrating (Hewitt et al., 2005). Additionally, some psychological issues may not become apparent until many years after treatment. For example, cervical CS, whose QOL had previously not differed from controls, reported significantly poorer emotional functioning than controls at 15 years post treatment (Le Borgne et al., 2013). Furthermore, approximately 37% of CS report increased psychological impairment and/or specific unmet needs years following treatment and, thus, may benefit from continued intervention and support (Harrison et al., 2011). These findings strongly suggest that psychological functioning, and specifically depression, may be a domain that is negatively affected by the cancer experience.

These varied and sometimes contradictory findings highlight the fact that patients do not experience cancer treatment and survivorship in a uniform manner. Changes in physical and mental distress across the continuum of cancer care and recovery appear to follow several distinct trajectories (Helgeson et al., 2004; Henselmans et al., 2010). While some individuals show noticeable improvement or declines in psychosocial functioning, others either never show impairment or, most notably, demonstrate persistent difficulties at all phases of their care.

Research has sought to better identify demographic and illness-related characteristics of those CS who are at a higher risk of experiencing these persisting or worsening physical and psychological issues. Age and female gender are frequently associated with high distress (Costanzo et al., 2007; Loge, Abrahamsen, Ekeberg, Hannisdal, & Kaasa, 1997), as younger patients and women of all ages report more psychosocial problems overall (Baker et al., 2005; Giese-Davis et al., 2012). Plus, an anxious preoccupation coping style, poor baseline psychological functioning, and a history of emotional disturbance predict elevated distress

following treatment (Boyes, Girgis, D'Este, & Zucca, 2012; Costanzo et al., 2007; Maunsell, Brisson, & Deschenes, 1992; Schag et al., 1993). Regarding disease characteristics, persisting emotional distress and depressive symptoms among CS has been associated with treatment type, treatment sequelae, physical functioning, and comorbidity (Costanzo et al., 2007; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005; Stommel et al., 2004).

In addition to specific personal and disease characteristics, the number of years post treatment may also affect psychosocial functioning, as each phase of survivorship brings different concerns to the forefront. For example, the first few months post-treatment, often termed the re-entry phase, is marked by emotional disruption and adjustment difficulties (Stanton et al., 2005). This period is one of transition for patients, as they must face less frequent contact with their oncology and support teams while also reengaging with former roles and responsibilities inside and outside the home. They often face a decline in social or medical support, lingering physical and emotional effects of treatment, fear of recurrence, cognitive problems, fatigue, and sexual dysfunction (Armes et al., 2009; Costanzo et al., 2007; Stanton, 2012; Wefel, Lenzi, Theriault, Davis, & Meyers, 2004). Oftentimes patients are poorly prepared for this transition and may experience increased worry and frustration after completing primary treatment (Chubak et al., 2012).

Most survivorship literature has focused on the care and treatment of CS within the first months to years after treatment, leaving a less-clear understanding of needs and treatment of long-term adult CS. However, long-term survivorship, described here as five or more years from time of diagnosis, does appear to include its own set of difficulties. In fact, long-term CS may face fear of recurrence, financial concerns, difficulties with sexual health, and adverse late-term effects of treatment (Foster et al., 2009; Meyerowitz, Kurita, & D'Orazio, 2008). Indeed, Wenzel

and colleagues found that a majority of long-term cervical CS reported an interest in participating in support services like counseling and support group to help with cancer-related concerns (Wenzel et al., 2005), and there is evidence suggesting that long-term CS benefit significantly from psychosocial interventions (Morey et al., 2009; Seitz et al., 2014). Even five or more years after treatment CS may continue to have needs worthy of clinical attention. Taken together, these findings from early and late-term CS suggest that the experience of cancer and its treatment is highly complex and continues to affect survivors in unique, nuanced ways that demand our continued attention and understanding.

Given the dynamic experiences of CS, there is a need to continue to monitor well-being and provide psychosocial services to those with unmet needs beyond their initial diagnosis and treatment. Psychological distress and QOL remain two of the major domains for assessing the well-being and psychosocial functioning of CS, and remain important outcomes of interest. These domains will be defined and explored in more detail below.

Psychological Distress

Definition. Psychological distress is a somewhat obscure construct, yet it remains regularly assessed in behavioral health research. In general terms, distress refers to psychological discomfort in response to a stressful event or circumstance and may manifest as a wide range of negative feelings or physical sensations. However, expansion of psychosocial screening and a recent mandate by the American College of Surgeons Commission on Cancer for distress screening have helped to solidify the nature of the construct within oncology. Indeed, the term "distress" was purposely selected by the NCCN Panel for Distress Management to be less stigmatizing and embarrassing than words like "psychiatric" and "emotional." The NCCN defined distress as "a multifactorial unpleasant emotional experience of a psychological

(cognitive, behavioral, emotional), social and/or spiritual nature" (National Comprehensive Cancer Network, 2012, DIS-2). The NCCN definition further specified the continuum of distress manifestations, which may range from normal feelings of vulnerability and sadness to disabling problems such as depression and panic. In this way, distress captures both the expected level of discomfort associated with a cancer diagnosis and treatment as well as more severe or critical reactions necessitating more immediate and intensive treatment. As it is defined by the NCCN, distress may be experienced as a reaction to the disease itself and the associated treatment or to the less direct consequences of the illness (e.g., employment, finances, and social functioning). This definition also reflects the broad nature of concerns that can be captured under the umbrella of distress. Psychosocial concerns among CS fall under a range of issues including: late effects of treatment, cognitive sequelae, reentry into previous social, occupational, and family roles, body image and sexuality changes, and psychological reactions (Hewitt et al., 2005).

In Cancer Survivors. Ongoing stress and monitoring of distress is important even into the post-treatment period, as differing sources of psychosocial concerns emerge throughout the cancer trajectory. As noted earlier, distress monitoring during survivorship becomes more sporadic, as oncology appointments decrease in frequency and shift focus to recurrence and surveillance. However, distress remains an important and prevalent issue for CS. Distress, and more specifically depressed mood, is an identified risk factor for non-adherence to treatment among health populations (DiMatteo, Lepper, & Croghan, 2000). Within oncology, heightened distress is associated with poorer emotional functioning, impaired decision making, and even reduced survival among cancer patients (Bober, Hoke, Duda, Regan, & Tung, 2004; Brown, Levy, Rosberger, & Edgar, 2003; Gessler et al., 2008). Those cancer patients who continue to experience psychological, cognitive, and physical sequelae into the post-treatment period are at a

higher risk of distress during survivorship (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). Furthermore, distress during primary treatment appears to precede difficulties in long-term adjustment (Loge et al., 1997). In CS similar trends surface, as CS with untreated distress demonstrate poor compliance with surveillance recommendations and a reduced likelihood of engaging in health promoting behaviors, such as exercise and smoking cessation (Carmack, Basen-Engquist, & Gritz, 2011). In addition, ongoing distress may increase health care costs for the individual cancer patient and the larger health care system, as distressed patients demand more time, require more resources, and accrue higher billing costs (Bultz & Holland, 2006; Carlson & Bultz, 2004).

While distress remains a prevalent part of the survivorship experience, not all CS experience enduring or worsening distress. Self-reported distress among CS can range from negligible in some groups to up to 30 to 40% in others (Kornblith et al., 2003; Loge et al., 1997). Furthermore, patterns of change in distress across the continuum of cancer care appear to follow several distinct trajectories. Most notably, 30% of CS display worse psychosocial distress post treatment than at diagnosis or report persistent distress into survivorship (Henselmans et al., 2010).

Correlates of Distress. Aspects of CS personal, disease, and environmental characteristics are also known to impact distress. For instance, marital status appears to be a strong predictor of distress and negative outcomes such that being married appears to reduce the impact of psychosocial problems for both men and women (Aizer et al., 2013; Giese-Davis et al., 2012). Age is also associated with distress in survivorship, with younger CS reporting higher distress levels than older patients (Costanzo et al., 2007; Mao et al., 2007; Zebrack, 2011). Differences in distress by race and ethnicity are not consistently evaluated or reported. For

instance, Deimling and colleagues (2006) found that African American CS indicated fewer cancer-related health worries, but Baker and colleagues (2005) reported that non-white CS identified more problems. Also, the resumption of work after treatment can act as a protective factor from distress, but an inability to return to work or reduced work load is associated with poorer functioning (Mols, Thong, Vreugdenhil, & van de Poll-Franse, 2009; Spelten, Sprangers, & Verbeek, 2002).

In regards to personal and environmental characteristics, Carver and colleagues (2005) found that even when controlling for baseline adjustment, optimistic breast CS experience less psychological distress, suggesting that a patient's outlook can impact functioning over time. Breast CS with chronically elevated distress scores ranked higher on neuroticism than women whose distress appeared to improve over time (Henselmans et al., 2010). Similarly, a history of emotional disturbance has been associated with a greater risk of depressive symptomatology during the months following treatment (Costanzo et al., 2007). There is also some evidence that establishing a sense of meaning and having good social support are associated with decreased distress among cancer patients (Arden-Close, Gidron, & Moss-Morris; Avis et al., 2013; Roland, Rodriguez, Patterson, & Trivers, 2013). Regarding functional capacity, there have been several studies showing that emotional distress is significantly, negatively associated with compromised performance status among CS (Kim et al., 2013; Norton et al., 2005).

Quality of Life

Definition. As with distress, QOL is a similarly difficult construct to clearly define, as no universally accepted model yet exists. In general, QOL is a term used widely to describe an individual's perception of his or her overall well-being and position in life. In regards to health and coping with illness, measures of QOL assess the extent to which a patient's normal life

activities have been affected by disease and treatment. Nonetheless, it is important to more fully understand the construct of QOL in order to make meaningful comparisons across groups, especially for use with health-related and, more specifically, cancer research.

One useful way of understanding and clarifying QOL is to divide it into two fundamental components, which have been identified as subjectivity and multidimensionality (Cella, 1994). Subjectivity reflects how QOL is inherently formed by an individual's perspective and cognitive processes as well as by his or her value system. Each individual's appraisal of their current QOL is not only a judgment of his or her current level of functioning but also a comparison with what might be possible or ideal as determined by social, cultural, and intrapsychic influences. In this way, QOL is an important part of understanding patient benefit in response to health or treatment programs, as it attempts to quantify patients' subjective evaluations of their health status. This element of subjectivity can be particularly helpful in understanding perceived program or treatment benefits among cancer populations.

The second component, multidimensionality, recognizes the broad range of content contained within QOL. Four primary dimensions of health-related QOL have previously been cited: physical, functional, social, and emotional well-being (Cella, 1994). Similarly, the IOM recognized the following four factors of QOL more specific to cancer survivorship: physical well-being and symptoms, psychological well-being, social well-being, and spiritual-well being (Hewitt et al., 2005). Standardized, self-administered questionnaires are usually structured to collect QOL information from CS by tapping into several domains (Jacobsen & Jim, 2011). The use of multidimensional assessment is important and necessary to understanding patient well-being; not only does it provide a structure for measuring patients' perceived changes to life quality, but also it accounts for the multipartite influences that can affect functioning and

constitute an individual's sense of well-being. It is particularly important to address multiple dimensions of well-being among a cancer population, given the known broad impact of the cancer experiences on mental, social, physical and emotional functioning. Furthermore, the multidimensionality of QOL accounts for the implicit influences of a patient's changing environment and value system that may naturally shift over time. Given the potential for change over time, the most accurate reflections of QOL are likely achieved through repeated, longitudinal assessment (Cella, 1994).

In addition to being an appropriate construct for understanding patient's appraisals of health status and well-being, QOL also has recognized practical value among cancer patients. QOL is associated with improved physical outcomes, survival, and medical adherence (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Sehlen et al., 2012). Indeed, CS who report higher QOL are more likely to adhere to diet and exercise recommendations (Blanchard, Courneya, & Stein, 2008; Inoue-Choi, Lazovich, Prizment, & Robien, 2013). Additionally QOL assessments provide a means to determine if the benefit of a supportive intervention outweighs its costs.

In Cancer Survivors. In general, overall QOL does not appear to be permanently or globally impaired for a majority of CS. Studies with long-term CS reveal that a majority of patients report maintained or improved physical and mental functioning after treatment and that CS have QOL life scores similar to individuals without a history of cancer (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Greimel, Daghofer, & Petru, 2011; Helgeson et al., 2004; Wenzel et al., 2005). However, a minority of CS experience declining QOL over time, as up to 30% report deterioration of physical and/or mental functioning up to four years after diagnosis (Helgeson et al., 2004). Furthermore, an assessment of global QOL is often the basis

for demonstrating good QOL into survivorship, a method that may not take into account differences in QOL at the domain-specific level (e.g., spiritual well-being, social well-being). This differentiation is important, for it appears that the cancer experience can have a persistent negative impact on certain areas of QOL that may or may not be reflected in a global QOL scores. Indeed, a sizeable minority of CS reported well-being concerns in at least one area of functioning, including psychological, sexual, social, physical and/or financial functioning, despite reporting good QOL overall (Foster et al., 2009).

A more comprehensive understanding of QOL among CS requires a more detailed review of functioning within the multiple dimensions of QOL. Physical concerns, in particular, are frequent among CS, and physical well-being appears to be a dimension of QOL that is negatively impacted by the cancer experience. Cancer and its associated treatments can negatively impact the immune system, leading to enhanced vulnerability to other illnesses. These persistent health problems can compromise QOL into the survivorship period. Approximately one-fourth of all CS report a physical health-related QOL that is at least one standard deviation below population norms. Specifically, fatigue is one of the most frequent physical complaints experienced by CS (Gielissen, Verhagen, Witjes, & Bleijenberg, 2006; Schlairet, Heddon, & Griffis, 2010; Servaes, Verhagen, & Bleijenberg, 2002) and reports of persisting fatigue are significantly associated with worsening long-term QOL across multiple domains (Schmidt et al., 2012). Pain is also widely reported among cancer patients. Approximately one-third of post-treatment cancer patients endorse significant pain (van den Beuken-van Everdingen et al., 2007), which can lead to decreased QOL and poor adherence to medical treatments (Pachman, Barton, Swetz, & Loprinzi, 2012).

In addition, survivors of certain cancers, like cervical, colorectal and hematologic, may be more likely to report even worse physical QOL than survivors of other cancer types (Weaver et al., 2012). Likewise, fewer long-term breast CS reported positive QOL than matched controls without a history of cancer and breast CS indicated persistent concerns about sexuality, physical functioning, and lymphedema (Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Ganz et al., 1996). In general, prostate cancer patients also report physical problems, which are typically related to sexual, urinary, and bowel dysfunction (Bloom et al., 2007). Overall, physical functioning is one domain of QOL that is likely to be lower among CS.

Emotional well-being also appears to be a dimension of QOL that suffers among CS regardless of good overall QOL. For instance, long-term cervical CS demonstrated few overall differences when compared with healthy, population controls yet reported lower emotional functioning and more mental fatigue (Le Borgne et al., 2013). Likewise, long-term gynecological CS reported significantly poorer mood states than healthy controls even though their overall QOL was comparable to healthy controls (Bradley et al., 2006). Among breast CS, emotional functioning appears to be lower than other aspects of QOL, such as social and physical functioning. Even into long-term survivorship (defined as a survival time of more than five years), breast CS report significantly worse emotional functioning than breast CS who are two to five years post initial treatment (Holzner et al., 2001). Chronic fear of recurrence is also commonly cited as an emotional concern impacting psychological well-being among CS (Dahl, Wittrup, Vaeggemose, Petersen, & Blaakaer, 2013; Van Liew, Christensen, Howren, Hynds Karnell, & Funk, 2013). Taken together physical and emotional concerns appear to contribute most to sustained QOL issues in survivorship, which is consistent with findings by Shi and colleagues (2011) whose analyses of a large group of CS revealed that depression, fatigue, and

pain had the greatest negative impact on a survivor's QOL. This continued impairment in physical and emotional well-being reported by CS demonstrates how cancer can have a long-term impact on QOL, even though global QOL findings among CS do not always demonstrate persistent difficulties.

Correlates of QOL. Cancer patients' self-reports of well-being have also been associated with particular demographic and illness-related patient characteristics. Unemployment and a lack of an intimate partner may be risk factors for mood difficulties and reduced emotional well-being among CS (Bradley et al., 2006). Similarly, social isolation is negatively associated with QOL among CS (Bloom et al., 2007). Poor social QOL may be associated with increased financial problems and greater worry about appearance after treatment (Carver, Smith, Petronis, & Antoni, 2006). Lower socioeconomic status and living in a rural area have been shown to uniquely predict poor QOL outcomes, at least among colorectal CS (Dunn et al., 2013).

In addition, age and life stage has been associated with QOL among CS. Older survivors report the poorest scores in the physical domain while younger survivors show poorer social functioning and overall QOL scores. Patients diagnosed with cancer during middle age appear to do the best of the three age groups (Cimprich, Ronis, & Martinez-Ramos, 2002). Lower physical QOL among older CS is associated with poorer health status in regards to fatigue, aches and pains, and comorbidities than younger patients. In contrast, the unique life-stage demands (e.g., reproductive, appearance, familial, and social concerns) of younger cancer patients help to explain lower social and overall QOL observed among younger CS. Despite these varying affects of age on QOL, length of time since diagnosis has not been found to be associated with QOL, as scores on global QOL and function-specific QOL subscales (e.g., emotional, social, cognitive, role, and physical) are very similar among short-term, long-term and very long-term

survivors when controlling for age (Wikman, Djarv, Johar, & Lagergren, 2012). Thus, it appears that age at diagnosis is a better predictor of QOL in survivorship than length of time since diagnosis, and the age-related, negative impact of cancer persists into survivorship regardless of the time that has passed since initial diagnosis.

In addition to demographic characteristics, some illness-related factors are also correlated with QOL outcomes among CS. First, performance status, which is a measure of functional capacity, has been shown to be negatively associated with self-reported QOL among cancer patients (Beisland et al., 2013; Cella et al., 1993; Iyer, Taylor-Stokes, & Roughley, 2013) Additionally, QOL has been show to vary by cancer type (Deshields, Potter, Olsen, & Liu, 2014). For instance, there is evidence to suggest that head and neck CS experience poorer QOL than other types of CS (Abendstein et al., 2005) and that QOL does not improve with greater time since diagnosis for prostate CS (Bloom et al., 2007). There is also strong evidence for the impact of treatment on QOL. Among breast and lymphoma survivors, a history of adjuvant chemotherapy has been shown to be a significant predictor of poor QOL, as has a higher disease stage at diagnosis (Ahles et al., 2005; Carver et al., 2006; Ganz, Kwan, Stanton, Bower, & Belin, 2011; Hwang, Chang, & Park, 2013). Other reviews have suggested that comorbid medical conditions have a greater negative impact on QOL than cancer stage, but chemotherapy is consistently cited as a strong predictor of poor QOL among breast CS (Mols et al., 2005). Women receiving radiotherapy for cervical cancer reported poorer physical QOL than both women who had surgery only and healthy controls with no cancer history (Frumovitz et al., 2005). In addition, high-dose chemoradiotherapy has been shown to more negatively impact QOL into survivorship than less dosage-intensive treatments (Hurmuzlu, Aarstad, Aarstad, Hjermstad, & Viste). Surgery type may also impact survivorship QOL. Among breast CS,

women who received a mastectomy rather than breast-conserving surgery reported poorer QOL (Casso, Buist, & Taplin, 2004), although not all studies demonstrate QOL differences by surgery type (Stover et al., 2014). In addition, a history of receiving a bone marrow transplant was associated with poorer perceived QOL and persistent complications among long-term CS (Bush, Haberman, Donaldson, & Sullivan, 1995; Smith et al., 2013). Taken together, these studies suggest that a history of higher disease burden and more aggressive treatment is associated with impairment in QOL long after initial cancer treatment is over.

Guidelines and Programming for Cancer Survivorship

Overall, psychosocial distress and QOL act as helpful and well-recognized guides in tracking the adjustment of cancer patients to survivorship. However, the continued emphasis in the literature on the unmet needs of CS suggests that survivorship remains an important treatment phase of comprehensive cancer care. Moreover, a recent 2008 report from the IOM identified continued failures of the health care system to adequately address the psychosocial needs of CS despite an increased awareness of the issues involved in survivorship (Adler & Page, 2008). To better tackle the variety of unmet survivorship needs (and respond to the call of IOM reports) several agencies have begun to develop systematic and evidence-based clinical practice guidelines for cancer survivorship.

Prior to the publication of the 2005 IOM report, the unique challenges and difficulties of CS were well recognized, yet few if any attempts had been made to compile guidelines for how to treat CS. In truth, CS have not been an easy population to clinically describe and respond to; heterogeneity of the population of CS along with difficulties in long-term surveillance and the previously mentioned disagreements on defining "cancer survivor" have posed real barriers to creating comprehensive practice guidelines for survivorship (Earle, 2007). For instance, since

1995 the NCCN has published over 100 guidelines for cancer care but until recently had refrained from creating recommendations specific to survivorship. Other organizations have also attempted to create survivorship guidelines, but their efforts were more circumscribed, focusing on restricted parts of survivorship, such as surveillance, a specific diagnosis, or self-advocacy skills (e.g., Meyerhardt et al., 2013; Walsh-Burke & Marcusen, 1999). The publication of the 2005 IOM report paved the way for survivorship to be well recognized as a distinct and important period of cancer care that deserved greater attention from researchers and clinicians. It opened the doors for funding and perhaps cemented the formation of several important and prominent cancer survivorship programs, such as the LIVESTRONG Survivorship Center of Excellence Network.

Beginning in the mid-2000s attempts at creating more unified and comprehensive cancer survivorship guidelines and treatment efforts have become more prevalent. A collaboration between the Center of Disease Control and Prevention and the LIVESTRONG foundation in 2004 resulted in a National Action Plan for Cancer Survivorship (Centers for Disease Control and Prevention), and as noted above, the NCCN finally published a formal guide for cancer survivorship (National Comprehensive Cancer Network, 2013b). Frequent among all of these guidelines is the recommendation that treatment summaries and care plans be provided for all CS. Treatment summaries and care plans provide each patient with an individualized brief review of the disease characteristics, tests, medications, and medical interventions received (i.e., treatment summary) as well as the future recommendations for surveillance and possible support needs specific to the cancer diagnosis and treatment (i.e., care plan). The treatment summary and care plan are frequently lumped together as one entity aptly named "survivorship care plans." The main elements of survivorship care plans include: 1) clinical recommendations for

follow up scans and appointments, 2) information about recurrence and education about late and long-term toxicities, and 3) psychosocial information such as the effects of cancer on relationships, sexual functioning, work, parenting, insurance, and finances. This latter portion of the survivorship care plans highlights the continued need to better inform CS and manage their persistent psychosocial needs. The American Society of Clinical Oncology and LIVESTRONG concurrently developed templates for disseminating these tools, which have become accepted as standard elements of survivorship care. In support of the importance of survivorship care plans, the American College of Surgeons mandated that organizations must implement a plan for the delivery of survivorship care plans by 2015 in order to maintain accreditation (2012).

In addition to clinical guidelines and recommendations, the oncology community has attempted to create specialized programs and determine evidenced-based services to address and treat the ever-growing needs of CS. LIVESTRONG with its Centers of Excellence has been at the center of many of these developments. Alongside the guidelines presented by NCCN and others, the LIVESTRONG foundation pooled together and ranked the aspects of quality survivorship programming (Rechis, Beckjord, Arvey, Reynolds, & McGoldrick, 2011). Their three-tier system reflects the difficulty of creating a comprehensive survivorship program, particularly given the many financial, institutional, clinical, and practical barriers that may limit the development and growth of programs such as those in the LIVESTRONG network (Campbell et al., 2011). Much research has focused on challenges to and suggestions for building effective programs or clinics for CS that incorporate the multi-faceted arenas of survivorship, such as surveillance, care coordination, education promotion, and psychosocial support among others (Chubak et al., 2012; Hamann & Kendall, 2013; Wolin, Colditz, & Proctor, 2011). While also being fairly individualized in nature, comprehensive survivorship

programs generally include coordination of care, surveillance for recurrence, recommendations for screening, health promotion strategies, evaluation and treatment of physical and psychosocial consequences of treatment, and creation and distribution of survivorship care plans (McCabe, Faithfull, Makin, & Wengstrom, 2013; McCabe & Jacobs, 2012).

Community-Level Survivorship Care

With increased publication of models and rationale for survivorship care, there has been a growth of survivorship clinics in both academic institutions and, to a much lesser extent, community oncology practices. Initiatives like the NCI Community Cancer Center Program have encouraged the development and expansion of survivorship care at the community level (McCaskill-Stevens, Lyss, Good, Marsland, & Lilenbaum, 2013), and some community-based initiatives have been successful in increasing access to more comprehensive cancer survivorship care at the community level (Lengerich et al., 2007; Shapiro et al., 2009). Yet, there are also important considerations in the development of survivorship care programs for underserved or more rural populations who are receiving care in a community setting. The transition to survivorship may be more challenging for underserved and community-based cancer populations due to limited accessibility and availability of resources (Butow et al., 2012). In addition, rural and racial/ethnic minority CS face additional barriers to post-treatment care such as overcoming cultural or language barriers (Lopez-Class et al., 2011), understanding the necessity of surveillance and obtaining screening services (Bennett, Probst, & Bellinger, 2012; Jackson et al., 2009), and accessing appropriately trained psychosocial support (Lawler, Spathonis, Masters, Adams, & Eakin, 2011). Furthermore, the majority of CS may not have access to appropriate survivorship services. Approximately 85% of cancer patients receive their medical care within community oncology settings or community hospitals (National Cancer Institute), which are less

likely than clinics associated with large academic medical centers to offer comprehensive survivorship care programming.

Given the deficiency of services that target the majority of CS who are treated in community oncology settings, there is a very specific need for community-based cancer survivorship centers that can extend services to these populations. Community-based survivorship programs may alleviate some of the follow-up demands on community oncologists, be better able to cater to the needs of local CS, and improve the transition from mainstream cancer care (Fisher, 2012). Thus, engaging an underserved population is important for survivorship research. By examining a community-based program, the proposed study may provide data that is more relevant to the majority of CS who seek care at the community oncology level.

Effective Survivorship Interventions

Despite an evident focus on the challenges to building comprehensive survivorship programming at both the academic and community level, research has also begun to identify individual interventions to effectively treat the needs of CS. Numerous controlled trials have upheld the effectiveness of non-pharmacological interventions to reduce symptoms of depression, fatigue, pain, and sexual dysfunction among post-treatment cancer patients (Stanton, 2012). Specific to mood issues, group-based cognitive-behavioral stress management (Antoni et al., 2006), individual cognitive-behavioral therapy (Osborn, Demoncada, & Feuerstein, 2006), and mindfulness-based psychotherapy (Lengacher et al., 2014; Piet, Wurtzen, & Zachariae, 2012) are effective modalities for decreasing symptoms of anxiety and depression among CS. Similarly, cognitive-behavioral and relaxation-based therapies have also proven to be effective in the treatment of fatigue, pain, and poor sleep (Espie et al., 2008). In addition, pharmacologic

interventions are often commonly used to treat CS for persistent physical, psychosocial and psychological distress. Use of various selective serotonin reuptake inhibitors and benzodiazepines are recommended to address mood and anxiety symptoms among CS (National Comprehensive Cancer Network, 2013b), and psychoactive drugs have also proven effective for the treatment of other psychosocial concerns including fatigue (Minton, Richardson, Sharpe, Hotopf, & Stone, 2010). Medications are also recognized as powerful agents for promoting tobacco cessation and managing residual pain among CS (Fiore et al., 2008; Paice & Ferrell, 2011).

Routine exercise is also frequently recommended for the treatment of psychosocial and psychological symptoms. In fact, clinical trials have demonstrated that regular exercise has significant effects in reducing symptoms of anxiety and depression among CS (Brown et al., 2012; Segar et al., 1998). There is also strong evidence for the use of physical activity to improve post-treatment fatigue (McNeely et al., 2006; Speck, Courneya, Masse, Duval, & Schmitz, 2010), and physical activity may be helpful as part of a multidisciplinary approach to managing cancer pain (Bloch, 2004). A recent study by Fitzpatrick and colleagues (2012) suggests that physical activity is also effective for improving cognitive functioning after cancer treatment, and structured exercise programs for CS have robustly been associated with perceived improvements in QOL (Cheifetz et al., 2014; Mishra et al., 2012; Wiggins & Simonavice, 2009). In addition, aerobic and resistance training has an overall positive impact on balance, body composition, and functional capacity among female CS, which all may indirectly impact perceived QOL (McNeely et al., 2006). Even alternative exercises such as yoga and tai chi, have displayed promising positive impacts on well-being among CS (Levine & Balk, 2012; Mustian, Palesh, & Flecksteiner, 2008). Taken together, the current literature on post-treatment

interventions indicates that numerous effective services and psychosocial programs are available to attend to the issues specific to a survivorship population.

Survivorship Program Outcomes

Despite the recognized benefit of individual survivorship services, few studies provide patient-reported outcome data from comprehensive cancer survivorship programs. As outlined above, the majority of the discussion about cancer survivorship focuses on program development or singular interventions to target specific needs; very little if any research has focused on analyzing outcomes of patients participating in multiple, complementary services. Polls of oncology healthcare professionals have suggested that clinicians are strongly supportive of centralized comprehensive survivorship clinics for the provision of psychosocial and physical activity services (Gage et al., 2011). Patients also have endorsed a desire for a more personalized needs assessment and improved attention to their psychological needs during survivorship (Hewitt, Bamundo, Day, & Harvey, 2007), and they have reported good satisfaction with survivorship care plans (Rosales et al., 2013). However, services for survivors at cancer treatment centers are rarely formally evaluated (Tesauro et al., 2002), a fact which emphasizes a need for more comprehensive and quantitative understanding of the patient-reported outcomes related to participation in survivorship support services. This gap in knowledge about psychosocial outcome among CS receiving supportive services has been recognized and articulated by other cancer researchers (e.g., Buffart et al., 2013).

In sum, cancer survivorship care remains in its nascent stages of development and policy with little research being conducted on patient-reported and clinical outcomes. Research has been proposed to more comprehensively clarify what types of programs for CS are effective and for whom, yet few if any studies to date examine patient-reported outcomes related to

participation in community-based cancer survivorship programs. Thus, the current study provided uncommon and somewhat unprecedented information that may be useful to the treatment of CS. The study employed two of the most utilized constructs in survivorship research, distress and QOL, to track the association between survivorship program participation and the psychosocial functioning of CS.

CHAPTER THREE

RATIONALE, STUDY AIMS, AND HYPOTHESES

Rationale

Little is known about the outcome of psychosocial and behavioral services implemented as part of routine programs of cancer survivorship care, and even less research has specifically focused on programs that are community-based rather than embedded into traditional academic medical centers. The primary purpose of this study is to monitor longitudinal changes in QOL and distress among CS participating in a variety of psychosocial and behavioral services as part of a community-based cancer survivorship program. In addition, this study further aims to explore potential associations of these longitudinal changes, such as utilization of psychosocial services, illness characteristics, and demographic features, in order to build insight into how to better treat the growing population of CS.

Aims and Hypotheses

The proposed research study has three broad aims. In addition to these primary aims, the project will also provide a comprehensive description of 1) the demographic and illness composition of the sample and 2) the type and quantity of program services (e.g., psychology, exercise, genetic counseling) utilized by the survivor cohort.

Aim I: Examine individual patterns of change in QOL and psychosocial distress among CS participating in a community-based cancer survivorship program over a 12-month time period (measured at baseline and at 3-month, 6-month, and 12-month follow-up periods).

Hypothesis Ia: Participants will report a statistically significant increase in overall QOL over time.

Hypothesis Ib: Participants will report a statistically significant decrease in psychological

distress over time.

Aim II: Identify baseline demographic and clinical characteristics associated with individual differences in the pattern of psychosocial change (psychological distress and QOL) over time. The pattern of psychosocial change is hypothesized to be associated with several variables in particular (baseline psychological distress, age, comorbid symptom burden, and time since diagnosis) as guided by previous research on psychosocial outcomes of CS.

Hypothesis IIa: The pattern of change in psychosocial outcomes will be associated with baseline distress level (e.g., BSI-18 scores), such that individuals who are more distressed at baseline (intercept) will display greater change in psychosocial functioning over time than individuals who are less distressed at baseline.

Hypothesis IIb: The pattern of change in the psychosocial outcomes will be associated with age, such that younger participants will display less change in psychosocial functioning over time than older participants.

Hypothesis IIc: The pattern of change in the psychosocial outcomes will be associated with comorbid symptom burden (e.g., comorbidity count), such that participants with high comorbid symptom burden at baseline will display less change in psychosocial functioning over time than participants with lower baseline comorbid symptom burden.

Hypothesis IId: The pattern of change in the psychosocial outcomes will be associated with time since diagnosis, such that participants who are newer to survivorship will display greater change in psychosocial functioning over time than those who are further along in survivorship.

Aim III: Explore the relationships between a) the type and amount of program service utilization (e.g., participation in psychological counseling, exercise) and b) the pattern of change in

psychosocial outcomes (psychological distress and QOL) over time within the survivorship cohort.

Hypothesis III: Service utilization will be positively associated with psychosocial outcomes among the CS cohort, such that high service utilization (both in general and for specific services) will predict greater improvements in psychosocial functioning over time.

CHAPTER FOUR

METHODOLOGY

The current study utilized data collected through the Fort Worth Program for Community Survivorship (ProComS), a community-based cancer survivorship program operating at the University of Texas Southwestern Medical Center Moncrief Cancer Institute (MCI) in Fort Worth, Texas. Health, demographic, and psychosocial information was obtained from participating cancer survivors (CS) using a combination of self-report measures and medical chart review. While MCI is an affiliate of a large, academic medical center, cancer programming was limited to ancillary services and occurred within a community cancer center rather than a traditional academic, oncology treatment setting.

Procedure and Subjects

Referral and Recruitment

The University of Texas Southwestern Medical Center Institutional Review Board approved the procedures of psychosocial outcome evaluation associated with this report. The purpose of ProComS was to establish a community-based survivorship clinic that provides ongoing physical, psychosocial, and behavioral needs to CS in the Fort Worth, Texas vicinity, and places special emphasis on engaging underserved and uninsured individuals. Study recruitment began in May of 2011 and ended in August 2013. Potential participants were either self-referred to MCI or referred by local hospitals and agencies in the Fort Worth, Texas region. Referring hospitals included Baylor All Saints Medical Center, Huguley Memorial Medical Center, John Peter Smith Hospital (JPS), Plaza Memorial Medical Center, and Texas Health Harris Methodist Hospital Fort Worth. Physician groups representing JPS Health Network, Texas Oncology, and the Center for Cancer and Blood Disorders in Fort Worth and surrounding

communities also made referrals. ProComS was also publicized through three local cancer service agencies: American Cancer Society, Cancer Care Services, and the Susan G. Komen for the Cure Greater Forth Worth Affiliate.

Special recruitment efforts were conducted at JPS, the county healthcare safety-net provider, in order to better target underserved populations. The ProComS study protocol was also approved by the JPS Institutional Review Board to permit these recruitment activities. These efforts included initial meeting with JPS administrators, physicians, nursing personnel and social workers to explain the survivorship program at MCI. Following these initial meetings, study staff were stationed weekly in oncology-specific clinic areas in JPS to provide patient education and schedule interested patients for an intake visit for ProComS. The research study manager also conducted ongoing individual and group meetings with JPS physicians and health providers to further educate providers about ProComS survivorship services. In addition, a visible reminder of ProComS in the form of a prescription pad for survivorship services was placed in oncology clinic exam rooms at JPS.

Eligibility Criteria

Following an external or self referral, staff from ProComS contacted potential applicants by phone to set up an initial appointment, gather basic demographic information, and conduct a brief screen for eligibility. Eligibility criteria were adults (at least 18 years old) with a cancer diagnosis who had completed primary cancer treatment. Initially, only individuals who were between 30 days and one year post primary cancer treatment were eligible for ProComS; however, the eligibility criteria were later extended to accommodate a notable demand from longer-term survivors. Specifically criteria were expanded in July 2011 to permit enrollment to CS who were up to 5 years post initial treatment and later expanded again in May 2012 to

include all adult CS regardless of time since the end of primary treatment. Although ProComS eventually became available to a limited number of individuals with a genetic predisposition to cancer as well as patients who had not fully completed primary treatment ("previvors"), the current analysis excludes these individuals. Participation in ProComS was completely voluntary for all eligible CS, and CS could decline study participation during their initial appointment or withdrawal at any point thereafter. Of note, patients who were ineligible for the current study or who declined participation could still partake in survivorship program services (e.g., exercise, dietary consultation, psychology) as a non-research patient.

Data Collection Procedures

Figure 1 provides a diagram of the data collection process. Prior to an initial in-person visit, participants were mailed an enrollment packet to complete and return by mail. The enrollment packet contained general information about the program as well as two clinical measures: the Pearlman-Mayo Survey of Needs (Survey of Needs; Schlairet et al., 2010) and a UT Southwestern Medical Center Confidential Health Questionnaire (CHQ). These two tools highlighted specific needs or interests of participants that could be evaluated further at the initial visit. Potential participants also provided basic illness and demographic information to staff members over the phone when scheduling their first appointment.

At the initial in-person visit, all participants received a survivorship portfolio, which was a binder that contained general information about topics relevant to cancer survivorship as well as information tailored to any needs or interests that surfaced from the Survey of Needs or CHQ. During the initial visit, all participants met with a registered research nurse who reviewed the study requirements and consent documents and oriented participants to ProComS. In addition to signing a consent form and an Authorization for Use and Disclosure of Protected Health

Information, the participants completed four baseline self-report questionnaires that measured psychosocial functioning, exercise habits, and diet. Specifically these questionnaires were the Functional Assessment of Cancer Therapy-General (FACT-G), the Brief Symptom Inventory 18 (BSI-18), the International Physical Activity Questionnaire (IPAQ), and the Multifactor Screener (all described later in this section). The research nurse then conducted a basic History and Physical assessment (i.e., blood pressure, height, weight, and medical history review) and discussed the participants' current psychosocial needs based on their medical history and responses to the questionnaires. The research nurse provided the patient with recommendations and referrals to ProComS services and, if needed, to off-site providers of services not available at MCI. Follow-up appointments with the recommended service providers within MCI were scheduled after the initial visit as appropriate. Additional information about the specific services at MCI is further described below.

All participants were offered the option of receiving a cancer treatment summary and care plan. Medical records for participants who elected to have a treatment summary and care plan were reviewed by the research nurse following the initial visit to collect additional information about cancer diagnosis and treatment. Once completed, this final document was mailed to the patient and the patient's designated physician. Where similar information about illness characteristics was collected by both self-report in the intake questionnaires and medical record review for the treatment summary and care plan, data from the medical record was used for the current study.

Following their initial visit, participants were contacted by mail to complete the two measures of psychosocial functioning (FACT-G and BSI-18) at 3 months, 6 months, and 12 months after enrollment. At the beginning of each month, research staff mailed packets

containing these questionnaires to the study participants eligible for follow-up that month. Survey packets were sent to participants regardless of whether participants had returned questionnaires from a previous timepoint. Study staff also placed up to two reminder phone calls to those participants who had not returned the packet of questionnaires within two weeks. Additional study packets were mailed as needed to participants who indicated that they had not received the original materials. Participants whose packet was not returned within sixty days of the expected follow up dates were considered missing data and not included in the analysis.

For participants who indicated a Spanish language preference, all communication was conducted in Spanish. All written materials, including the study invitation letter, all questionnaires, and the study consent forms were available in Spanish, and all self-report outcome measures (e.g., BSI-18, FACT-G) have validated Spanish-language versions that were used for this study. Further details about the Spanish-language version of these measures are provided later in this section. In addition, in-person translators for Spanish-speaking clients were used during the initial in-person visit and as needed during survivorship service visits.

ProComS Services

ProComS offered various types of evidenced-based services to address psychosocial and health concerns of CS. Each of the services incorporated into ProComS is recognized as having a strong, evidenced-based rationale for use with CS. Table 1 lists the practice recommendations supported by national oncology and professional organizations for each ProComS service type. Participants received referrals from research and/or clinical staff prior to making an appointment for a particular service. The types of services offered through the survivorship program were specifically selected based on evidenced-based or best practices research and included appointments with psychologists, social workers, dieticians, oncology exercise specialists,

genetic counselors, a financial advocate, a pain physician specialist, a lymphedema specialist, and a fatigue specialist. Specialty referral services for smoking cessation and alternative exercise (e.g., tai chi, yoga) were also available. As noted above, all participants also completed one visit with a registered research nurse at intake.

All participants had equal access to all services, which were available at either no charge or a reduced fee to minimize any potential financial barriers. Furthermore, all providers were centralized within one system, which provided a unified referral process, and many of the services were offered at the same location. While study participants always had equal access to services, various protocols for services were established and removed over the course of the program to improve recruitment, retention, and overall service provision. For example beginning in April 2012, the initial intake with the research nurse was paired with a visit with a psychosocial screening by a social worker. Similarly, from February 2012 to March 2013, a participant's first exercise visit was coupled with a visit with the dietician. Some of the services also had restrictions on the frequency of use that were added over the course of the program. Specifically, participants were limited to 12 exercise sessions with the oncology-certified fitness trainers beginning in February 2012. In addition, from October 2011 through August 2013 participants were allotted eight free psychology visits, which beyond this session limit required a $25 fee per visit.

Measured Variables

The following demographic, psychosocial, and health information was obtained through self-report and medical chart review, where noted. All self-report study measures mentioned below also have validated Spanish-language versions. English-version copies of all open access self-report measures utilized in the proposed research can be found in Appendix C.

Outcome Variables

Distress: Psychological distress, one of the primary outcome variables of this study, was repeatedly measured using the BSI-18. The BSI-18 (Derogatis, 2001) is an 18-item self-report questionnaire designed to measure psychological distress. Participants are instructed to rate a list of behaviors and symptoms (e.g., "faintness or dizziness," "feeling blue") by how much they have been bothered by these behaviors and symptoms over the past week. The items employ a Likert-type scale from 0 (not at all) to 4 (extremely). The measure provides a total score, termed the Global Severity Index, as well as scores on three subscales: Somatization (6 items), Depression (6 items), and Anxiety (6 items). Higher scores on the individual subscales as well as the total score represent worse, levels of distress. The publisher of this measure has produced a validated, Spanish-language version of the BSI-18.

The BSI-18 is a shortened version of the Brief Symptom Inventory (53 items; BSI), which has demonstrated good reliability and validity in numerous research studies with samples of CS (e.g., Trask, Paterson, Griffith, Riba, & Schwartz, 2003), including some with longitudinal designs (e.g., Kornblith et al., 2003). Among a large sample of cancer patients, the internal consistency for the BSI-18 ($\alpha = .89$) was comparable to the full BSI ($\alpha = .95$) (Zabora et al., 2001). Factor analysis has also confirmed the dimensional composition of the BSI-18 and further established its appropriateness for use with cancer patients (Zabora et al., 2001). The Spanish-language version of the BSI-18 has also shown good internal consistency for the total score ($\alpha = .82$) and satisfactory structural validity with use among a sample of Spanish-speaking cancer patients (Galdon et al., 2008). Participants were asked to complete the BSI-18 at enrollment in ProComS and at 3 months, 6 months, and 12 months after enrollment.

Baseline BSI-18 scores were transformed into standardized T-scores according to the oncology normative sample published in the measure manual (Derogatis, 2001). Participants were categorized as either low or high distress based on baseline T-scores. Recent literature has determined that the original case-rule established for the BSI-18 (Derogatis, 2001) is not appropriate for use among CS and has suggested lower, alternative case rules (Merport & Recklitis, 2012; Recklitis & Rodriguez, 2007; Zabora et al., 2001). Consistent with this literature, participants who had a T-score greater than or equal to 50 on the BSI-18 Global Severity Index were classified as "highly distressed" and those with a T-score less than 50 on the BSI-18 Global Severity Index were classified as "less distressed."

Quality of Life: Information about QOL, another primary outcome variable, was obtained using the FACT-G (Version 4). The FACT-G is a measure of QOL of patients with cancer (Cella et al., 1993). It consists of 27 items, which are rated on a Likert-type scale as to how true each statement has been during the previous seven days, ranging from 0 (not at all) to 4 (very much). Example items include "I am bothered by side effects of treatment," "I feel close to my friends," and "I feel nervous." The measure contains four subscales representing physical, functional, social/family, and emotional well-being in addition to an overall score. Higher scores on each subscale, as well as a higher overall score, represent better QOL.

The FACT-G has been widely used with various samples of CS (e.g., Holzner et al., 2001; Levine & Balk, 2012) and has demonstrated appropriate reliability and validity. Specifically, the FACT-G has demonstrated high test-retest reliability for all of its subscales and its overall score (α = .82 - .92), excellent internal consistency for its total score (α = .89 - .92), and acceptable internal consistency for its subscales (α = .65 - .90) (Cella et al., 1993; Winstead-Fry & Schultz, 1997). The Spanish-language version of the FACT-G has shown comparable

psychometrics to the original English-speaking patient data with internal consistency coefficients ranging from .66 to .89 and good concurrent validity when compared to several similar measures (Cella et al., 1998).

A cancer patient normative sample with has also been published for the FACT-G (Brucker, Yost, Cashy, Webster, & Cella, 2005), and these norms were used to compare baseline QOL raw scores and T-scores of the current study sample to a larger reference population. A two-point difference on the FACT-G subscale raw scores and a five-point difference on the FACT-G total raw score were used as cut-offs for determining a minimally important difference between normative and study sample raw scores (Brucker et al., 2005; Webster, Cella, & Yost, 2003).

Although the FACT-G was originally designed for cancer patients receiving active treatment, it was chosen as the most appropriate and well-accepted measure for post-treatment cancer patients due to the absence of more survivorship-specific QOL measures. More general health-related QOL measures (e.g., Short Form-36) were deemed insufficient to address the unique challenges of oncology patients and thus were not selected for use in this study. Participants completed the FACT-G, as with the BSI-18, at enrollment in ProComS and at 3 months, 6 months, and 12 months after enrollment.

Service Utilization: Overall utilization of the various ProComS clinic services is the third primary outcome variable for this study. Service utilization is defined as participant attendance to ProComS services and is reported as the total number of service visits completed per month. In addition to a total number of visits per month, service utilization can also be broken down by service type. The following service types were offered through ProComS: psychological counseling, monitored exercise with an oncology exercise specialist, genetic counseling,

smoking cessation, social work consultation, dietary consultation, financial advocacy, pain management with a physician specialist, lymphedema consultation, alternative exercise (e.g., yoga, tai chi), and fatigue management. Service utilization information was collected from ProComS staff and service providers (e.g., psychology appointments) and through review of the medical record (e.g., exercise appointments, dietary consults). Of note, some services included additional telephone contacts that were not documented and therefore not included in the overall count of appointments. For instance, most participants who were referred for genetic counseling and testing had one in person visit and one or two follow-up telephone sessions with a genetic counselor, although service utilization varied according to individual need. Social workers, too, frequently contacted patients by telephone for brief, undocumented follow-up consultation on an as-needed basis.

Other Measured Variables

Demographic Characteristics: The current project collected the following self-reported demographic variables: age at baseline visit, gender (male or female), language preference (English or Spanish), education level (some high school, high school graduate/GED, some college/technical school, college graduate, or graduate school/professional degree), marital status (married, divorced, widowed, separated, never married, or member of an unmarried couple), race/ethnicity (Non-Hispanic white, Non-Hispanic black, Hispanic, Asian/Pacific Islander, Native American, and Other/Multi-racial), and distance from MCI. Mapping software ArcGIS version 10.2.1 was used to calculate the direct distance in miles between MCI and the centroid of each participant ZIP code. The majority of this information was self-reported on the CHQ (Rev. 09.05), which as noted above, is a tool designed for clinical use within the Division of Hematology/Oncology at the University of Texas Southwestern Medical Center. This form

collects information about personal medical history, family medical history, social history, and current subjective symptoms. Participants also reported personal and demographic information directly to study staff.

Illness Characteristics: The current project collected information about the following illness characteristics for each participant: primary cancer diagnosis, history of recurrence or multiple cancers, cancer stage (early stage [0, I or II] and late stage [III or IV]), time since diagnosis (in years), history of surgical treatment (yes or no), history of chemotherapy (yes or no), and a history of radiation treatment (yes or no). Information about medical history and illness history was collected from each participant using self-report questionnaires. The CHQ (described above) was the primary means of collecting information about illness history. However, some additional illness-related information was self-reported on the Pearlman-Mayo Survey of Needs and obtained by the research nurse during the History and Physical assessment. In addition, more comprehensive information about cancer history and treatment was collected via medical chart review for those participants who requested a treatment summary and care plan. As noted earlier, information from the medical chart review took priority over self-reported data whenever there was a discrepancy between the two sources. In instances where participants did not clearly identify a single cancer diagnosis as primary, the primary cancer diagnosis was inferred using date of diagnosis.

Physical Activity Index: At the time of enrollment participants were classified as either meeting or not meeting the current NCCN's recommended exercise guidelines for CS (National Comprehensive Cancer Network, 2013b), which are based on the U.S. Department of Health and Human Service national recommendations for adults (U.S. Department of Health and Human Services, 2008). Specifically, participants were classified as meeting the guidelines if they

reported at least 150 minutes of moderate activity per week, 75 minutes of vigorous activity per week, or a combination of moderate and vigorous activity totaling 150 minutes per week. Physical activity data were self-reported on the IPAQ (Short Last 7 Days Self-Administered Format).

The IPAQ (Craig et al., 2003) was designed to obtain data on health-related physical activity using a format that could be employed internationally. It consists of 7 questions that ask participants about the frequency and duration of various activities including vigorous exercise, moderate exercise, walking, and sitting. It is designed for use with young and middle age adults between the ages of 15 and 69. The version of the IPAQ used in the current study is a shortened version of the original 27-item IPAQ, which has previously been used in research with cancer patients (Johnson-Kozlow, Sallis, Gilpin, Rock, & Pierce, 2006; Oechsle et al., 2011). Test-retest reliability for this short, self-report version was acceptable (ρ = .74) and categorical estimates of sufficient physical activity (defined as 150 minutes or more) were repeatable with percent agreement ranging from 93 to 100 (Craig et al., 2003). The IPAQ also has displayed fair criterion validity (ρ = .26 - .27) when compared to accelerometers among United States samples (Craig et al., 2003). The Spanish-language version of the short form IPAQ has demonstrated only modest correlations (r = .55) between subsequent survey administrations and poor correlations ($r \sim .30$) between the Spanish-language IPAQ and accelerometer data (Medina, Barquera, & Janssen, 2013).

Comorbid Symptom Burden (comorbidity count): The comorbidity count provides a general estimate of comorbid symptoms that may impact health and overall functioning. The comorbidity count was computed from information provided in the Review of Symptoms section of the CHQ by summing the number of organ systems with self-reported concerns or problems.

Based on the number of endorsed symptoms, participants were classified as either "low," "moderate," or "high" on the comorbidity count. More specifically, participants who endorsed problems within 0-3 organ systems were considered "low"; within 4-7 organ systems were considered "moderate"; and within 8 or more organ systems were considered "high." Count scores could range from 0-13, as the Review of Symptoms section of the CHQ is comprised of 13 separate symptom clusters (excluding an open-ended "other" category) labeled by their overarching organ systems, such as respiratory, cardiac, and genitourinary.

A review of symptoms has been recognized as integral to identifying general symptom burden and persistent dysfunction among CS (LIVESTRONG Foundation, 2011). Furthermore the 13 organ systems included in the Review of Symptoms section of the CHQ are comparable to the 13 clinical problems (plus an "other" category) listed on the Self-Administered Comorbidity Questionnaire (Sangha, Stucki, Liang, Fossel, & Katz, 2003), which is a validated measure of comorbidity that has been used with CS to assess the presence of non-oncologic conditions (Smith et al., 2013).

Performance Status: The Karnofsky Performance Scale (KPS) was used to measure participant's performance status. KPS is a standard way of measuring functional capacity of cancer patients with scores ranging from 0 to 100. Lower scores indicate poorer physical or functional capacity. This scoring system was first created by David Karnofsky and Joseph Burchenal as a means for physicians to evaluate a patient's suitability for chemotherapy (Karnofsky & Burchenal, 1949). Physicians have since begun to more broadly use it to measure cancer patient's progress and prognosis. For this study, the research nurse clinically determined KPS at the intake visit based on subjective assessment of participant's ability to perform ordinary

tasks. KPS has demonstrated good construct validity and interrater reliability (r = .89, κ = .53) in use with cancer patients (Schag, Heinrich, & Ganz, 1984).

CHAPTER FIVE

STATISTICAL ANALYSES

Data were initially stored in a SQL-server database with a front-end ACCESS application. Data relevant to this proposed study were then imported into and analyzed by the Statistical Package for Social Sciences (SPSS) version 22.0 (IBM Corp., Armonk, NY). Prior to conducting the planned analyses, data were screened for outliers that may impact analysis and the distribution of outcome data was examined. Descriptive results were produced for all variables, including frequencies and percentages for categorical variables, and means and standard deviations for continuous measures. A thorough description of the study sample, including a breakdown of demographic and illness characteristics, was generated along with summary counts of the services utilized by the study cohort through February 2014. The primary outcome measures were quality of life (Functional Assessment of Cancer Therapy; FACT-G), psychological distress (Brief Symptom Inventory-18; BSI-18), and overall service utilization.

Preliminary one-way analysis of variances (ANOVA) and t-tests were performed on baseline distress and quality of life (QOL) variables to determine potential covariates for the statistical models. Specifically, these preliminary analyses examined differences in the baseline assessment of the outcome measures by gender, marital status, age, education level, race/ethnicity, comorbidity count, cancer type, cancer stage, baseline physical activity, distance from the survivorship clinic (median split), history of chemotherapy, history of radiation, history of surgery, history of recurrence or previous cancer, and time since diagnosis ($\leq$ 5 years or > 5 years). Variables showing a significant relationship with baseline outcome variables were included as covariates in the mixed models. This method of covariate selection by baseline comparisons avoided sample size reduction that would have occurred with univariate repeated

measure analyses and is consistent with other studies using mixed modeling techniques to examine change over time in cancer patients and their families (Heckman et al., 2011; Sterba, Swartz, Basen-Engquist, Black, & Pettaway, 2011).

All hypotheses were addressed using linear mixed modeling (LMM) techniques to assess change over time (Bryk & Raudenbush, 1987; Hedeker, 2004; Raudenbush & Bryk, 2002; Singer, 1998). A repeated measures model with random intercept and full maximum likelihood estimation was used for all longitudinal analyses. LMM was selected to evaluate longitudinal trajectories of psychosocial change as it has several distinct advantages over traditional regression techniques (Gibbons et al., 1993). First, LMM permits systematic analyses of variance at two levels. The first level analyzes individual growth rates for QOL and distress (i.e., within-subject variance over time). The second level examines between-subjects differences in the pattern of psychosocial change across time and considers time-invariant variables that might predict individual differences between subjects (e.g., race, gender, cancer diagnosis, cancer stage). The model was specified such that repeated measures of distress and QOL (level 1) were nested within each participant (level 2). The level 1 equations model the relationships between QOL across time and distress across time for each individual; level 2 equations identify if and how the overall relationships between these two psychosocial measures and time depend on the participants' individual and disease characteristics. Another key advantage of LMM is that it allows for missing observations as well as unequal measurement timepoints. Thus, even participants who did not have information at all study timepoints or had inconsistent data intervals were included in the analyses.

To account for the influence of missing data and dropout patterns, a more specific type of LMM, pattern mixture modeling, was tested for each aim (Hedeker & Gibbons, 1997; Little,

1995). Consistent with this approach, dummy variables representing patterns of missing data were used as grouping variables. First, to better understand differences in baseline distress, baseline QOL, and illness and demographic characteristics by patterns of data missingness, two dummy variables were created for each outcome variable (BSI-18 and FACT-G) to represent participants who completed all timepoints and those who had missing data for at least one timepoint. Chi square and *t*-tests were conducted to compare participants who completed all timepoints with those who had missing data for at least one time-point. Next, another eight dummy variables (four for psychosocial distress and four for QOL) were created to represent patterns of missing data based on the last available measurement wave for each participant. Chi-square and *t*-tests analyses compared frequency counts and averages among these various patterns of missing data for the following variables: gender, marital status (married vs. unmarried), age, education level, race/ethnicity (non-Hispanic white vs. minority), comorbidity count (low, medium, high), cancer type (breast cancer vs. other cancer type), cancer stage (early stage vs. late stage), baseline physical activity, distance from the clinic, history of chemotherapy, history of radiation, history of surgery, history of recurrence or previous cancer, service utilization, baseline distress, baseline QOL, and time since diagnosis. In these analyses, participants belonging to each pattern of missing data were compared to all other participants (e.g., participants who only completed baseline measures were compared to all other participants). The patterns that showed numerous significant differences in baseline outcomes measures and demographic or illness characteristics were included as covariates in the mixed models. Below is a more through description of the LMM models utilized to examine each aim.

Aim I: Examine the individual patterns of change in QOL and psychosocial distress among CS participating in a community-based cancer survivorship program over a 12 month time

period. To address Aim I, LMM analyses provided estimates of the changes in QOL and distress over time for each individual. Separate models were run with either QOL or distress as the dependent variable. Intercepts were allowed to vary by individual, and time since enrollment in months was included as a fixed covariate. Steeper slopes indicated that distress and QOL were changing more rapidly with time since enrollment. We expected there to be a significant within-person effect for time since enrollment for both psychosocial outcomes. Specifically, we expected QOL scores and distress scores to improve with longer time since enrollment. Following recommendations by Peugh and Enders (2005), three sets of models were conducted in a step-wise approach to determine the model of best fit. In the first set of models, no factors or covariates were included. This generated unadjusted estimates of the average QOL and psychosocial distress across participants (intercepts) and an average change in these values over the months of study participation (slopes). Next, covariates were added to the models as fixed factors. These models were then compared to the corresponding unadjusted models using the likelihood ratio test to determine if there was in improvement in model fit with the inclusion of controlling factors. Then, dummy variables for the pattern of missing data were added to the adjusted models. These models were compared to the previously adjusted model for improvement of model fit again using the likelihood ratio test.

While not part of the step-wise approach presented above, two additional LMM were run with time as a categorical fixed factor in order to further explore the pattern of psychosocial change displayed in preliminary analyses. Estimated marginal means and Bonferroni-corrected pairwise comparisons of these means were used to identify significant differences in change in psychosocial outcomes between timepoints. Covariates and dummy variables for patterns of missing data were included in these models.

Aim II: Identify baseline demographic and clinical characteristics associated with individual differences in the pattern of psychosocial change (psychological distress and QOL) over time. For Aim II, additional LMM analyses were used to examine between-group differences in changes of psychosocial functioning across time. These analyses examined whether differences in individual slopes could be predicted by demographic and clinical characteristics shown in previous investigations to be related to CS well-being and psychological distress. Specifically, four separate stratified models were conducted for each of the two outcome variables by adding baseline distress level (high vs. low), age (median split), comorbidity count (Low, Medium, or High), or time since diagnosis ($\leq$ 5 years or > 5 years) as a fixed factor of interest. Analyses focused primarily on interaction effects of the stratified variable and time. Covariates and dummy variables for missing data were also included as fixed factors in the models. Post-hoc interpretations were made using the marginal means and standard errors produced from the models.

Aim III: Explore the relationships between a) the type and amount of program service utilization (e.g., participation in psychological counseling, exercise) and b) the pattern of change in psychosocial outcomes (psychological distress and QOL) over time within the survivorship cohort. Analyses similar to those for Aim II were conducted for Aim III to examine the association between service utilization and change in psychosocial outcomes across time. First, overall service utilization was incorporated as a continuous covariate into a LMM for each outcome variable with the interaction of service utilization with time as the primary analysis of interest. Then, six additional stratified LMM analyses were conducted for each outcome variable (QOL and distress) to examine the impact of each service type (i.e., exercise, psychology, nutrition, financial advocacy, genetic counseling, or social work) on psychosocial change over

time (interaction of service type utilization with time). Specifically, a dichotomous utilization variable for each service type (e.g., did the participant attend exercise appointment(s)? Yes or No) was included as the fixed factor of interest. As with previous models, baseline covariates were included as fixed factors in the models. Post hoc interpretations were made using the estimated marginal means and standard errors produced by the models. Additional LMM analyses were conducted with sub-samples of the data to explore potential dosage (i.e., number of visits) effects of service types that displayed significant interaction effects on the pattern of change in QOL and psychological distress.

CHAPTER SIX

RESULTS

Characteristics of the Sample

A total of 394 cancer survivors (CS) attended an initial visit at the survivorship clinic, and of these, 291 were initially eligible and approached for the study. Thirty-two individuals were ineligible (due to time since diagnosis) and an additional 71 potential participants were never approached about the study (due to staffing or time limitations). Of the 291 who were eligible and approached, 205 (70.4%) consented to participate in the study. Among the 205 consented participants, 51 individuals were not yet eligible for 12-month follow-up at time of analyses and were, therefore, excluded from the present report. One participant withdrew before completing baseline questionnaires, and one additional participant did not complete either psychosocial measure at any timepoint. Thus, a total of 152 participants were included in the final analyzed sample. Table 2 displays participant sample size at each timepoint and study completion rates, defined as completion of the final study timepoint (12 months), for each psychosocial outcome measure.

Demographic and Illness Characteristics

Baseline demographic and illness characteristics were available for all 152 analyzed participants and are summarized in Table 3. The majority of the sample were female (n = 136, 89.5%) and Non-Hispanic white (n = 102, 67.1%) with an average age of 56.1 years (SD = 8.9). The sample was highly educated with 78.9% having attended at least some college; approximately half of the study sample was married (n = 79, 52.0%). Almost the entire sample spoke English as a primary language (n = 144, 94.7%). Seventy-five percent of participants lived within 13.8 miles of the clinic, and the median distance for all participants was 8.9 miles.

Distance from the clinic was not calculated for three participants whose ZIP codes were associated with areas containing only Post Office Boxes.

Regarding illness characteristics, the majority of patients reported a primary diagnosis of breast cancer (n = 117, 77.0%). Cancer stage was widely distributed; the majority of participants reported an early stage diagnosis (i.e., stage 0, I, or II; n = 101, 66.4%), but information about cancer stage was not reported for 20 (13.2%) participants. The median time since diagnosis was 1.6 years (M = 3.3, SD = 4.7, range = 0.08 - 33.2 years). Eighteen participants (11.8%) reported a history of at least one recurrence or secondary diagnosis with 10 (55.6%) reporting a recurrence of their primary cancer, six (33.3%) reporting a second primary cancer diagnosis, and two (11.1%) reporting a combination of recurrence and additional primary cancer diagnoses. Data about treatment history was collected for 147 (96.7 %) of the 152 participants. A history of chemotherapy, radiation, and surgery was documented for 108 (73.5%), 79 (53.7%), and 127 (86.4%) participants, respectively.

Comorbidity counts were relatively well distributed with 35 (23.0%) participants classified as low, 62 (40.8%) as medium, and 55 (36.2%) as high. Most participants (n = 108, 71.1%) demonstrated high functional capacity at intake (i.e., Karnofsky Performance Status score of 100%). Most participants (n = 90, 62.9%) did not meet current exercise recommendations for CS upon study entry. Of note, the Physical Activity Index was not calculated for nine study participants, as these individuals were outside of the appropriate age range (15 – 69 years old) for valid use of the International Physical Activity Questionnaire (IPAQ).

Baseline Psychosocial Functioning

Table 4 contains information about raw scores for both measures of psychosocial functioning at all timepoints including baseline. As measured by the Functional Assessment of Cancer Therapy (FACT-G), participants' average total quality of life (QOL) raw score at baseline was 77.9 (N = 151, SD = 18.4, range = 25 – 108). Baseline physical well-being subscale (PWB) scores averaged 20.5 (SD = 5.3, N = 152). Baseline emotional well-being subscale (EWB) scores averaged 17.7 (SD = 5.1, N = 152). Baseline functional well-being subscale (FWB) scores averaged 19.1 (SD = 5.7, N = 152), and baseline social/family well-being subscale (SWB) scores averaged 20.6 (SD = 6.2, N = 151). Baseline FACT-G scores displayed good internal consistency within the sample (α = .92). Baseline SWB, EWB, PWB and global FACT-G scores were slightly lower and FWB scores were slightly higher than the oncology-specific normative group; however, these differences did not exceed criteria for a minimally important difference (i.e., > 2 points for subscales, > 5 for total score; Brucker et al., 2005). Furthermore, baseline QOL T-scores were evenly distributed, with approximately half scoring below the average T-score of 50 (n = 74, 49%) and half above average (n = 77, 51%). Thus, at baseline the CS in the current study report a QOL that is similar to the general population of CS.

In regards to baseline distress as measured by the Brief Symptom Inventory 18 (BSI-18), participants reported an average Global Severity Index raw score of 14.3 (SD = 11.2, range = 0 – 53). Average baseline subscale scores included 4.5 (SD = 3.8) for the Somatization scale, 4.7 (SD = 4.7) for the Depression scale, and 5.0 (SD = 4.7) for the Anxiety scale. Like the FACT-G, baseline BSI-18 displayed good internal consistency in the sample (α = .90). Following a transformation from raw scores to t-scores using oncology-specific norms (Merport & Recklitis, 2012), 41 (27.0%) participants were classified as 'low distress' (t-score < 50) and 111 (73.0%)

were classified as 'high distress' (T-score ≥ 50) at baseline. This unbalanced distribution of high vs. low baseline distress scores suggests that the current study population was overall more distressed at study entry than the general population of cancer patients. Baseline distress and QOL total raw scores were significantly correlated (r = -.84, p < .001).

Overall Service Utilization

Information about service utilization includes all appointments through February 2014. Descriptive data for both the total number of service visits and broken down by service type are displayed in Table 5. In total, participants attended 2,203 multidisciplinary service appointments, which included encounters with psychology, genetic counseling, social work, nutrition, individual exercise, nursing, pain management, and financial advocacy. All participants received an initial nurse assessment (included in the total count of appointments reported above), which was completed during at least one in-person visit. One hundred forty five participants (95.4%) completed at least one additional service appointment beyond the initial nurse assessment. Participants completed a median of 13 encounters (M = 14, SD = 11.62) across the various disciplines. Exercise was the most frequently attended, with 85.5% (n = 130) of all study participants attending at least one individual exercise session. These participants attended a median of 11 (M = 12, SD = 10.9) exercise visits. Participants receiving nutrition services (n = 93) had a median of 1 visit each (M = 2, SD = 1.47), while those receiving psychological counseling (n = 29) attended a median of 5 (M = 6, SD = 5.10) sessions. Seventy-three participants met with a social worker for a median of 1 (M = 1, SD = 0.28) visit, and six participants met with a genetic counselor for one in-person visit each. Five participants met with a financial advocate for one visit each. Pain management was the least frequently attended service, as only one participant completed a single session within this discipline. The majority of

service utilization (n = 1552, 75.7%) occurred within the first three months of participant enrollment. As such, 12.2% (n = 250) of appointments occurred between 3 and 6 months of enrollment, and 12.2% (n = 249) occurred 6-12 months after enrollment.

Preliminary Analyses

Transformation of the Outcome Variables

A square root transformation was performed to reduce positive skewness in the BSI-18 global raw scores, and a reflected square root transformation was performed to reduce negative skewness in FACT-G total raw scores. Table 4 presents total raw and transformed scores for both psychosocial outcomes at all timepoints.

Determination of Covariates

In order to determine model covariates, multiple one-way Analysis of Variance (ANOVA) and independent sample t-tests were conducted to understand relationships between the wide array of demographic and clinical characteristics and baseline assessment of the outcomes of interest. These analyses reflected significantly lower mean baseline global BSI scores among participants who lived closer to clinic (M = 3.14, SD = 1.53) compared to those who lived further away (M = 3.70, SD = 1.59), $t(147) = -2.20$, $p = .03$. Comorbidity count also was significantly associated with mean differences in baseline global distress among participants ($F(2, 149) = 17.17$, $p < .001$). Participants classified as low comorbidity (M = 2.25, SD = 1.33) reported significantly less distress than participants classified as either medium (M = 3.55, SD = 1.45) or high (M = 4.05, SD = 1.46) per post-hoc analysis ($p < .001$). While no significant group difference was observed in mean baseline distress by marital status, $t(150) = -1.87$, $p = .064$, married participants (M = 3.21, SD = 1.46) trended towards having lower baseline distress than unmarried participants (M = 3.68, SD = 1.68).

Regarding QOL, those participants living further from the clinic (M = 5.61, SD = 1.71) reported worse baseline QOL than those living closer to the clinic (M = 4.98, SD = 1.61), $t(146) = -2.32$, $p = .02$). In addition, married participants (M = 4.94, SD = 1.65) reported significantly better baseline QOL than unmarried participants (M = 5.73, SD = 1.64), $t(149) = -2.97$, $p = .003$. There was also a significant difference in baseline QOL between individuals with a low and high level of baseline distress, $t(103.26) = -12.82$, $p < .001$, such that participants with a lower baseline distress (M = 3.47, SD = 0.92) reported better baseline QOL than participants with high distress at baseline (M = 5.98, SD = 1.38). Finally, significant differences in mean baseline QOL scores were observed within comorbidity count, $F(2, 148) = 17.49$, $p < .001$. Post-hoc analyses revealed significant mean differences ($p < .01$) among all three groups such that those classified with a high level of comorbidity (M = 6.17, SD = 1.63) displayed worse QOL than participants classified as medium (M = 5.16, SD = 1.62) or low (M = 4.24, SD = 1.17), and participants classified as medium reported significantly worse distress than those classified as low. Based on these analyses, marital status, distance from clinic, and comorbidity count were included as covariates in subsequent analyses examining changes in both psychological distress and QOL over time.

Analysis of Response Pattern

Sixty-eight individuals completed all four timepoints for the BSI-18 and the FACT-G. The 68 who completed all four timepoints for the BSI-18 were significantly less distressed at baseline than those who did not complete the BSI-18 at all four timepoints, $t(150) = 3.95$, $p < .001$. Additionally, individuals who completed the BSI-18 at all timepoints attended significantly more service visits than those participants with missing data, $t(143) = -3.43$, $p = .001$. Otherwise, there were no significant differences in gender, age, time since diagnosis,

cancer type, race/ethnicity, treatment history, comorbidity count, baseline physical activity level, education level, or marital status between those who completed the distress measures at all timepoints and those who did not. Similar to distress, there was a significant relationship between service utilization and the completion of QOL measures at all timepoints, $t(144) = -3.57$, $p < .001$. Participants who had completed QOL measures at all timepoints attended more service visits than participants who did not complete a QOL assessment at all timepoints. Individuals who completed all timepoints also reported significantly higher baseline QOL scores than those participants with missing data, $t(149) = 3.37$, $p = .001$. There were no other significant differences between those 68 participants who completed the FACT-G at all four timepoints and those who had missing QOL data for at least one timepoint ($p \geq .05$). These initial comparisons suggest that participant response may be associated with outcome variables such that missing data may be non-ignorable or not "missing at random," as defined by Little and Rubin (Little & Rubin, 1987; Rubin, 1976). That is, the probability of non-response may depend on unobserved outcomes, such as worsening QOL or distress, and/or measured covariates.

To further understand and account for the pattern of missing data, chi-square and *t*-tests were performed to explore differences in baseline demographic and illness characteristics and baseline assessment of outcomes of interest by dropout pattern. Specifically, participants were classified into one of 4 groups based on the last available measurement wave (baseline, 3 months, 6 months, or 12 months). Tables 6 and 7 display descriptive information (averages, standard deviations, and frequency counts) by dropout pattern for FACT-G and BSI-18, respectively. For both FACT-G and BSI-18, participants who dropped out after baseline and participants who completed the final wave of assessment displayed the most differences in baseline characteristics. Specifically, those who dropped out after baseline for both psychosocial

outcomes were significantly younger than all other participants (BSI-18, $t(150) = 3.77$, $p < .01$; FACT-G, $t(150) = 3.77$, $p < .01$). In contrast, those who completed the final wave of assessment were significantly older than participants who did not complete a 12-month assessment (BSI-18, $t(150) = -3.40$, $p = .02$; FACT-G, $t(150) = -2.01$, $p = .047$). Overall service utilization displayed significant difference by last available measurement wave, such that those who dropped out after baseline attended significantly fewer visits than other participants (BSI-18, $t(150) = 3.04$, $p = .003$; FACT-G, $t(150) = 3.03$, $p = .003$), and those who completed the study attended significantly more service appointments than participants who dropped out at any earlier timepoint (BSI-18, $t(150) = -4.15$, $p = .03$; FACT-G, $t(150) = -2.23$, $p = .027$). This suggests that participants who did not complete the final assessment wave of study questionnaires may have also stopped participating in program services. For both BSI-18 and FACT-G, those who completed the final wave were newer to survivorship (BSI-18, $t(81.41) = 2.28$, $p = .03$; FACT-G, $t(92.23) = 2.01$, $p = .048$) and a larger percentage identified as White than those who dropped out (BSI-18, $\chi^2(n = 152, df = 2) = 4.89$, $p = .03$; FACT-G, $\chi^2(n = 152, df = 1) = 5.97$, $p = .02$). Significant differences in baseline distress and QOL were also observed between the first and last patterns of dropout. Baseline distress scores were high among those who dropped out after baseline assessment, $t(150) = -3.10$, $p = .002$, and low among those who completed the final assessment wave, $t(150) = 3.02$, $p = .003$. A comparable pattern was observed for QOL scores. Lower QOL scores were observed among those who dropped out at baseline, $t(149) = -2.85$, $p = .005$, and higher scores among those who completed a FACT-G after 12-months of study enrollment, $t(149) = 2.65$, $p = .009$. Few significant differences in baseline characteristics were observed for the other two patterns of dropout for either distress or QOL data. On the basis of

these analyses of response pattern, two patterns of dropout (baseline and 12-month) were included in LMM analyses as fixed factors to help account for the impact of missing data.

Results of Linear Mixed Models

Aim I: Change Over Time (Within-Subject Effects)

A set of unadjusted, adjusted, and adjusted with dummy variables models were run to examine the change in psychological distress and QOL over time, and likelihood ratio tests were conducted to compare model fits. The adjusted model was a significantly better fit for distress (-2 Log likelihood = 1449.14 for unadjusted vs. 1391.75 for adjusted, $df = 4$, $p < .01$) and QOL (-2 Log likelihood = 1401.87 for unadjusted vs. 1346.65 for adjusted, $df = 4$, $p < .01$) than the unadjusted model. A comparison of the fixed effect for time in the adjusted and unadjusted models is displayed in Table 8, and Table 9 provides a summary of fixed effects for all variables included in the adjusted models. Including the dropout patterns in the adjusted model improved the fit for both the distress (-2 Log likelihood = 1391.75 for unadjusted vs. 1377.93 for adjusted with dummy variables, $df = 3$, $p < .01$) and QOL (-2 Log likelihood = 1346.65 for adjusted vs. 1338.01 for adjusted with dummy variables, $df = 3$, $p = .03$) models. Thus, the adjusted model with dummy variables was the best fit of the three models.

Table 10 displays a summary of the estimated fixed effects for the adjusted with dummy variables models. When controlling for marital status, distance from clinic, comorbidity count, and patterns of missing data, significant changes in both QOL, $F(1, 250.34) = 7.93$, $p = .01$, and distress, $F(1, 249.35) = 13.31$, $p < .01$, were observed over time. Specifically, a significant improvement in QOL was observed over time such that (inversely) transformed QOL scores decreased by 0.024 units for each month of enrollment ($p = .02$). Transformed distress scores also improved over time with a decrease of 0.031 units for each month after enrollment ($p = .01$).

Overall, these findings suggest significant improvements in both QOL and psychological distress among program participants across the 12-month intervention period. The 12-month Completer Pattern x Time effect for distress was significant, $F(1, 249.35) = 4.59$, $p = .03$, indicating that that the improvement in distress across time was significantly more pronounced for dropouts than completers. In contrast, the 12-month Completer Pattern x Time interaction was not significant for QOL ($F(1, 250.36) = 2.34$, $p = .13$), suggesting that improvement in QOL across time was not significantly different for dropouts than completers.

Two additional adjusted LMM analyses were conducted to compare differences in the amount of change between the four timepoints. As with the previous model, marital status, distance from clinic, comorbidity count, baseline dropout pattern, and 12-month completer pattern were included as fixed factors. Table 11 displays coefficients for the estimated fixed effects for these models and Figures 2 and 3 display estimated marginal means at each timepoint for QOL and distress, respectively.

Results for psychological distress indicate that time was significantly associated with distress, $F(3, 202.45) = 9.43$, $p < .01$. Pairwise comparisons (Bonferroni corrected) of estimated marginal means for distress were conducted to examine differences in distress scores by time point when collapsing over all other fixed factors in the model. These comparisons displayed significant differences between baseline distress and distress scores at all other time points ($p < .01$). Differences in marginal means for distress were not significant between any other time points. The largest sequential decrease in distress was observed between baseline and 3 months (Mean difference = 0.417, $p < .01$), followed by the non-significant difference between 3 and 6 months (Mean difference = 0.15, $p = .96$), and 6 and 12 months (Mean difference = -0.088, $p = 1.00$). These findings suggest that distress improved the most during the first three months of

study participation and continued to remain significantly lower than baseline scores throughout study participation.

Time was also significantly associated with QOL, $F(3, 214.70) = 5.85$, $p < .01$, and Bonferroni-corrected pairwise comparisons revealed that the marginal mean estimates for QOL at 3 and 6 months were significantly different from baseline ($p < .01$). No other pairwise comparisons of QOL estimated marginal mean scores were significant. QOL showed a pattern of change over time similar to distress, such that the largest and most significant sequential decrease in QOL was observed between baseline and 3 months (Mean difference = 0.327, $p < .01$), followed by the non-significant difference between 3 and 6 months (Mean difference = 0.032, $p = 1.00$), and finally 6 and 12 months (Mean difference = -0.001, $p = 1.00$). These comparisons suggest that QOL improved the most during the first 3 months of study participation and remained low until the 6-month time-point. However, the lack of a significant difference between baseline and 12-month QOL scores may suggest that QOL scores worsened somewhat during the last 6-months of study enrollment.

Aim II: Demographic and Illness Characteristics (Between Subject Effects)

Analyses for Aim II explored whether illness and demographic characteristics relevant in other investigations of cancer survivorship were associated with the change in psychosocial outcomes over time. In particular, this study examined the influence of age, comorbidity count, time since diagnosis, and baseline distress level on the pattern of change in distress and QOL over time. The unstandardized coefficients and standard errors for all the variables included in each of the LMM analyses conducted for Aim II are provided in Tables 12 through 15. As with Aim I analyses, marital status, distance from clinic, comorbidity count, baseline dropout pattern, and 12-month completer pattern were accounted for in all models as fixed factors.

The first set of LMM for Aim II included baseline distress level (high vs. low, as indicated from the BSI-18) as the fixed factor of interest. There was not a significant Distress Level x Time interaction for distress, $F(1, 251.27) = 0.20$, $p = .66$, or QOL, $F(1, 268.645) = 0.27$, $p = .61$, which suggested that participants with high distress at the start of the study did not differ in the rate of psychosocial change over time from participants with lower baseline distress. This was inconsistent with our hypothesis, which predicted that those who were more distressed would show a more pronounced rate of change than participants who were less distressed at study enrollment.

In the second set of LMM for Aim II, a median split of age was included as a fixed factor in the models. The Age x Time interaction effect was not significant for either QOL, $F(1, 164.16) = 0.05$, $p = .82$, or distress, $F(1, 165.18) = 0.07$, $p = .80$, suggesting that rates of change in the two psychosocial outcomes do not vary by age. Of note, when age was entered into the models as a continuous covariate, the interaction effects remained non-significant ($p > .05$).

The third set of LMM analyses for Aim II examined the impact of comorbidity (low, medium, high) on changes of psychosocial functioning over time. An interaction effect between comorbidity count and time was observed for distress, $F(2, 163.35) = 4.52$, $p = .01$. Inconsistent with our hypothesis, individuals classified as either high ($b = -0.06$, $SE = 0.03$) or medium comorbidity ($b = -0.05$, $SE = 0.03$) displayed more pronounced improvement in distress for each month of enrollment than those with the lowest level of comorbid symptoms. However, the Comorbidity Count x Time interaction was not significant for QOL ($F(2, 163.13) = 0.59$, $p = .56$), suggesting that level of comorbid symptom burden was not associated with the rate of improvement for QOL over time.

In the final set of LMM analysis for Aim II, time since diagnosis was added as a fixed factor with two levels (≤ 5 years vs. > 5 years since diagnosis). A Time Since Diagnosis x Time interaction was not significant in the QOL model, $F(1, 166.14) = 0.08$, $p = .78$, or in the distress model, $F(1, 166.94) = 0.06$, $p = 0.81$, showing no differences in the rate of psychosocial change between early and late survivors. This is inconsistent with our hypothesis, which predicted that survivors newer to survivorship would improve at a greater rate than those who were further along into survivorship. When time since diagnosis was entered into the models as a continuous covariate, there continued to be no significant interaction effect for either psychosocial outcome.

Aim III: Service Utilization

For the final aim, LMM analyses were conducted to explore the impact of service utilization on the change in psychosocial outcomes over time. Table 16 contains the unstandardized coefficients and standard errors for the estimates of fixed effects for these two models. First, the total number of appointments attended was entered as a continuous covariate to the models, which also included comorbidity count, marital status, distance from the clinic, baseline dropout pattern, and 12-month completer pattern as fixed factors. Service Utilization x Time interaction effects were non-significant for both models (QOL, $F(1, 156.84) = 1.66$, $p = .20$; distress, $F(1, 155.18) = 1.21$, $p = .28$), suggesting that service utilization was not associated with the rate of psychosocial improvement over time. This was inconsistent with our hypothesized positive association between service utilization and psychosocial improvement over time. When service utilization was entered into the models as a fixed factor (median split), rather than a continuous variable, the Service Utilization x Time interaction effects remained non-significant.

Next, six separate models were run for each psychosocial outcome to examine if receipt of a particular service type predicted individual's change in QOL and distress over time. For QOL, the only significant Service Type x Time interaction effects were observed for exercise, $F(1, 155.03) = 4.19$, $p = .04$, and nutrition services, $F(1, 158.68) = 6.14$, $p = .01$. These interaction effects indicate that those who attended exercise and nutrition services displayed improved QOL at a more pronounced rate than those who did not. The unstandardized coefficients and standard errors for the two LMM analyses predicting QOL with Exercise and Nutrition attendance are displayed in Tables 17 and 18**,** respectively. All other services (inclusive of psychology, social work, genetic counseling, financial advocacy) had non-significant interactions with time for QOL, indicating no difference in rate of QOL change between those who utilized each service compared to those who did not.

To follow-up on the significant interactions effect for exercise and nutrition services, two additional LMM analyses were conducted to examine dose-dependent effects of attendance of these services on change in QOL across time. These analyses included only those participants who received exercise services ($N = 130$) or nutrition services ($N = 93$), and exercise and nutrition attendance were entered as continuous variables. Tables 19 and 20 contain the estimates of fixed effects for all variables included in these analyses. Both the Number of Exercise Appointments x Time, $F(1, 137.80) = 0.08$, $p = .77$, and the Number of Nutrition Appointments x Time, $F(1, 104.49) = 0.11$, $p = .92$, interaction effects were insignificant, suggesting that the amount of appointments attended was not associated with a the rate of change of QOL over time; attending more nutrition or more exercise appointments was not associated with a more pronounced rate of improvement in QOL. Interaction effects remained insignificant

when exercise and nutrition attendance were entered as quartile-split and median-split fixed factors, respectively ($p > .05$).

Models assessing changes in distress, revealed no significant Service Type x Time interaction effects for changes in distress over time. The lack of an interaction effect is inconsistent with our hypothesis, which expected some services to be associated with more pronounced improvements in distress than other services.

CHAPTER SEVEN

DISCUSSION

Overview of the Study

The purpose of this study was to examine the association between participation in a community-based cancer survivorship program and change in psychosocial functioning over time. In Aim I we examined patterns of change in quality of life (QOL) and psychological distress over a 12-month period of program participation. Aim II focused on associations between changes over time in psychosocial functioning (QOL and psychological distress) and baseline demographic and clinical characteristics (time since diagnosis, age, level of comorbidity, and baseline distress). In the third aim we explored associations between program service utilization and the pattern of change in psychosocial outcomes over time.

Discussion of Aim I Findings

Participants displayed significant improvements in both QOL and distress during the 12-month period following enrollment in the survivorship program. This improvement in psychosocial well-being suggests that, in general, the cancer survivorship program was effective in addressing the unmet psychosocial needs of CS. The largest improvements in QOL and distress occurred during the first three months of study participation, and while psychosocial functioning improved overall, it appeared to level out in the last six months of enrollment. This pattern mirrors participants' involvement with the program, as nearly three-fourths of services were received during the first three months of participant enrollment. CS attended the fewest appointments (12.2% of all services provided) after six months of enrollment. Giese-Davis and colleagues (2012) have observed a similar response among groups of cancer outpatients participating in supportive care services, such that patients/survivors benefitted from intervention

the most during the first three months with subsequent attenuation of the positive effects over a year.

The statistically significant changes in psychosocial outcomes among CS also have clear clinical implications. Based on the BSI-18 oncology cut-off scores, 73% of the study sample were highly distressed at baseline; this proportion dropped to 61%, 56%, and 55% at 3, 6, and 12 months, respectively. Like distress, the improvement in QOL has clinical importance. The six-point improvement observed in average FACT-G raw total scores over time exceeds criteria for a clinically meaningful difference in QOL (Brucker et al., 2005; Webster et al., 2003). Similarly, when observing T-score changes in QOL, the number of participants with below average QOL decreased from nearly half (49%) to just more than a third (37%). Cella and colleagues (2002) found that small raw score improvements in the FACT-G can have significant clinical meaning, even when accounting for ceiling effects. Overall, results interpreted with an emphasis on clinically meaningful change reveal promising improvements associated with the community survivorship program.

Discussion of Aim II Findings

Aim II analyses addressed whether specific demographic and clinical factors were disproportionately related to the rate of change in psychosocial outcomes. Baseline distress was not associated with rate of change of either psychosocial outcome over time. That is, baseline distress level, as measured by the BSI-18, was not helpful in determining how well patients responded to intervention. This finding is inconsistent with large-scale examinations of the effect of psychosocial interventions on cancer patients. For instance, pre-intervention distress was found to significantly moderate intervention effects in a meta-analysis of psychosocial treatments targeting anxiety and depression in cancer patients (Schneider et al., 2010). Similarly,

in a meta-analysis of psychological interventions with cancer patients, Sheard and Maguire (1999) found large effect sizes for interventions targeting individuals with high psychological distress; although their observations were based on a small number of studies. Furthermore, the moderation effect of baseline distress may not be restricted to psychological interventions, as Hart et al. (2012) found that a cancer genetic counseling and screening intervention was particularly effective for reducing cancer-related intrusive thoughts among participants with greater baseline distress. However, research on the impact of baseline distress on response to treatment among cancer patients is mixed. For example, Classen et al. (2008) noted that highly distressed breast cancer patients participating in a group therapy intervention did not derive greater benefit from treatment than less distressed participants.

The definition of high vs. low distress categories could explain the lack of an interaction effect between time and baseline distress. Indeed, a lower T-score cut-off was utilized in accordance with recent survivorship literature rather than the cut-off recommended by the BSI-18 handbook. Perhaps a higher threshold of distress than was used in this study is required to differentiate between highly and less distressed CS, and differences in the response to treatment over time by baseline distress level may have been observed if a higher case rule was used. However, using a higher cut-off score would have notably reduced the number of individuals classified as high distress and would not have been consistent with published guidelines for understanding distress levels in CS.

Also contrary to study hypotheses, age was not associated with the rate of change in psychosocial variables. Previous literature has been inconsistent with this finding, since other studies have noted more pronounced rates of change in psychosocial functioning among older patients (Avis et al., 2013; Dunn et al., 2013; Giese-Davis et al., 2012). It is possible that the

current sample did not include enough variation in age to detect age differences, as nearly three-fourths (72%) of the study participants were over 50 years old. Furthermore, as noted by Stanton, Danoff-Burg, and Huggins (2002), coping strategies may predict adjustment during cancer survivorship above and beyond age. Other individual characteristics not measured in this study may have confounded the effect of age over time, especially as study participants may have learned new coping strategies through the intervention.

Contrary to the original hypotheses, CS with a low number of comorbidities were more resistant to improvement in distress than participants with medium or high comorbidity. It may be that individuals with medium or high comorbidity had more symptoms, health concerns, and unmet needs that benefited from programmatic intervention targeting emotional functioning. In support of this idea, comorbidity count was significantly correlated with the number of post-intake service appointments ($r = .173$, $p < .001$), such that individuals with a medium or high comorbidity classification also appeared to attend a larger number of service visits. This association might suggest that patients with a medium to high level of comorbid symptoms expressed a greater need or received greater benefit from post-intake service visits than individuals with lower comorbidity, especially since participants self-selected the type and frequency of services. Changes in overall well-being among CS may be less affected by comorbidity than changes in psychological distress, since no significant differences in the rate of improvement in QOL were observed by number of comorbid conditions.

Improvement in psychosocial variables over time was not associated with time since diagnosis. Few psychosocial interventions have been directed toward long-term survivors, and even less have compared the rate of adjustment among early and late-term CS. Findings from this study suggest that CS, regardless of time since diagnosis, experience a similar benefit from

participation in a survivorship program. This finding was inconsistent with our hypothesis, which predicted that CS newer to diagnosis would display psychosocial improvement at a greater rate than later-term CS. Perhaps the long-term CS who enrolled in the survivorship program represent a subset of long-term CS who have continued to experience distress well into survivorship. In support of this idea, no significant differences in baseline psychosocial functioning by time since diagnosis were observed. Holzner and colleagues (2001) also found that long-term CS (greater than 5 years post-treatment) experience restrictions in QOL that are similar to those in the initial phases after cancer treatment, and work by Kornblith et al. (2003) reported the persistence of psychological sequelae, particularly symptoms of posttraumatic stress disorder, among long-term cancer patients. Findings from the current study suggest that late-term CS may equally benefit from psychosocial interventions, and in fact, may maintain a need for services to improve their functioning.

Overall, few of the examined demographic or illness related characteristics were helpful in predicting between-participant differences in rate of psychosocial improvement. Only comorbidity count differentiated between those CS who may have a greater or lesser response to intervention.

Discussion of Aim III Findings

Like several of the demographic and illness characteristics presented above, service utilization (i.e., the number of service appointments attended) did not significantly impact the rate of change in psychosocial outcomes over time. Regardless of the number of appointments attended, participants' QOL and distress improved at the same rate. It might be that participants received adequate support in the first enrollment visit and nursing assessment to promote sustained improvement. All participants in the current study received a considerable amount of

both generalized and targeted information about cancer survivorship at enrollment. Combined with the individualized attention of supportive care staff familiar with the needs of CS, this information may have fostered some of the improvement over time observed in this study. Indeed, Meneses and colleagues (2009; 2007) found that a psychoeducational intervention alone was effective in improving QOL over a 6-month time period among groups of breast CS, including CS in underserved or rural areas. Also, Carlson et al. (2010) found that new cancer patients who received full psychosocial screening, a personalized feedback report, and referral options reported less distress after three months than patients who received minimal screening only. The intake visit and referral process likely had lasting, positive effects on QOL and distress and principally contributed to the notable improvement during the first 3-months of program participation. These results suggest that, in general, relatively brief survivorship care may help improve psychosocial functioning by helping to normalize and validate patients' experience while also providing helpful information on navigating the survivorship phase of cancer care.

While overall service utilization did not predict response to treatment, some service types were associated with varying rates of improvement in QOL. Specifically, participants who received nutrition and exercise services showed greater improvement in QOL during the 12-month period than participants who did not receive these service types. These results support previous literature highlighting exercise and nutrition as key and efficacious components of survivorship care (Aziz, 2002; Blanchard et al., 2008; Stull, Snyder, & Demark-Wahnefried, 2007). Regular exercise and a healthy diet are prominent among recommendations for CS (National Comprehensive Cancer Network, 2013b; Wolin, Dart, & Colditz, 2013), and perhaps attending exercise and nutrition appointments helped CS feel an increased sense of well-being as

their own behaviors became better aligned with ideal standards of survivorship care. Furthermore, poor QOL of life has been associated with obesity, fatigue, and limited mobility among CS (Basen-Engquist et al., 2009; Janz et al., 2007; Smits, Lopes, Das, Bekkers, & Galaal, 2014). By targeting these physical concerns, nutrition and exercise may have better addressed QOL needs among the study participants receiving these services. Indeed, the physical and functioning well-being subscales of QOL have demonstrated strong associations with meeting physical exercise guidelines among CS (Peddle, Au, & Courneya, 2008). In addition, these positive effects of exercise and nutrition may be more immediately visible to patients than the effects of services like social work and psychology, which require longer lengths of time and result in less observable changes to functioning. That is, not all program services may have encouraged change in QOL that would have been observable within 12-months. Other services associated with an observable or quick change, like financial advocacy or genetic counseling, simply may not have had the power to document a more pronounced rate of improvement.

Unlike QOL, no services, regardless of visibility or immediacy of effects, were associated with a greater or lesser rate of change in distress. While QOL is multidimensional and measures several aspects of well-being, including more overt aspects of physical and social well-being, distress is concerned with less visible emotional and mental health. Thus, effects of services such as nutrition and exercise, which are targeted at physical well-being, may not be captured in measures of distress. In addition to this conceptual limitation of distress, the measure itself, the BSI-18, may have been restricted in its ability to address the nuanced improvements or benefit of certain types of services. For instance, positive benefits of social work and psychology services, such as feelings of acceptance, support, relief, and hope, are likely not captured by the BSI-18 subscales of Anxiety, Depression, and Somatization.

Of all the available program service types, it was particularly surprising that participation in psychological services was not associated with a faster rate of improvement in distress since counseling theoretically best targets psychological health. Counseling and psychotherapy encompass a wide variety of techniques that are often chosen or employed in response to patient-specific needs. While psychological counseling has demonstrated effectiveness in improving mental health problems among cancer patients (Osborn et al., 2006), this study did not document if evidence-based approaches to care were uniformly utilized across all of the participants. The use of varied approaches or therapeutic techniques, while likely clinically appropriate on a patient-by-patient basis, may be associated with different trajectories and types of change across participants. When aggregated, this variation may have made it difficult to detect significant differences among those who received psychology services and those who did not, especially since a relatively small proportion of the study sample received psychological counseling.

It should also be noted that in post-hoc analyses, CS who engaged in psychology services had significantly worse baseline psychological distress ($M = 4.26$, $SE = 0.29$) and baseline QOL ($M = 6.31$, $SE = 0.30$) than those who did not attend a psychology appointment (distress, $M = 3.38$, $SE = 0.16$; QOL, $M = 5.24$, $SE = 0.17$). Therefore, this group may represent individuals with particularly intractable psychosocial concerns and are unlikely to show disproportionately higher rates of psychosocial improvement. Even though baseline distress was not related to significant differences in outcome change trajectories, the qualitatively different nature of high distress may play a role in the nature of response to psychological service provision. All improvements in distress may not have equal clinical relevance; improvement from highly to more moderately distressed (as seen among those engaging in psychology services) may actually have more clinical relevance than the same numeric improvement from moderate to low distress.

Clinical Relevance and Practical Recommendations

This study is one of the first to examine patient-reported outcomes among a group of CS participating in a cancer survivorship program. By characterizing the trajectory of both QOL and psychological distress during CS' participation in a survivorship program, this study sheds light on the ability of cancer survivorship programs to improve psychosocial functioning. Furthermore, findings from this study provide useful suggestions for the development and design of survivorship programs. Chiefly relevant to clinical application, study results suggest that "a little intervention goes a long way;" CS displayed overall improvements in psychosocial functioning during program participation and no added benefit of multiple service sessions was found. In addition, survivorship programs may be wise to focus services on the first three months of participation, since service attendance and intervention response may be the greatest during these initial few weeks. These recommendations may be particularly helpful for survivorship programs with limited resources and capital as well as for CS who are interested in survivorship care but have limited time availability. Another suggestion is that programs should not enforce strict age or time since diagnosis limits, since it appears that participants at any stage of life or phase of survivorship benefit equally from survivorship services.

Limitations and Future Directions

Several study limitations originated from the initial study design and methodological procedures. Most notably, the lack of a comparison group (either randomized or non-randomized) restricted interpretation of results, as the largest interpretive challenge stems from making sense of the psychosocial trajectories in the absence of a non-intervention comparative sample. It is possible that the overall improvements in psychosocial functioning better reflect further time since diagnosis instead of intervention effects. That is, perhaps the observed

improvements in QOL and psychological distress would be noted even in the absence of an intervention. Among observational (i.e., non-interventional) studies, Kwak and colleagues (2013) found that adolescent and young adult survivors of cancer experienced a significant decline in distress (as measured by the BSI-18) over a one-year period, and Ganz et al. (2011) reported significant recovery of both physical and mental aspects of QOL over a 12-month period after treatment. However, these studies did not control for outside participation in supportive services, and both studies were only concerned with patients during the first year after primary treatment completion. Typically, this "reentry" period is associated with the largest amount of change in psychosocial functioning, with later survivorship periods beyond the first year of treatment being more stable (Helgeson et al., 2004). The current study sample included greater variation in the time since diagnosis, as most individuals (70%) enrolled beyond their first year post-treatment, when change is less common. Though participants may have improved over time regardless of receiving an intervention, there is evidence to support the idea that participation in survivorship programming may enhance this improvement, especially among CS beyond one year from the end of treatment.

A second methodological challenged focused on the non-standardized way in which patients were "assigned" to various program services. Following guidance from the initial nursing assessment to pinpoint unmet needs, program participants self-selected the type and frequency of services they attended. In this way, service utilization was based on patient need rather than manipulated assignment (as in a randomized controlled trial) or a strict program regimen of services. This pragmatic study design allowed for a combination of assessment- and patient-driven service selection that is consistent with routine clinical practice within community clinics. Therefore, results from this study may provide a more practical reflection of patient

involvement and response to intervention at the community level. As discussed by Roland and Torgerson (1998), pragmatic study designs are integral to making robust and thorough conclusions about intervention effects, and including the clinically relevant patient factors provides a valid perspective. However, since participants were not randomly assigned to the various service types, meaningful comparisons of the effects of different service types on psychosocial outcomes are tenuous. Furthermore, the non-standardized method of service assignment may reduce external validity and add a level of participant selection "error" that must be considered when interpreting the data. Although the current study procedure of need-based (versus random or structured assignment) service attendance is more consistent with real-world application, future studies are needed to replicate the results within a different context and with a distinct cohort.

Several additional limitations originate from a lack of consistent recruitment and referral procedures. First, the convenience sampling of the current study, whereby participants could enroll in the program regardless of initial levels of distress, may have facilitated a floor effect. Linden and Girgis suggest that this effect is common among psycho-oncology research and results in small treatment effects (2012). In the present study, such a floor effect could have potentially attenuated the effect of the program intervention. However, a significant improvement over time was still observed and study participants were actually more distressed at study entry than comparable oncology samples. Second, the changes to study eligibility criteria and availability of services introduced additional variability to the study design. Participants who enrolled early in the study when eligibility criteria were more restrictive may be qualitatively different than those who enrolled at a later date. Also, the addition of limits on the amount of sessions by service type may have reduced the effectiveness of certain services or

made them less acceptable to CS looking for ongoing support. Third, there was no control for participant's use of external resources that may have impacted distress or QOL. It is unclear if outside factors may have influenced, either negatively or positively, a participant's well-being or psychological health. Hypothetically, the effect of external resources may have masked effects of program participation on psychosocial functioning. Overall, future studies that utilize comparison groups, alternate modalities of service assignment, and consistent recruitment can help shed light on the potential complications associated with current study methodology.

Another important limitation to the present study is the overall sample size and statistical power. By the final timepoint, nearly 40% of the sample was lost to follow-up and sample size had dropped to approximately 90 participants for both QOL and distress. While LMM methods were selected for their ability to retain much of the data, the impact of reduced sample size on power and overall validity of the results should be considered when interpreting results. With a smaller sample size the chance of observing a statistically significant difference given a true difference is much reduced, even if the effect size, or strength of the intervention, is large. This had wide implications for the current study. In fact, observed significant results, such as the overall improvement in QOL and distress over time, may actually be more meaningful than suggested, or conversely a non-trivial effect size might exist when a significant difference was not observed. Specifically, low sample size may have made it more difficult to detect associations between demographic and illness related characteristics, like age and time since diagnosis, and the rate of response to intervention. Analyses looking at change over time by participation in certain program services also may have been underpowered. As mentioned above, some services were infrequently attended, and services such as psychology did not show a significant difference in the rate of improvement in psychosocial functioning over time, despite a

trend to suggest that those who received psychology services displayed a more pronounced rate of improvement in distress (b = -0.054) and QOL (b = -0.043) than those who did not receive psychological counseling (distress, b = -0.037; QOL, b = -0.026). Thus, study results should be interpreted with likely power limitations in mind, and future studies should attempt to replicate results with a somewhat larger study sample in an effort to optimize power.

Additionally, some sampling bias may be present. While recruitment efforts focused on enrolling underserved participants, the majority of the study sample was female, white, English-speaking, educated beyond high school, and survivors of breast cancer. Despite substantive outreach efforts, the current study sample looks demographically similar to groups of CS receiving care within academic medical settings (Abernethy et al., 2010; Paxton et al., 2012). Thus, results from this study may not generalize well to more diverse population of CS. Argenbright et al. (2014) discussed some of the challenges to consistent referral and enrollment of underserved populations within ProComS. However, given the evolving and deliberate recruitment strategies of ProComS, the composition of the study sample may represent the types of individuals who are interested and able to attend survivorship services. For instance, older or retired individuals may be better able to attend regular daytime appointments than younger or employed patients and, thus, be more likely to accept a referral to a survivorship program. In this way, the current study sample may provide a valid and more practical assessment of CS attending psychosocial support services in a community setting. While this study provides more "real-world" insight into the impact of survivorship programming within a community, it will be important to conduct this study on a program with more structured, empirical, and consistent recruitment efforts in order to provide an additive perspective on how psychosocial services affect the community-based CS.

Likewise, the relatively low number of minority participants made it difficult to conduct analyses with enough power to explore psychosocial change with sub-samples of participants based on race, ethnicity, or language preference. Explorative post-hoc analyses suggested that response to programmatic treatment was similar among minority and white participants, although sample sizes were low, especially at the 12-month follow-up. A larger sample size and more racial heterogeneity might make these preliminary, tentative observations more powerful and, thus, provide a more meaningful and accurate depiction of racial differences in response to treatment. Reexamining and adjusting current recruitment and promotional efforts may help to improve the possible sampling bias in the future, and continuing to provide culturally appropriate services and hiring more bilingual staff may help to make programming more accessible to underserved populations.

Although statistical methods adjusted for the impact of missing data, we should be cautious in our conclusions about improvements in psychosocial functioning. Attrition was observed at each timepoint for both distress (25.6%, 11.5%, 10.0%) and QOL (27.7%, 8.2%, 9.9%). Plus, analyses suggest that those who did not complete follow-up data points were more distressed at baseline than those who completed the final assessment wave. Therefore, similar to other behavioral health studies (Cnaan, Laird, & Slasor, 1997), attrition was likely associated with unmeasured distress and QOL, such that those participants with worse psychosocial functioning were less likely to complete and return the outcome measures. It is possible that the observed improvement in psychosocial functioning is partially an artifact of the dropout of those participants with the worst QOL and/or distress outcomes. However, it should be noted that significant effects were observed even after controlling for the last wave of assessment completed (i.e., dropout pattern) maximizing the interpretive strength of the overall conclusions.

Data collection procedures could also account for some of the missing data, since the psychosocial measures were administered as separate forms rather than in a single, integrated questionnaire. In order to help prevent missing data, future studies should combine all outcome measures into a single document.

Correspondingly, the questionnaires selected to measure distress and QOL were not specific to the phase of cancer survivorship following primary treatment but rather were created more generally for use with all cancer patients at any point in the trajectory of cancer care. As a result, these measures may not have fully captured the experience of study subjects and/or assessed aspects of the cancer experience that are not applicable to the concerns of post-primary treatment cancer survivorship. While these measures were selected based on their common use with CS as well as the lack of other validated, more appropriate measures, they may be less sensitive to psychosocial change among post-treatment cancer patients. Future studies should focus on designing and validating measures of well-being and emotional health that are specific to the survivorship phase following primary cancer treatment.

The current study is one of the first to examine patient-reported outcomes among CS participating in a community-based cancer survivorship program, and much about the survivorship experience and relevant programming is left to be understood. For instance, further research is needed to better understand the nature and mechanisms of change experienced by program participants. Additional research including a comparative "control" (i.e., non-interventional or minimal intervention) group may help elucidate these effects. Specifically, it might be helpful to compare patterns of change in psychosocial outcomes between CS participating in full survivorship programming (i.e., in-person evaluation, referral, and attendance to psychosocial services) with those receiving a more streamlined psychoeducational

service. This type of experimental study design might help to tease out how the survivorship program is beneficial to CS and, in particular, the impact of validation and information on psychosocial adjustment during the post-treatment survivorship phase. Additionally, it would be interesting to explore whether patients' perceived improvements in QOL and distress, as measured by self-report questionnaires, are consistent with observed improvement by third parties, such as clinical providers, caregivers, and significant others (e.g., spouse). This comparison may facilitate an enhanced referral process whereby patients could be offered the services that not only meet their perceived needs but also those that address providers', caregivers', and loved ones' objective observations and concerns.

As the number of individuals surviving cancer grows, so does the demand for services to manage the emotional and physical consequences of the disease. Until we begin to better manage individuals' specific needs during survivorship, cancer will continue to have a life-long impact on those suffering from the sequelae of the illness and place a high burden on individual, societal, and healthcare resources years after initial treatment. Examining the impact of community-based survivorship programming on psychosocial functioning is one way to begin to improve the quality of care provided to CS and promote services that are appropriate to CS living in more rural or underserved areas. As we better understand the impact of survivorship services and the trajectory of psychosocial outcomes among CS, we can better design and implement interventions that promote greater physical and emotional health in the years following cancer treatment.

APPENDIX A

TABLES

Table 1
Evidenced-Based and Best Practice Guidelines for ProComS Services

Topic	Guidelines	Service Type at MCI
Distress Management	*Distress will be assessed, monitored, documented, and treated promptly at all stages*. Psychosocial/Behavioral Interventions (2A): Strong support for psychological, social, and pharmacological interventions. CBT reduces psychological and physical symptoms. Supportive psychotherapy groups help to improve distress and psychological symptoms and provide meaning. Pharmacological Treatment: SSRI's widely used for depression and anxiety.	▪ Psychologist ▪ Social Worker ▪ Financial Advocate
Tobacco Cessation	*Tobacco use should be addressed throughout treatment and effective cessation services should be offered.* Tobacco cessation can lead to improved treatment outcomes, reduced adverse effects, improved survival, and better QOL. Psychosocial Interventions: Individual, group, and telephone counseling are effective (A). Pharmacological Interventions: Use of medications for nicotine dependence is effective except when medically contraindicated (A).	▪ Psychologist
Lymphedema	*Initial assessment of lymphedema for all at-risk patients with an additional referral to a specialist as needed.* Recommended: Complete decongestive therapy, compression bandaging, and treatment of infections. Likely to be Effective: Maintenance of optimal body weight, manual lymph drainage. Benefits Balanced with Harms: Exercise, prophylactic antibiotics, and surgical intervention.	▪ Lymphedema specialist
Food/Nutrition	*Cancer patients should eat a healthy diet, maintain a normal weight and engage in physical activity. Nutritional status should be assessed and appropriate education provided. Cancer survivors should seek additional consultation from qualified nutrition professionals.* Diet: eat a plant-based diet, limit red meat, avoid processed meats, limit salt and limit alcohol. Body Fat: be lean and within normal weight range. Physical Activity: be active daily and limit sedentary activities.	▪ Dietician
Physical	*All patients should be asked about exercise habits and*	▪ Monitored

Activity	*encouraged to be physically active and return to daily activities as soon as possible. Activity recommendations should be tailored to each individual's abilities and include a combination of cardiovascular activity, strength training, and stretching (NCCN). Weekly activity should total 150 minutes of moderate-intensity activity or 75 minutes of vigorous-intensity or an equivalent combination* Post-treatment aerobic and resistance training can improve cardiovascular and overall strength along with positive effects on balance, body composition, and QOL (2A). Associated with decreased recurrence and decreased mortality (2A). Breast Cancer: improved physical fitness, increased functioning, and better QOL (2A).	Exercise ▪ Alternative exercise (tai chi, yoga)
Fatigue	*Monitor fatigue at regular intervals, assess causes, and treat with appropriate interventions. Contributing factors should also be treated.* Nonpharmacologic: Educate patient about self monitoring and energy conservation (2A). Increase or maintain an adequate level of physical activity (1). Provide psychosocial interventions such as CBT/BT, psych-educational therapies, or supportive-expressive therapies (1). Also, CBT for sleep (1). Nutritional consultation (1). Pharmacologic: Psychostimulants provided after ruling out other causes and failure of other interventions (2A). Supplements such as ginseng and vitamin D (2A)	▪ Fatigue specialist
Pain	*Screen for cancer pain or cancer treatment-related pain at regular intervals and provide multidisciplinary pain management.* General Measures: Provide psychosocial support and behavioral interventions like CBT and relaxation training (2A), adjuvant analgesics (2A), and opiates (2A). Physical therapy and exercise (2A). Referral to pain management specialist for refractory pain (2A).	▪ Pain specialist
Surveillance Screening	*A periodic assessment is recommended for all survivors to determine any needs and necessary interventions. Needs assessment should also include appropriate referrals*	▪ Nursing Assessment ▪ Social Worker
Genetic Services	*Identify individuals who may benefit from cancer risk assessment and provide genetic testing and counseling.* Post-treatment genetic testing and counseling help individuals to learn about additional factors related to a diagnosis, to derive personal meaning, and to make educated, informed decisions in the future. Breast &	▪ Genetic Counselors

Ovarian: Up to 10% of breast cancers are due to specific, inherited mutations in genes such as BRCA1/BRCA2, TP53 and PTEN (2A).

Note: Guidelines for distress management are from the National Comprehensive Cancer Network (2012). Guidelines for Tobacco Cessation are from Fiore et al. (2008). Guidelines for Lymphedema are from Poage, Singer, Armer, Poundall, and Shellabarger (2008). Food and Nutrition Guidelines are from World Cancer Research Fund/American Institute for Cancer Research (2007). Guidelines for physical activity, fatigue, pain, and surveillance screening are from National Comprehensive Cancer Network (2013b), and Genetic Service Guidelines are from National Comprehensive Cancer Network (2013a).

Evidence Coding Key: **Comprehensive Cancer Network (NCCN):** Category 1: High level evidence (RCTs) uniform NCCN consensus; Category 2A: Lower level evidence with uniform NCCN consensus; Category 2B: Lower level evidence, non-uniform NCCN consensus, no major disagreement; Category 3: Recommendation is based on any level of evidence but reflects major disagreement. **Oncology Nursing Society:** Ranges from Recommended to Likely to be Effective to Benefits Balanced with Harms to Effectiveness not Established to Effectiveness Unlikely to Not Recommended. **Clinical Practice Guidelines Treating Tobacco Use**: Level A: Multiple well designed RCTs directly relevant, consistent findings; Level B: Some evidence from RCTs, scientific support not optimal; Level C: Consensus in absence of RCT

Table 2
Sample Size and Retention at Each Timepoint

Measures	Baseline (N)	3 Months (N)	6 Months (N)	12 Months (N)	Study Completion (%)
BSI-18	152	113	100	92	60.5
FACT-G	151	110	101	91	60.3

Note: Study completion is defined as the percentage of participants from the total sample (N = 152) who completed psychosocial outcomes measures at the final timepoint, which was 12 months after enrollment in ProComS.

Table 3
Descriptive Demographic and Illness Data (N=152)

Source	Mean (SD) or N (%)	Source	Mean (SD) or Percent
Demographics		*Illness Characteristic*	
Age (years)	56.1 (8.9)	Time Since Diagnosis (years)	3.3 (4.7)
Gender		Primary Cancer Location	
Female	136 (89.5)	Breast	117 (77.0)
Male	16 (10.5)	Prostate	6 (3.9)
Race/Ethnicity		Head and Neck	5 (3.3)
Non-Hispanic White	102 (67.1)	Colorectal	5 (3.3)
Non-Hispanic Black	24 (15.8)	Lung	4 (2.6)
Hispanic	22 (14.5)	Gynecological	5 (3.3)
Asian	1 (0.7)	Lymphoma	2 (1.3)
Multi-Racial	1 (0.7)	Other	8 (5.3)
Other	1 (0.7)	Cancer State	
Unknown	1 (0.7)	0	9 (5.9)
Marital Status		I	40 (26.3)
Married	79 (52.0)	II	52 (34.2)
Divorced	33 (21.7)	III	26 (17.1)
Widowed	7 (4.6)	IV	5 (3.3)
Separated	2 (1.3)	Unknown	20 (13.2)
Never Married	27 (17.8)	Hx of Recurrence/2nd cancer	
Unmarried Couple	4 (2.6)	Yes	18 (11.8)
Education Level		No	134 (88.2)
Grades 9-11	4 (2.6)	Treatment Type[ff]	
Grade 12 or GED	28 (18.4)	Chemotherapy	108 (73.5)
Some college/Tech School	60 (39.5)	Radiation	79 (53.7)
College Graduate	56 (36.8)	Surgery	127 (86.4)
Grad School/Prof Degree	2 (1.3)	Comorbidity Index	
Unknown	2 (1.3)	Low	35 (23.0)
Preferred Language		Medium	62 (40.8)
English	144 (94.7)	High	55 (36.2)
Spanish	8 (5.3)	KPS (Median)[**]	100
Distance from Clinic (miles)[f]	12.1 (15.4)	Meeting Exercise Guidelines[*]	
		Yes	52 (36.4)
		No	90 (62.9)
		Not Enough Information	1 (0.7)

[*] N = 143, as only participants within the appropriate age range for the measure (15-69 years) were included

[**] N = 149, a KPS score was not assigned to 3 participants

[f] N = 149, as distance was not able to be calculated for 3 participants

[ff] N =147, participants could endorse more than one treatment type; treatment history information was not collected for 5 participants.

Table 4
Mean Raw and Transformed Scores by Timepoint and Psychosocial Outcome

	Baseline		3 Months		6 Months		12 Months	
Sub-scale	BSI-18	FACT-G	BSI-18	FACT-G	BSI-18	FACT-G	BSI-18	FACT-G
Somatization	4.5	---	3.6	---	3.6	---	3.3	---
Anxiety	5.0	---	3.2	---	3.0	---	3.1	---
Depression	4.7	---	2.9	---	2.9	---	3.4	---
Physical Well-being	---	20.5	---	22.5	---	22.8	---	22.4
Emotional Well-being	---	17.7	---	19.4	---	19.3	---	19.5
Functional Well-being	---	19.1	---	20.6	---	20.9	---	20.8
Social/Family Well-being	---	20.6	---	21.5	---	21.4	---	21.2
Total Score (Raw)	14.3	77.9	9.6	83.9	9.5	84.5	9.8	83.9
Total Score (Transformed)	3.4	5.3	2.7	4.8	2.7	4.7	2.7	4.7

Note: Raw FACT-G scores ranged from 0 to 108, and raw BSI-18 scores ranged from 0 to 72. Total Score (Transformed) values represent the average scores at each timepoint after a square root transformation was performed on the BSI-18 global raw scores and a reflected square root transformation was performed on FACT-G total raw scores.

Table 5
Service Utilization Summary

Service Type	Total # of Visits	N	Average	SD
Exercise	1605	130	12	10.9
Nutrition	182	93	2	1.5
Nursing	152	152	1	0.0
Social Work	77	73	1	0.28
Psychology	175	29	6	5.1
Pain Management	1	1	1	0.0
Genetic Counseling	6	6	1	0.0
Financial Advocacy	5	5	1	0.0
All Service Types	2203	152	14.5	11.7

Table 6
Demographic and Illness Data by Last Completed Assessment Wave for Functional Assessment of Cancer Therapy-General

Source	Baseline N = 28 Mean (SD) or N (%)	3 Month N = 8 Mean (SD) or N (%)	6 Months N = 25 Mean (SD) or N (%)	12 Months N = 91 Mean (SD) or N (%)
Age (years)	50.6 (7.8)	53.6 (8.3)	58.8 (8.2)	57.3 (8.8)
Service Utilization	8.6 (8.0)	10.13 (7.9)	16.3 (9.7)	16.2 (12.9)
Time Since Diagnosis	4.0 (6.8)	3.5 (5.0)	4.9 (5.0)	2.6 (3.7)
Distance from Clinic (miles)	13.6 (12.4)	27.9 (50.2)	8.6 (6.5)	11.2 (10.7)
Gender				
Female	24 (85.7)	7 (87.5)	22 (88.0)	83 (91.2)
Male	4 (14.3)	1 (12.5)	3 (12.0)	8 (8.8)
Race/Ethnicity				
Non-Hispanic White	15 (53.6)	5 (62.5)	14 (56.0)	68 (74.7)
Other	13 (46.4)	3 (37.5)	11 (44.0)	23 (25.3)
Marital Status				
Married	10 (35.7)	7 (87.5)	13 (52.0)	49 (53.8)
Unmarried	18 (64.3)	1 (12.5)	12 (48.0)	42 (46.2)
Education Level				
Grade 12 or less	11 (39.3)	1 (12.5)	4 (16.0)	16 (17.6)
Some college	9 (32.1)	2 (25.0)	13 (52.0)	36 (39.6)
College Degree or higher	8 (28.6)	5 (62.5)	8 (32.0)	37 (40.7)
Unknown	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.2)
Preferred Language				
English	23 (82.1)	8 (100.0)	24 (96.0)	89 (97.8)
Spanish	5 (17.9)	0 (0.0)	1 (4.0)	2 (2.2)
Cancer Location				
Breast	21 (75.0)	5 (62.5)	20 (80.0)	71 (78.0)
Other	7 (25.0)	3 (37.5)	5 (20.0)	20 (22.0)
Cancer Stage				
Early Stage (0-II)	16 (57.1)	5 (62.5)	20 (80.0)	60 (65.9)
Late stage (III or IV)	9 (32.1)	3 (37.5)	2 (12.0)	16 (17.6)
Unknown	3 (10.7)	0	3 (8.0)	15 (16.5)
Hx of Recurrence/2nd cancer				
Yes	2 (7.1)	2 (25.0)	4 (16.0)	10 (11.0)
No	26 (92.9)	6 (75.0)	21 (84.0)	81 (89.0)
Comorbidity Count				
Low	6 (21.4)	0 (0.0)	2 (8.0)	27 (29.7)
Medium	10 (35.7)	3 (37.5)	15 (60.0)	34 (37.4)
High	12 (42.9)	5 (62.5)	8 (32.0)	30 (33.0)
KPS (Median)	100	95	100	100
Meeting Exercise				

Guidelines				
Yes	7 (25.0)	3 (37.5)	7 (28.0)	38 (41.8)
No	20 (71.4)	5 (62.5)	18 (72.0)	53 (58.2)
Unknown	1 (3.6)	0 (0.00)	0 (0.00)	0 (0.00)
Hx of Chemotherapy				
Yes	24 (85.7)	6 (75.0)	15 (60.0)	63 (69.2)
No	4 (14.3)	2 (25.0)	10 (40.0)	28 (30.8)
Hx of Surgery				
Yes	21 (75.0)	6 (75.0)	21 (84.0)	79 (86.8)
No	7 (25.0)	2 (25.0)	4 (16.0)	12 (13.2)
Hx of Radiation				
Yes	15 (53.6)	4 (50.0)	15 (60.0)	45 (49.5)
No	13 (46.4)	4 (50.0)	10 (40.0)	46 (50.5)

Table 7
Demographic and Illness Data by Last Completed Assessment Wave for Brief Symptom Inventory-18

Source	Baseline N = 28 Mean (SD) or N (%)	3 Months N = 7 Mean (SD) or N (%)	6 Months N = 25 Mean (SD) or N (%)	12 Months N = 92 Mean (SD) or N (%)
Age (years)	50.6 (7.8)	51.3 (5.6)	58.5 (8.2)	57.5 (8.9)
Service Utilization	8.6 (8.0)	8.3 (6.4)	16.8 (9.3)	16.1 (12.9)
Time Since Diagnosis	4.0 (6.8)	4.0 (5.2)	5.1 (5.8)	2.5 (3.3)
Distance from Clinic (miles)	13.6 (12.4)	30.7 (53.5)	7.8 (6.5)	11.4 (10.5)
Gender				
Female	24 (85.7)	6 (85.7)	23 (92.0)	83 (90.2)
Male	4 (14.3)	1 (14.3)	2 (8.0)	9 (9.8)
Race/Ethnicity				
Non-Hispanic White	15 (53.6)	5 (71.4)	14 (56.0)	68 (73.9)
Other	13 (46.4)	2 (28.6)	11 (44.0)	24 (26.1)
Marital Status				
Married	10 (35.7)	6 (85.7)	14 (56.0)	49 (53.3)
Unmarried	18 (64.3)	1 (14.3)	11 (44.0)	43 (46.7)
Education Level				
Grade 12 or less	11 (39.3)	1 (14.3)	3 (12.0)	17 (18.5)
Some college	9 (32.1)	2 (28.6)	13 (52.0)	36 (39.1)
College Degree or higher	8 (28.6)	4 (57.1)	9 (36.0)	37 (40.2)
Unknown	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.2)
Preferred Language				
English	23 (82.1)	7 (100.0)	24 (96.0)	90 (97.8)
Spanish	5 (17.9)	0 (0.0)	1 (4.0)	2 (2.2)
Cancer Location				
Breast	21 (75.0)	4 (57.1)	20 (80.0)	72 (78.3)
Other	7 (25.0)	3 (42.9)	5 (20.0)	20 (21.7)
Cancer Stage				
Early Stage (0-II)	16 (57.1)	4 (57.1)	20 (80.0)	61 (66.3)
Late stage (III or IV)	9 (32.1)	3 (42.9)	2 (8.0)	17 (18.5)
Unknown	3 (10.7)	0 (0.0)	3 (12.0)	14 (15.2)
Hx of Recurrence/2nd cancer				
Yes	2 (7.1)	2 (28.6)	5 (20.0)	9 (9.8)
No	26 (92.9)	5 (71.4)	20 (80.0)	83 (90.2)
Comorbidity Count				
Low	6 (21.4)	0 (0.0)	2 (8.0)	27 (29.3)
Medium	10 (35.7)	3 (42.9)	14 (56.0)	35 (38.0)
High	12 (42.9)	4 (57.1)	9 (36.0)	30 (32.6)
KPS (Median)	100	90	100	100

Meeting Exercise Guidelines				
Yes	7 (25.0)	2 (28.6)	6 (24.0)	40 (43.5)
No	20 (71.4)	5 (71.4)	19 (76.0)	52 (56.5)
Unknown	1 (3.6)	0 (0.0)	0 (0.0)	0 (0.0)
Hx of Chemotherapy				
Yes	24 (85.7)	6 (85.7)	14 (56.0)	64 (69.6)
No	4 (14.3)	1 (14.3)	11 (44.0)	28 (30.4)
Hx of Surgery				
Yes	21 (75.0)	5 (71.4)	23 (92.0)	78 (84.8)
No	7 (25.0)	2 (28.6)	2 (8.0)	14 (15.2)
Hx of Radiation				
Yes	15 (53.6)	3 (42.9)	14 (56.0)	47 (51.1)
No	13 (46.4)	4 (57.1)	11 (44.0)	45 (48.9)

Table 8

Comparison of the Effect of Time in the Unadjusted, Adjusted, and Adjusted with Dummy Variables Models Predicting Distress and Quality of Life Outcomes

	Model								
	Unadjusted			Adjusted			Adjusted with Dummy		
	b	*SE*	*p*	*b*	*SE*	*p*	*b*	*SE*	*p*
BSI-18	-.044	.011	<.001	-.044	.011	<.001	-.031	.011	.006
FACT-G	-.031	.009	.001	-.031	.009	.001	-.024	.010	.015

Table 9
Summary of the Estimates of Fixed Effects for the Adjusted Models for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.498	.248	<.001	6.673	.266	<.001
Time	-.044	.011	<.001	-.031	.009	.001
Marital status (married vs. not married)	-.691	.212	.001	-.765	.229	.001
Distance from Clinic (near vs. far)	-.472	.214	.029	-.517	.231	.027
Comorbidity Count (low vs. high)	-1.558	.284	<.001	-1.786	.306	<.001
Comorbidity Count (medium vs. high)	-.611	.244	.013	-.966	.263	<.001

Table 10
Summary of the Estimates of Fixed Effects for the Adjusted Models Including Last Assessment Wave Patterns for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.638	.438	<.001	6.881	.465	<.001
Time	-.031	.011	.006	-.024	.010	.015
Marital status (married vs. not married)	-.643	.211	.002	-.714	.227	.002
Distance from Clinic (near vs. far)	-.446	.211	.036	-.484	.228	.035
Comorbidity Count (low vs. high)	-1.495	.281	<.001	-1.733	.306	<.001
Comorbidity Count (medium vs. high)	-.591	.238	.014	-.943	.259	<.001
Baseline dropout (Non-dropout vs. dropout)	-.453	.381	.236	-.480	.398	.230
12-month dropout (Noncompleters vs. Completers)	.541	.293	.067	.376	.307	.222
12-month dropout (Noncompleter vs. completers) x Time	-.088	.041	.033	-.056	.037	.127

Table 11
Summary of the Estimates of Fixed Effects for the Adjusted Models with Time as a Fixed Factor for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.824	.420	<.001	7.011	.452	<.001
Marital status (married vs. not married)	-.638	.208	.003	-.709	.227	.002
Distance from Clinic (near vs. far)	-.449	.210	.034	-.485	.228	.035
Comorbidity Count (low vs. high)	-1.496	.280	<.001	-1.736	.305	<.001
Comorbidity Count (medium vs. high)	-.593	.237	.014	-.947	.258	<.001
Baseline dropout (Non-dropout vs. dropout)	-.480	.369	.194	-.492	.389	.208
12-month dropout (Noncompleters vs. Completers)	.350	.268	.195	.247	.287	.391
Time (3 months vs. baseline)	-.417	.098	<.001	-.327	.094	.001
Time (6 months vs. baseline)	-.566	.117	<.001	-.359	.106	.001
Time (12 months vs. baseline)	-.478	.127	<.001	-.358	.112	.002

Table 12
Summary of the Estimates of Fixed Effects for Models Stratified by Baseline Distress for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.894	.284	<.001	6.952	.380	<.001
Time	-.020	.011	.064	-.017	.012	.146
Marital status (married vs. not married)	-.020	.011	.032	-.517	.189	.007
Distance from Clinic (near vs. far)	-.299	.138	.286	-.329	.190	.086
Comorbidity Count (low vs. high)	-.907	.186	<.001	-1.340	.257	<.001
Comorbidity Count (medium vs. high)	-.435	.155	.006	-.834	.215	<.001
Baseline dropout (Non-dropout vs. dropout)	-.623	.250	.013	-.509	.327	.121
12-month dropout (Noncompleters vs. Completers)	.179	.175	.307	.247	.239	.303
Baseline distress (low vs. high)	-1.841	.133	<.001	-1.119	.147	<.001
Baseline distress (low vs. high) x Time	.008	.018	.655	.003	.019	.874

Table 13
Summary of the Estimates of Fixed Effects for Models Stratified by Median Age for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.660	.436	<.001	6.765	.471	<.001
Time	-.040	.015	.008	-.030	.013	.025
Marital status (married vs. not married)	-.678	.207	.001	-.753	.225	.001
Distance from Clinic (near vs. far)	-.371	.211	.081	-.404	.228	.079
Comorbidity Count (low vs. high)	-1.609	.282	<.001	-1.851	.306	<.001
Comorbidity Count (medium vs. high)	-.610	.234	.010	-.967	.255	<.001
Baseline dropout (Non-dropout vs. dropout)	-.626	.364	.087	-.547	.384	.157
12-month dropout (Noncompleters vs. Completers)	.233	.266	.382	.189	.283	.506
Age (younger vs. older)	.426	.231	.067	.464	.244	.058
Age (younger vs. older) x Time	.005	.021	.800	.004	.019	.822

Table 14
Summary of the Estimates of Fixed Effects for Models Stratified by Comorbidity Count for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.999	.424	<.001	7.070	.455	<.001
Time	-.061	.018	.001	-.032	.016	.047
Marital status (married vs. not married)	-.629	.208	.003	-.704	.227	.002
Distance from Clinic (near vs. far)	-.449	.210	.034	-.486	.228	.034
Baseline dropout (Non-dropout vs. dropout)	-.688	.366	.062	-.629	.387	.105
12-month dropout (Noncompleters vs. Completers)	.262	.268	.330	.204	.287	.479
Comorbidity Count (low vs. high)	-1.828	.303	<.001	-1.828	.321	<.001
Comorbidity Count (medium vs. high)	-.630	.256	.015	-.937	.272	.001
Comorbidity Count (low vs. high) x time	-1.828	.303	.006	.021	.024	.384
Comorbidity Count (medium vs. high) x Time	-.630	.256	.710	-.003	.022	.891

Table 15
Summary of the Estimates of Fixed Effects for Models Stratified by Time Since Diagnosis for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*p*
Intercept	4.648	.551	<.001	7.004	.590	<.001
Time	-.029	.028	.310	-.033	.025	.186
Marital status (married vs. not married)	-.644	.210	.003	-.697	.228	.003
Distance from Clinic (near vs. far)	-.444	.213	.039	-.469	.231	.044
Comorbidity Count (low vs. high)	-1.475	.284	<.001	-1.748	.310	<.001
Comorbidity Count (medium vs. high)	-.587	.239	.015	-.962	.260	<.001
Baseline dropout (Non-dropout vs. dropout)	-.638	.372	.088	-.620	.393	.116
12-month dropout (Noncompleters vs. Completers)	.338	.276	.223	.216	.295	.467
Time since diagnosis (≤ 5 yrs vs. > 5 yrs)	.205	.314	.515	.041	.332	.902
Time since diagnosis (≤ 5 yrs vs. > 5 yrs) x time	-.007	.030	.812	.007	.027	,783

Table 16
Summary of the Estimates of Fixed Effects for Models Including Service Utilization as a Covariate for Distress and Quality of Life

	Psychosocial Outcome Measure					
	BSI-18			FACT-G		
Effect	*b*	*SE*	*p*	*b*	*SE*	*P*
Intercept	4.849	.437	<.001	7.083	.469	<.001
Time	-.022	.017	.196	-.012	.015	.417
Marital status (married vs. not married)	-.637	.209	.003	-.711	.227	.002
Distance from Clinic (near vs. far)	-.455	.211	.032	-.480	.228	.037
Comorbidity Count (low vs. high)	-1.501	.286	<.001	-1.777	.311	<.001
Comorbidity Count (medium vs. high)	-.601	.238	.013	-.963	.258	<.001
Baseline dropout (Non-dropout vs. dropout)	-.702	.372	.060	-.623	.391	.113
12-month dropout (Noncompleters vs. Completers)	.291	.269	.280	.201	.288	.487
Service utilization	.005	.010	.637	-.001	.010	.899
Service utilization x Time	-.001	.001	.274	-.001	.001	.199

Table 17
Summary of Estimates of Fixed Effects Including Exercise Attendance as a Fixed Factor in Predicting Change in Quality of Life Across Time

	FACT-G		
Effect	*b*	*SE*	*p*
Intercept	6.903	.489	<.001
Time	-.034	.010	.001
Marital status (married vs. not married)	-.673	.231	.004
Distance from Clinic (near vs. far)	-.453	.232	.052
Comorbidity Count (low vs. high)	-1.689	.312	<.001
Comorbidity Count (medium vs. high)	-.999	.263	<.001
Baseline dropout (Non-dropout vs. dropout)	-.477	.413	.250
12-month dropout (Noncompleters vs. Completers)	.210	.298	.482
Attendance to Exercise (No vs. Yes)	.451	.429	.295
Attendance to Exercise (No vs. Yes) x Time	.072	.035	.042

Table 18
Summary of Estimates of Fixed Effects Including Nutrition Consult Attendance as a Fixed Factor in Predicting Change in Quality of Life Across Time

	FACT-G		
Effect	*b*	*SE*	*p*
Intercept	6.849	.482	<.001
Time	-.048	.012	<.001
Marital status (married vs. not married)	-.676	.230	.004
Distance from Clinic (near vs. far)	-.479	.231	.040
Comorbidity Count (low vs. high)	-1.727	.309	<.001
Comorbidity Count (medium vs. high)	-.972	.261	<.001
Baseline dropout (Non-dropout vs. dropout)	-.510	.397	.400
12-month dropout (Noncompleters vs. Completers)	.251	.298	.201
Attendance to Nutrition Consult (No vs. Yes)	.340	.247	.170
Attendance to Nutrition Consult (No vs. Yes) x Time	.048	.019	.012

Table 19
Summary of Estimates of Fixed Effects of Analyses Including the Number of Exercise Sessions as a Continuous Factor in Predicting Change in Quality of Life Across Time (N = 130)

	FACT-G		
Effect	*b*	*SE*	*p*
Intercept	7.264	.531	<.001
Time	-.030	.015	.049
Marital status (married vs. not married)	-.677	.243	.006
Distance from Clinic (near vs. far)	-.557	.243	.024
Comorbidity Count (low vs. high)	-1.869	.326	<.001
Comorbidity Count (medium vs. high)	-1.216	.277	<.001
Baseline dropout (Non-dropout vs. dropout)	-.443	.441	.316
12-month dropout (Noncompleters vs. Completers)	.177	.302	.558
Number of Exercise Sessions	-.015	.012	.202
Number of Exercise Sessions x Time	-.000	.001	.774

Table 20
Summary of Estimates of Fixed Effects of Analyses Including the Number of Nutrition Consults as a Continuous Factor in Predicting Change in Quality of Life Across Time (N = 93)

	FACT-G		
Effect	*b*	*SE*	*p*
Intercept	6.719	.601	<.001
Time	-.046	.020	.024
Marital status (married vs. not married)	-.963	.275	.001
Distance from Clinic (near vs. far)	-.681	.275	.015
Comorbidity Count (low vs. high)	-1.943	.384	<.001
Comorbidity Count (medium vs. high)	-1.296	.306	<.001
Baseline dropout (Non-dropout vs. dropout)	-.092	.470	.845
12-month dropout (Noncompleters vs. Completers)	.557	.320	.079
Number of Nutrition Consults	.043	.099	.665
Number of Nutrition Consults x Time	-.001	.008	.915

APPENDIX B

FIGURES

Data Collection Procedures

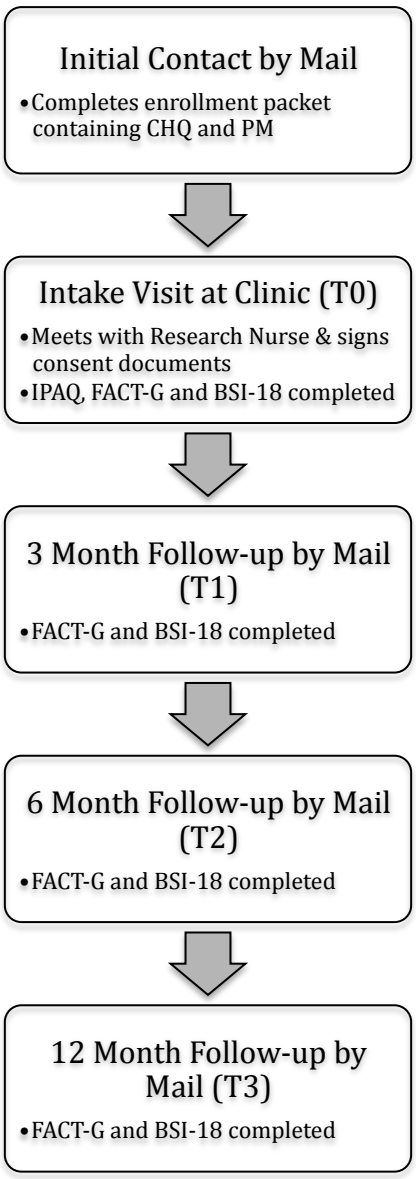


Figure 1. Process of data collection that began with an initial mail contact followed by a baseline (T0) in-person visit to the clinic and 3 follow-up mail contacts at 3 months (T1), 6 months (T2) and 12 months (T3) after enrollment. Measures collected at the various timepoints included the Functional Assessment of Cancer Therapy (FACT-G), the Brief Symptom Inventory 18 (BSI-18), a Confidential Health Questionnaire (CHQ), the Pearlman-Mayo Assessment of Needs (PM), and the International Physical Activity Questionnaire (IPAQ).

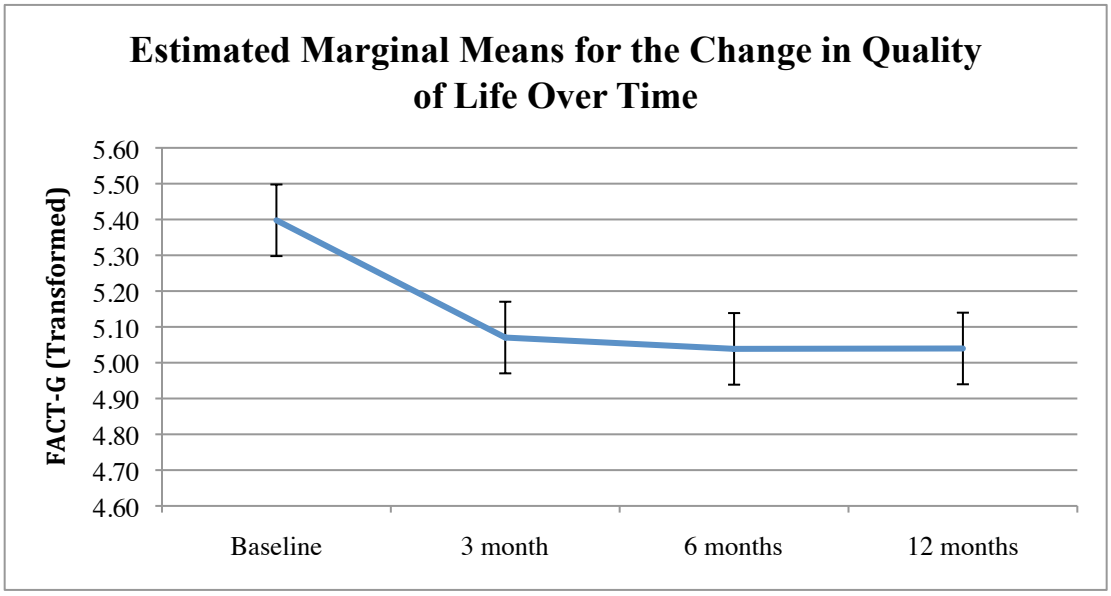


Figure 2. Estimated marginal means at each timepoint for quality of life, as measured by the Functional Assessment of Canter Therapy-General, while controlling for level of comorbidity, marital status, distance from the survivorship clinic, and two patterns of missing data.

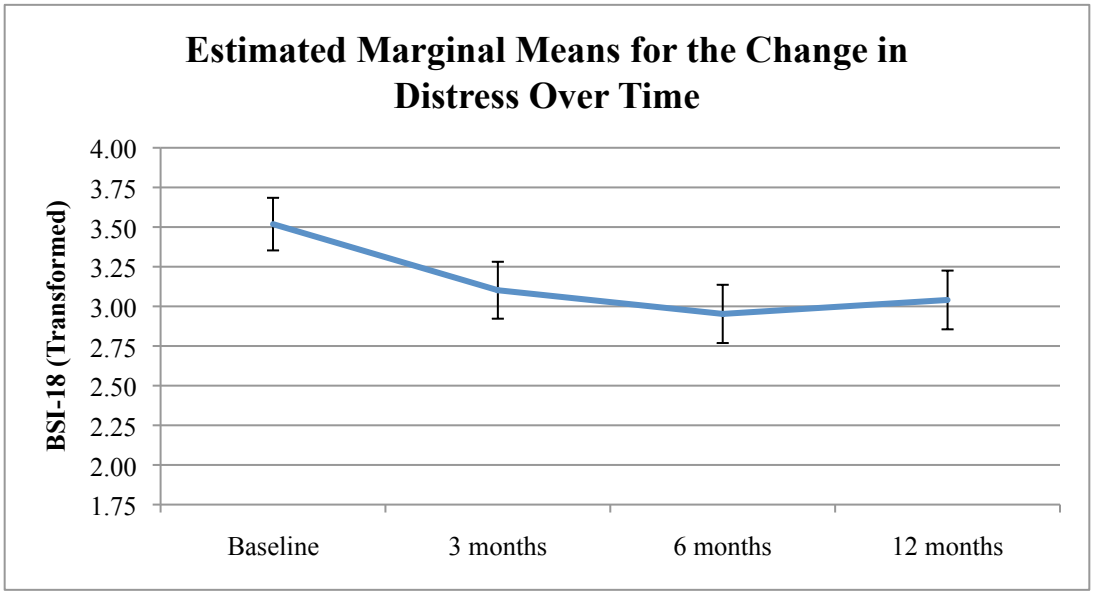


Figure 3. Estimated marginal means at each timepoint for distress, as measured by the Brief Symptom Inventory 18, while controlling for level of comorbidity, marital status, distance from the survivorship clinic, and two patterns of missing data.

APPENDIX C

SELF-REPORT MEASURES

Functional Assessment of Cancer Therapy – General

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

	<u>PHYSICAL WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

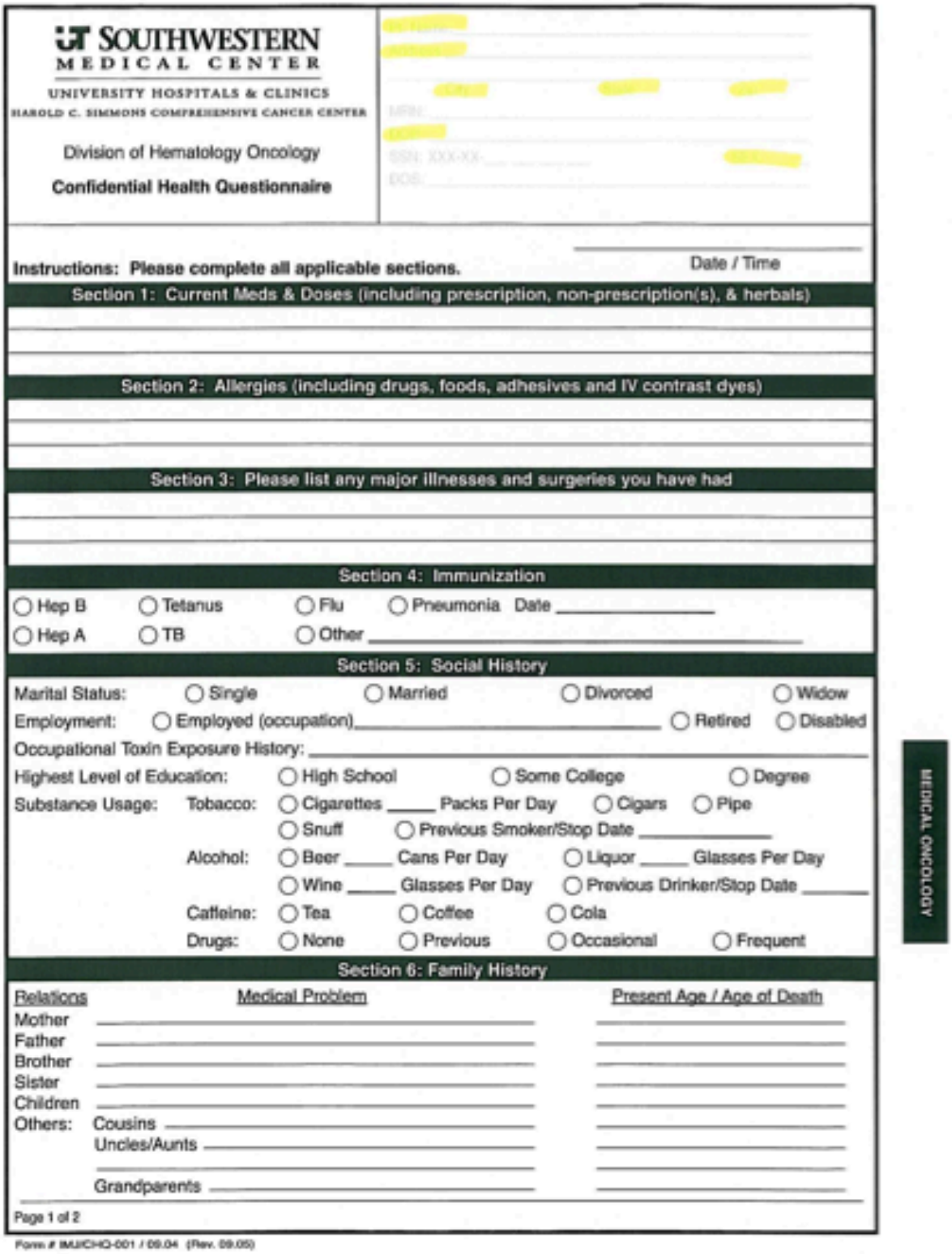
	<u>SOCIAL/FAMILY WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark ☐ box and go to the next section.*					

GS7	I am satisfied with my sex life	0	1	2	3	4

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness ..	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse.....	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home).....	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun.....	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Confidential Health Questionnaire



UT SOUTHWESTERN MEDICAL CENTER
UNIVERSITY HOSPITALS & CLINICS
HAROLD C. SIMMONS COMPREHENSIVE CANCER CENTER

Division of Hematology Oncology

Confidential Health Questionnaire

Name:
Address:
City: State: Zip:
MRN:
Gender:
SSN: XXX-XX-
DOB:

Date / Time

Instructions: Please complete all applicable sections.

Section 1: Current Meds & Doses (including prescription, non-prescription(s), & herbals)

Section 2: Allergies (including drugs, foods, adhesives and IV contrast dyes)

Section 3: Please list any major illnesses and surgeries you have had

Section 4: Immunization

○ Hep B ○ Tetanus ○ Flu ○ Pneumonia Date _____
○ Hep A ○ TB ○ Other _____

Section 5: Social History

Marital Status: ○ Single ○ Married ○ Divorced ○ Widow
Employment: ○ Employed (occupation)_____ ○ Retired ○ Disabled
Occupational Toxin Exposure History: _____
Highest Level of Education: ○ High School ○ Some College ○ Degree
Substance Usage: Tobacco: ○ Cigarettes ____ Packs Per Day ○ Cigars ○ Pipe
○ Snuff ○ Previous Smoker/Stop Date _____
Alcohol: ○ Beer ____ Cans Per Day ○ Liquor ____ Glasses Per Day
○ Wine ____ Glasses Per Day ○ Previous Drinker/Stop Date _____
Caffeine: ○ Tea ○ Coffee ○ Cola
Drugs: ○ None ○ Previous ○ Occasional ○ Frequent

Section 6: Family History

Relations	Medical Problem	Present Age / Age of Death
Mother		
Father		
Brother		
Sister		
Children		
Others: Cousins		
Uncles/Aunts		
Grandparents		

Page 1 of 2

Form # IMUCHQ-001 / 09.04 (Rev. 09.05)

MEDICAL ONCOLOGY

UT SOUTHWESTERN MEDICAL CENTER
UNIVERSITY HOSPITALS & CLINICS
HAROLD C. SIMMONS COMPREHENSIVE CANCER CENTER

Division of Hematology Oncology

Confidential Health Questionnaire

Pt. Name:
Address:
City State Zip
MRN:
DOB:
SSN: XXX-XX- SEX:
DOS:

Section 7: Review of Systems (Mark Appropriate Bubble)

1. Constitutional
- ◯ Weight Loss
- ◯ Weight Gain
- ◯ Loss of Appetite
- ◯ Fever
- ◯ Unusual Weakness
- ◯ Night Sweats
- ◯ No Problem Noted

2. Eyes/Ears/Nose
- ◯ Recent Visual Change
- ◯ Double Vision
- ◯ Hearing Loss
- ◯ Ringing in Ears
- ◯ Nose Bleeds
- ◯ No Problem Noted

3. Mouth/Throat
- ◯ Ulcers
- ◯ Thyroid Problems
- ◯ Gum Bleeding/Pain
- ◯ Hoarseness
- ◯ Difficulty Swallowing
- ◯ No Problem Noted

4. Respiratory
- ◯ Asthma
- ◯ Chest Pain
- ◯ Shortness of Breath
- ◯ Wheezing
- ◯ Cough
- ◯ Pleurisy
- ◯ History Pneumonia/Bronchitis
- ◯ No Problem Noted

5. Cardiac
- ◯ High Blood Pressure
- ◯ Palpitations
- ◯ Chest Pain (angina)
- ◯ Leg/Foot Edema
- ◯ Shortness of Breath
- ◯ Aneurysm
- ◯ History of Heart Attack
- ◯ Murmur
- ◯ Heart Failure
- ◯ No Problem Noted

6. GI
- ◯ Nausea
- ◯ Vomiting
- ◯ Pain
- ◯ Colitis
- ◯ Diarrhea
- ◯ Constipation
- ◯ Blood in Stool
- ◯ Ulcer
- ◯ Change Bowel Habits
- ◯ Vomiting Blood
- ◯ Hemorrhoids
- ◯ Hepatitis
- ◯ No Problem Noted

◯ There are no new changes from last visit on _____.

I have read and reviewed this form.

_____
Patient's Signature

_____
Date

7. Genitourinary
- ◯ Frequent Urination
- ◯ Incontinence of Urine/Stool
- ◯ Burning on Urination
- ◯ Blood in Urine
- ◯ Kidney Stones
- ◯ Hysterectomy
- ◯ Sexual Problems
- ◯ Hot Flashes
- ◯ Vaginal Discharge
- ◯ Last Pap _____
- ◯ Last Menstrual Period_____
- ◯ Last Mammogram_____
- ◯ No Problem Noted

8. Musculoskeletal
- ◯ Muscle Aches
- ◯ Arthritis/Joint Pains
- ◯ Weakness
- ◯ Paralysis
- ◯ No Problem Noted

9. Skin
- ◯ Rashes
- ◯ Hives
- ◯ Ulcers
- ◯ Sores
- ◯ Pigmented Moles
- ◯ Skin Cancer
- ◯ No Problem Noted

10. Neurological
- ◯ Seizures
- ◯ Fainting
- ◯ Headaches
- ◯ Stroke
- ◯ TIA
- ◯ Speech Problems
- ◯ Balance Problems
- ◯ Paralysis
- ◯ Weakness
- ◯ No Problem Noted

11. Psychiatric
- ◯ Depression
- ◯ Anxiety
- ◯ Sleep Problems
- ◯ Others
- ◯ No Problem Noted

12. Endocrine
- ◯ Intolerance to Heat/Cold
- ◯ Diabetes
- ◯ Thyroid Disease
- ◯ Other
- ◯ No Problem Noted

13. Heme/Lymphatic
- ◯ Enlarged Lymph Nodes
- ◯ Anemia
- ◯ Leukemia
- ◯ Platelet Problems
- ◯ Lymphoma
- ◯ Red Cell Problems
- ◯ Blood Clots - When/Where_____
- ◯ Anticoagulants - Dose_____
- ◯ No Problem Noted

14. ◯ Other _____

Form # IMJ/CHQ-001 / 09.04 (Rev. 09.05)

Pearlman-Mayo Survey of Needs

Please take a few minutes to provide us with information about how your cancer and your treatments have affected you, and turn it in to your nurse or therapist before you leave today. We'll use your responses to help us plan the next phase of your care, survivorship.

Diagnosis _____
Chemotherapy Regimen _____
Radiation Description _____
_____

Doctor /
Primary Care Provider

As a cancer survivor you may experience some lasting side effects from your treatment. Please rate each topic according to how much distress it causes you now. The scale runs from 0 (no distress) to 5 (extreme distress).

Physical Effects

	no distress					extreme distress		no distress					extreme distress
Fatigue	0	1	2	3	4	5	Hot flashes / Menopause	0	1	2	3	4	5
Pain	0	1	2	3	4	5	Trouble swallowing	0	1	2	3	4	5
Sleep disturbance	0	1	2	3	4	5	Hair and skin care issues	0	1	2	3	4	5
Sexual issues / Intimacy	0	1	2	3	4	5	Dental or mouth problems	0	1	2	3	4	5
Body changes	0	1	2	3	4	5	Osteoporosis / Bone health	0	1	2	3	4	5
Balance / Walking / Mobility	0	1	2	3	4	5	Memory and concentration	0	1	2	3	4	5
Bowel or bladder changes	0	1	2	3	4	5	Physical therapy / Rehab	0	1	2	3	4	5
Weight changes	0	1	2	3	4	5	Tingling & numbness in feet & hands (neuropathy)	0	1	2	3	4	5
Nausea / Vomiting	0	1	2	3	4	5							
Poor appetite	0	1	2	3	4	5	Other (specify): _____	0	1	2	3	4	5
Swelling in legs or arms (lymphedema)	0	1	2	3	4	5	Other (specify): _____	0	1	2	3	4	5

Social Issues

	no distress					extreme distress		no distress					extreme distress
Managing household activities	0	1	2	3	4	5	Returning to work	0	1	2	3	4	5
Caring for family members	0	1	2	3	4	5	Health insurance	0	1	2	3	4	5
Fertility issues	0	1	2	3	4	5	Legal concerns	0	1	2	3	4	5
Genetic counseling (worry about your children getting cancer)	0	1	2	3	4	5	Financial concerns	0	1	2	3	4	5
							Debt from medical bills	0	1	2	3	4	5
Talking about cancer with family & friends	0	1	2	3	4	5	Other (specify): _____	0	1	2	3	4	5
							Other (specify): _____	0	1	2	3	4	5

Emotional Aspects

	no distress					extreme distress		no distress					extreme distress
Defining a new sense of normal	0	1	2	3	4	5	Looking for the bright side: (hope, gratitude, forgiveness, love, happiness, contentment)	0	1	2	3	4	5
Managing difficult emotions: (anger, fear, sadness, depression, guilt, anxiety, uncertainty)	0	1	2	3	4	5							
							Connecting to counseling services	0	1	2	3	4	5
Coping with grief and loss	0	1	2	3	4	5	Changing relationships with spouse, family, friends, co-workers	0	1	2	3	4	5
Finding support resources	0	1	2	3	4	5							
Living with uncertainty	0	1	2	3	4	5	Other (specify): _____	0	1	2	3	4	5
Fear of recurrence	0	1	2	3	4	5	Other (specify): _____	0	1	2	3	4	5
Managing stress	0	1	2	3	4	5							

Spiritual Issues

	no distress				extreme distress		no distress				extreme distress
Religious or spiritual support	0	1	2	3	4 5	End of life distress	0	1 2 3 4			5
Loss of faith	0	1	2	3	4 5	Isolation / Feeling alone	0	1 2 3 4			5
Religious distress	0	1	2	3	4 5	Other (specify): _____	0	1 2 3 4			5

Other Issues

	no distress				extreme distress		no distress				extreme distress
Staying connected with the medical system	0	1	2	3	4 5	Use of complementary and alternative therapies	0	1 2 3 4			5
Who to call for medical problems	0	1	2	3	4 5	Concern about long-term effects of treatment	0	1 2 3 4			5
Keeping your primary care physician informed of your cancer treatment & risk of recurrence	0	1	2	3	4 5	Having a sense of well being	0	1 2 3 4			5
						Other (specify): _____	0	1 2 3 4			5
						Other (specify): _____	0	1 2 3 4			5

What specific topics are you interested in learning about?

HEALTHY LIVING CHOICES:	Nutrition	Safe exercise	Smoking cessation
FINANCIAL CONCERNS:	Estate planning	Living wills	Disability
ENHANCING COMMUNICATION:	With your doctors	With your spouse	
HEALTH SCREENINGS:	Cancer	Heart	
COMMUNITY EDUCATION PROGRAMS ON VARIOUS TOPICS		Yes	No

What questions, concerns, or thoughts do you have regarding your healthcare needs?

Additional comments:

International Physical Activity Questionnaire

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

   _____ **days per week**

   ☐ No vigorous physical activities → ***Skip to question 3***

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

   _____ **hours per day**

   _____ **minutes per day**

   ☐ Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

   _____ **days per week**

   ☐ No moderate physical activities → ***Skip to question 5***

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ **days per week**

☐ No walking → ***Skip to question 7***

6. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

This is the end of the questionnaire, thank you for participating.

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